Press Release:
RSRT Welcomes David Scheer and James Trainor to Advisory Council

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The Rett Syndrome Research Trust (RSRT) is very pleased to name David Scheer and James Trainor to our Professional Advisory Council, effective today. Mr. Trainor and Mr. Scheer join forces with other individuals whose talents support RSRT's mission to free children and adults of the devastating symptoms of Rett Syndrome.

The most physically disabling of the autism spectrum disorders, Rett Syndrome primarily affects girls, with symptoms usually beginning between six and eighteen months of age. What appears to be normal development slows or reverses, and children suffer a loss of motor and communication skills. Functional hand use is replaced by compulsive wringing or other stereotypies; autonomic nervous system abnormalities manifest in disturbed cardiac and breathing rhythms, circulation and digestion; orthopedic problems including weak bones and scoliosis are common. Various types of seizures may develop, some of which are resistant to treatment. Most children live into adulthood, often confined to wheelchairs, unable to speak or use their hands. They require lifelong, 24-hour-a-day care.

"When RSRT families and trustees bring people onto our team, we want them to match our level of passion in finding a cure for this disease," says RSRT Executive Director and Co-Founder Monica Coenraads, whose daughter was diagnosed with Rett Syndrome in 1998. "We see that passion in David and Jim. They are donating their time because they see value in the work we do, and we are very grateful."

David Scheer is president of New Haven-based Scheer & Company, Inc, a science advisory and venture capital firm. After receiving his degree from Harvard in biochemical sciences he went on to graduate work in molecular biology at Yale before entering the business world. He has worked as a serial entrepreneur building life science companies and has served as an advisor in the field for more than 30 years. Among the portfolio of companies he has founded is Aegerion Pharmaceuticals, which focuses on rare genetic disorders. He is Chairman of the Board of this publicly held company, which is advancing a drug towards commercialization for homozygous familial hypercholesterolemia (HoFH) patients. He also has broad cultural interests and is a member of the Board of Trustees and Vice-Chair for the Long Wharf Theatre in New Haven.

Until recently, he says, he had little knowledge of Rett Syndrome. "My next-door neighbor has a granddaughter with Rett. He knew I had a background in rare diseases and introduced me to Monica earlier this year. We began to talk, and I was extremely impressed by her level of scientific expertise and the network she has built and the research that she and RSRT has supported. Our conversation has continued ever since that day."

Rett Syndrome is caused by mutations of the gene MECP2. This discovery was made in 1999 in the laboratory of RSRT scientific advisor Huda Zoghbi, M.D., a Howard Hughes
Investigator at Baylor College of Medicine and head of the new Jan and Dan Duncan Neurological Research Institute in Houston. In 2007, RSRT trustee Adrian Bird, Ph.D., of the University of Edinburgh demonstrated the groundbreaking reversal of Rett Syndrome in fully symptomatic adult mouse models.

"The fact that Rett Syndrome is a single-gene disorder that can be mimicked in a mouse makes it scientifically tractable, and it has attracted exceptionally talented and accomplished people in the neuroscience field," Scheer says. "And since Rett Syndrome is related to autism there are collateral benefits with research in that arena. We have every reason to be optimistic."

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James Trainor is a partner at the New York law firm White & Case, where he has practiced since 2000. He is an intellectual property lawyer specializing in the biotechnology and pharmaceutical industries. “Since I’ve been at White & Case, I’ve been committed to keeping at least one pro bono matter on my desk at all times,” he says. He had just completed a long-term project when his colleague and RSRT advisory council member Jason Rothschild approached him with a new one. “Jason knocked on my door and said he‘d heard I had experience with intellectual property transactions at academic institutions, and he asked whether I would like to help RSRT.”

Mr. Trainor was unfamiliar with Rett Syndrome. “But Jason’s daughter has this condition, and I found her story extremely compelling.” After that meeting, he did his homework on the disease and met Monica Coenraads. “Monica was inspiring. She has remarkable positivity. She is so committed as a professional that you often forget the impetus is her very own daughter.”

As a board member Mr. Trainor will keep RSRT protected legally and will also do his best to move promising research forward. “Stories are legion where science doesn’t progress for all the wrong reasons,” he says. “I want make sure that doesn’t happen for the Trust by seeing to it that their interests are constantly protected, such that no single advance that the Trust made possible can be hampered from further development.”

Monica Coenraads says the success of the RSRT mission depends on recruiting creative advisors like David Scheer and James Trainor, just like attracting first-rate employees makes a business thrive.

“It’s difficult to overestimate the impact that David and Jim will have on growing our organization,” she says. “David knows the biotech world inside out and understands what great possibilities lie in the science right now. Jim has superb legal expertise in the intellectual property field, which will become increasingly important as drug development for Rett progresses. I am delighted to welcome them both.”

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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.