

Press Release:
Philanthropist Alba Tull Joins RSRT Board of
Trustees - Tull Family Foundation Contributes
\$500,000 to Speed to a Cure

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Media Contacts:

Monica Coenraads
Executive Director, RSRT
203.445.0041
monica@rsrt.org

Amy Prenner
The Prenner Group
310.709.1101
amy@theprennergroupp.com

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TRUMBULL, CT – The Rett Syndrome Research Trust (RSRT) is pleased to announce that Alba Tull has joined its Board of Trustees. Additionally, The Tull Family Foundation, the funding agency of Alba and her husband, has pledged a gift of \$500,000 to RSRT. The funding from the Foundation, which is based in the Los Angeles area, will facilitate innovative projects aimed at curing Rett Syndrome by targeting the very root of the disorder – the defective gene.

Inspired by a friend's two-year-old daughter who was diagnosed with Rett Syndrome, Alba was moved to help RSRT, a non-profit, in its mission to spur research that is leading to treatments and a cure for this devastating neurological disorder.

Rett Syndrome, which afflicts 350,000 worldwide, is caused by random mutations on the MECP2 gene located on the X chromosome. The disease almost exclusively strikes little girls and takes effect in toddler-hood following a normal infancy. As the cascade of Rett symptoms descends, children regress and lose acquired skills such as walking, talking and control of their hands. Scoliosis, extreme anxiety, tremors, seizures, hyperventilation and digestive problems are common. Imagine the symptoms of cerebral palsy, Parkinson's, epilepsy, and anxiety disorder all in one little girl and you can begin to understand Rett Syndrome. Tragically, girls and women with Rett understand what is happening around them but are locked in bodies that can't respond. Most Rett victims live into adulthood, requiring round-the-clock care.

"We are honored to be a part of finding a cure for the 350,000 girls and women who suffer from Rett Syndrome, including our dear friends' two year-old daughter, Sadie. We are confident that our contribution will make a meaningful difference to the Rett Syndrome Research Trust and these impactful projects, and I am delighted to take on an active role with the organization."

ALBA TULL

Trustee, RSRT

The funds contributed by the Tull Family Foundation will support RSRT initiatives that are bold and potentially curative. Specifically, the funds will bolster RSRT's *MECP2 Gene Therapy Consortium* as well as protein replacement and RNA editing efforts. Investigators working with RSRT on these approaches include **Brian Kaspar** at **Nationwide Children's Hospital**, **Steven Gray** at **University of North Carolina at Chapel Hill Medical School**, **Gail Mandel** at **Oregon Health & Science University**, and **Stuart Cobb** at the **University of Glasgow** as well as the biotech company, **Armagen**.

In 2007 Professor Adrian Bird of the University of Edinburgh and RSRT Trustee announced a landmark study that proved that symptoms of Rett are reversible in mouse models, even in late stage disease. This finding is corroborated by the fact that the disease does not lead to neurodegeneration.

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The Rett Syndrome Research Trust funds more research than any other Rett organization in the world. Since 2008, RSRT has awarded \$36 million to research projects in the US and abroad. An average of ninety-six percent of every dollar donated to RSRT goes directly to its research program.

"I know Alba's leadership on the RSRT board will be transformative to the organization and to the cause. Without a cure, my daughter will face a frightening future, one I cannot bear to think about. Propelled by the incredibly generous gift from The Tull Family Foundation, RSRT can pursue three promising studies that may yield the cure, reverse Sadie's symptoms and give her back the childhood she so deserves."

STEPHANIE BOHN

Mother of Sadie

Every two hours a girl is born with Rett Syndrome. After breast cancer, no other women's disease affects more people. RSRT is determined to enable the 350,000 heroic girls and women who battle debilitating symptoms every minute of their lives to reach their full potential.

"I couldn't be more thrilled that Alba will bring her ardor and leadership to the RSRT board to help us make Rett Syndrome a disease of the past. We believe that the greatest potential for profound recovery of symptoms lies in targeting the very genetic mutations that wreak such havoc. This can be done in a variety of ways. Since we do not know a priori which method will work best it is important to drive the projects forward aggressively and in parallel. The gift from The Tull Family Foundation allows us to do just that. I am incredibly grateful for this support."

MONICA COENRAADS

Executive Director, RSRT

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About the Rett Syndrome Research Trust

The Rett Syndrome Research Trust (RSRT) is a non-profit organization with a highly personal and urgent mission: a cure for Rett Syndrome and related *MECP2* disorders. In search of a cure and effective treatment options, RSRT operates at the nexus of global scientific activity. We enable advances in knowledge and drive innovative research through constant engagement with academic scientists, clinicians, industry, investors and affected families. These relationships catalyze the development and execution of a research agenda that neither academia nor industry could achieve alone. RSRT refutes the conventional practice of labs working in isolation, instead seeking out, promoting and funding collaborations and consortia in which scientists work across multiple disciplines. Since 2008, RSRT has awarded \$36 million to research projects. To learn more about the Trust, please visit www.ReverseRett.org.