



Selecting a Sarcoma Treatment Center:

How to Find a Chondrosarcoma Oncologist / Treatment Center



CHONDROSARCOMA
FOUNDATION

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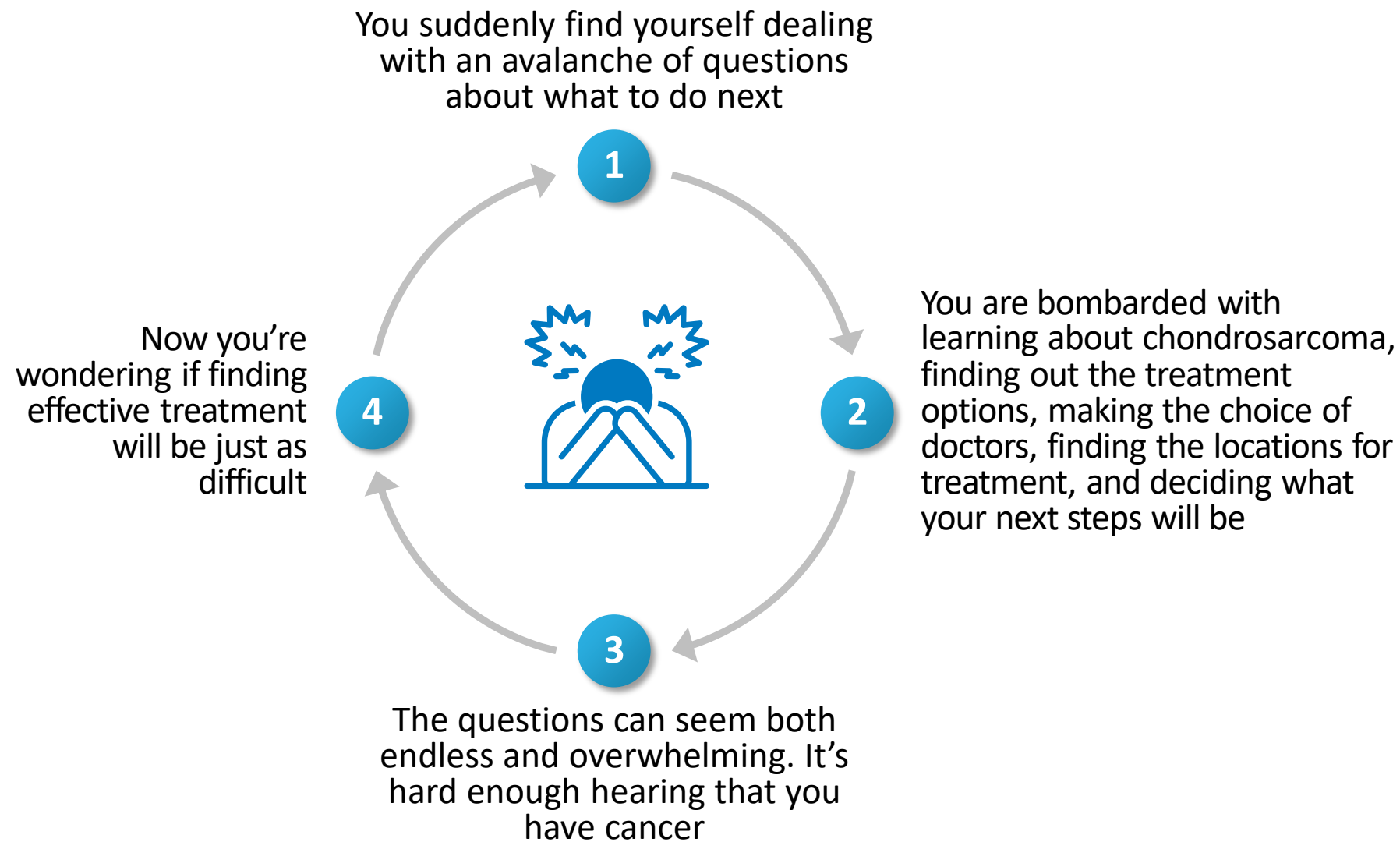
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1 Introduction

You've been told the one of most difficult news that you or a loved one has ever heard. **You have chondrosarcoma**, a rare form of bone cancer. You are devastated like the rest of us when we get this news



The goal here is to help you understand what's going on and what medical decisions you will need to make.

