



Jennifer Eubanks Chiari Community Columnist

Eubanks is a

professional writing and researching scholar from Purdue University Northwest. After being diagnosed with a Chiari I Malformation in 2011, she quickly decided that being conquered was not an optionshe was committed to fight and pursue a budding love of healthcare/medical writing. Spreading awareness and hope to others battling Chiari is her largest motivator alongside educating others who have not heard about the condition. Reporting for Ideas in Motion Media and tutoring at the Writing Center (Purdue University North Central) has been immensely beneficial to her success as well as all the remarkable individuals who helped her become the composer and analyst she is today.

Ed. Note: Ms. Eubanks is not a medical doctor and does not give medical advice. Anyone with a medical concern is strongly encouraged to seek professional medical care.

## Dr. Kevin Kaut, CCRC Researcher

March 14th, 2014 - Last year in December, Conquer Chiari awarded Dr. Kevin Kaut a \$53,000 grant to examine the impact Chiari has on children in school. Since Dr. Kaut has had formal education and clinical experience as a school psychologist, he cares deeply about issues which directly impact children, families, and others who help children cognitively develop. In a study set to begin this summer, he hopes to help families and education professionals understand Chiari and what accommodations are needed to assist those with the disorder.

"By providing better information for parents as well as school faculty members, children fighting Chiari in elementary school, middle school, and high school will be encouraged to succeed through their journey. It's important to understand the mental, emotional, and social impacts of Chiari and how it can directly affect a child's life," Dr. Kaut said.

After receiving his doctorate in Biomedical Science in 2000, neuroscience research, regarding the role of various brain structures in learning and memory, has been one of the many project highlights he has experienced. As the Associate Chair of the Psychology Department at the University of Akron, Dr. Kaut has helped students understand the same learning areas of the brain in invertebrates (e.g. insects) and how they compare to the fundamentals of memory in different species. He has a deep appreciation for psychology and behavior, and further understands how biomedical issues can impact one's ability to adapt.

Dr. Kaut's knowledge of structural and functional areas of the brain helped him understand the elements of Chiari; he first heard of a Chiari Malformation when one of his colleagues asked him about some neurological aspects of the condition.

His colleagues at The Conquer Chiari Research Center, found within the University of Akron, welcomed Dr. Kaut with open arms after he submitted a research proposal which involved child development and neuroscience. His previous position as a school psychologist (Mahoning County Public Schools, Ohio) along with his additional research interests further assist him in investigating the effects of Chiari on school-aged children and their families.

"After corresponding with moms and dads of young Chiari patients, I knew this study was important. Currently, there are no studies of academic struggles related to Chiari, but many psychological and neurological complications can arise while in school such as limited physical ability, pain and discomfort, fatigue, and the inability to maintain social interactions."

Decompression surgery may or may not improve one's ability to adapt while in school; it does have a possibility to cause multiple complications and because of this, Dr. Kaut will be examining schoolchildren with and without decompression surgery.

Dr. Kaut, Dr. Phillip Allen, and a doctoral student (specializing in assessment and evaluation) will be using a two-pronged approach to understand how Chiari affects elementary to high school students as well as their parents. Those conducting this study will be utilizing an online data collection platform, called Qualtrics, which will allow parents of children diagnosed with Chiari to provide extensive information regarding developmental history, medical status and treatments, educational history, and perceptions of cognitive difficulties. The information is then sent electronically to the University of Akron for data collection purposes. The experiences and perceptions of the parents and children will be examined so possible developmental issues caused by Chiari can then be identified during the period of formal education.

"This part of the research program is intended to capture broad and extensive information, while also providing for us the opportunity to follow up with individual interviews as needed. We see this as an excellent opportunity to gain insight into the effects of Chiari in various facets of psychological, educational, and emotional development," Dr. Kaut said.

Dr. Kaut and his team will be conducting this study in the summer and finalizing their data in the spring or summer of 2015. They are also hoping to make this a country wide research project instead of solely statewide.

It's important to Dr. Kaut and the rest of the Chiari community to know why and how Chiari affects diagnosed individuals and those closest to them. By examining how Chiari impacts schoolchildren and their families, the information that will be collected aims to improve quality of life and further inspire both compassion and understanding for those fighting and hoping for a cure.

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