### Civitan International Research Center

January 2017



#### UPCOMING EVENTS

B'ham Sci Café January 17, 2017

Governor Elect's Tour January 23, 2017

Past-Governors February 4, 2017

CIRC Symposium April 20, 2017

Centennial Celebration June 24 – 27, 2017

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#### **DIRECTORS**

Alan Percy, MD Interim Director

Lucas Pozzo-Miller, PhD Scientific Co-director

Rita Cowell, PhD Director Communications and Outreach

Vicki Hixon, BS Managing Director





# HAPPY NEW YEAR from the Civitan International Research Center!!!

As we reflect on the successes of years past, we anticipate 2017 with excitement about the future of The Civitan International Research Center (CIRC). We want to thank you for your support and dedication over the years. Without your commitment and diligent work, we would not be where we are today.

We are excited about the research currently being done at the CIRC. Research continues at a rapid pace with the help of the new state-of-the-art full-body magnetic resonance imaging scanner. The imaging equipment is being used for both research purposes and patient care in conditions such as autism, dementia, Alzheimer's disease, Parkinson's disease, schizophrenia, macular degeneration, spinal cord injury, glioma, ALS and traumatic brain injury.

#### **Global Study on Rett Syndrome**

UAB part of global study of breathing issues in Rett syndrome by Bob Shepard - December 16, 2016

UAB will study a drug originally developed for Parkinson's disease that may help reduce breath holding in patients with Rett syndrome.

Researchers at the University of Alabama at Birmingham are part of the international STARS study to see if a drug originally developed for Parkinson's disease might help reduce breathing issues common in patients with Rett syndrome. The drug, sarizotan, may help reduce the frequency of breath holding, a potentially significant effect of Rett syndrome.

"We often see Rett patients holding their breath for long periods of time, up to 30 seconds at a time, behavior that can go on for hours," said Alan Percy, M.D., professor of neurology in the Department of Pediatrics, medical director of the UAB Civitan International Research Center and a leading Rett syndrome expert. "Patients often end up swallowing large amounts of air, which can have a very detrimental effect on nutrition, a major issue for Rett patients."

The study, to be held in four sites in the United States and several international locations, is looking to enroll patients with Rett syndrome who are 13 years and older, have a body weight of at least 55 pounds and experience multiple episodes of breath holding while awake during the day.

"Breath holding can be quite disruptive in younger Rett patients, although it usually subsides in early adulthood," Percy said. "We currently do not have an effective medication that addresses breath holding. This is the first multisite trial of a potential therapy."

"While this is certainly not curative for Rett syndrome, it could be disease modifying," Percy said. "This has the potential to be an important drug, as breath holding can be very disruptive and distressing to the family."

The National Institutes of Health defines Rett syndrome as a neurodevelopmental disorder that affects girls almost exclusively. It is characterized by normal early growth and development followed by a slowing of development, loss of purposeful use of the hands, distinctive hand movements, slowed brain and head growth, problems with walking, seizures, and intellectual disability.

The study is sponsored by Newron Pharmaceuticals U.S., Inc. Other study sites in the United States are the Altman Clinical and Translation Research Institute, University of California San Diego; Rush Medical University Center, Chicago; and Texas Children's Hospital, Houston.

## **Upcoming Events**

**SAVE-THE-DATE** 

Thursday, April 20, 2017

## Civitan International Simpson Ramsey Neurodevelopment Symposium

Hill Center
8:30 a.m. – 3:00 p.m.
Poster Session
The Edge of Chaos
3:30 p.m. – 5:30 p.m.

The event will feature keynote speakers along with UAB researchers who will share knowledge about their on-going research.



## Celebrating 100 Years!

## Civitan International Centennial Celebration Birmingham, Alabama June 24 – 27, 2017



Excitement is growing in anticipation of the Centennial Celebration to be held at the beautiful Sheraton Birmingham Downtown Hotel. For more information visit:

http://www.civitan.org/convention2017/ConventionInformation2017.pdf

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