Navigating the Healthcare System

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• Become empowered
• Educate yourself
• Selecting a treatment team
• Dealing with insurance companies
• Working with your treatment team
• Staying Safe
• Resources
Becoming Empowered
Becoming Empowered

• Take ownership of your treatment
• Don’t be a “good patient”
• Stand up for yourself if things don’t seem right
• Be willing to make your doctor uncomfortable
• Ask questions until you understand
• Prepare for your doctor visits
Educating Yourself
Learn the Specifics of your Chordoma

• Location
• Tumor size
• Has it metastasized?
The Internet

- Decide what you are looking for (treatments, support groups, clinical trials, etc)
- If searching raises your anxiety take a break
- Choose sites carefully
  - Are they reputable? (There is a lot of misinformation on the internet)
  - Paid links
• Is the information you are finding appropriate for the location of your chordoma?
Reputable Sites

• Chordoma Foundation: http://www.chordomafoundation.org
American Academy Orthopaedic Surgeons:
http://orthoinfo.aaos.org/topic.cfm?topic=A00084

Chordoma

Chordoma is a rare tumor that usually occurs in the spine and base of the skull. It is a malignant tumor that grows fairly slowly. It can spread to other organs, usually the lungs. It represents only about 1 percent of all malignant bone tumors.

Description

Chordomas develop in a structure called the notochord. The notochord forms the early spine in the beginning stages of fetal development. Most of the notochord is replaced by the spine during the first six months of development. Small areas can remain, and chordomas can form in these areas.

Most chordomas occur at the base of the spine (sacrum), in the tailbone (coccyx) or at the base of the skull (40 percent), but they can occur other places in the spine.

Most patients with chordomas are between 40 and 70 years of age. Occasionally this tumor can occur in younger patients, even children. The average age of people affected is about 55 years.

Chordomas are life-threatening. They can cause death by direct growth or by spreading to other organs. They spread to the lungs about 20 to 30 percent of the time.
For Newly Diagnosed Patients

If you have recently been diagnosed with chordoma, we want you to know that you are not alone. The Chordoma Foundation and many chordoma survivors are here to help you to be well. We believe passionately that every chordoma patient deserves to benefit from our collective knowledge and wisdom about chordoma, so that we are able to make informed decisions that will lead to the best possible outcomes. This page provides a starting point for finding the information and resources you need to successfully navigate your new diagnosis.

1. Learn about chordoma
   Knowledge is power when it comes to dealing with chordoma. These pages contain the basic information you need to know about the disease.
   - Overview of chordoma
   - Frequently Asked Questions

2. Plan your treatment
   The treatment plan that you choose, especially for your first treatment, can have a major impact on your outcome. It is therefore very important to evaluate your options carefully. These pages will help you make informed decisions about your course of treatment.
   - Treatment
   - Find a doctor

3. Consider donating part of your tumor for research
   Tumor tissue is critical for research needed to develop improved treatments for chordoma. The Chordoma Foundation Biobank enables chordoma patients to donate excess tumor tissue removed during surgery – tissue that would otherwise go to waste – to be used for research. Its free, won’t interfere with your treatment and will greatly help to advance the search for a cure.
   Please contact us as soon as surgery is scheduled so that our Biobank team can make arrangements to properly save and collect your tumor tissue. If you have already had surgery, we can also attempt to retrieve tissue that might have been saved at the hospital where you had surgery.

4. Get connected with the Chordoma Foundation
   Register with the Foundation to receive the latest information about new treatments and clinical trials, opportunities to participate in research and events, and updates about our progress in advancing the search for a cure.

5. Get support
   Others who have been in your situation are available to provide support, perspective, and advice for dealing with chordoma. You may want to consider seeking support from the resources listed below.
   - Peer Connect – our peer connect program matches you with trained peer mentors from the chordoma community
Clinical Trials

- **Chordoma Foundation:**

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### Clinical Trials

This page lists all open clinical trials that are specifically recruiting chordoma patients.

Clinical trials give patients an opportunity to receive new, experimental treatments that have the potential to offer more benefit than clinically available alternatives, or to receive clinically available treatments at no cost. In addition to having the potential to benefit from the latest treatments, chordoma patients who participate in clinical trials contribute to knowledge that can guide therapy for future patients and potentially help identify new ways of treating this rare cancer. Before enrolling in a clinical trial it is important to understand the potential risks and benefits, and to discuss your options with your physician.

