

Conquer Chiari Awards Two New Research Grants

January, 2016 - Conquer Chiari is excited to announce the award of two new research grants. The grants were made at the end of 2015 to researchers at the Conquer Chiari Research Center:

Non-invasive Therapies for the Treatment of Chronic Pain in Chiari Malformation, \$129,973, Dr. Phil Allen

Dr. Allen is a key member of the CCRC and has been studying the cognitive effects of Chiari for several years. Now, in addition, he is taking on what many patients report is the most problematic aspect of Chiari...pain. For many individuals, Chiari malformation results in chronic debilitating pain, which often persists even after surgery. This project will test whether physical exercise or Acceptance and Commitment Therapy (ACT) over the course of 15 weeks can reduce chronic pain levels in Chiari patients, or allow these individuals to better cope with their chronic pain.

Targeting Syrinx Transporters for Syringomyelia Treatment Strategies, \$128,275, Dr. Nic Leipzig

This project is a follow-up award to Dr. Leipzig's previous work. Dr. Leipzig successfully used a rat model to study the molecular level damage caused by syrinxes. This phase of the work entails two parallel investigations which will position the CCRC to advance potential treatments for syringomyelia. The first activity is to further define the precise molecular mechanisms at work in syrinx expansion, while the second activity is to assess a delivery system for treatments, which in the future could be used to counter the damage caused by a syrinx.

With these grants, Conquer Chiari has funded **\$795,000** of research in 2015.

Thanks to all of our donors and volunteers who make this possible.

Join the Chiari 1000 and Make a Difference!!

Building on the success of the Conquer Chiari Patient Registry, the Chiari 1000 is an effort to collect self-report surveys, neuropsychological assessments, and MRI data from at least 1000 patients with Chiari. Some participants will also be asked to provide biological samples (such as saliva and blood) for further study.

By collecting uniform data from such a large sample of patients, Conquer Chiari hopes to overcome many of the limitations of existing Chiari research and address the following 10 key research questions:

1. What MRI based measurements, beyond tonsillar herniation, can be used to more accurately diagnose symptomatic Chiari in children and adults?
2. How do MRI based measurements relate to specific symptoms?
3. Can MRI based measurements be used to predict surgical outcome and/or guide surgical technique?
4. What genetic factors are involved in classical Chiari?
5. Is pediatric onset Chiari fundamentally different than adult onset Chiari?
6. Why are women more affected than men for adult Chiari?
7. What are the different Chiari subtypes, and what are their diagnostic and treatment implications?
8. What is the neuropsychological impact of Chiari and can it be quantified to aid treatment planning?
9. What factors contribute to chronic Chiari symptoms even after surgery?
10. What factors contribute to Chiari related pain?

We believe that answering these questions will hopefully, in turn, lead to the following advances:

1. A more accurate set of diagnostic tests and criteria.
2. Evidence based tools to aid in surgical planning and assessment.
3. Evidence based identification of Chiari subtypes, and in turn, treatment optimization for each group.
4. New techniques to limit the body's inflammatory response to surgery, and thus improve outcomes.
5. New therapeutics to address the stress and cognitive impact of Chiari and improve patient experiences.

Those who participate, and complete all parts of the project, will receive an exclusive Chiari 1,000 t-shirt (left). To learn more, or to register, please visit <https://chiari1000.uakron.edu/> Questions? Ask the Chiari 1,000 study coordinator: chiari@uakron.edu

NOTE: The study is also looking for people who have head MRIs, but who do not have Chiari. If you know someone like this who is willing to participate, please contact the Chiari 1,000 study coordinator: chiari@uakron.edu



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