

Males Have Rett Syndrome Too. IRSF is Launching a \$1 Million Fund to Make Sure Rett Research Includes Them.

The fund targets barriers keeping males with Rett from timely diagnosis, appropriate care, clinical trial inclusion, and access to treatments.

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The International Rett Syndrome Foundation (IRSF) today announced the launch of MR., the Males with Rett Fund. The \$1 million fund is dedicated to research that includes males with Rett syndrome. Families of the boys and men it serves hold governing oversight of the fund alongside IRSF scientific and regulatory expertise.



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When our son Henry was alive, hope sustained us. And even after his loss, we remain hopeful for the male Rett syndrome community. We don't want to lose any more males to this awful disease.”

Mary and Richard Engel

Rett syndrome was long described as a disease affecting girls. That understanding has left too many boys with Rett syndrome unseen, undiagnosed, or misdiagnosed, and without research or care designed to reflect their experience. [The Male Rett Spectrum Study](#) recently put evidence behind what these families had been saying for years: boys have Rett, their experiences vary widely, and outdated assumptions have delayed diagnosis and limited inclusion.

“For decades the medical literature and general

understanding called Rett syndrome a girls' disease, while families of boys with Rett had to fight to be seen and properly diagnosed. Boys paid for that mistake,” said Laura Hameed, CEO of IRSF. “MR. exists to help fix that. No project moves forward unless it explicitly includes males with Rett syndrome. Every child who has Rett, whether male or female, deserves the same chance at a timely diagnosis, the right care, a fair place in clinical trials, and ultimately, access to treatments that can benefit them.”

IRSF has committed the first \$200,000 to support an initial project aimed at erasing scientific

gaps that continue to limit male inclusion in research and therapeutic development. The remaining \$800,000 will be raised through community events and individual donors. The \$1 million is a starting point, not a finish line: enough to fund the first wave of male-inclusive research and generate the evidence needed to attract larger investment.

Moving from Recognition to Inclusion

Through the Male Rett Spectrum Study led by Drs. Tim Benke and Talia Thompson of the University of Colorado School of Medicine and the addition of male-specific questions to the IRSF Rett Syndrome Registry, what boys and men with Rett actually experience is now far better understood. IRSF holds the largest collection of male Rett registry data in the world, and MR. represents the next evolution of IRSF's commitment: addressing the gaps that continue to stand between males and full inclusion in research, clinical trials, care, and access to treatments.

"When our son Henry was alive, hope sustained us. And even after his loss, we remain hopeful for the male Rett syndrome community. We don't want to lose any more males to this awful disease. Unfortunately, males have largely been left out of clinical trials despite the urgent need for these interventions. This must change," said Mary and Richard Engel, who lost their son Henry to Rett syndrome and serve on the MR. Fund Advisory Board. "The MR. Fund is focused on improving the diagnosis and treatment of males. We are proud to serve on the Advisory Board of this life-changing and life-saving fund."



Mary and Richard Engel with their son, Henry



The Otis Family with their son, Barrett, who lives with Rett syndrome

Every project MR. funds must be 100% male-inclusive: no project will move forward unless it directly advances understanding, access, or inclusion of boys and men with Rett. MR. adds dedicated funding to close a specific gap without redirecting resources from the broader Rett syndrome research agenda.

“As parents of a son with Rett syndrome, we fight every day against the establishment that has left males behind. Males are routinely sidelined in research priorities and shut out of clinical trials, solely because of their sex, for the very treatments that could save or dramatically improve their lives,” said Rick and Alyssa Otis, members of the MR. Fund Advisory Board and parents of Barrett, who is living with Rett syndrome. “As a result, too many never receive a timely diagnosis and are denied access to the care and therapies they urgently need. This is not a minor gap — it is a serious failure with lasting consequences for these children and their families. Still, real progress is underway, and we remain hopeful that participation in the MR. Fund family governance will accelerate real change that these boys so desperately need.”

Projects are already scoped, with the first expected to begin in September. How quickly projects move depends on how quickly the fund is filled. Every gift shortens the wait for families whose sons are still too often shut out of the clinical research needed to move trials forward.

Governance and Oversight by Families of Males with Rett

Initial family Advisory Board members include Mary and Richard Engel, Rick and Alyssa Otis, Jeff and Jenna Manz, and Kate and Bill Ferdinandsen. Initial scientific and clinical advisors include Dr. Tim Benke of Children’s Hospital Colorado and Dr. Bernhard Suter of Texas Children’s Hospital. Funding decisions are subject to scientific merit, feasibility, alignment with IRSF’s broader research strategy, and one non-negotiable condition: every funded project must ensure access and inclusion of males with Rett.

Learn more or support MR. at rettsyndrome.org/malesfund.

About Rett Syndrome

Rett syndrome is a rare genetic neurological disorder that affects boys and girls and leads to severe impairments in nearly every aspect of life. It is usually recognized in children between 6 and 18 months old as they miss developmental milestones or lose abilities, including speaking, walking, eating, and even breathing. Individuals may experience seizures, scoliosis, breathing issues, GI issues, and more. Rett syndrome is lifelong.

About International Rett Syndrome Foundation (IRSF)

IRSF is the leading Rett syndrome research and advocacy organization, advancing research toward a cure while supporting families. Through its legacy foundation pioneers, IRSF has invested over \$60M in research, including work that identified Rett syndrome’s cause and supported the clinical trials leading to the first FDA-approved treatment. Learn more at

rettsyndrome.org.

Media note

Families of males with Rett syndrome, IRSF leadership, and Male Rett Spectrum Study investigators Drs. Tim Benke and Talia Thompson are available for interviews. B-roll, family photography, and information about the published study are available on request.

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