

SEPTEMBER IS CHIARI AWARENESS MONTH

Managing Expectations....One Person's Opinion

Today's awareness item is a little different. It is not taken from the medical literature or the Chiari 1000, rather it is the opinion of Rick Labuda, the Founder and Executive Director of Conquer Chiari. It is only his opinion....

I had decompression surgery 19 years ago. While many of the details have faded over time, one thing that stands out in my memory is my surgeon telling me about a week AFTER the surgery that what I went through was a big deal and it would take time to recover. Before surgery, I was living a very active life and was physically fit. My expectation going into surgery was that it would fix everything and in two weeks I would be feeling great. Needless to say, that's not how things went. My surgeon, who was technically very skilled, never really indicated that it was likely I would have residual issues, that cutting the neck muscles might be tough to recover from etc. In working for Conquer Chiari over the years, I have come to realize that many surgeons (not all) do a poor job of setting expectations. If you look at the hundreds of MRIs that have been collected as part of the Chiari 1000, it becomes clear that a significant portion of patients, especially adults, have anatomical issues such as anterior(front) crowding of the brainstem, that will not be addressed by decompression surgery. How many of these people were told before surgery that they were likely to still have issues afterwards? Would it change someone's view of their outcome if they expected that only some symptoms would improve? In defense of the surgeons, there is a lack of good quantitative data to go symptom by symptom as to what is likely to improve. In fact, one international surgeon told me recently he only tells patients that the surgery will help their classic Chiari headache, but that other symptoms may or may not improve. I believe an experienced surgeon should be able to give an indication of whether a specific person has anterior compression, instability, or other issues that might result in limited improvement from surgery. But I also believe that it is up to the patient to ask, and to be specific! Do you think my headaches will improve? Do you think my balance issues will improve? Whatever your worst, most limiting symptoms are, ask if the surgery is likely to address them. Of course one thing to keep in mind, especially for many kids, is that decompression surgery can result in a very positive outcome with most if not all symptoms resolving. What the Conquer Chiari Research Center is working on is trying to identify which patients will have great outcomes and which may not, so that informed decisions can be made with realistic expectations.