

Research Update: July 2018

This month's research update is a little different. On July 21st, more than 150 people attended the Conquer Chiari Research Center Open House on the campus of the University of Akron.

We have put as much of the material from the open house as possible on our website. This includes presentations, research posters, and educational posters. You can view it all here: [CCRC Open House](#)

As part of the proceedings, I presented what I believe are the top ten findings of the CCRC to date. They are discussed below, not in any particular order, and more information about these findings is available in the presentations and posters.

- 1. Up to half of adult Chiari patients have cognitive issues** - Data from the Chiari 1000, and other projects, has demonstrated rather convincingly that Chiari is linked to cognitive deficits above and beyond what may be due to chronic pain. This is not to say that chronic pain doesn't also cause cognitive issues, it does. But rather, that some Chiari patients feel the effects of both chronic pain and Chiari directly.
- 2. Advanced imaging shows damage to both the cerebellum and frontal cortex** - Diffusion tensor imaging (DTI) is an MR technique which can show damage to the nerve connections in the brain. A DTI study on Chiari patients showed not only damage to these connections in the cerebellum, but also portions of the frontal cortex, which is responsible for higher order, executive functioning.
- 3. Emotional impact of Chiari is severe, with high rates of clinical depression and anxiety** - The Chiari 1000 contains what are referred to as validated scales. These are questionnaires used by clinicians and researchers that have been shown to be accurate and useful (or valid). Unfortunately, the data from these scales shows very high rates of depression and anxiety among Chiari patients that is at the level where they should be seen clinically. To be clear, this does not mean the Chiari symptoms are "in their head", rather it means that in addition to other symptoms, Chiari can often take an enormous emotional toll.
- 4. Anatomically, many differences found beyond tonsillar position; entire hindbrain seems to sag** - In a series of studies involving hundreds of adult women, the CCRC has found that Chiari patients have many anatomic, or morphometric, differences beyond just tonsillar position. Historically, many people have viewed Chiari as just involving the cerebellar tonsils, but the data shows this is an oversimplification, and in fact it appears the entire hindbrain is lower, or sags, in Chiari patients.
- 5. Clivus bone is dramatically different, three dimensionally, not just shorter** - Previous research has shown that the midline of the clivus bone (a bone that comes up from the skull base and forms the side of the posterior fossa near the face) is shorter in Chiari patients. However, the CCRC used CTs to look at the clivus bones three dimensionally and found a striking difference in both the volume and shape of the Chiari patient's clivus bones. Using a 3D printer makes it even easier to see this difference, it essentially looks like a piece of the clivus bone is missing in CM patients.
- 6. Some evidence the cerebellum is being stretched by an active process** - Chiari patients are often told they were born that way, but this has never really been proven. It is not clear what an adult patient's cerebellum looked like when they were young. In fact, there is some early evidence that the cerebellum is being acted on by a dynamic process, however more work is needed to verify this.

7. Advanced imaging (DENSE) shows areas of high levels of strain in the brainstem and cerebellum - The CCRC is using DENSE imaging to capture the motion of brain tissue during the cardiac cycle in Chiari patients. This can then be used to calculate the strain being placed on different brain regions and the data shows pretty clearly that the cerebellums and brainstems of Chiari patients are under much more strain than healthy people. However, it is not yet clear if this strain is enough to cause cellular damage.

8. Patient perceived outcomes for adults are not as good as clinically published - The responses of hundreds of patients who have had surgery and participated in the Chiari 1000 show that they don't think their outcome was as good as is generally reported in the medical literature. This is perhaps not surprising but does show the need to incorporate patient perceived outcomes into how Chiari outcomes are assessed.

9. Very high rates of autoimmune diagnoses among adult women with CM - This is true across many autoimmune diseases. The high rates for some, such as chronic fatigue or fibromyalgia may be explained by symptom overlap and misdiagnoses. However, the rates are also high for diseases such as Lupus, which is diagnosed with blood tests. There are no theories as to why this is but it is a finding that needs to be investigated further.

10. ACT therapy shows promise in helping patients cope with residual symptoms and pain - A pilot study at the CCRC showed that ACT therapy can have a positive impact on patients dealing with chronic symptoms. The CCRC is now investigating how this can be delivered over the web so patients everywhere can have access.

The team at the CCRC is incredibly dedicated, and I am confident that this is just the beginning.

Rick Labuda, Executive Director