

For Immediate Release

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Unraveling the Mysteries of Rett Syndrome and the Brain

6th World Rett Syndrome Congress gathers researchers from around the globe

PARIS (Oct. 7, 2008) -- Could new findings about Rett syndrome lead the way in developing new techniques for unraveling other diseases that affect the brain? October is Rett Syndrome Awareness Month, and over 800 of the world's leading Rett Syndrome researchers, clinicians, organizations and families will meet at the Maison de la Mutualie, Paris October 10 -13 for the 6th World Rett Syndrome Congress hosted by Professor Philippe Evrard, who leads a research department in neurosciences in brain development and neuroprotection and sponsored by The International Rett Syndrome Foundation. This congress is expected to be the largest, most comprehensive meeting of its kind. These distinguished scientists and thought leaders will gather together to discuss the development of treatments and cures for Rett syndrome and other spectrum disorders. Many believe that with an aggressive and focused research strategy, Rett syndrome may be the first brain disorder to be reversed.

"Rett syndrome could indeed prove the Rosetta Stone, allowing scientists to develop techniques for understanding the effects of other mutant proteins that affect neurons," said Dr. Laura Mamounas, program director for the National Institute of Neurological Diseases and Stroke (NINDS) at the National Institutes of Health. The NINDS is a US federal agency that supports research on Rett syndrome. "People with disorders from autism to Fragile X could benefit from findings in the area of Rett, an autism spectrum disorder affecting mainly females."

In 1999, Dr. Huda Zoghbi, professor of pediatrics, neurology, neuroscience and molecular and human genetics at Baylor College of Medicine in Houston found the Rett gene responsible for the production of MeCP2, a protein that affects the function of nearly every neuron in the brain.

In 2007, a team of researchers led by Dr. Adrian Bird at Edinburgh University reversed Rett Syndrome symptoms in a mouse bred to display many of the outward signs of the disorder. While his technique is not applicable in the human disease, it did show that it is possible to reverse the damaging symptoms of the disease.

"Since this discovery there has been a sea change in attitude about the way we think about neurological disorders. This seminal discovery supports the view that perhaps Rett is a neurological disorder that could possibly be treated by therapeutic interventions," said Dr. Mamounas. "Until now, we hoped that was the case, but did not have concrete scientific evidence to support this idea. This has all changed."

Genetic similarities between Rett and other neurological and brain disorders mean that it may be possible to reverse some neurological conditions thought untreatable before. According to Dr. Tony Horton, Chief Scientific Officer of the International Rett Syndrome Foundation, the world's largest private funder of Rett syndrome research, "The major challenge now is to lay the foundation for translating these recent exciting discoveries into the development and testing of new therapeutics which could one day be used to treat Rett syndrome and perhaps other related disorders. This is our current focus."

"The breadth and scope of this congress will be a first for Rett syndrome and related spectrum disorders," according to Dr. Helen Leonard, an Australian researcher and head of the program committee for the World Congress, "It will extend from a detailed exploration of the neurobiology of Rett syndrome, particularly incorporating the work being done on mouse models to basic clinical and epidemiological research relating clinical presentation to genetic determinants. We have reason to hope."

About Rett Syndrome

Rett syndrome (RTT), a brain disorder affecting development in childhood, has been identified almost exclusively in females. RTT results in severe movement and communication problems following apparently normal development for the first six months of life. The characteristic features include loss of speech and purposeful hand use, occurrence of repetitive hand movements, abnormal walking, abnormal breathing, and slowing in the rate of head growth. Current treatment for girls with RS includes physical and occupational therapy, speech therapy, and medication for seizures. No cure for Rett syndrome is known. In 2008, researchers heralded a major breakthrough by reversing RTT symptoms in mouse models. Rett syndrome is recognized as the "Rosetta Stone" of other neurological disorders, with genetic links to other disorders like autism and schizophrenia. It is the most physically disabling of the autism spectrum disorders.

About International Rett Syndrome Foundation

IRSF is the world's leading private funder of basic, translational and clinical Rett syndrome research and is the most comprehensive non-profit organization dedicated to providing thorough and accurate information about Rett syndrome, offering informational and emotional family support, and stimulating research aimed at accelerating treatments and a cure for Rett syndrome and related disorders. To learn more about IRSF and Rett syndrome, visit www.rettsyndrome.org or call IRSF at 1-800-818-RETT.