

# International Rett Syndrome Foundation Establishes Research Fund for Males with Rett Syndrome

*The fund is established thanks to an inaugural gift from the Otis Family in honor of their son, Barrett.*

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-- The [International Rett Syndrome Foundation](#) (IRSF) today announced

the establishment of The Barrett Otis Research Fund for Males with Rett to support research focused exclusively

on expanding knowledge of Rett syndrome in males. The fund was established thanks to an inaugural gift from longtime IRSF supporters Rick & Alyssa Otis in honor of their two-year-old son, Barrett, who has Rett syndrome.



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Our hope is that this research fund will honor all males who have suffered from Rett Syndrome...and help to create a brighter future for all males who suffer from Rett Syndrome in the years to come.”

*Rick & Alyssa Otis*

“When Barrett was diagnosed with Rett Syndrome at age 1, we vigorously researched everything we could on the topic. We were horrified to discover the amount of misinformation regarding males with Rett Syndrome, particularly information that incorrectly characterizes males as rarely surviving past infancy,” shared Rick & Alyssa Otis. “Our hope is that this research fund will honor all males who have suffered from Rett Syndrome in the past, advance research to accurately describe the current male community, and help to create a brighter future for all males who suffer from Rett Syndrome in the years to

come.”

Rett syndrome is usually recognized in children between 6 to 18 months as they begin to miss developmental milestones or lose abilities they had gained, including their ability to speak, walk, eat, and even breathe. While it was initially incorrectly believed that males could not have Rett syndrome, it is now known that males do have Rett and many more than originally believed.

Other than research focused on activating the silent X chromosome, which males do not have, there is no reason to believe that other treatments will not work for men and boys with Rett syndrome, which is why IRSF is committed to making strategic investments in research to benefit males too.

“For males with Rett (MECP2), research initiatives like this, provided by a foundation that cares about these conditions, are direly needed,” said Dr. Bernhard Suter, medical director of the Blue Bird Circle Rett Center at Baylor University and Rett expert. “Males with Rett are so often overlooked in the search for a cure, yet their community is steadily and rapidly growing. The Barrett Otis Research Fund will undoubtedly stimulate research driving our understanding of this severe neurodevelopmental disorder forward on the way to clinical trials.”

To learn more about the fund, how to contribute, and IRSF's research strategy, please visit [rettsyndrome.org/otisfund](https://rettsyndrome.org/otisfund).

About International Rett Syndrome Foundation (IRSF)

As the leading Rett syndrome research and advocacy organization, the International Rett Syndrome

Foundation (IRSF) builds upon its nearly 40-year commitment to breakthrough discoveries and life-changing advancements in research toward a cure while supporting families affected by Rett syndrome. Through its legacy foundation pioneers, IRSF has invested over \$58M in research leading to identifying Rett syndrome's cause, proving Rett syndrome is reversible in mice, and developing multiple clinical trials for Rett syndrome. IRSF fights for families living with Rett syndrome and a world without it. Learn more at [rettsyndrome.org](https://rettsyndrome.org).



Barrett Otis



The Otis Family

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