

## Discussion Tethered Cord Research Study

May 31st, 2009 --

Dr. John Oro is the Medical Director of the Chiari Care Center in Aurora, Colorado. According to the Chiari Care website... "Dr. Oro's commitment to advancing Chiari care developed during his tenure as Professor and Chief of Neurosurgery at the University of Missouri. 'In 1998, I developed a special interest in Chiari I Malformation because I saw that many people were not receiving adequate evaluation and treatment.' Since his initial interest, his commitment to providing the best surgical procedures and patient care has increased and in 2005 he moved his practice to Colorado further advance the care of persons with Chiari and/or Syringomyelia."

This year, Conquer Chiari awarded Dr. Oro a small clinical research grant to study the effectiveness of tethered cord surgery. Dr. Oro agreed to share what he hopes to accomplish with this research...

**You have been treating Chiari patients for quite a while now, do you have an idea about how many Chiari patients you've seen in your career?**

I have evaluated approximately 2,800 patients for the Chiari malformation or syringomyelia in my career.

**At the recent Conquer Chiari research conference, one of the main discussion points was the idea of identifying sub-groups of Chiari patients. Do you think this is a good avenue to explore, and if so how many sub-groups do you think there might be?**

There may be various subgroups of patients with the Chiari malformation. These may include:

- Chiari I malformation with a small posterior fossa and with a normal posterior fossa
- Chiari I malformation with Syringomyelia and without Syringomyelia
- Chiari I malformation with basilar invagination and without basilar invagination
- Chiari I malformation with pseudotumor cerebri & without pseudotumor cerebri
- Chiari I malformation with tethered cord and without tethered cord

**Obviously some people believe that one of the sub-groups of Chiari patients would be those with tethered cord. At this point, prior to your research, what are your thoughts on the relationship between tethered cord due to a tight filum terminale and Chiari? Is there clearly a relationship, and if so is it co-incidental or causal in nature?**

The relationship between tethered cord and Chiari I malformation is unknown. The literature on this is minimal. At least one national clinical team is evaluating a possible relationship in some patients, but their results have not yet been published. There are anecdotal reports from patients and families that some persons with Chiari I malformation improve following section of the filum terminale. However, there are also anecdotal reports that the symptoms can recur after an initial period of improvement.

**What is the purpose of your current project?**

The primary purpose of the study is to determine the 3 month, 1 year, and 2 year outcome of section of the filum terminale in 1) patients presenting with tethered cord symptoms 2) patients with syringomyelia without Chiari malformation, 3) patients with failed Chiari surgery with signs/symptoms of brainstem elongation and tethered cord, and 4) patients with predominant symptoms from tethered cord who also have mild Chiari malformation.

The study will also evaluate the nature of symptoms in patients with TCS, the neurological and radiological findings, the safety of minimally invasive surgical release of the tight filum terminale, changes in syrinx size or scoliosis when present, and changes in herniation of the cerebellar tonsils when present.

**How will this be accomplished?**

In patients undergoing surgery for section of the filum terminale who give permission to be included in the study will have clinical data recorded in a prospective manner. The study is observational and the treatment of the patient will be the same whether they are in the study or not.

Pre-operative data to be collected includes age, gender, symptoms, duration of symptoms, neurological and MRI findings. Surgical data will include level of laminectomy, size of filum terminale, response in evoked potential monitoring, response of filum terminale to sectioning, and any complications.

Outcome will be measured at 3 months, 1 year, and 2 years after surgery and include MRI of syringomyelia or Chiari malformation if present, plain films of scoliosis is present, self-reported improvement on symptoms checklist, MOS 36-Item Short Form Survey Instrument (SF-36), pain medication use, and return to work/school (if pertinent).

**What are the criteria for patients to receive tethered cord surgery?**

Patients considered for the study are those suffering from symptoms or neurological deficits of syringomyelia or tight filum terminale. Some of these patients may also have evidence of scoliosis or mild herniation of the cerebellar tonsils on radiographic studies.

**Do you feel that the tethered cord surgery is less risky and less traumatic than a traditional Chiari decompression?**

This depends on the type of surgery used. If the surgery for tethered cord is a complete laminectomy in the lower lumbar area with wide opening of the dura, wide lysis of the arachnoid membrane and section of the filum terminale, then I believe the intensity of the surgery is similar that of a posterior fossa decompression.

If section of the filum is performed through a small opening in the lamina while preserving the main structure of the lamina and is performed through a minimally invasive procedure, the intensity is less than that of a posterior fossa decompression.

**If the tethered cord surgery does not work, will you then offer a traditional decompression?**

I do not recommend section of the filum terminale as the treatment of choice for persons primarily suffering with Chiari malformation related symptoms. Patients primarily suffering from the Chiari I malformation are treated conservatively or with posterior fossa decompression.

**Beyond your research, what do you think it will take to settle the tethered cord issue?**

Eventually a multicenter trial will be needed. However, prior to that, smaller trials should be performed to help shed light on what should be measured and how it should be measured. The information from these trials should help guide the development of a large multicenter trial designed as best as possible to determine when filum section may be of benefit and the duration of the improvement.

**It is impossible to ignore the controversy surrounding tethered cord surgery that has been in the media, how do you make the potential benefits and risks clear to patients prior to the surgery?**

The job of the physician in non-emergent and non-life threatening situations is to inform the patient and their family of the issues involved, the treatment options, the nature of the surgical procedure, and the risks and benefits involved. Patients should have the opportunity to see their studies and have the findings explained. The patient, not the physician, should make the decision about having surgery. In my view, every operation is a serious operation. With a brain or spinal operation there is always the risk of infection, spinal fluid leak, neurological injury or stroke.

**Beyond the tethered cord issue, do you think in general Chiari patients have better outcomes today than they did 10 years ago?**

The answer is two-fold. I believe surgeons using a regimented technique with secure-as-possible closure of the dura are having better outcomes than 10 years ago. On the other hand, nationally, the degree of inadequate or excessive decompression, of spinal fluid leak, and of infection is still a major concern.

**Do you think they will have even better outcomes 10 years from now, and if so, why?**

I believe with better understanding of the disorder and its subtypes, better diagnostic studies to determine the persons most likely to benefit from surgery, and development of a consensus on the best technical approach to the surgery, the outcome 10 years from now will be better.

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