

January 27<sup>th</sup>, 2022

In September, 2015, Conquer Chiari undertook a groundbreaking research project – the Chiari1000. The goal was to use the internet to create a consistent dataset on a large, diverse population of at least 1000 Chiari patients.

Today, we would like to announce that the Chiari1000, having exceeded expectations in many ways, will no longer be actively collecting new data. Work will continue for years on processing and analyzing the enormous volume of data that was collected thanks to the enthusiastic participation of the Chiari community.

Since its launch, nearly 2,000 Chiari patients have participated in some way by completing surveys, taking neuropsychological tests, sharing medical imaging (MRIs, CTs, etc.), and/or providing biological samples.

The Chiari1000's contribution to research has been extraordinary, and includes:

- 16 peer-reviewed journal publication, with more to come
- Quantitative confirmation of the cognitive impact of Chiari
- Identification and characterization of the psychological impact of Chiari on patients
- Valuable clues to the underlying pathology of Chiari, leading to the development of a new theory of symptomatic Chiari (Research Update on this topic will come soon)
- Identification of collagen related genetic mutations that are common in Chiari patients

Conquer Chiari has made selected results from the Chiari1000 available for patients to review at:

<http://chiari1000results.info/>

Although the Chiari1000 will no longer be collecting new data, this is not the end. Given the tremendous success of this project, we are already working on new, ambitious, groundbreaking projects that will leverage the strength of the Chiari community.

Stay tuned.....