Conquer Chiari Research Agenda: A Roadmap For Success

Goal #1: Reduce the average time to an accurate diagnosis to less than 2 years from time of first symptoms.

Objectives:
- Develop a standard, simple, objective definition and test of symptomatic Chiari
- Enable the introduction of new technologies, such as inexpensive, portable imaging, which will reduce the barriers to diagnosis

Goal #2: Develop an effective, widely adopted, and minimally traumatic standard of care.

Objectives:
- Design, and encourage the adoption of, a standard outcome measure, such that the results from different studies can be compared and combined
- Establish whether the surgical variations that currently exist have a significant effect on long-term patient outcomes, and further develop a standardized surgical approach
- Encourage the development of minimally invasive surgical techniques
- Pursue non-surgical treatment approaches which don't just address symptoms, but are targeted at the core problem(s)

Goal #3: Minimize the impact that Chiari has on the quality of life of patients.

Objectives:
- Develop, and encourage the adoption of, a Chiari Impact Measure, which takes into account patient focused issues such as career, family, economics, recreation, and socialization
- Understand, and develop treatments for, the neuropsychological effects of Chiari, including both cognitive and emotional manifestations
- Develop widely accepted protocols for physical, occupational, and other types of therapies designed to maximize functional capabilities
- Enable the development of innovative technologies and treatments targeted at the neuropathic pain and loss of function associated with Chiari

Goal #4: Understand the pathophysiology, natural history, and epidemiological characteristics of Chiari.

Objectives:
- Establish, with reasonable accuracy, the incidence and prevalence of Chiari and Chiari related syringomyelia
- Characterize, and quantify, the Chiari experience, such as average age of diagnosis, time to diagnosis, number of doctors seen, major symptoms, etc.
- Develop a sound theoretical model for the pathophsyiology of Chiari, which explains how symptoms develop, and will enable predictions about who needs surgery, who will develop syringomyelia, etc.
- Identify and characterize the genetic basis of Chiari