PRESS RELEASE:

Marc Tesler Joins Rett Syndrome Research Trust Board of Trustees

June 14, 2018

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TRUMBULL, CT — The Rett Syndrome Research Trust is pleased to announce that Marc Tesler has joined its Board of Trustees. Marc's granddaughter, Magnolia, who was diagnosed with Rett Syndrome in 2013, is the inspiration behind his passion to do everything in his power to help find a cure for the 350,000 children and adults living with this devastating neurological disorder.

"I became an RSRT supporter shortly after Magnolia was diagnosed," says Tesler. "It was clear to me that this organization's goals, approach, and people are most likely to succeed in finding a cure. I'm honored to be joining the board, and I look forward with all my heart to the day when Magnolia and all afflicted can be freed from the grips of this disorder."

In addition to his dedication to the cause, Tesler will bring prodigious experience in venture capital and business to the board. Over the course of his career he was instrumental in the major growth of two separate private equity firms, first at Citicorp Investment Management (later known as Chancellor Capital Management), and then at Technology Crossover Ventures, which is now a leading provider of growth capital to information technology companies. Tesler also co-founded a non-profit, *The Restorative Neurological Clinic at Burke Medical Research Institute*, which pioneered the provision of advanced therapies with a "right to try" model that facilitated serving veterans for free. Marc and his wife Ellen have been very generous supporters of RSRT, becoming Roadmap Trailblazers in 2017.

"I'm thrilled that Marc has joined us as an RSRT trustee," says Tony Schoener, Chairman of the board. "His business acumen and wide-ranging experience, coupled with his strong personal connection to our cause will be invaluable to the board. His voice and perspective as a grandparent is also vital to ensuring that our attack on Rett Syndrome is multi-generational."

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About the Rett Syndrome Research Trust

The Rett Syndrome Research Trust (RSRT) is a nonprofit organization with a highly personal and urgent mission: a cure for Rett Syndrome and related MECP2 disorders. RSRT operates at the nexus of global scientific activity enabling advances in knowledge and driving innovative research. In March of 2017 RSRT announced *Roadmap to a Cure*, a three-year, $33 million strategic research plan. The plan, for which over $16 million has been pledged or contributed by generous donors, prioritizes four curative approaches with gene therapy as our lead program. In June of 2017 the biotechnology company, AveXis, announced its intent to advance RSRT's gene therapy program to clinical trials. Since 2008, RSRT has awarded $47 million to research. To learn more, please visit ***www.reverserett.org***

About Rett Syndrome

Rett Syndrome is a genetic childhood neurological disorder caused by random mutations of the *MECP2* gene on the X chromosome that affects predominantly girls but can rarely also affect boys. Its symptoms typically become apparent between the ages of 12 to 18 months. Rett Syndrome is devastating as it deprives young children of speech, hand use, and normal movement often including the ability to walk. As the children enter childhood the disorder brings anxiety, seizures, tremors, breathing difficulties, and severe gastrointestinal issues. While their bodies suffer, it is believed that their cognitive abilities remain largely intact. Although most children survive to adulthood, they require total round-the-clock care.