<table>
<thead>
<tr>
<th>Identifier</th>
<th>Treatment</th>
<th>Setting</th>
<th>Phase</th>
<th>Mechanism</th>
<th>Target</th>
<th>Locations</th>
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<tr>
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<td>Chordoma</td>
<td>Advanced</td>
<td>Phase I</td>
<td>Controlled infection of tumor by bacteria</td>
<td>Hypoxia</td>
<td>Memorial Sloan Kettering, MD</td>
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<td></td>
<td></td>
<td>tumor</td>
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<td>(“bikscrip”) plus radiotherapy</td>
<td></td>
<td>Anderson</td>
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<tr>
<td></td>
<td></td>
<td>no</td>
<td></td>
<td>Direct bone involvement</td>
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<td>NCT0234198</td>
<td>BRD4</td>
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<td>Phase I</td>
<td>Induced immune response to cells</td>
<td>Brachy</td>
<td>National Cancer Institute</td>
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<td>Multicenter with international</td>
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<td>INI-1</td>
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<td>locations, sponsor approval required for chordoma</td>
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To receive email updates about new clinical trials that are open to chordoma patients, [sign up here](http://www.chordomafoundation.org/clinical-trials/).
Patient Navigation Service

The Chordoma Foundation serves as a resource for patients and families in need of support around the world. Our Patient Navigation Service helps individuals facing chordoma overcome barriers to getting the best care possible, whether it's finding the right doctors, understanding treatment options, or getting emotional support.

Some examples of the assistance we provide through our Patient Navigation Service include:

- Answering questions and explaining important concepts about chordoma and treatment options
- Facilitating referrals to experienced physicians and treatment centers
- Identifying and providing information about clinical trials for which a patient could be eligible
- Recommending home health services, medical equipment providers, and other relevant vendors and service providers
- Providing information about programs and organizations that offer travel and lodging assistance, co-pay relief, and other benefits
- Supporting requests and appeals to insurance companies

Request help from a Patient Navigator

Our Patient Navigator is available to help by email and phone, Monday through Friday from 8AM to 5PM ET. Please complete the form below to request help and a Patient Navigator will be in touch within 1-2 business days.

Title: [Please select]
First name: [Enter name]
Last name: [Enter name]
Email: [Enter email]
Phone: [Enter phone number]
I am a: [Please select]
Selecting a Treatment Team
When You First Receive a Diagnosis

• In most cases you have time to explore options
• Exception: Acute spinal cord compression
• Unless you live near an academic medical center will most likely will be referred to a local specialist
During Doctor’s Visit

- Bring written questions
- Bring a notebook, take notes
- Bring an advocate
Important Questions

• Are you familiar with chordoma?
• **How many chordoma patients have you treated?**
• What were the outcomes?
  – Recurrence rate
• What were the complications?
Second Opinion

- Always a good idea
- Don’t see a doctor in the same practice
- Don’t see a good friend of the first doctor
- Get an opinion from an expert
How Do You Find Experts?

- Pub Med – Search for papers on chordoma & see who the authors are then check hospital web site
When Seeking a Second Opinion

• Facility may request records & imaging before visit.
• May require travel
• Explain what first doctor suggested and ask what this doctor thinks about it
If the Second Doctor Agrees with the First

• Who do you like more?
  – Training & experience
  – Results
  – Bedside manner
  – Support services

• Who is more convenient?
  – Closer to home
  – Insurance issues
If Second Doctor Disagrees with the First

• Change doctors
  – May require travel

• Consider a 3d opinion

• Stick with the original doctor
  – Ask what he thinks about the 2nd doctors opinion
Dealing With Insurance Companies
Some Facts

• Chordoma is expensive to treat
• Your insurance company makes money by NOT paying for your healthcare
• Your insurance company has a large bureaucracy dedicated to the prior authorization process
• Insurance companies outsource parts of the approval process to third parties
• Chordoma is rare & until recently there were few treatment guidelines
• You will probably know more about chordoma than the healthcare professionals you will speak with at your insurer
Pre-Approval Process

• Provider files request for service
• Reviewed by clerical personnel
  – Works strictly off of algorithms
• Reviewed by nurse (RN or LPN)
  – Still working off of set of standards may be able to approve tests
• Reviewed by MD
  – Initial rejection common
• Peer to Peer
• If rejected have to follow insurance company appeals process
What You Can Do

• Ask for a case manager
• Quote NCCN Guidelines
• Be persistent, fight for the care you need
• Work with your provider’s office
• If necessary threaten to go public
Know What to Expect After Treatment
Schematic demarcation of dermatomes (according to Keegan and Garrett) shown as distinct segments. There is actually considerable overlap between any two adjacent dermatomes. An alternative dermatome map is that provided by Foester.

