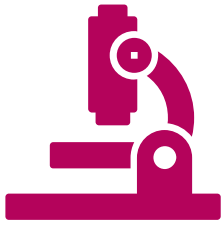


2017 RESEARCH TO RESULTS

We are growing closer to the time when our loved ones living with Rett syndrome will be able to communicate with us, to use their hands and to live a better life. Every day, researchers, doctors, nurses, families and funders are working together in relentless pursuit of the eradication of Rett syndrome. It is with pride that Rettsyndrome.org presents its 2017 Impact Report, highlighting what a committed and caring community can accomplish when the stakes are high.



accelerating
research.

\$45M+ COMMITTED TO RESEARCH THROUGH 2017



empowering
families.

\$10M+ INVESTED IN FAMILY PROGRAMMING AND SERVICES THROUGH 2017



37 ACTIVE RESEARCH & GRANT PROGRAMS

In 2017, our training program has reached over 50 post-doctoral researchers ensuring a promising future for Rett syndrome research.



10,202
DONORS IN 2017



Continued expansion of our proprietary Scout Program yielded two compounds that will begin Phase 2 clinical trials in 2018.



- Expert clinical care available at 22 hospitals in North America reaching 2,500+ children and adults
- 14 Clinical Research Centers of Excellence
- Natural History Study continues in 2018 in 15 US sites, making it one of the largest studies of its kind for a developmental disability.



FDA approval to launch the first Phase 3 trial for Rett syndrome studying trofinetide. Trial slated to begin in 2018.



120 FAMILY FUNDRAISING EVENTS



232 NEWLY DIAGNOSED FAMILIES RECEIVED A COMPREHENSIVE CARE PACKET



Rettsyndrome.org 2016 advocacy efforts led Congress to add Rett syndrome as a 2017 topic of interest for the US Department of Defense and Congressionally Directed Medical Research Program. Dr. Colleen Niswender received \$1.9 million dollars for drug discovery research.



“As parents of a newly diagnosed one year old, we were given renewed hope when we read about the promising research trials on drugs like trofinetide and IGF-1. RSO has been vital to our getting through these first few months...”

Lindsey Benjamin, mom to Leah age 1