

Conquer Chiari Receives \$40,000 Grant for Chiari Research

November, 2015 - Conquer Chiari is excited to announce that we have received a \$40,000 research grant from a private foundation. The money will be used to extend work on the Chiari 1000.

The Chiari 1000 is an innovative research project which is analyzing the MRI images from 1,000 patients and volunteers, along with demographic, symptoms, surgical, and biomarker data.

As part of the Chiari 1000, the researchers at the CCRC are measuring 42 separate parameters of the brain and skull from the submitted MRIs. This grant money will be used to automate that process and reduce the time needed to make the measurements and also reduce human error.

Nearly 500 people have already registered for the Chiari 1000. If you have not yet done so, please consider participating in this important research.

If you have registered, please remember to complete the on-line portion of the project and just as importantly submit your MRIs to the CCRC.

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, visit <https://chiari1000.uakron.edu/> Questions? Ask the Chiari 1,000 study coordinator: chiari@uakron.edu

NOTE: We are 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



