

*by Ken Casanova*

The Massachusetts CFIDS/ME & FM Association Spring 2000 *UPDATE*

There are times when many of us with the Chronic Fatigue Syndrome/Chronic Fatigue and Immune Dysfunction Syndrome/Myalgic Encephalopathy (CFS/CFIDS/ME) and fibromyalgia (FM) feel desperate. When I am having a bad relapse and am again in a lot of pain and back where I've been more times than I can count, I begin to feel desperate for a cure. I think it's time to try anything—I don't care anymore about normal precautions. But seconds later I say to myself, treatment yes, but no treatment that might be harmful or risky.

Periodically new treatments appear on the scene that proponent's claim will dramatically improve or even cure CFS/CFIDS/ME or FM. Those of us who feel desperate may seek out that treatment, even though it may be risky or yet unproven.

Before undertaking a new treatment, it's wise to take some time to find out as much as possible about what is known and not known about it. What evidence demonstrates its effectiveness against the illnesses? What are the serious risks in the treatment? If serious potential risks exist and the treatment's effectiveness is unproven, then it is usually better to wait until research produces more answers. As more CFS/CFIDS/ME and FM research is undertaken, the potential effectiveness of a new treatment may be clarified fairly quickly.

When I first read that several neurosurgeons were performing brain surgery to treat CFS/CFIDS/ME and FM, I was alarmed. Several doctors and researchers have put forward a theory that in a percentage of patients, CFS/CFIDS/ME and FM are related to Chiari malformation—an anatomical condition in which a portion of the brain is squeezed too tightly into the top of the spinal canal or, alternatively, the upper portion of the spinal cord is squeezed into a spinal canal that is too narrow.

These doctors hypothesize that the mechanical pressure exerted against the brain or spinal cord causes fatigue, headaches, and many neurological symptoms. The remedy in patients with this condition is to surgically remove bone in the skull or the spinal column to relieve the

pressure on the nerve tissue.

A major article on chiari surgery by reporter Thomas Burton appeared on Nov. 11, 1999 in *The Wall Street Journal Europe (WSJE)*.

The article reported that the "complicated and potentially dangerous operation" has already been performed on over 300 FM and CFS/CFIDS/ME patients. On March 10 of this year, ABC's 20/20 with Dr. Tim Johnson gave the chiari surgery a positive report as a potentially exciting new treatment for some patients with CFS/CFIDS/ME and FM. He cautioned, however, that the new treatment should be considered "experimental" and "that it is too early to tell how long results will last and which patients might most benefit."

Should FM and CFS/CFIDS/ME patients undergo serious brain surgery? Does sufficient and reliable scientific evidence indicate that chiari malformation causes primary symptoms in a percentage of patients? Does the surgery relieve or remedy a sufficient number of symptoms in a sufficient percentage of patients to justify the risks of surgery? Experts disagree on the percentage of CFS/CFIDS/ME or FM patients who have chiari malformation as well as the effectiveness of the surgery in the relief of symptoms.

Dr. Michael J. Rosner, a primary proponent of the theory and the surgeon who has performed most of the surgeries to date—an estimated 250, according to the *WSJE* article—compared the effect of the surgical treatment to "the story of the discovery of insulin." Dr. Rosner claims, "Fibromyalgia and chronic fatigue syndrome may be many diseases, but clearly there is a big chunk of them who may be surgical candidates" (*CFIDS Chronicle*, May/June, 1999).

Dr. Sam Banner, a physician and CFS/CFIDS/ME patient who was operated on by Dr. Rosner, reported that he experienced a very significant relief of CFS/CFIDS/ME symptoms. Now Dr. Banner refers CFS/CFIDS/ME and FM patients to Dr. Rosner. Out of 300 of Dr. Banner's referrals, Dr. Rosner has operated on 90 (a rate of 30% of referrals). Dr. Banner claims "50 to 80% of CFIDS/FM patients have malformations." (*WSJE*)

Other medical professionals demonstrate less confidence in the treatment. Thirteen doctors who had examined many of the patients Dr. Banner referred to Dr. Rosner expressed concern that an "inordinately high" number of operations were being performed and that many of the patients' MRI results had been normal. (*WSJE*) Dr. Daniel Clauw, a well-known FM researcher,

contends that only "an extremely low percentage" of CFS/CFIDS/ME and FM cases would involve a chiari malformation. In a magnetic resonance study, he found no difference in the results between the patient and control groups. (

