



CONQUER CHIARI PATIENT REGISTRY



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IMPORTANCE FOR CHIARI PATIENTS

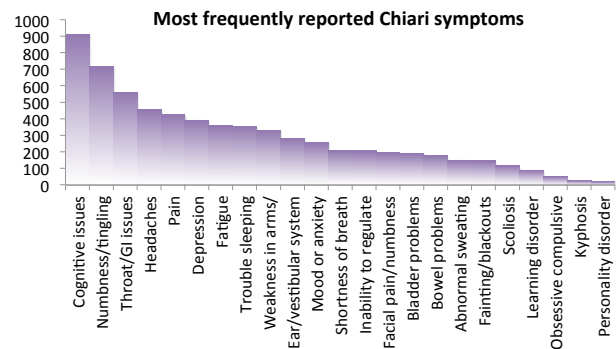
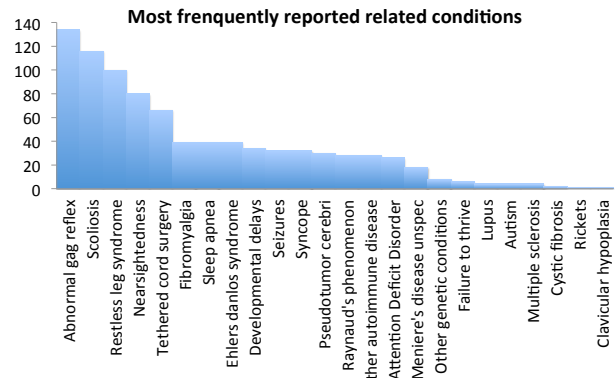
We have created the world's first web-based Chiari patient registry. You can help us by entering your own information in the registry online. The information being gained from the registry will be used to:

1. Identify potential Chiari patients that could participate in research studies
2. Identify potential areas of research
3. Perform internal research
4. Enable external researchers to perform research

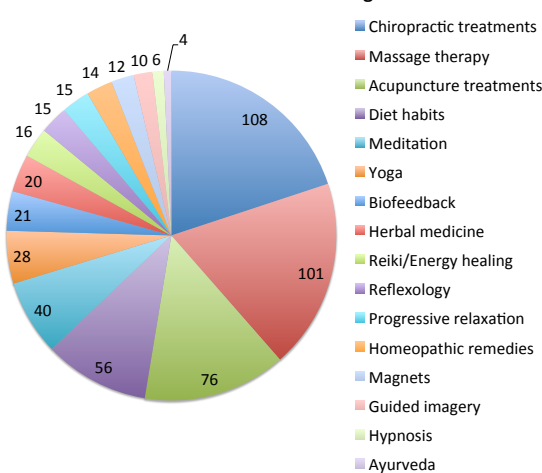
The database will also be made freely available to qualified researchers for approved projects.

WHY BUILD A PATIENT REGISTRY?

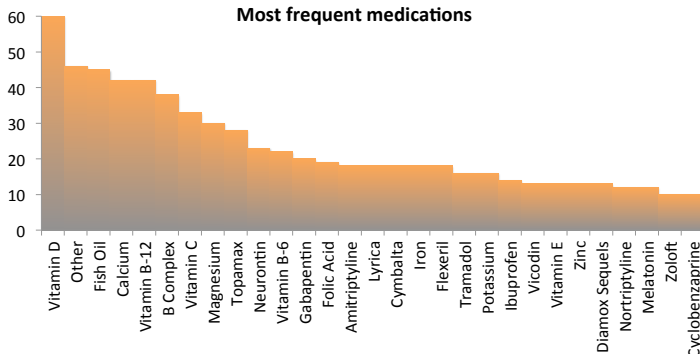
To fully understand Chiari malformation it is imperative to gain information about the disease in a large population of patients. Thus, Conquer Chiari funded an internal project to create a web based, secure database of demographic and health related information about Chiari patients. The database enables patients to enter their own data on topics ranging from diagnostic history, to surgical history, to the impact Chiari has had on their lifestyle, all to help answer fundamental questions about Chiari.



Alternative treatments sought



Most frequent medications



INFORMATION PRIVACY

Participation in the Conquer Chiari Patient Registry is completely voluntary. Participants may enter as much or as little information about themselves as they like. The information collected will be used by Conquer Chiari and qualified researchers to study various aspects of Chiari malformation and its impact.

In general, and particularly for research purposes, the information collected is non-identifiable. This means that Conquer Chiari, and other researchers who are accessing the database, will not have access to the identity of the participants who have entered information into the database. It is important to understand the exceptions to this as stated in the privacy section of the Terms of Use and Privacy Policy document.

USAGE OF INFORMATION

By collecting information about Chiari patients, Conquer Chiari hopes to advance the general understanding of Chiari and how it affects patients and their families. Specifically, but without limitation, the Conquer Chiari Patient Registry will be used:

- A. By Conquer Chiari to study the natural history, epidemiology, diagnosis, treatment, and impact of Chiari on patients and their families
- B. By external researchers, with both IRB (Institutional Review Board) and Conquer Chiari permission, to study various aspects of the natural history, epidemiology, diagnosis, treatment, and impact of Chiari on patients and their families
- C. As a means to contact, anonymously, Chiari patients who may be interested in participating in research studies