Getting the information about chondrosarcoma will:

- Help you understand this rare bone cancer
- What treatment options are available
- What you can expect moving forward

2 What is chondrosarcoma?

The Mayo Clinic defines it as *“...a rare type of cancer that usually begins in the bones but can sometimes occur in the soft tissue near bones”*

- As with many cancers, chondrosarcoma has various sub-types. Some are benign and others are very aggressive
- Chondrosarcoma is classified by its level of severity and specific location within the body. Many cases occur in the limbs such as legs or arms, but it can occur in the spine, at the base of the skull and at other locations in the body
- Chondrosarcoma is often first detected with X-rays and CT or MRI scans
- Its symptoms are usually pain and swelling of a specific bone or joint area
- To get a proper diagnosis, a tissue or bone biopsy must be done and evaluated by a pathologist to verify whether the swelling is a bone cancer tumor. Preferably the pathologist specializes in diagnosing bone and soft tissue cancers



3 Finding a Sarcoma Treatment Center



- To get a proper diagnosis and to determine what treatment options are available for you, it may be necessary to get a referral and find a **Sarcoma Treatment Center**
 - Sarcoma centers provide access to the full range of care and the latest clinical research. Diagnostic work-up and treatment should be ideally performed at a sarcoma treatment center, where patients will have access to care and expertise from a multidisciplinary team specializing in sarcomas
 - Primary care physicians are encouraged to refer patients to these centers, where patients not only benefit from specialized care, but often receive treatment as part of prospective clinical trials or established treatment protocols
- Once you've been diagnosed, you will need to think about treatment. The most common treatment for chondrosarcoma is the surgical removal of the tumor
- While this is effective, there are instances where it is simply not practical or feasible, based on the tumor's location
- Some types of radiation are effective, such as proton radiation, but this varies widely, as do the use of medications that inhibit, suppress, or destroy the cancer cells
- It is important to select an oncologist who knows the options and has experience in treating chondrosarcoma
- Many doctors, even many oncologists who deal with sarcomas, may not be familiar with the specifics of chondrosarcoma itself

4 What to consider when finding a Sarcoma Treatment Center (1/3)

Location

- You want to be treated close to home, but that might not always be the best course in terms of finding the most effective center.
- Look for Sarcoma Centers as close to home as possible, but make sure they provide the best care and have experience in treating chondrosarcoma.
- There are websites that list sarcoma treatment centers in the United States (listed by State) and internationally (see resources section).



5 What to consider when finding a Sarcoma Treatment Center (2/3)

Multidisciplinary team

Given the complexity of this rare disease coordination of care is needed. Chondrosarcoma management should take place in a sarcoma center and involve a multidisciplinary team

The core group of medical professionals should include:

- Orthopedic oncologist
- Bone pathologist
- Medical/pediatric oncologist
- Radiation oncologist
- Musculoskeletal radiologist

In addition, in some cases the following specialists should also be available:

- Thoracic surgeon
- Plastic surgeon
- Interventional radiologist
- Physical therapist
- Vascular/general surgeon
- Neurosurgeon/orthopedic spine surgeon
- Otolaryngologist (Ear, Nose, Throat doctor)
- Palliative care physician
- Additional surgical subspecialties as indicated.



Multidisciplinary care at the sarcoma center should be available from diagnosis to life-long follow-up.

- Initial work-up should include medical history, physical examination, radiological assessment, and tissue biopsy.
- Pathological diagnosis should be made by a bone tumor expert.
- Genetic sequencing / Molecular analysis is highly recommended.
- Imaging assessments and surveillance (CT, MRI (whole body scans) should be carried out to determine presence and extent of metastases.

