

# International Rett Syndrome Foundation Launches Clinical Trial Committee to Support Rett Syndrome Treatments

*The Clinical Trial Committee includes 14 leading U.S. Rett syndrome specialists.*

CINCINNATI, OHIO, UNITED STATES, May 31, 2022 /EINPresswire.com/ -- The International Rett Syndrome Foundation (IRSF) announced today that its Clinical Trial Committee (CTC) has launched, having completed its first protocol review, and is available as a resource to drug developers and pharmaceutical companies planning [clinical trials](#) to treat and cure Rett syndrome.



Rett syndrome is a rare genetic disorder that affects an estimated 1 in 10,000 females and even fewer males. It profoundly impacts life for affected individuals and their families.



Our new clinical trial committee capitalizes on our foundation's relationships to help drug developers get the insights they need to make the most of their investment in Rett syndrome clinical trials."

*Melissa Kennedy, IRSF CEO*

The committee is made up of IRSF Center of Excellence Directors, as well as caregivers of individuals with Rett. It provides the most comprehensive and efficient review of potential protocols, providing drug developers and pharmaceutical companies access to expert recommendations that will enhance the chance for a successful Rett syndrome clinical trial.

Prior to the launch of IRSF's clinical trial committee, drug developers and pharmaceutical companies interested in feedback had to reach out to individual Rett syndrome

clinicians and investigators. They would also have to compile the feedback and reconcile any differences between the recommendations. The IRSF CTC offers an opportunity to garner input from Rett syndrome key stakeholders in a single session. Sponsors leave with a set of

recommendations that represent stakeholder consensus.

“Through their depth of translational and clinical science expertise, the CTC provides an efficient means for communicating recommendations for safe clinical trials that will provide meaningful benefit to the Rett community,” says Tim Benke, MD, PhD, medical director of the Rett Clinic at Children’s Hospital Colorado/University of Colorado and medical advisor to IRSF.

Recent advances made through Rett syndrome research have dramatically increased industry interest in developing treatments for the disorder. Just eight years ago, there was only one company investing in Rett syndrome drug development. Today, there are over 20. In anticipation of this change, IRSF has cultivated strong relationships with physician experts in Rett syndrome over the years. It is also well-connected to families with Rett syndrome that are eager to play a role in creating a better future for their loved ones through its family empowerment efforts. These relationships are key to making IRSF’s clinical trial committee work.

“Our new clinical trial committee capitalizes on our foundation’s relationships to help drug developers get the insights they need to make the most out of their investment in Rett syndrome clinical trials,” says Melissa Kennedy, IRSF’s CEO. “We’re committed to providing every company with a Rett syndrome treatment development program with access to this committee. It’s part of our duty as an organization dedicated to giving new potential treatment options the best chance of making it into the hands of Rett families.”

#### About International Rett Syndrome Foundation

The International Rett Syndrome Foundation (IRSF) is the leading research and empowerment organization for Rett syndrome. Investing over \$54 million in research that has advanced therapeutics to clinical trials, including Rett syndrome’s first-ever phase 3 clinical trial. IRSF’s vision is to create a world without Rett syndrome and is reaching that vision by developing a robust pipeline of treatments and empowering families with information, knowledge and connectivity. Further information can be found at: [www.rettsyndrome.org](http://www.rettsyndrome.org).

Meghan Cordeiro

International Rett Syndrome Foundation

+1 513-809-1758

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