

International Rett Syndrome Foundation Expands Center of Excellence Clinic Network

Three additional clinics recognized for best-in-class Rett syndrome care.

CINCINNATI, OHIO, UNITED STATES, July 11, 2024 /EINPresswire.com/ -- The [International Rett Syndrome Foundation \(IRSF\)](#) proudly announces the designation of three new clinics as Centers of Excellence (COE). Nicklaus Children's Hospital in Miami, Rady Children's Hospital-San Diego, and Children's Hospital of Orange County

have each been recognized for their exemplary clinical care for Rett syndrome, a rare neurological and developmental disorder. This prestigious designation includes funding support from IRSF and integration into IRSF's Center of Excellence Network, which now comprises 21 clinics.



Seeing this network expand is essential in making treatment options and curative therapies a reality for all families living with Rett syndrome."

Melissa Kennedy, IRSF CEO

As a rare disease, it is common for families to have to travel to access a physician knowledgeable about Rett syndrome. IRSF's Center of Excellence network helps to identify go-to clinics for families and educate other physicians about Rett syndrome care.

"It's our goal that the vast majority of families affected by Rett syndrome have access to expert care within driving

distance of their homes," said IRSF CEO Melissa Kennedy. "These Centers of Excellence provide an expert-level of clinical care that allows Rett patients to thrive. Seeing this network expand is essential in making treatment options and curative therapies a reality for all families living with Rett syndrome."

To achieve the Center of Excellence designation, clinics must demonstrate compliance with criteria established by IRSF's Medical Advisory Board, including:

- Maintaining a physician director with expertise in Rett syndrome care



- Providing healthcare services that meet the unique needs of individuals with Rett
- Participating in Rett syndrome clinical trials
- Contributing to the IRSF Rett Syndrome Registry to increase understanding of the disorder and support drug development

The three-year designation officially commenced on June 1 for the new clinics, who join 18 other clinics across the United States whose designation was renewed.

"We are honored to once again receive COE designation from IRSF. Since our inception, our clinic has been committed to improving the quality of life for children with Rett syndrome

and their families through comprehensive multidisciplinary care and clinical and translational research," shared Cary Fu, MD, Director of the Rett Clinic at Vanderbilt University which received renewed designation. "We share in IRSF's mission to improve care today while laying the foundation for better treatments in the future. We look forward to our continued partnership with IRSF and the other COEs as we work in unison on better care for Rett syndrome today and a cure tomorrow."

To learn more about Rett syndrome and IRSF's Centers of Excellence, please visit rettsyndrome.org/COE.

About Rett Syndrome

Rett syndrome is a rare genetic neurological disorder that occurs almost exclusively in girls (1 in 10,000 births), more rarely in boys, and leads to severe impairments, affecting nearly every aspect of life. Rett syndrome is usually recognized in children between 6 to 18 months as they begin to miss developmental milestones or lose abilities they have gained, including their ability to speak, walk, eat, and even breathe. The hallmark of Rett syndrome is near constant repetitive hand movements while awake, and individuals with Rett may experience seizures, scoliosis, breathing issues, GI issues, and more. Rett syndrome is not a degenerative disorder; individuals can live to middle age or beyond. There is no treatment currently available for Rett syndrome.

About International Rett Syndrome Foundation (IRSF)

As the leading Rett syndrome research and advocacy organization, the International Rett



The IRSF Center of Excellence seal

Syndrome Foundation (IRSF) builds upon its 40-year commitment to breakthrough discoveries and life-changing advancements in research toward a cure while supporting families affected by Rett syndrome. Through its legacy foundation pioneers, IRSF has invested over \$58M in research leading to identifying Rett syndrome's cause, proving Rett syndrome is reversible in mice, and developing multiple clinical trials for Rett syndrome. IRSF fights for families living with Rett syndrome and a world without it. Learn more at www.rettsyndrome.org.

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