

UAB named Center of Excellence in Rett Syndrome

by [Bob Shepard](#)

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Alan Percy, M.D.

The University of Alabama at Birmingham is one of 15 institutions across the United States honored with International Rett Syndrome Foundation Center of Excellence designation or redesignation. The award recognizes UAB's continued dedication to providing best-in-class clinical care for Rett syndrome, a rare neurological and developmental disorder.

UAB first received this designation in 2017. The new two-year designation will officially go into effect June 1, 2021. It comes with funding support from IRSF and membership in IRSF's Center of Excellence Network formed by the appointed clinics.

To qualify as a Center Of Excellence, clinics had to demonstrate that they met four requirements established by IRSF's Medical Advisory Board:

- A physician director with expertise in Rett syndrome care
- Health care services that meet the unique needs of individuals with Rett
- Involvement in clinical trials
- Work to increase understanding of Rett syndrome by contributing to a clinical registry

UAB's Civitan Rett Syndrome Clinic, part of the Sparks-Civitan clinics, is led by Alan Percy, M.D., professor of pediatric neurology. Percy is considered one of the world's leading experts on this unique developmental disorder that affects one in every 10,000 female births worldwide. When at Baylor College of Medicine in the 1980s, Percy was one of the first physicians in the United States to identify the condition.

"We are honored with this recognition from IRSF and pleased to be a part of their clinical network," Percy said. "We are committed to maintaining the high standards of care that define a Center of Excellence."

Currently, many families must travel for an entire day to visit a physician who is knowledgeable about Rett syndrome. UAB's continued recognition as a leader in Rett syndrome care will make it the go-to clinic for local families as well as help to educate other physicians about Rett syndrome care.

"This network is part of IRSF's goal to get families the expert Rett clinical care that their loved ones need to thrive," said IRSF CEO Melissa Kennedy. "Our goal is that the vast majority of families living with Rett syndrome have access to a Rett syndrome expert by 2024."

There are no approved treatments for Rett syndrome, and the network's clinical trial research will play an essential role in ensuring therapeutic development progresses as quickly as possible. Rett syndrome causes severe cognitive impairment, including loss of communication and motor skills, reduced growth, and unusual breathing patterns.

"The infrastructure created by our Center of Excellence partners allows us to aggressively engage in clinical research," said IRSF CSO Dominique Pichard, M.D. "This is the only way to make treatment options and curative therapies a reality for all families living with Rett syndrome."

Survival into adulthood is now expected barring other illnesses or serious physical complications. Girls and women with Rett syndrome can be expected to demonstrate a full range of emotions and enjoy satisfying social, recreational and educational experiences at home and in the community.

For information regarding the UAB Rett Center and Rett Syndrome Clinic, call Jane Lane, R.N., at 800-822-2472, ext. 7, or 205-996-4927.