Levels of principal dermatomes:

- C5: Clavicles
- C5, 6, 7: Lateral parts of upper limbs
- C8, T1: Medial sides of upper limbs
- C6: Thumb
- C6, 7, 8: Hand
- C8: Ring and little fingers
- T4: Level of nipples
- T10: Level of umbilicus
- T12: Inguinal or groin regions
- L1, 2, 3, 4: Anterior and inner surfaces of lower limbs
- L4, 5, S1: Foot
- L4: Medial side of great toe
- S1, 2, L5: Posterior and outer surfaces of lower limbs
- S1: Lateral margin of foot and little toe
- S2, 3, 4: Perineum

MASSACHUSETTS GENERAL HOSPITAL
CANCER CENTER
Working with your Treatment Team
Doctor Patient Relationship

• Important part of good patient care
  – Helps you get the best treatment
  – Facilitates the healing process
• Requires mutual understanding
  – Patients are stressed and scared
  – Doctors work hard and want to be appreciated
Understanding Your Doctor

• Becoming a doctor takes sacrifice
• Doctor are trained to maintain professional distance
• External pressures stress doctor’s empathy
• Your doctor and you have the same the same goal, the best possible outcome
Bringing Your Doctor Closer

- Help your doctor see you as a person, not just another patient
  - Find things in common
- See your doctor as a person
  - Notice & comment on his experience
  - Offer support/sympathy/praise
- Invest in the relationship
  - Empathy begets empathy
Communicating with Your Doctor

• Questions to ask:
  – Can you explain ALL of my options
  – What are the efficacy, risks, side effects of each option
  – How will each treatment option affect my quality of life
Communicating with Your Doctor

• Say what is on your mind
  – Pain
  – New symptoms
  – Side effects

• Be sure to get your test results
  – Don’t assume no news is good news
Communicating with Your Doctor

• Get organized
  – Get copies of everything
    • Imaging reports
    • Operative reports
    • Discharge summaries
  – Make a notebook
    • Section for questions
    • Section for your notes
What if Your Doctor is Difficult

• Try to figure out why?
  – Ego
    • Would feeding the ego get you what you want?
  – Feeling challenged
    • Try to negotiate and see his point of view
When Your Doctor is Difficult

• When you know more than you doctor
  – Be sensitive to his ego
    • “I am sure you already know this”

• When the doctor isn't engaged
  – Do you need him?
    • Expert
  – Does is lack of engagement matter?
    • Yes- dump him
    • No –Let it go
Staying Safe
In the ER

• Don’t be afraid to ask questions
• Make no assumptions
  – They must know I am here
  – The doctor must be working on my case
  – This must be the correct medicine
  – They must know about my allergy
In the Hospital

• Ask about every medicine before you swallow
  – Electronic med systems are just software
• If something doesn’t seem right speak up
• Be sure that your regular medications were ordered
• Everyone should wash their hands or use hand sanitizer before they enter your room
In the Hospital

• Make sure your doctors are communicating with each other

• Find out when rounds are
  – Surgeons round very early in the AM
  – Entire team may not round every day
Resources
Travel

• Join frequent traveler programs (airlines, hotel, rental car)

• Air travel
  – Corporate Angel Networks:  
    http://www.corpangelnetwork.org/
  – Patient Airlift Services (Northeast):  
    http://www.palservices.org/
  – Angel Flight  
    http://www.angelflight.com/
• Lifeline Pilots: https://lifelinepilots.org/
Lodging

• Hope Lodge: [http://www.cancer.org/treatment/supportprograms/services/hopelodge](http://www.cancer.org/treatment/supportprograms/services/hopelodge)
  – Sponsored by American Cancer Society
  – 31 locations
  – Free

• Hospitality Homes: [http://www.nahhh.org/](http://www.nahhh.org/)

• Hospital Facilities
Support Groups

• Chordoma Survivors Facebook Page: https://www.facebook.com/groups/ChordomaSurvivorsPrivate/
In Summary
Gathering Information

• Use only reputable web sites
• Ask the same question of multiple doctors
• Write everything down
Find an Expert Treatment Team

- Chordoma Foundation Doctor List
- Treatment center web sites
- Search PubMed for authors
- As local doctors for recommendations
Working With Your Treatment Team

• Stick up for yourself but be gentle with egos

• If your doctor is being difficult consider
  – Stroking his ego
  – Compromising
  – Dumping
Staying Safe

• Always ask questions
• Get copies of your records & test results
• Make sure people wash or use hand sanitizer
Thank You

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