

International Rett Syndrome Foundation Welcomes Parthy Evans and Steve Marconi to Board of Directors

CINCINNATI, OHIO, UNITED STATES, August 21, 2024 /EINPresswire.com/ --The International Rett Syndrome Foundation (IRSF), a leading patient advocacy foundation dedicated to funding research and supporting families affected by Rett syndrome, is pleased to announce the appointment of Parthy Evans and Steve Marconi to its Board of Directors, effective July 1, 2024.



"We are thrilled to welcome Parthy Evans and Steve Marconi to our Board," said Melissa Kennedy, Chief Executive Officer of IRSF. "Their extensive professional expertise, combined with their personal connections to Rett syndrome, make them uniquely suited to help drive our

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Parthy Evans, Esq., brings over three decades of leadership experience from her service on non-profit boards, large law firm leadership, and professional associations. As a partner at one of the nation's largest law firms, she served on the Board of Directors, chaired the Client Development Committee, and led the Environment and Natural Resources Practice Group. She has also held significant

leadership roles within the American Bar Association, including chairing the Section of Environment, Energy and Resources and serving on the Standing Committee on Membership and the Special Commission on Women in the Profession.

Evans' granddaughter Vivian was diagnosed with Rett syndrome in 2019 at 13 months old. Since then, she has dedicated herself to supporting Vivian's parents and fundraising for IRSF. "I am

honored to join the IRSF Board of Directors and contribute to the incredible work being done to support families and advance research," said Evans. "As a grandmother to a beautiful granddaughter with Rett syndrome, I am deeply committed to supporting the foundation's mission and helping to find a cure."

Steve Marconi, CPA, is an Audit Partner at Rogers & Company, bringing 16 years of public accounting experience focused on the nonprofit sector. He provides audit, accounting, and advisory services to a diverse array of associations, charities, foundations, and other exempt organizations. Marconi's expertise includes overseeing financial statement audits under both U.S. and international standards, Uniform Guidance audits, and grant audits for various foreign agencies.

Marconi has been actively involved with IRSF since his daughter Charlotte's diagnosis in 2020, hosting an annual Rett Racers fundraiser and meeting with elected officials in D.C. to advocate for Rett research funding. "My family's journey with Rett syndrome has inspired me to take on a more active role within the IRSF community," said Marconi. "I look forward to leveraging my professional skills and personal experience to support the foundation's goals and make a meaningful impact for families like ours."

For more information, visit rettsyndrome.org.



Parthy Evans, Esq.



Steve Marconi, CPA

About Rett Syndrome

Rett syndrome is a rare genetic neurological disorder that occurs most often 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.

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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