International Rett Syndrome Foundation Launches Family Listening Sessions to Strengthen Support for Rett Community

New initiative invites parents and caregivers to share their experiences, ensuring that programs and resources reflect the real needs of families.

CINCINNATI, OH, UNITED STATES, October 28, 2025 /EINPresswire.com/ -- The International Rett Syndrome Foundation (IRSF), the leading nonprofit organization dedicated to accelerating research and empowering families affected by Rett syndrome, announced today the launch of a new series of Family Listening Sessions designed to better understand and respond to the evolving needs of parents and caregivers.

Taking place virtually throughout November, these small-group discussions will provide parents and caregivers with an open, confidential space to share their experiences navigating life with Rett syndrome—from the early years through adulthood. Each two-hour session will be facilitated independently by Dr. Elisabeth Krimbill, an experienced educator and counselor, to ensure participants can speak freely and honestly.

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>
> *Laura Hameed*

"Over my first six months at IRSF, I've been out and about in the community listening to families, clinicians, and researchers across the country, and one thing has become very clear—our strength as an organization begins with the voices of our community," said Laura Hameed, Chief Executive Officer of IRSF. "These Listening Sessions are a structured opportunity to collectively hear directly from parents and caregivers about what's working, what's missing, and how we can continue to grow in ways that truly meet families where they are across the entire journey with Rett syndrome."

Families and caregivers are invited to participate in sessions tailored to different life stages:

- November 11: Transitioning to Early Adulthood (ages 19-26)
- November 12: Later Adulthood (ages 27+)
- November 13: Secondary School Ages (ages 13-18)
- November 18: Elementary School Ages (ages 5-12)
- November 19: Early Years (ages 0-4)
- November 20: Males with Rett Syndrome (all ages)

Each topic will be offered twice per day—at 10:00 a.m. CT and 4:00 p.m. CT—with each session lasting two hours.

Participation is open to parents and caregivers of individuals with Rett syndrome. Families can express interest by completing a brief form at this link. Spots are limited to ensure meaningful dialogue, and expressing interest does not guarantee participation.

"In addition to accelerating and advancing great science aimed at bringing life-altering treatments to individuals with Rett syndrome, our dual mission keeps families in the front seat of all we do," Hameed added. "These conversations are an important part of how we continue building a stronger, more connected foundation for every family impacted by Rett syndrome. By listening first, we can make sure every program, resource, and engagement we create is informed by the people it's meant to serve and support."

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.

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