

International Rett Syndrome Foundation Announces Expansion of Scientific Leadership

The new leadership appointments include a key promotion and new hire to advance research and clinical development for Rett syndrome.

CINCINNATI, OHIO, UNITED STATES, July 2, 2024 /EINPresswire.com/ -- The [International Rett Syndrome Foundation \(IRSF\)](#) is pleased to announce a pivotal restructuring of its scientific leadership team to further its mission of accelerating research and therapeutic advancements for Rett syndrome. Dr. Nupur Garg has been promoted to Vice President of Research, and Dr. Drew Jones has joined the Foundation as the new Vice President of Clinical Development.



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Melissa Kennedy, IRSF CEO

Dr. Nupur Garg has a long-standing commitment to the rare disease space, bringing extensive experience in managing funding programs aimed at advancing basic and translational research. She holds a PhD in Biochemistry and Molecular Biology from the University of Medicine and Dentistry of New Jersey (UMDNJ), and Rutgers, The State University of New Jersey. Dr. Garg’s career began as Director of Research at the Jain Foundation, focusing on Limb Girdle Muscular Dystrophy 2B (LGMD2B), and continued as Program Director for the Lymphatic Malformation Institute. Most recently, she worked at AGC

Biologics in Business Development Operations before joining IRSF in 2022 as the Director of Research.

“It is an honor to be part of the IRSF team and take on this expanded role leading our research initiatives,” said Dr. Garg. “I am excited to continue to work with the research community to not only expand our knowledge of Rett syndrome but advance treatments and cures. I am grateful for the opportunity to directly support the researchers who make such a difference in this

community.”

Dr. Drew Jones joins IRSF with over 25 years of clinical development and medical affairs experience in both private and NASDAQ-listed biotechnology companies. He holds an MD from East Carolina University School of Medicine and an MPH from the University of North Carolina. His broad therapeutic experience spans areas including GI, CNS/Neuropsychiatry, and rare diseases, with a notable focus on gene therapy work in Spinal Muscular Atrophy, Giant Axonal Neuropathy, and Rett Syndrome. Prior to joining IRSF, Dr. Jones was Senior Director of Clinical and Strategic Planning at SSI Strategy.

“I am pleased to join the talented team at IRSF,” said Dr. Jones. “Being able to work with industry partners, clinicians, and families all while guiding our clinical network is truly a privilege. My goal is to have a meaningful impact both on the scientific front of Rett syndrome as well as the growth of the clinical network and data registry, which will speed the process of bringing life-changing treatment to families. I'm excited to get started.”

CEO Melissa Kennedy on the New Appointments

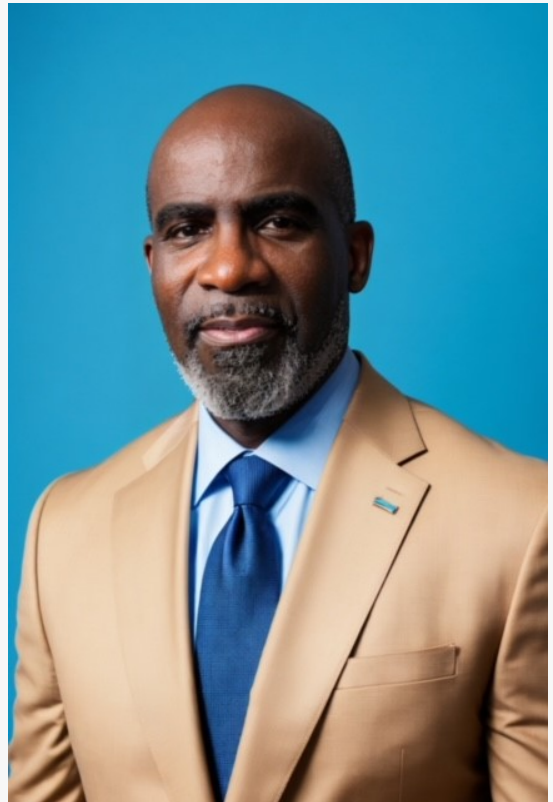
“With the dramatic advancements in Rett research these past few years, IRSF believes that this expansion will better serve our Rett syndrome community, bringing more treatments more quickly to those who are living with Rett syndrome,” said IRSF CEO Melissa Kennedy. “I am so thrilled to have the expertise and leadership of Drs. Garg and Jones on our team as we continue to expand our scientific strategy to seek out solutions for all.”

2024 IRSF Rett Syndrome Scientific Meeting

The announcement of the new team structure coincided with the first day of the [annual IRSF Rett Syndrome Scientific Meeting](#) on June 18,



Dr. Nupur Garg, VP of Research at IRSF



Dr. Drew Jones, newly appointed VP of Clinical Development at IRSF

2024. This event, led by Dr. Garg and marking Dr. Jones' official introduction to the Rett syndrome community, brought together over 200 scientists, researchers, industry professionals, and governmental representatives from around the world. The two-day meeting is the only global and comprehensive research event focused exclusively on Rett syndrome, facilitating the sharing of the latest research advances and promoting collaboration to accelerate the translation of lab findings to clinical applications.

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 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 rettsyndrome.org.

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