

Press Release: Rett Syndrome Research Trust Hires Program Director to Focus on Fundraising and Organization Growth

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Media Contact: Monica Coenraads Executive Director, RSRT monica@rsrt.org 203.445.0041 Rett Syndrome Research Trust Hires Program Director to Focus on Fundraising and Organization Growth

The Rett Syndrome Research Trust (RSRT) is pleased to announce that Tim Freeman, who has nearly 20 years of experience in fundraising, public relations, and strategic planning, began his new role on June 17th as RSRT's Program Director. Tim's four-year-old daughter, Eleanor, was diagnosed with Rett Syndrome in 2011, so RSRT's mission is of great personal importance to him.

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For the past seven years Tim has served in Princeton, New Jersey as head of the Development and External Relations Office at the Woodrow Wilson National Fellowship Foundation, which offers fellowships to math and science teachers. Tim was responsible for raising more than \$20 million a year, working with a 27-member Board of Trustees and leading grant writing, major gifts, research, annual fund, and events operations.

From 1996 to 2006, Tim worked at Columbia University's Teachers College, where he had numerous roles, including Director of Corporate and Foundation Relations and Executive Director of Strategic Initiatives. Tim played a major role in planning and implementing Teachers College's successful five-year \$160 million campaign. Proposals and program plans that he developed resulted in grants from most of the largest foundations in the country. He has led seminars for faculty, students, and staff at Columbia and other institutions on grant writing, fundraising, program creation, and the foundation funding process.

"On behalf of the Board of Trustees, I welcome Tim to RSRT. His extensive experience, coupled with his strong personal commitment, is a powerful combination," said Tony Schoener, the Chairman of the RSRT Board of Trustees. "We are fortunate that such a capable and dedicated person has taken on this newly created position in the organization, and have every confidence that together we will move RSRT to the next level in pursuit of our shared mission: to cure Rett Syndrome."

Before coming to Teachers College Tim was a professional classical musician and served as Assistant to the Dean at Manhattan School of Music. Tim grew up in suburban Philadelphia and graduated from Westtown School (1987). He holds a BA from Carleton College in Minnesota (1991), and an MA from Columbia University's Teachers College (1997). As Tim recently wrote in the RSRT blog, "I am tremendously grateful to Monica Coenraads, to the RSRT Board, and to all of you who contribute your time, energy, and resources to RSRT, for your confidence in me. I promise Eleanor and all of our daughters that I will do my best in everything I do for RSRT. I will need your help, advice, and counsel—most of you know RSRT and all of its accomplishments far better than I do—so I hope I can call on you. Please don't hesitate to contact me any time. My office line is 609.309.5676; my cell is 609.815.5102; and my email is tim@rsrt.org. I look forward to meeting you."

First Pre-Clinical Gene Therapy Study to Reverse Rett Symptoms

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.

About the MECP2 Consortium

The MECP2 Consortium, launched by the Rett Syndrome Research Trust in 2011, fosters novel alliances among leading scientists to interrogate the molecules at the root of Rett Syndrome and apply these discoveries to treatments. Consortium members include Adrian Bird of the University of Edinburgh, Michael Greenberg of Harvard University and Gail Mandel of Oregon Health and Sciences University.

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, Rocky Mountain Rett Association, Anastasi Fund, Claire's Crusade, New Jersey Rett Syndrome Association, Rett Syndrome Association of Massachusetts, and the MECP2 Duplication Syndrome Fund at RSRT.