*WSJE*

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A letter, "Is chiari malformation associated with increased levels of substance P and clinical symptoms in persons with fibromyalgia?" from Bradley and Alarcon in the *Journal of Arthritis and Rheumatism* (v. 42, no. 12, Dec. 1999) states that in their ongoing study, 20% of FM patients had chiari malformation, as opposed to 6% of con-trols. However, the authors also found "that there was no dif-ference in ratings of pain or fatigue or in CSF [cerebrospinal fluid] substance P lev-els between FM patients with chiari and those without chiari." Hence, according to these pre-liminary findings, chiari might not be a cause of generalized pain and fatigue in FM patients.

Dr. Rosner asserts that standard MRI testing can overlook chiari malformation and that only specialized scanning is diagnostic. (In other words, studies not using the specialized protocol would not detect the malformation). However, he adds that even the correct MRI scanning may provide only vague results, and that neuro-logical testing and evaluation of symptoms is also necessary. (An important article on chiari malformation in the May 1999 *Journal of Neurosurgery*, is helpful in clarifying and distin-guishing the primary symptoms of CFS/CFIDS/ME and FM and chiari malformation. The article also contains important information on diagnosis by MRI.)

According to Dr. Rosner, "The real diagnostic clue [to chiari malformation] is anything that signals neurological impairment-abnormal reflexes, tingling in both arms or both legs, shooting pain, urinary frequency, inability to stand on one foot... dropping things out of the hands." He goes as far as to say that neurally mediated hypotension (NMH) may prove to be "a good objective marker." (*CFIDS Chronicle*) The problem here is that these neurological symptoms are quite common in CFS/CFIDS/ME and FM. So they may or may not be caused by chiari or narrowing of the spinal canal. For instance, neurological symptoms may be caused by inflammation of tissue in other parts of the brain. Dr. Rosner states that swelling of nerve tissue against spinal and skull bones may be one of the reasons for the symptoms. [Might relief of the inflammation by medication be a less invasive means of reducing tissue pressure?]

What about the effectiveness of the surgery in substantially curing the illnesses or at least relieving major symptoms? No scientific studies yet describe the effect of the surgery. Right now, reports are only anecdotal. "Several of Dr. Rosner's patients say they were disabled and

that they dramatically improved after-ward." However, four patients sued Dr. Banner and Dr. Rosner claiming the surgery was unnecessary or their symptoms had worsened. A number of other doctors who had seen patients before and after surgery claimed the surgery "was unnecessary and unhelpful." (*WSJE*). An article, "N.C. Doctor's Treatment Debated," by Karen Garloch in *The Charlotte Observer* (2/27/2000) quoted Dr. Charles Lapp, a well known CFS/CFIDS/ME and FM clinician, "There is great potential for Rosner's approach, but he too called for controlled studies." Lapp said he has seen several patients after Rosner operated on them. "He claims great success, and I see them later and don't see much success," Lapp said. One patient, for example, improved initially but, six weeks later, Lapp said the patient called him to say that his fibromyalgia pain was back and he couldn't get out of bed.

Rae Gleason, director of the National Fibromyalgia Research Association, in a very positive statement said, "The treatment is not 100%... Each person gets back a different kind of quality... the most dramatic improvement is that headaches are gone... fatigue is greatly decreased." (*CFIDS Chronicle*)

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What can we conclude? Nothing definitive—either a "big chunk" or "an extremely low percentage" of CFS/CFIDS/ME or FM patients may be surgical candidates. Some patients say they have been dramatically helped, while others are suing because they are the same or worse. It is simply too early to tell what percentage of CFS/CFIDS/ME or FM patients have symptoms caused by chiari and whether or not the symptoms are substantially relieved by the surgery. Further scientific research could answer these questions.

Until we get more answers to these questions, we should be very cautious about a rush to surgery. Brain surgery involves the drilling of skull and spinal bone. It invades an area that controls all of the life-and-death autonomic functions such as breathing and heartbeat. This is serious surgery. Let's be active and reasonably experimental in seeking treatments that have shown some effectiveness and are not harmful.