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## **Have You Heard of Rett Syndrome?**

**Celebrate Rett Syndrome Awareness Month and Help Get Closer to a Cure**

Cincinnati, OH-The International Rett Syndrome Foundation (IRSF) would like to announce the onset of October as Rett Syndrome Awareness month. National Rett Syndrome awareness month is an opportunity to educate on the leading genetic cause of severe impairment in girls. We hope you will join us in efforts to raise awareness about Rett syndrome and support the efforts that are in place to facilitate Rett syndrome research and advancements on a search for a cure and treatments.

Have you heard of Rett syndrome? Rett syndrome is the only autism spectrum disorder with a known genetic cause. It is often misdiagnosed as autism or cerebral palsy. Rett Syndrome strikes without warning. The girl with Rett syndrome starts out as a happy, healthy baby until 12-18 months of life. Then something goes terribly wrong. She loses the ability to speak. She can't use her hands to play with toys, feed herself or wave hello. She may lose the ability to walk, she makes constant hand washing or hand wringing movements. By the time she is 3 years old, the girl with Rett syndrome is severely handicapped. The genetic mutation that causes Rett syndrome was found in 1999 and in 2007 researchers reversed the symptoms of Rett syndrome in mice models. Research is urgently needed to bring about treatments and a cure for this devastating disorder.

In honor of this exciting time, IRSF and MRSRA are conducting numerous projects to spur awareness throughout the community. Country music sensation Clint Black, the uncle of a girl who recently lost her battle to Rett syndrome, will be participating in a series of public service announcements highlighting the importance of wiping out Rett syndrome. Additionally, IRSF will host its 12<sup>th</sup> annual Phantom Tea Fundraiser and we are excited to announce the first online fund raising effort, "The Care and Cure Café!" To make it easier to give to the special Rett angel in your life we have moved the café online. Participating is easy, just log onto the website at [www.rett syndrome.org](http://www.rett syndrome.org) select the Cure Café, choose the Rett angel of your choice and dedicate a special toast and donation in her honor. Locally, Gillette Children's Hospital of Saint Paul will be partnering with MRSRA to host an event, details to follow.

We hope you will join us in towns and cities all over the world as we share a cup of joe or tea, whatever you choose, and toast to the cure for Rett syndrome. We hope to have a very large group of people around the world toasting in celebration of Rett Syndrome awareness month.

It is not too late to make a difference this October by raising awareness of Rett syndrome and how it impacts thousands of lives around the world. If you think you recognize these symptoms, want to help, or for more information about Rett syndrome, please call 1-800-818-RETT or visit [www.rett syndrome.org](http://www.rett syndrome.org).

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**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.

**About International Rett Syndrome Foundation**

IRSF is the world's leading private funder of basic 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](http://www.rettsyndrome.org) or call IRSF at 1-800-818-RETT.