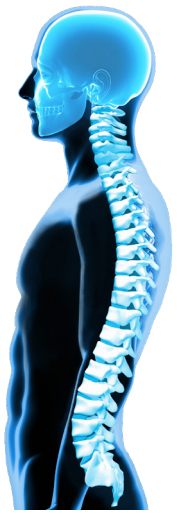
CHORDOMA
What you need to know

CHORDOMA FOUNDATION

What is chordoma?



- **Rare, malignant tumor** that occurs in the bones of the skull base and spine
- Incidence of **1 in 1 million people** per year
- Delayed diagnosis and initial misdiagnosis are common
- **Complicated to treat** due to the involvement of critical structures such as the brainstem, spinal cord, and important nerves and arteries
- **Local recurrence is common**; many patients experience more than one recurrence
- Metastasis occurs in about 30-40% of patients, usually late in the course of the disease
- There are **no known risk factors** (e.g., environmental, dietary, or lifestyle) for chordoma and less than 20 familial cases have been identified around the world

How is chordoma treated?

Surgery and radiation are the recommended initial treatments for chordoma. Radical resection and high doses of radiation are usually required, sometimes resulting in damage to cranial or spinal nerves. Reconstructive surgery (e.g., bone grafts, tissue grafts, metal implants) is typically needed.

There are currently **no approved systemic therapies for chordoma**, and only a few clinical trials are available for which chordoma patients are eligible. Off-label treatments are given when possible, but coverage by insurance providers and health systems can be difficult to obtain.

How are chordoma survivors affected?

In a study on quality of life among chordoma patients[1]:

- The most common challenges reported include **chronic pain, depression or severe anxiety, chronic fatigue, difficulty walking, and balance impairment**.
- The vast majority of chordoma patients (93%) report experiencing at least one challenge, while 36% experience five or more.

Skull base

- 56% double vision
- 35% depression or anxiety
- 34% chronic sinus issues

Sacral

- 62% difficulty sitting
- 54% difficulty walking
- 51% chronic pain
- ~50% bowel/bladder/sexual dysfunction

Mobile spine

- 57% chronic pain
- 40% difficulty walking
- 39% chronic fatigue

[1] Song PH, Beyhaghi H, Sommer J, Bennett AV. Symptom burden and life challenges reported by adult chordoma patients and their caregivers. Qual Life Res. 2017 Mar 17; 26(8): 2237–2244. doi: 10.1007/s11136-017-1544-2.

What my providers should know about me

Today's date: _____

My name: _____ Date of birth: _____

I was diagnosed with chordoma on: _____

The tumor is/was located at: _____

I have had:

- ☐ Surgery
- ☐ Radiation
- ☐ Systemic therapy
- ☐ Other treatments

Treatment details I'd like to share:
(e.g., date(s) of surgeries, types of other treatments, complications)

_____

_____

_____

I have had a local recurrence: ☐ Yes ☐ No If yes, how many? _____

My tumor has spread: ☐ Yes ☐ No If yes, to what areas? _____

Other things to know about me:
(e.g., quality of life challenges, treatment side effects)

_____

_____

_____

_____

_____

CHORDOMA FOUNDATION

The Chordoma Foundation is a nonprofit organization working to improve the lives of those affected by chordoma and lead the search for a cure. **Please visit chordoma.org for in-depth information that can help you learn more about chordoma and how it may impact your patient's life.**