CIVITAN INTERNATIONAL RESEARCH CENTER
Empowering Minds Through Science℠

THIS EDITION

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Summer 2018

CIVITAN INTERNATIONAL CONVENTION

At the Civitan Convention held in Reno, Nevada on July 22 – 25, 2018, Civitan International interim director Alan Percy, M.D., spoke to the crowd about some of the highlights of the previous year and then introduced the 2018 Civitan International Research Center (CIRC) video.

This year's video included special efforts by videographer, Jim Willett, who highlighted some patients being seen at CIRC. Seeing actual patients and their families, made the video a big success and gave the viewers an opportunity to see some of the clinical work being done by various researchers.

At the conclusion of the video, Dr. Percy introduced Craig Powell, M.D., Ph.D. as the new director of the CIRC who was selected after an extensive nation-wide search. Dr. Powell is a national leader in research pertaining to molecular mechanisms of learning and memory, synaptic plasticity, and neuropsychiatric disorders such as autism, intellectual disability, and Alzheimer's.

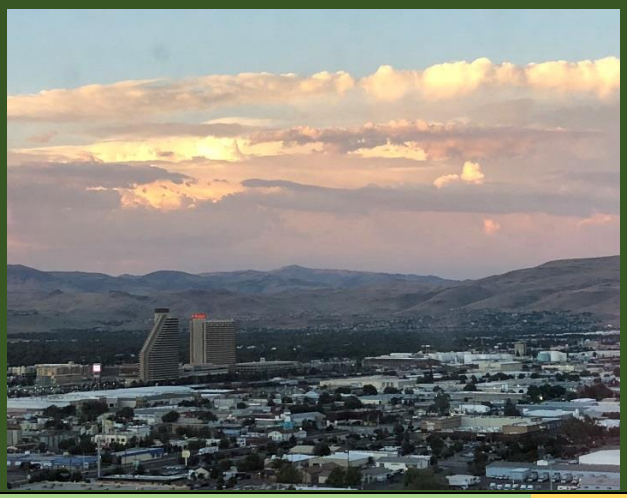
Dr. Powell addressed the crowd and expressed his appreciation to Drs. Percy and Pozzo-Miller for their leadership over the last two years. He also shared his vision for the future of the CIRC. Dr. Powell expressed sincere appreciation to Civitan International for their support of the CIRC over the years and noted that without Civitan International, the CIRC would not be where it is today.

For more highlights visit:
http://www.uab.edu/medicine/circ/test/328-civitan-convention-

Convention Highlights

July 22 – 25, 2018

Welcome to Reno, Nevada!!!



Research Spotlight

"The course of awake breathing disturbances across the lifespan in Rett syndrome"

A study of the significant breathing issues while awake in Rett syndrome (breath-holding and hyperventilation) was recently published in *Brain and Development*. Led by Dr. Daniel Tarquinio together with the members of the Rare Disease Clinical Research Consortium for Rett Syndrome, *MECP2* Duplication Disorder, and RTT-related Disorders under the direction of the consortium PI, Dr. Alan Percy, this paper describes the pattern and progression of these issues across the age spectrum in Rett syndrome (RTT). This study highlights the need for and the on-going studies to address this significantly disabling feature of RTT.

Abstract
Rett syndrome (RTT), an X-linked dominant neurodevelopmental disorder caused by mutations in MECP2, is associated with a peculiar breathing disturbance exclusively during wakefulness that is distressing, and can even prompt emergency resuscitation. Through the RTT Natural History Study, we characterized cross sectional and longitudinal characteristics of awake breathing abnormalities in RTT and identified associated clinical features. Participants were recruited from 2006 to 2015, and cumulative lifetime prevalence of breathing dysfunction was determined using the Kaplan-Meier estimator. Risk factors were assessed using logistic regression. Of 1205 participants, 1185 had sufficient data for analysis, including 922 females with classic RTT, 778 of whom were followed longitudinally for up to 9.0 years, for a total of 3944 person-years. Participants with classic or atypical severe RTT were more likely to have breathing dysfunction (nearly 100% over the lifespan) compared to those with atypical mild RTT (60–70%). Remission was common, lasting 1 year on average, with 15% ending the study in terminal remission. Factors associated with higher odds of severe breathing dysfunction included poor gross and fine motor function, frequency of stereotypical hand movements, seizure frequency, prolonged corrected QT interval on EKG, and two quality of life metrics: caregiver concern about physical health and contracting illness. Factors associated with lower prevalence of severe breathing dysfunction included higher body mass index and head circumference Z-scores, advanced age, and severe scoliosis or contractures. Awake breathing dysfunction is common in RTT, more so than seizures, and is associated with function, quality of life and risk for cardiac dysrhythmia.
https://doi.org/10.1016/j.braindev.2018.03.010

VIDEOS

Orders for the 2018 Civitan International Research Center video which premiered at the Civitan Convention can be placed by contacting Vicki Hixon at vhixon@uab.edu. In an effort to offset production costs, an invoice for $15 will be included in the shipment.

New focus is being made to spotlight the Civitan International Research Center with brief video clips.

http://www.uab.edu/medicine/circ/test/328-civitan-convention

http://www.uab.edu/medicine/circ/test/324-what-is-the-circ

http://www.uab.edu/medicine/circ/test/316-athens-ladies-civitan-club

http://www.uab.edu/medicine/circ/test/303-priceville-junior-civitans-2

http://www.uab.edu/medicine/neurobiology/news-events/news-archive/203-neurobiology-labs

For updates on the Civitan International Research Center
visit the website at:
www.uab.edu/medicine/circ

To schedule a private tour of the
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Contact Vicki Hixon – vhixon@uab.edu

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