

WASHINGTON, DC - Congressman Steny Hoyer today congratulated researchers at Toronto's Hospital for Sick Children, the Center for Addiction and Mental Health and the University of Toronto, for identifying a new form of the protein MECP2 which regulates the complex expression of Rett Syndrome (RS) and other neurological disorders including autism, childhood schizophrenia and some forms of mental retardation. This research is reported in the April issue of the journal Nature Genetics, which recently became available online. Congressman Hoyer has been a leader in Congress on Rett Syndrome for over a decade.

"Over 15 years ago, I first met Kristi, a young girl in my church with Rett Syndrome," said Hoyer. "Meeting Kristi, and her father, Allen, changed the course of my work. Allen introduced me to Kathy Hunter, President and Founder of IRSA, and I have worked with Kathy to obtain research dollars at the National Institutes of Health. Together, we worked to increase funding for research at the NIH on this unique and puzzling neurological disorder that affects one in every 10,000 girls.

"This most recent discovery is an illustration of how this federal investment will have an impact on thousands of children afflicted with RS and I am thrilled that I have been able to work with Kathy and the International Rett Syndrome Association to leverage almost \$40 million in funding between 1986 and 2004 for research on Rett Syndrome at the NIH.

"We have made significant progress in our pursuit of learning how to treat and, perhaps, prevent RS in the near future. In 1999, Dr. Huda Zoghbi discovered the gene for Rett Syndrome and the discovery we celebrate this month marks another tremendous advancement in our understanding of RS. I will continue to advocate for research funding to ensure that these advancements continue.

"I want to congratulate IRSA and the biomedical researchers for their continued commitment to this important issue. There really is no cause greater than the health and happiness of our children, our 'Kristis,'" added Hoyer.

"The previously identified gene MECP2 was only found in approximately 80% of Rett Syndrome patients," said Dr. Berge Minassian, the study's principal investigator, a neurologist and scientist at Toronto's Hospital for Sick Children and an Assistant Professor in the Department of Pediatrics at the University of Toronto. "Our discovery suggests that a defective alternate form of the MECP2 gene causes Rett Syndrome."

Kathy Hunter, Founder and President of the International Rett Syndrome Association, applauded the new research and emphasized the critical importance of supporting more research immediately. “This is truly an exciting time for Rett Syndrome research and is a major leap forward in our understanding of how MECP2 works in the nervous system. This critical discovery may be put into immediate practice. This finding will gladden the hearts of the thousands of families that must meet the challenges of Rett Syndrome everyday. It brings us all hope that we are closer to finding answers that can ease our struggles.”

Rett Syndrome is a neurological disorder seen almost exclusively in females and is genetically linked to more widespread neurological disorders such as autism and schizophrenia. Children with RS usually shows an early period of apparently normal or near normal development until 6-18 months of life and eventually incapacitates the afflicted children so that they cannot survive without constant care. The disorder causes seizures, respiratory and gastrointestinal abnormalities, and a variety of muscular and motor impairments.

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