6 What to consider when finding a Sarcoma Treatment Center (3/3)

Other Considerations

- **A medical group consisting of all specialties**, including surgical, orthopedic, and medical oncologists; radiologists; pathologists; and oncology nursing as well as rehabilitation services. It should also include strong support personnel including social workers, psychologists, and psychiatrists.
- **Tumor Boards:** Cases should be discussed at least once a month by the multidisciplinary team at diagnosis, pre- and post-therapy, and during follow-up assessments.
- **Experience in treating chondrosarcoma** including sarcoma specialists / oncologists who belong to a sarcoma-oriented medical organization, such as the Connective Tissue Oncology Society
- **Sarcoma Oncologists / Experts** that have publications researching and/or treating chondrosarcoma in peer-reviewed journals.
- **Access to Clinical Trials:** Contrary to the opinion of many people, including some doctors, clinical trials are NOT a treatment of last resort, nor are they scenarios where you are treated like a lab rat. Care and treatment under clinical trials is highly regulated and controlled. The medical staff are highly trained in the specific treatment you are getting. And you are free to stop the treatment at any time, no questions asked.

It is important to ask a lot of questions and not be afraid to ask for a second opinion, or even a third if needed

- Ask about the experience of the oncologist with treating chondrosarcoma.
- Ask what treatments have been done and what treatment options are available.
- Assess how the doctor reacts when you say you want to get a second opinion? Be wary if your doctor doesn't like questions or the idea of getting another opinion. They should welcome both. If this isn't the case, find another doctor. Someone who doesn't like questions probably isn't going to be open-minded about treatment options, including those options that might save your life.
- Do not proceed with a treatment unless you are comfortable doing so and all your questions have been answered. You must be your own best advocate and you are a member of your chondrosarcoma care team.
- For each of these areas there are many details to consider and think about. No brief narrative can cover every bit of information available. Nor can it provide quick and easy answers to questions that are very complex and very important.
- Selecting the treatment, you want and need, along with deciding where you'll receive that treatment, is decisions that should be made by you and your family, not anyone else.

8 Resources

Take advantage of the resources that are available. Ask questions. Talk with your healthcare providers, family, friends, other cancer patients and support groups; both those with chondrosarcoma and other types of cancer. An old cliché says knowledge is power. Use this knowledge to give yourself the best chance of winning against chondrosarcoma and living life on your terms, not cancer's

- **Sarcoma Alliance:**
<https://sarcomaalliance.org>
- **The Sarcoma Alliance for Research Through Collaboration: SARC:**
<https://sarcomacoalition.us/what-is-sarcoma-and-sarcoma-centers-of-excellence/>
- **National Comprehensive Cancer Network Guidelines:**
<https://www.nccn.org/patients/guidelines/content/PDF/bone-patient.pdf>
- **Facebook Support Groups**
 - Chondrosarcoma Support Group (available [here](#))
 - Chondrosarcoma Care and Support Group (available [here](#))
 - Mesenchymal Chondrosarcoma (available [here](#))
 - Skull Base Chondrosarcoma (available [here](#))
 - Chondrosarcoma CS Foundation Support (available [here](#))



9 Biography



Mike Snyder lives in Albuquerque, New Mexico with his wife, Sarah. They have two children, Nicholas, and Stephanie. Mike has worked in broadcast engineering for 40 years.

He has been dealing with chondrosarcoma since 1996. The fight became intense in 2005 when he lost his leg to the disease, and it began to metastasize to his lungs. After several unsuccessful drug trials, Mike first joined the trial for AG-120 in late 2014 and it has successfully slowed the growth of his tumors. He is currently participating in the INBRX 109 clinical trial.

Mike continues working full-time, enjoying time with Sarah, and grilling whenever he gets the chance. He says, “Cancer doesn’t get to win; not now, not ever.” Mike is also the author of the book entitled:

No Treatment Options Left: Fighting and Surviving Inoperable Cancer

