International Rett Syndrome Foundation Names Laura Hameed as Chief Executive Officer

Accomplished nonprofit and biotech leader brings decades of rare disease experience to guide IRSF's next chapter of impact and growth.

CINCINNATI, OH, UNITED STATES, April 15, 2025 /EINPresswire.com/ -- The International Rett Syndrome Foundation (IRSF), the leading nonprofit organization dedicated to accelerating research and empowering families affected by Rett syndrome, is proud to announce Laura Hameed as its new Chief Executive Officer. A nationally recognized leader in rare disease and nonprofit innovation and growth, Hameed brings extensive experience leading mission-driven organizations, building high-impact partnerships, and expanding access to life-changing treatments.

> [Laura's] unique blend of scientific insight, policy experience, and deep compassion makes her exceptionally well-suited to lead IRSF forward."
>
> *David Pass, PharmD, IRSF Board Chair*

"I'm humbled and energized to join IRSF and lead this extraordinary organization into its next chapter," said Hameed. "The Rett community is courageous, resilient, and deeply deserving of progress. Together—with researchers, industry, families, and advocates—we have an opportunity to accelerate hope and turn possibility into reality."

Hameed most recently served as Executive Director of CureDuchenne, overseeing transformative organizational initiatives, developing strategy for an Impact Investment Fund, and strengthening relationships with families, industry leaders, and regulators alike. Her career spans executive roles in nonprofit gene therapy and biotech startups, where she helped advance multiple ultra-rare disease programs from research through clinical trial readiness. She also brings a background in public service, including serving in the Minnesota House of Representatives and as a University of Minnesota Regent.

"We knew from the outset that finding the right leader for this next chapter would be critical," said David Pass, PharmD, Chair of the IRSF Board of Directors. "Laura brings a proven track record of empowering families and advancing therapies from the lab to the clinic. Her unique blend of scientific insight, policy experience, and deep compassion makes her exceptionally well-suited to lead IRSF forward. The Board is incredibly excited about what lies ahead."

The national search was led by IRSF's Board of Directors in partnership with the executive search firm Gilman Partners. Board Member and Interim CEO Leslie Mehta guided the organization during the leadership transition and shared her excitement for what lies ahead.


Laura Hameed, IRSF's new CEO

"As a mother to a child who lived with Rett syndrome and as someone deeply committed to this community, it's been an honor to help lead IRSF during this time," said Mehta. "Laura brings the right mix of vision, compassion, and proven experience. I'm incredibly hopeful about what we will accomplish together, and proud to pass the baton to someone who clearly shares our passion and purpose."

Hameed will oversee IRSF's full scope of work—from advancing cutting-edge fundamental research and therapeutic and curative therapies to championing advocacy initiatives and ensuring families have the resources, support, and connections they need. Her leadership will help drive progress across the Rett syndrome landscape, both in the U.S. and around the world.

Hameed officially began her tenure as CEO on April 14, 2025. She will be based out of San Antonio, Texas, with plans for regular travel to connect with families and partners nationwide.

For more information about IRSF and its mission to accelerate research and empower families living with Rett syndrome, visit rettsyndrome.org.

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. It is usually recognized in children between 6 and 18 months old 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 $60M in research leading to identifying Rett syndrome's cause, demonstrating Rett syndrome is reversible in mice, and supporting the clinical trials that led to the first-ever FDA-approved treatment. IRSF fights for families living with Rett syndrome and a world without it. Learn more at rettsyndrome.org.

Meghan Cordeiro
International Rett Syndrome Foundation
+1 513-809-1758
email us here
