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Chiari1000: An International Patient Registry and Database

Dorothy Loth, Peter Mallik, Maggie Eppelheimer, James Houston, Richard Labuda, Aintzane Urbizu,
Bryn Martin, Philip Allen, Francis Loth

Purpose

The Chiari1000 is a custom, web accessed, secure database that collects and stores demographic and health related data provided through self-report questionnaires, responses to selected validated scales, and imaging voluntarily provided by Chiari patients. The purpose of the Chiari1000 platform is to gather the same information from a large, clinically diverse, group of Chiari patients for analysis.

Methods

Subjects were recruited through the email contacts of Conquer Chiari and postings on relevant websites and social media. People with a diagnosis of Chiari malformation were asked to register on a secure website (Developer Matrix 301) to complete online questionnaires on: demographics, symptomatology, diagnostic history, surgical history, additional medical diagnoses of related conditions, and quality of life. After completing the self-report questionnaires, participants were asked to respond to 11 standardized assessments: memory, pain, anxiety, depression, coping with, and attitudes towards illness and traumatic life events, loneliness, psychological well-being, and hypermobility. Finally, participants were asked to share their pre-surgical MRIs via a shared drive, the mail, or by signing a release. Participants were also given the opportunity to indicate if they were interested participating in additional research studies.

Results

As of June 6th, 2018, 2209 people have registered; 1469 people have completed all of the self-report questionnaires; and 1181 people have also completed all of the standardized assessments. In total, 627 patients have shared their images. The vast majority of respondents have been adult white women. Geographically, several countries are represented as are most states in the US. The data collected has been used in multiple research projects and produced several publications to date.

Conclusions

The Chiari1000 platform has successfully collected detailed self-report data, validated scales, and imaging on a large cohort of Chiari patients, who were treated by many different physicians. This database represents a valuable tool and is instrumental in several on-going research projects.

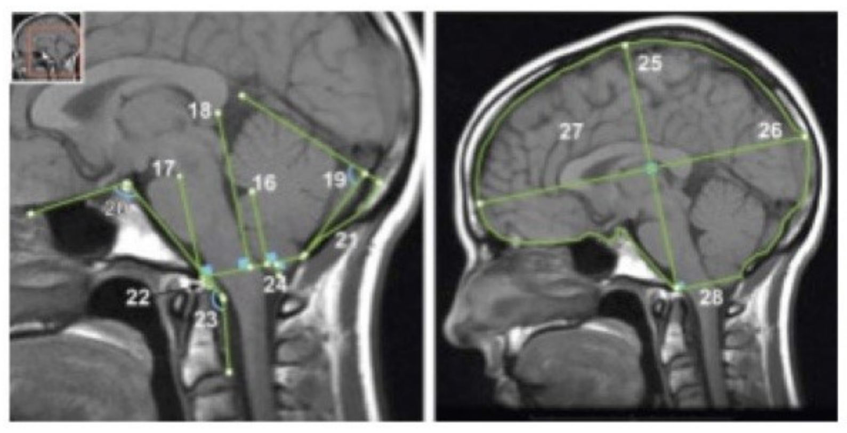
Chiari1000

1. Chiari participant completes online Chiari1000 survey and gives MR images to the CCRC
2. Participant is mailed a specially designed t-shirt
3. Data is analyzed

Survey Data
~250 questions on:
- Demographics
- Chiari diagnosis
- Symptoms
- Additional Diagnoses
- Surgical History
- Quality of Life
- Neuropsych variables
  - Depression
  - Anxiety
  - Memory
  - Coping
  - Pain
  - Hypermobility

Analysis

Morphometric Data
Detailed measurements on MR brain images



Completed Chiari1000 surveys by state