

## Tip: Finding A Neurosurgeon

The first step in getting proper treatment for Chiari is to find the right doctor. While many patients are referred first to a neurologist, given that the only real treatment for Chiari is surgical, Conquer Chiari recommends that patients see a neurosurgeon for evaluation.

As a policy, Conquer Chiari does not refer people to specific neurosurgeons.

This is because:

1. There is no professional certification or sub-specialty for Chiari
2. There is no objective data available on how successful individual surgeons are
3. Each patient is unique and is likely to look for different things in a neurosurgeon

As such, we recommend that each patient (or parent) do the work necessary to find the neurosurgeon that is right for them.

Thus, the question becomes how do you find a good neurosurgeon? There are many ways to go about it, and below are some suggestions. Keep in mind these are just suggestions, you may decide to use all of them, use some of them, or not to use any of them at all. There is no right answer, but like anything else, the more work you put into it, the better the result is likely to be.

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. What is right for one person may not be right for someone else. Think through what YOU, as a patient, feel is important in a doctor. Some items to consider:
  - a. *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.
  - b. *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.
  - c. *Someone who does a lot of Chiari surgeries or a general surgeon?* Like (b.) 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.
- d. *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.
  - e. *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.
  - f. *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:
- a. The professional societies' websites often contain databases of doctors which can be used to find ones in certain areas. The AANS site, [www.neurosurgerytoday.org](http://www.neurosurgerytoday.org) can be searched by ZIP code to find board certified neurosurgeons in specific geographic areas.
  - b. If you live near one or more Universities with medical schools, their websites will list neurosurgical faculty.
  - c. Ask everyone you know, especially people in the medical community, who they would go see.
  - d. Use the internet - refer to site in (3a.) - to identify surgeons and other doctors who do research on Chiari and SM.
  - e. 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 message boards. 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 Doctors?

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. **Trust Yourself.** When you meet with the doctor do you get a good feeling? Can you communicate with him/her easily? In the end you may have to trust yourself to this person. Can you see yourself doing that? If so, you probably have found a good doctor for you. If not, consider seeing someone else.

Don't let other people tell you who you should see. Do the work yourself; be smart and do your homework, only you can decide who's right for you.



**For More Information Visit: [www.conquerchiari.org](http://www.conquerchiari.org)**

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