

Reclaiming Moments of Childhood

Every minute of childhood is important: moments to play, grow and learn and occasions to make connections with family and friends. Missed experiences and opportunities can affect a child's well-being, confidence, and maturity. Children wouldn't choose to miss a second of their busy active lives, but what if something unconsciously caused them to miss out on the important moments of their lives?

A child with absence epilepsy can miss brief pieces of their lives seconds at a time, dozens of times a day, through seizures. Absence epilepsy, also known as petit mal epilepsy, has its onset in childhood or adolescence, and most children outgrow it. An episode usually lasts less than 10 seconds but no more than 20 seconds with the child appearing to be daydreaming or inattentive. These seconds, though, are enough time to place a child in harm's way, to cause the child to miss a teacher's lesson or to attract unnecessary attention to the child's condition. Over time, the child may have lower self-esteem as a result of the seizures' impact. Giving this time back to ensure safety, learning and self-esteem is the foremost reason to help children control their seizures.



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"I asked Leah to follow me in the grocery store to produce, and she stood there just staring," Allyson says of the first time she noticed her daughter's seizures, "It looked like she was daydreaming." In another case, Leah was playing with her dolls and her eyes rolled back. Leah's pediatrician referred them to Dr. May Griebel, an ACH neurologist. During her EEG test, Leah experienced three seizures. Dr. Griebel discussed the possibility of Leah's enrollment in a childhood absence epilepsy trial, and the family agreed.

Dr. Griebel is the site principal investigator for an NIH-funded clinical study begun in 2004 of the three most used medications for absence seizures. This multi-center study is being conducted by the Network of Pediatric Pharmacology Research Units (PPRUs), funded by NIH. The PPRU at Arkansas Children's Hospital is one of 13 PPRUs in the nation established by the National Institute of Child Health and Human Development in response to the need for appropriate drug therapy for pediatric patients. "The study is the only NIH childhood absence epilepsy study and the largest one of any kind, anywhere for this type of epilepsy," says Dr. Griebel. One goal of this study is to determine what medication controls the seizures quickest with the least amount of side effects.

The study requires children with active absence epilepsy that have not taken medication for the condition. "The EEG techs at the hospital have been great in helping with recruitment by identifying abnormal EEGs," says Research Nurse Lee Howard, RN, CCRC. The Arkansas site is one of the lead enrolling sites. Since 2005, 21 patients have consented to be in the ACH trial; 435 patients are in the entire study network.

Leah was the first child enrolled at ACH. "She was good first experience for us as we began the study," says Dr. Griebel. "She was darling and so bright and made our work seem negligible...it was encouraging for us." More importantly, Allyson says that Leah was seizure free after the

first round of medication. Her only side effect was some tiredness; "...but she never missed a beat," her mom adds.

During her two years of treatment on the study, Leah would receive neurological examinations and blood draws in the Pediatric Clinical Research Unit (PCRU). Leah completed the treatment phase of the study last year and now, at age 10, continues with follow-up visits at the PCRU. "The unit setting is conducive to child comfort, especially with the family area," says Dr. Griebel. "It has a nourishing atmosphere and has the same faces for the families." "The personal care and attention we were able to receive was incredible...we are grateful and happy for such excellent care," says Allyson.



Established in 1989, Arkansas Children's Hospital Research Institute provides an on-site research environment for faculty of the University of Arkansas for Medical Sciences working on the Arkansas Children's Hospital campus. Over 120 pediatric researchers with expertise and experience that span the breadth of medical disciplines comprise ACHRI's roster of investigators who work to fulfill its mission to improve children's health, development, and well-being through high quality research. For more information, visit <http://achri.archildrens.org>.