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Rettsyndrome.org Launches Rett Research Ready™ and myRett Trial Finder

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Program supports participation in clinical trials to develop treatments for the rare condition

Rett Research Ready™
Exploring the Journey Toward a World Without Rett

Rettsyndrome.org has launched a program to enable families with loved ones affected by Rett syndrome to explore and participate in clinical research. Rett Research Ready™ is an online platform that includes education, resources and support to help families consider volunteering for research studies.

A key resource of Rett Research Ready™ is a search tool called myRett Trial Finder. Using this tool, families can easily search for clinical trials specific to Rett syndrome, find accurate and easy-to-understand information, and connect directly with investigators to discuss participation in a trial.

Rett syndrome is a rare genetic neurological disorder that affects 1 in 10,000 females (and even more rarely males). Children with Rett syndrome often begin missing milestones or regressing around 6 – 18 months, leading to severe impairments in speech, movement, eating and breathing. Mutations on the X chromosome on a gene called MECP2 cause Rett syndrome.

No treatments exist for those with Rett syndrome, but the number of research studies and clinical trials to understand the condition and develop therapies is growing. Rettsyndrome.org has been investing in every area of research for 20 years, which includes bringing the first therapeutic compound to a clinical trial. As the organization works with pharmaceutical companies to design clinical studies for Rett syndrome patients five different compounds are now in various phases of the clinical trial process specifically for Rett syndrome and more are in the pipeline.

“Our Rett Research Ready™ and myRett Trial Finder initiatives build a bridge between our Foundation’s investment in research to find a cure for Rett syndrome and our mission to empower and support families each day. We can now provide families a trusted resource to explore and participate in clinical trials from any sponsor, as well as other volunteer research opportunities,” says Melissa Kennedy, Rettsyndrome.org Executive Director. “By connecting volunteers to studies, we move closer to finding effective treatments and therapies to enhance quality of life sooner.”

The technology behind myRett Trial Finder was built upon WCG CenterWatch iConnect tool. Working with WCG CenterWatch iConnect moved the project forward much faster than creating a custom search tool from scratch. “We are grateful to the team at The Michael J. Fox Foundation for Parkinson’s Research. They generously shared best practices of their research programming, including the Fox Trial Finder clinical study matching tool. Their encouragement was valuable in moving our initiative forward,” Kennedy commented.”

Steve Smith, President of WCG Patient Advocacy, notes, “As advancements in science bring hope that treatments for rare diseases will be developed, families search for information about clinical trials, and are eager to find out if they can participate. For many rare disease families, clinical trials are the fastest path to medicine. The International Rett Syndrome Foundation’s use of WCG CenterWatch iConnect solution is a model for how to provide families one place to find reliable, accurate information about the variety of relevant clinical trials.”

Dominique Pichard, MD, Rettsyndrome.org’s Chief Science Officer, regards the Rett Research Ready™ program as an essential piece of the puzzle to empower families to participate in clinical research. “Research is a promising path to find new treatments and bring us closer to a cure for this complex and life-changing disorder. We recognize that knowledge is power. With myRett Trial Finder and the Rett Research Ready™ program, we can connect families to clinical trials, as well as other research studies and information to demystify the details of participation, which equips families to participate in research.”

To explore Rett Research Ready™, visit www.rettsyndrome.org/rett-research-ready.