rett syndrome research trust

Press Release:
British Partner Joins Board of Global Group Striving to Reverse Rett Syndrome

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

Media Contact:
Rachael Bloom
Executive Director, Reverse Rett UK
rachael@reverserett.org.uk
0161.955.4261

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Trumbull, CT/Manchester, UK — The Rett Syndrome Research Trust (RSRT) has appointed Rachael Bloom to its Board of Trustees. She is a founder and the Executive Director of its United Kingdom-based partner organization, Rett Syndrome Research Trust UK. Her appointment further solidifies the global reach of RSRT's mission to initiate and fund the most advanced Rett research worldwide.

Rett Syndrome causes a terrifying regression in children, robbing them of speech, normal movement and functional hand use. Caused by random mutations in an X-linked gene this autism spectrum disorder is characterized by disordered breathing, Parkinsonian tremors, severe anxiety, seizures, and digestive, circulatory, and orthopedic problems. Victims of Rett are predominantly little girls, some of whom do not survive Rett's many complications. Those who do, face a life of total dependency.

In 2007, RSRT Trustee, Professor Adrian Bird demonstrated that Rett Syndrome can be reversed even in late stages. This astonishing outcome fundamentally changed the course of research and reset the hopes and motivation of families everywhere.

"This is a global issue, not a national issue," says Bloom, whose daughter Amber, now seventeen, is wheelchair bound. "In every country, children with Rett Syndrome are suffering tremendously. This relentless disorder impacts children and the families who love them across all cultures and races. The more we unite to strategically and aggressively support the most promising avenues of research, the sooner we will all find a cure."

"We are delighted to welcome Rachael to our board," says Heidi Epstein, Vice-Chairman of the Board of RSRT and mother to 8-year old Hannah affected by Rett. "In 2012 RSRT committed $4.2 million to Rett research, the largest annual research commitment of any Rett non-profit worldwide. Last year the Rett Syndrome Research Trust UK donated $1 million to our research program – a substantial percentage of RSRT's overall commitment for the year. RSRT invests this money transparently, for the whole world to see, in the most advanced research now underway. We are proud of our cherished relationship with the Rett Syndrome Research Trust UK and with the Rett Syndrome Research & Treatment Foundation in Israel. In the months to come, we hope to develop similar partnerships with other countries."

About Rett Syndrome

Rett Syndrome is a genetic neurological disorder that almost exclusively affects girls. It strikes randomly, typically at the age of 12 to 18 months, and is caused by random mutations of the MECP2 gene on the X chromosome. Rett Syndrome is devastating as it deprives young girls of speech, hand use, normal movement often including the ability to walk. As the girls enter childhood the disorder brings anxiety, seizures, tremors, breathing difficulties, severe GI 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.

About the Rett Syndrome Research Trust

RSRT is a non-profit organization with a highly focused and urgent mission: eradicate Rett Syndrome and related MECP2 disorders. In search of a cure and effective treatment options, RSRT operates at the center of global scientific activity, funding bold projects that are unlikely to be supported by the NIH or other more traditional funding agencies. 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. These relationships enable the development and execution of a research agenda that neither academia nor industry could achieve alone. Since 2008, RSRT has provided $25 million of financial support to: 4 clinical trials testing 3 compounds, 33 scientists in 27 academic institutions and 3 biotech firms. To learn more about the Trust, please visit **www.ReverseRett.org**.

Our Partners

Our partners in supporting this work are parents' organizations worldwide including **Reverse Rett (UK)**, **Rett Syndrome Research & Treatment Foundation (Israel)**, **Skye Wellesley Foundation (UK)**, **Rett Syndrome & CDKL5 Ireland**, **Rett Syndrom Deutschland**, **Stichting Rett Syndrome (Holland)**.

Our U.S. partners that helped make this research possible include **Girl Power 2 Cure**, **Eva Fini Fund at RSRT**, **Kate Foundation for Rett Syndrome Research**, R**ocky Mountain Rett Association**, **Anastasi Fund**, **Claire's Crusade**, **New Jersey Rett Syndrome Association**, R**ett Syndrome Association of Massachusetts**, and the **MECP2 Duplication Syndrome Fund** at RSRT.