



Chiari Academy Video Transcription

Navigating the Chiari Experience – Finding A Doctor

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In the previous module, we talked about reacting to the shock of a Chiari diagnosis and how to

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talk about a Chiari diagnosis with other people. In this module, we will review the

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first important decision that most people must make, specifically finding the right doctor.

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Chiari patients may see several different specialists during their diagnostic journey,

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but once an MRI has confirmed there is a herniation, since the primary treatment

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is surgical, Conquer Chiari recommends they be evaluated by a neurosurgeon.

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So the question becomes how do you find a neurosurgeon? There is no right or wrong

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answer to this question, but there are some important things to consider and

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steps you can take to increase your chances of finding someone you are comfortable with.

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First, set emotion aside and ask someone to help. This can be difficult to do, especially if the

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diagnosis was a surprise, or if you have been told for years there is nothing wrong. However,

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this is an important decision and a methodical approach can pay dividends. Research has shown

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that even within the same surgical practice, the specific surgeon can have a significant

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impact on complication rates and outcomes. Therefore, consider asking a friend or family

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member to help you work through this process. Second, decide what is important to YOU. It is

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common for people to want to find the best Chiari doctor in the world. Unfortunately, there is no

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objective way to define who is the best. Chiari is not a recognized neurosurgical sub-specialty

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and data comparing outcomes and complication rates between surgeons is not available.

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What is right for one person may not be right for someone else. Think through what you, as a

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patient or parent, feel is important in a doctor. Some things to consider in this regard include

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Location. Are you willing to travel or would you rather stay local near your support system? Think

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about this carefully, traveling when you are going to have surgery can entail a lot of added effort.

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Another question to ask yourself is what type of surgeon do you want? Oftentimes, people want

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to know where Chiari research is occurring which will tend to be at large, university based medical

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facilities. This is a perfectly fine approach, but keep in mind there are many surgeons who have not

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published research on Chiari but are perfectly capable of treating Chiari patients. Similarly,

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consider whether you want someone who does a lot of Chiari surgeries or a general surgeon?

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Some people are only comfortable with someone who does many Chiari surgeries a year,

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and that's ok. But if you don't want to travel, another measure of a surgeon's skill is how many

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surgeries they do a year of any kind. A very busy surgeon is likely a skilled surgeon who has built

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up a wide base of surgical experience. One way to approach this question is to consider do you have

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a straightforward case or a complicated one with multiple problems? Someone with a "simple" Chiari

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and no other abnormalities may be comfortable with someone who does not focus their practice

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on Chiari. On the other hand, someone with a complex anatomy, or whose surgery failed

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the first time, might want to get an opinion from someone with a lot of Chiari experience.

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Another important consideration is whether bedside manner is important to you? Do

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you care more about the surgeon's skill, his ability to be compassionate and listen to you,

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or a combination of both. There is no right answer to this question, just individual opinions.

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A final consideration is insurance and cost. Depending on your specific health insurance,

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your in-network choices might be limited and you might have to factor in whether it is

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worth it to seek care outside of your network. Once you have thought these things through,

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the third step is to create a list of candidates. You can build the list from a number of sources,

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including the American Association of Neurological Surgeons website which has

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a database of members that can be searched by city, state, and zip code. If you live near

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one or more universities with medical schools, their websites will list neurosurgical faculty

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and you can contact the department to see which surgeons perform Chiari surgeries.

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A great way to add to your list is to ask everyone you know, especially people in the

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medical community such as nurses and other doctors, who they would go see if they had

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an uncommon neurological condition. You may find that the same one or two names

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keep coming up because they have the best reputation among professionals in the area.

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Now that you have a list of surgeons, the fourth step is to rank them based on your specific

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criteria. To do this, you will likely have to do additional research. You can look up their bios

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online and see where they went to medical school, did their residencies, how long they have been in

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practice for, awards they've won, etc. You can also use Google Scholar or Pubmed to see if they

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have published any Chiari related research. From this, you may be able to find roughly

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how many Chiari surgeries they've performed, get a feel for how aggressive or conservative they

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are in terms of recommending surgery, what their surgical complication rates are, and how their

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patients have done overall. Just keep in mind that outcomes reported by surgeons tend to be

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more positive than outcomes reported by patients. Also, now that you have specific names, circle

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back around to people you know in the medical community to see what their reputations are like.

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With your ranked list, the final step is to make an appointment and see what

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you think. Start at the top, meet with the surgeon and see what your impressions are.

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Do you get a good feeling? Can you communicate with him or her easily?

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Did they answer your questions? Does their treatment plan make sense? Can you see letting

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this person operate on you or your child? If so, you probably found a good doctor for you. If not,

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consider going to the next person on your list. If you decide to see multiple doctors,

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keep in mind there's a good chance you will hear different opinions, which for

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some people creates more confusion. In the end, trust yourself, you know what's best for you.