

History

The International Rett Syndrome Foundation (IRSF) was formed on July 1st, 2007 when the International Rett Syndrome Association (IRSA) and the Rett Syndrome Research Fund (RSRF) consolidated resources in a historic merger.

The International Rett Syndrome Association was formed in 1984 when a determined group of parents (led by Kathy Hunter) banded together to try to fund research for cures and treatments, support other families with Rett syndrome, and raise public awareness. Over the years the organization raised tremendous public awareness, brought life-changing care to families, and helped foster and fund some significant research breakthroughs (including the discovery of the MECP2 gene that causes Rett syndrome).

The Rett Syndrome Research Foundation was formed in 1999 by a passionate group of parents who wanted to more aggressively and exclusively pursue biomedical research to accelerate the discovery of treatments and a cure. Their achievements in funding new research, bolstering strategic studies, unifying and focusing the research community, and expanding the scope of knowledge was unsurpassed (including the discovery that the most symptoms of Rett syndrome may one day be reversed).

Both organizations had a proud and illustrious history of making significant progress towards bringing answers, insight, and care for loved ones with Rett syndrome; however, although both organizations were fighting for the same cause there were sometimes redundancies and challenges in creating unity with all the communities.

It became clear that, since Rett syndrome is such a rare disorder and that resources were limited, a more unified effort to the challenges was the wiser and more strategic course of action. In other words, by working together the community could get more done in less time. This philosophy spurred the leaders of both organizations to come together and discuss the potential of a single, unified organization.

It was quickly apparent that, at their core, both sides shared a similar mission: curing Rett syndrome and helping improved those living with Rett syndrome's overall quality of life.

The response from the Rett syndrome community was overwhelmingly positive and supportive.

On June 4, 2007 the following announcement was released to the press:

International Rett Syndrome Association and
Rett Syndrome Research Foundation

Announce Merger Agreement to Form

International Rett Syndrome Foundation

New Organization to Focus on Research, Family Support, Awareness and Advocacy

Cincinnati, Ohio - The International Rett Syndrome Association (IRSA) and the Rett Syndrome Research Foundation (RSRF) today announced the intent to merge their organizations to form the International Rett Syndrome Foundation (IRSF).

"The rapid increase in scientific knowledge and pace of innovation in the field of Rett syndrome research and treatment call for increased coordination, increased funding and the development of a solid, comprehensive research repository," said Kathryn Schanen Kissam, chairman of the board of IRSA. "By joining forces, we are able to combine the unique expertise of IRSA and RSRF to better serve children with Rett syndrome and their families."

"Both RSRF and IRSA have made significant contributions to the advancement of understanding in Rett syndrome," said Steve Gallucci, chairman of the board of RSRF. "We are looking forward to the many opportunities that will develop from the merging of our organizations and our mutual determination to make a meaningful difference in the lives of those who have been touched by Rett syndrome."

The merger, which has been unanimously approved by both organizations' boards, is expected to close around July 1 following the completion of appropriate due diligence and a two-thirds vote of approval by IRSA's members. IRSA will declare a special membership meeting to be held at IRSA's offices on June 27 at 9:00 a.m.; a proxy vote will be mailed to all members on June 4.

"I applaud the members of the governing boards of IRSA and RSRF for their hard work and due diligence at this pivotal point in the history of Rett syndrome. It has been my privilege to initiate the Rett syndrome movement, and my greatest honor to see others who share the same determination and passion join the cause," said Kathy Hunter, president and founder of IRSA. Hunter, who will retire from her full-time staff position with IRSA when the merger is complete, will continue to work for the new organization in a part-time position as Ambassador, continuing to provide ongoing support services to families.

The core mission of IRSF will be to fund research for treatments and a cure for Rett syndrome and to enhance the overall quality of life for those living with Rett syndrome by providing information, programs and services. IRSF will also place great importance on advocacy and raising awareness about individuals with Rett syndrome so the scientific and medical communities, along with policy-makers, educators, caregivers and the general public, are better informed about Rett syndrome and motivated to help research efforts.

Chuck Curley, the executive director of RSRF, will be the future executive director of IRSF. Curley cited the critical progress made by a recent landmark study, in which the symptoms of Rett syndrome (RTT) were reversed in a genetic mouse model, as one example of the types of critical research IRSF will support in the future.

"Continuing research to find a cure and treatments for Rett syndrome is absolutely imperative, but also expensive," Curley said. "This merger empowers us to leverage significant revenue growth created by shared fundraisers, collaborative minds, broader resources and combined best practices to create one strong, unified leader in the search for a cure while providing support services to families impacted by this disorder."

The IRSF board of directors will be formed with six people chosen by IRSA's board and six chosen from RSRF's board. Kissam will serve as chairman of IRSF. As noted, Curley will serve as Executive Director of IRSF. Other executive staff appointments include Monica Coenraads, who will serve as Biomedical Research Director, and Paige Nues, who will serve as Family Support Director.

IRSF's executive offices will be located at the RSRF location in Cincinnati, Ohio, with family support services operating from IRSA's office in Clinton, MD. IRSF's web site will be www.rettssyndrome.org.

About Rett Syndrome

Rett syndrome is a neurological disorder which predominately impacts girls. While there are nearly 4,000 known cases of Rett syndrome in the United States, the disorder is genetically linked to more widespread neurological disorders such as autism, mental retardation and schizophrenia. Rett symptoms begin to manifest between the first six to eighteen months of life and eventually incapacitates the affected 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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