

Finding A Doctor, You Have To Do The Work

"Can you recommend a doctor near Anytown, USA?"

This is, by far, the most common question I receive from people. Unfortunately, it is also one of the most difficult to answer. So difficult, in fact, that even after years of trying, I have yet to be able to answer it.

A list of doctors people could see for Chiari and SM would be a valuable tool and creating such a list is a high priority for this organization. It is also a dauntingly difficult task. You see, the medical professional societies do not recognize Chiari as a sub-specialty, so what would the criteria be for creating such a list?

- Have to perform a certain number of Chiari surgeries per year? This would leave out very qualified surgeons and funnel people to only a few doctors.
- Success rate of surgery? How do you define, and verify, successful outcomes???
- Up to date on the latest Chiari advances? Again, how do you define this, and what if someone disagrees with the latest thinking?
- Patient recommendations? In a broad sense this is completely arbitrary, and one person's experience doesn't mean someone else will have the same experience.
- Handpick a few doctors who do research on Chiari? This would exclude a large number of well qualified doctors with proven track records of success.
- Self-referred list, meaning doctors put themselves on the list. This is something we're looking into, but if it is not widely accepted by the medical community would be of limited value to patients.

A second, and equally unfortunate, reason we have not been able to come up with a doctor list is the issue of liability. While we could probably protect ourselves with disclaimers, in today's society if someone has a bad experience with a doctor they picked from our list, there is a good chance the Foundation would get sued. While we may be protected from a legal point of view, getting involved in lawsuits is something we just can't afford.

We are, however, not giving up. I intend to approach the professional societies with the issue to see if they can help come up with a solution. Clearly, with surgical failure rates as high as 20%, picking a good doctor is important. In fact, it lays the groundwork for your entire Chiari experience. But for now, the reality is that you, the patient, have to do the work to find the doctor that is right for them.

So how do you go about it? I have some suggestions, but please keep in mind they are just that. There are many ways to go about this, these are just some thoughts I have developed over the years that you may (or may not) want to consider.

1. Set emotion aside. This can be extremely difficult to do, especially if the diagnosis has come as surprise, or if you have been told for years there is nothing wrong. However, this is an important decision, and a methodical approach to the matter can help. If necessary, recruit a family member to help you through the process.
2. Establish your criteria. Everyone is looking for something different. This is why creating a list is so difficult. Think through what YOU, as a patient, feel is important in a doctor. Some items to consider:
 1. Location - are you willing to travel or would you rather stay local near your support system. Think about this carefully, traveling when you are going to have surgery can entail a lot of added effort.
 2. University Based or Private Practice - oftentimes, people want to know where the research is going on. This is a perfectly fine approach, however, keep in mind there are many surgeons in private practice, who have not published research on Chiari, who are perfectly capable of treating Chiari patients. Think through carefully what you want.
 3. Someone who does a lot of Chiari surgeries or a general surgeon. Like #2 above, some people are only comfortable with someone who does many Chiari surgeries a year, and that is fine. But if you don't want to travel, another measure of a surgeon's skill is how many surgeries they do a year of any kind. A very busy surgeon is likely a skilled one (because many people want to see him or her) and has also built up a wide base of surgical experience.
 4. Is bedside manner important? Do you care more about the surgeon's skill, or his ability to be compassionate and listen to you, or a combination of both. There is no right answer, just individual opinions.
 5. With what you know about yourself, do you have a straightforward case, or a complicated one with multiple problems? Someone with a "simple" Chiari and no other abnormalities may be comfortable with someone who does not focus their practice on Chiari. On the other hand, someone with a complex anatomy, or whose surgery failed the first time, might want to get an opinion from someone with a lot of Chiari experience.
 6. Insurance and cost. The harsh reality is that most insurances won't pay (or will pay less) to go out of region/network. You have

to weigh the costs of going outside of insurance (if you have insurance) against the benefits to you.

3. Create a list of candidates. This is the step where you create a pool of potential doctors to match against your list of criteria. You can build the list from a number of sources, including:
 1. The professional societies' websites often contain databases of doctors which can be used to find ones in certain areas. The AANS site, www.aans.org can be searched by ZIP code to find neurosurgeons.
 2. If you live near one or more Universities with medical schools, their websites will list neurosurgical faculty.
 3. Ask everyone you know, especially people in the medical community, who they would go see.
 4. Use the internet, especially this site, to identify surgeons and other doctors who do research on Chiari and SM.
 5. A lot of people use chat rooms and message boards to find doctors. I would offer a word of caution here. Be careful about getting doctor recommendations from here. People who have had good experiences with doctors may not necessarily participate in chat rooms, so while it may be good input, it should be considered in the context of all the information gathered.
4. Create a short list based on your criteria. Do what research you have to do to create a short-list of candidates. You can use the internet and phone to learn more and eliminate people from your list based on what is important to you. Or create multiple lists, for example doctors near by, or doctors you would see if you decide to travel.
5. Do more thorough research on the doctors that made the short list. Ask everyone again about these specific doctors. Have they published any research? Have they won any awards? Are they listed in America's Top Docs?
6. Compare your list (plus research) to your criteria list and make a prioritized list. From this, you can set up appointments and see who you like.
7. Finally, if you're not comfortable with what one doctor is telling you, get another opinion. My personal philosophy is to get as many opinions as I need to understand what I am hearing. There is a caveat to doing this however. Research has shown that there is not a lot of agreement on how to treat Chiari, so it is likely you may hear different things from different doctors. If this is what you want, great. If this would confuse you and make you apprehensive, you may be better off just sticking with someone.

If it sounds like a lot of work, it is; but isn't your future worth it? Do you have to do every step? No, you can pick and choose and find your own way. Just remember, this could be one of the most important decisions you make.

Be smart, do your homework, only you can decide who's right for you.

--Rick Labuda

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