Chordoma Survivors & Support – Private Facebook Group – Questions for Surgeons or Oncologists

For anyone newly diagnosed: Chordomas are typically very slow growing. You must be your own advocate, research the best options, and do not rush in to surgery. We invite you to watch a "**Do your Homework**" video at **this link.**

The **Expert Recommendations** for the Diagnosis and Treatment of Chordoma booklet lists evidence-based consensus guidelines from a group of 40 chordoma experts from around the world who came together to discuss and determine the best and most effective methods for treating chordoma. Download link **HERE**. This is an **excellent resource** and the Facebook group members (unaffiliated the Chordoma Foundation) feel newly diagnosed patients should read this booklet in its entirety.

On page 6, find the Right Medical Team: *"Chordoma is a rare disease, and it affects very important and complex parts of the body. For these reasons, appropriate diagnosis and treatment of chordoma requires very specialized care provided by multiple types of doctors. This team approach involving multiple specialists is called* ***multidisciplinary (team)*** *care. It is typically only found at larger hospitals called referral centers, which see large numbers of (chordoma) patients, and is not available at most local hospitals"*

On page 13, Initial Treatment: "*The first treatment you have makes a big difference for your quality of life and the chances of the tumor coming back*". "***Because chordoma is a complex disease to treat****, it is important to have a medical team that includes multiple specialists who work together to coordinate your care. A doctor specializing in radiation therapy for cancer, called a radiation oncologist, will need to be part of your medical team even before surgery to plan with your surgeons for any radiation treatment you will receive before or after surgery*"

- The Facebook Group strongly encourages you to print the following questions, and add other questions that you may have
- Bring someone with you for support and to write down answers.
- Hearing some of the surgical realities and challenges can put people in to a fog. This is normal, so do bring support!
- From written notes, recap the conversation and the recite the doctor's answers that you wrote down before he or she leaves the room.

  You will likely end up feeling frustrated because you may forget to note something important. (Very common)
- Don't forget to thank the physicians for their time in advance… and take deep breaths!

Questions… don't forget to write additional questions down.

1. Am I clival, cervical, lumbar, thoracic, or sacral _____ and which vertebrae are impacted?

2. Can you please tell me how many chordoma surgeries you perform yearly in my area and what have the typical surgical outcomes been?

3. If you've had a prior surgery: Has pathology confirmed the 'type' of chordoma, i.e. conventional, chondroid, or dedifferentiated? (if they don't answer directly it may not be a good sign)

4. What are the dimensions of the tumor _____ and can you offer a visual representation; the size of a walnut, a plum, a peanut, or?

5. Has a multi-disciplinary tumor board reviewed my case, what were their conclusions, and who would I speak to for notes for a second opinion

6. Do you feel any hardware may be required? _____ if yes, how might this affect future radiation?

7. Do you think I'll have less mobility if my tumor is removed and if so, can you estimate by about what percentage?

8. Do you think it's possible to achieve negative margins given my scenario?

9. What is the plan if any, for pre and/or post-operative radiation, and what type of radiation do you recommend?

10. How long do you estimate surgery will last and what are the complications that could happen during surgery?

11. What are the common post-operative complications I might expect during recovery?

12. What are some uncommon complications?

13. Can you walk me through the stages of hospitalization after surgery, how many days including rehab?

14. Would you recommend physical or occupational therapy?

15. What lifestyle changes do you foresee, if any?

16. Given this treatment roadmap, what is my long-term prognosis?

17. Is there an option to "watch and wait?" And if so, how fast could it grow if I do nothing right now, and what am I risking?

18. Are there any other viable treatment options other than surgery that can be considered? Proton Beam Therapy only, Single high-dose radiation only, a clinical trial, chemo, and/or?

19. Rare and complex diseases warrant multiple opinions by experts, who would I speak with to get CDs with MRIs, CTs (if any), and all applicable reports for a second and third expert opinion?

20. What is the best way to reach you with questions?

Questions for Radiation Oncologists:

21. How many chordoma cases have you treated? _____ How many similar to mine _____ and what were the outcomes?

22. My understanding is that Proton or Carbon Ion are recommended for chordomas: Can you walk me through the type of radiation you recommend, and the process of administering radiation?

23. What are my short and long term benefits to receiving radiation treatments, and what are the risks?

24. What are the common and uncommon complications?

25. Who from my care team will be available to me while I am receiving treatment in case I have a complication, and how will I reach them?

And Finally…

More about understanding chordoma **here.** Within the chordoma Facebook community we've noticed a non-scientific pattern: **dedifferentiated** and poorly differentiated variations seem **much more common in infants**, **toddlers**, and **young adults.** Interestingly, much more common in **young females** than males. If there's been a prior surgery especially with children and young adults, we feel it's very important to understand the type/pathology. Chemo or a clinical trial may considerations for poorly/dedifferentiated types.

Friendly Reminders:

- Recap details from your notes before the doctor leaves the room.
- Chordoma is a rare one-in-a-million bone cancer and the treatment protocol is evolving. It's very important to be treated by multidisciplinary chordoma expert teams
- Chordomas are typically very slow growing. **Don't rush** treatment, do your homework (link)! You must educate yourself to learn the best options to make informed decisions
- Be your own advocate, deputize friends or family members to attend all appointments with you!
- The Chordoma Survivors Facebook page is private: Only members can see posts within the group. The group members understand first hand that this is a lot to absorb… do **ask questions**!
- While many members of the private Facebook group serve the Chordoma Foundation as volunteers, the group is private and separate/unaffiliated with the Foundation
- These questions are not all-inclusive – Write down and ask any other questions you may have too!

Links:

- CF Doctor Directory. http://www.chordomafoundation.org/doctor-directory/
- Link for physicians http://www.chordomafoundation.org/healthcare-professionals/
- Chordoma Foundation Patient Services http://chordoma.org/requesthelp
- Expert Recommendations booklet https://www.chordomafoundation.org/expert-recommendations/
- Expert Answers - Video Series https://www.chordomafoundation.org/living-with-chordoma/expert-answers-video-series/

You are not alone… we are all in this together!