In the 4th century B.C., an oracle declared that anyone who could untangle the Gordian knot would go on to rule Asia.

Alexander the Great cut the Gordian knot with a single strike of his sword...
Chiari is like the legendary Gordian knot,
But we can not cut it with a sword like Alexander did...
We must untangle it one thread at a time:

Pathophysiology
Symptoms
Diagnosis
Treatment
Outcomes
Quality of Life
Related Conditions
State of Chiari: The Challenge

Pathophysiology
No Disease Model
Several Theories

Symptoms
Varied, Diverse, Overlapping
Physical Causes Not Clear

Diagnosis
No Single Definitive Test
TP Not A Good Marker

Quality of Life
Residual Symptoms
Impact Not Known

Treatment
Who Will Respond To Surgery
Traumatic Procedure

Related Conditions
Are All CMs Alike
How Do They Link To Chiari

Outcomes
How To Objectively Assess
Adult Outcomes Not Great
Conquer Chiari Research Strategy

*Improve Patient Experiences & Outcomes*

Quantitative Measures

Pathophysiology

Quality of Life

Infrastructure

$>3.6$ Million Invested to Date
## Goals

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<thead>
<tr>
<th><strong>Quantitative Measures</strong></th>
<th><strong>Pathophysiology</strong></th>
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<tbody>
<tr>
<td>Provide clinicians with quantitative data in order to: assess disease severity; identify candidates for surgery; predict and measure surgical outcome; evaluate new treatments; and classify patients into sub-groups.</td>
<td>Develop a complete, practical, and accurate disease model of Chiari, which would answer fundamental questions, enable the categorization of patients, and suggest new techniques for diagnosis and treatment.</td>
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<tr>
<th><strong>Quality of Life</strong></th>
<th><strong>Infrastructure</strong></th>
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<tbody>
<tr>
<td>Minimize the impact of Chiari on patients and their families, by maximizing patients’ physical, mental, emotional, vocational, recreational, and interpersonal quality of life.</td>
<td>Develop the research infrastructure necessary to create a vibrant Chiari research community, including: easy access to patient data; cross-disciplinary projects; leveraging 21\textsuperscript{st} century technologies; quickly and broadly disseminating results.</td>
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## Projects

<table>
<thead>
<tr>
<th>Quantitative Measures</th>
<th>Pathophysiology</th>
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<tr>
<td>Morphometrics</td>
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<tr>
<td>Cognitive Impact</td>
<td>Genetics</td>
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<tr>
<td>Pressure &amp; Strain</td>
<td>Cognitive Impact</td>
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<tr>
<td>Biomarkers</td>
<td>Animal Models</td>
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<tr>
<td>CSF Analysis</td>
<td>Syrinx Analysis</td>
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<td>Longitudinal Impedance</td>
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<tr>
<td>Educational Impact</td>
<td>Research Center (CCRC)</td>
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<tr>
<td>Vocational Impact</td>
<td>Chiari 1000</td>
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<tr>
<td>Psychological Impact</td>
<td>Software Platforms</td>
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<tr>
<td>ACT Therapy</td>
<td>Apps</td>
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<tr>
<td>Aquatic Therapy</td>
<td>Conferences</td>
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Conquer Chiari Research Center

Staff
• Executive Director: Loth
• Deputy Director: Allen
• 10 professors, 8 departments
• 2 Full-time post-docs
• 1 Project manager
• 8 PhD students
• 3 Undergrad students

➢ $2.9M Total Funding
➢ $1M Active Projects
➢ $.5M NIH Grant
➢ 36 Journal Publications
1. Up to half of Chiari adults have cognitive issues
2. Advanced imaging (DTI) shows damage to the cerebellum and frontal cortex
3. Emotional impact of Chiari is severe with high rates of clinical depression and anxiety
4. Anatomically, many differences found beyond tonsillar position; entire hindbrain seems to sag
5. Clivus bone is dramatically different, three dimensionally, not just shorter
Top 10 Findings To Date From CCRC - (Not Ranked)

6. Some evidence that the cerebellum is being stretched by an active process

7. Advanced imaging (DENSE) shows areas of extremely high levels of strain in the brainstem and cerebellum

8. Patient perceived outcomes (adults) not as good as clinically published

9. Very high rates of autoimmune diagnoses among adult women – even for diseases with markers, such as Lupus

10. Both ACT and aquatic therapy show promise in helping patients with sub-optimal outcomes
Future Directions

**QUANTITATIVE MEASURES**
- Morph for pediatric & men
- Link to symptoms/outcomes
- Develop cogn protocol for CM
- Automate morph measurements

**PATHOPHYSIOLOGY**
- Why is clivus bone different?
- What role do CTDs play?
- Identify specific genes
- Explore autoimmune issue

**QUALITY OF LIFE**
- Develop ACT protocol for CM
- Quantify vocational impact
- Develop ways to treat SM

**INFRASTRUCTURE**
- C1000 follow-up surveys
- Mobile app development
- Continue CCRC growth
Research Is Expensive
Research Takes Time

We Need Your Help...

Conquer Chiari
Walk Across America
Cycle 4 Chiari

Get Involved!!

Chiari 1000
Will You Raise Your Voice?