

Press Release:
Building on Progress Reversing Childhood
Neurological Disease, Rett Syndrome
Research Trust Establishes Professional
Advisory Council

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

Building on Progress Reversing Childhood Neurological Disease, Rett Syndrome Research Trust Establishes Professional Advisory Council



The Rett Syndrome Research Trust (RSRT) announced today the creation of a Professional Advisory Council in support of RSRT's goal of curing Rett Syndrome. The severe neurological damage of this childhood disorder was recently shown to be reversible in a dramatic proof-of-concept experiment. The Trust is pleased to welcome James and Ann Gianopulos, Jonathan Epstein, Stephen Levit, Doris Tulcin, and Lord Christopher Wellesley – an outstanding group of individuals who have generously agreed to take on our cause.

Rett Syndrome is the most physically disabling of the autism spectrum disorders. Primarily affecting little girls, it usually strikes by 18 months of age, often just after a child has learned to walk and talk. As Rett's grim symptoms descend, she loses acquired skills, normal movement and speech, and begins the long regression that may leave her in a wheelchair, unable to communicate or use her hands. Extreme anxiety, Parkinson-like tremors, and orthopedic problems are common. Many children have intractable seizures. Some must be fed through tubes. Breathing, cardiac, circulatory and digestive functions are impaired. Most children live to adulthood, requiring total, 24-hour-a-day care.

RSRT Executive Director Monica Coenraads said, "Two years ago, RSRT Trustee Professor Adrian Bird reversed Rett Syndrome symptoms in mice. Launched in the wake of this unexpected result, RSRT has a singular focus – to make Rett Syndrome the first reversible brain disorder. Our children cannot wait decades for a cure. We are indebted to our newly appointed advisory council members, Ann and Jim Gianopulos, Jonathan Epstein, Doris Tulcin, Lord Wellesley and Stephen Levit for sharing their talents in pursuit of our mission."

RSRT is extremely honored by the gracious participation of Ann and Jim Gianopulos. They learned of Rett Syndrome through their friendship with RSRT trustee Heidi Epstein and her husband Jonathan, parents of a recently diagnosed little girl.

"Hannah has captured our hearts. We were saddened to learn of her diagnosis, but deeply moved by the promise of a cure. We are impressed with the intellectual capital behind the Rett Syndrome Research Trust and are fully committed to supporting their mission", said Ann. Determined to raise funds to accelerate the timeline to treatments and cures, Ann and Jim will be hosting an event in their home this fall in support of RSRT's portfolio of research projects.

Mr. Gianopulos, Chairman and CEO of Fox Filmed Entertainment, oversees all of the feature film and television production, marketing and distribution activities of the Fox Entertainment Group, as well as the studio's activities in home video, television distribution, and all media and technologies. Among many notable successes of his tenure are the Oscar winners Titanic and Braveheart, in addition to the phenomenon of simultaneously having four of the top five all-time grossing pictures internationally: Titanic, Star Wars, Independence Day and Star Wars: Episode 1 – The Phantom Menace.

Ann Gianopulos shifted her focus in 2002 from the film industry to raising three children. Along with working as a marketing consultant for Amplitude Consulting, specializing in eco-friendly, "green" marketing, she gives her free time to help charities and community organizations whenever possible. These include The Help Group, the Byzantine-Latino Quarter Foundation, The Cambodian Children's Fund, and various school efforts.

Jonathan Epstein, a partner and President of Hackman Capital Partners, joins his friends, the Gianopuloses, on the Advisory Council. "On the day of Hannah's diagnosis, Heidi and I began a quest to identify and support the world's best Rett science. After meeting with leading scientists in the field, including Professors Adrian Bird and Huda Zoghbi, we determined that our goals were aligned with the mission of the Rett Syndrome Research Trust. The Trust's laser focus on research and extensive network within the scientific community is the best chance our daughter has at a better future," said Jonathan.

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Doris Tulcin, the extraordinary founder of the Cystic Fibrosis Foundation and Chairman Emeritus of CFF's Board of Trustees joins our Council, bringing decades of non-profit expertise to the Trust. The CFF set the gold standard for how non-profits can drive drug development for a rare disease. We are grateful to count her as a treasured advisor. Mrs. Tulcin said, "I am so proud of Monica Coenraads, Executive Director of the Trust, and what she has been able to accomplish in such a short time. I know what it is to be a parent personally driven by the need to relieve a child's suffering, and I know that the unique tenacity and devotion she brings to this cause will lead to finding the answers."

Lord Christopher Wellesley, another new parent strongly committed to research, joins us from across the pond. His young daughter Skye was diagnosed with Rett Syndrome last year. He and his wife Emma have created the Skye Wellesley Foundation, a registered UK charity. The Foundation will channel all research proceeds to RSRT. Lord Wellesley, who is the son of the Duke of Wellington, said, "We can't bear to imagine Skye trapped by Rett Syndrome for her entire life. Research is the key to unlocking her future. We know the leadership of RSRT feels the same urgency, and this is reflected in every aspect of the Trust."

Stephen Levit is Executive Vice President and Chief Creative Officer for McCann Los Angeles/Detroit. Stephen was introduced to Rett Syndrome in the fall of 2008 when the daughter of close family friends was diagnosed. We welcome his tremendous marketing savvy.

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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](#), [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.