

## Be Part of the Solution



The Chordoma Foundation was started and is driven by patients and families determined to create a brighter future for everyone affected by chordoma. By

working together and pooling our resources, we are making encouraging progress toward better treatments, better care, and a better experience for chordoma patients. We invite you to join us in the fight against chordoma. Learn about the many ways you can help at [chordomafoundation.org/take-action](http://chordomafoundation.org/take-action)

## Donate Your Tumor

Scientists need tissue from chordoma patients to find a cure. Because chordoma is so rare, every patient's tumor is extraordinarily valuable for research. If you are planning to



have surgery, you can help advance the development of better treatments by participating in our Tumor Donation Program, which will enable you to contribute excess tumor tissue removed during surgery for research. Contact us as far in advance of surgery as possible at (877) 230-0164 or [tumordonation@chordoma.org](mailto:tumordonation@chordoma.org). For more information, visit [chordomafoundation.org/tumor-donation](http://chordomafoundation.org/tumor-donation)

## About the Foundation

The Chordoma Foundation is a nonprofit organization that serves the needs of the worldwide chordoma patient community, and partners with healthcare providers, scientists, and companies to advance chordoma research and improve patient care.

Our vision is a future in which everyone affected by chordoma is able to overcome the disease and maintain their quality of life. Since 2007, we have served thousands of chordoma patients across the world and have dramatically accelerated the search for better treatments.

To learn more about the Foundation and the progress we are making, visit [chordomafoundation.org/about-us](http://chordomafoundation.org/about-us)

## Get Connected

Stay up to date on the latest Chordoma Foundation news, treatment advances, and opportunities to get involved.

 [facebook.com/chordomafoundation](https://facebook.com/chordomafoundation)

 [@chordomaFDN](https://twitter.com/chordomaFDN)

**Visit Us:** [chordomafoundation.org](http://chordomafoundation.org)

**Phone:** (919) 809-6779

**Toll Free:** (888) 502-6109



*Improving the lives of those affected by chordoma  
Leading the search for a cure*

## Understanding Chordoma

Chordoma is a rare type of bone cancer that forms in the skull or the bones of the spine.

### WHO GETS CHORDOMA?

People of all ages and races can get chordoma. It is more common in men, and it is most often diagnosed in people in their fifties and sixties.

### WHAT CAUSES CHORDOMA?

Chordoma tumors develop from cells of a tissue called the notochord—a structure in an embryo that is important in the development of the spine. Chordomas form when notochord cells that are left over in the skull or spine change over time and become cancerous. Everyone has notochordal remnants, but very few people get chordoma. Scientists are working to understand what causes these cells to change in some people.

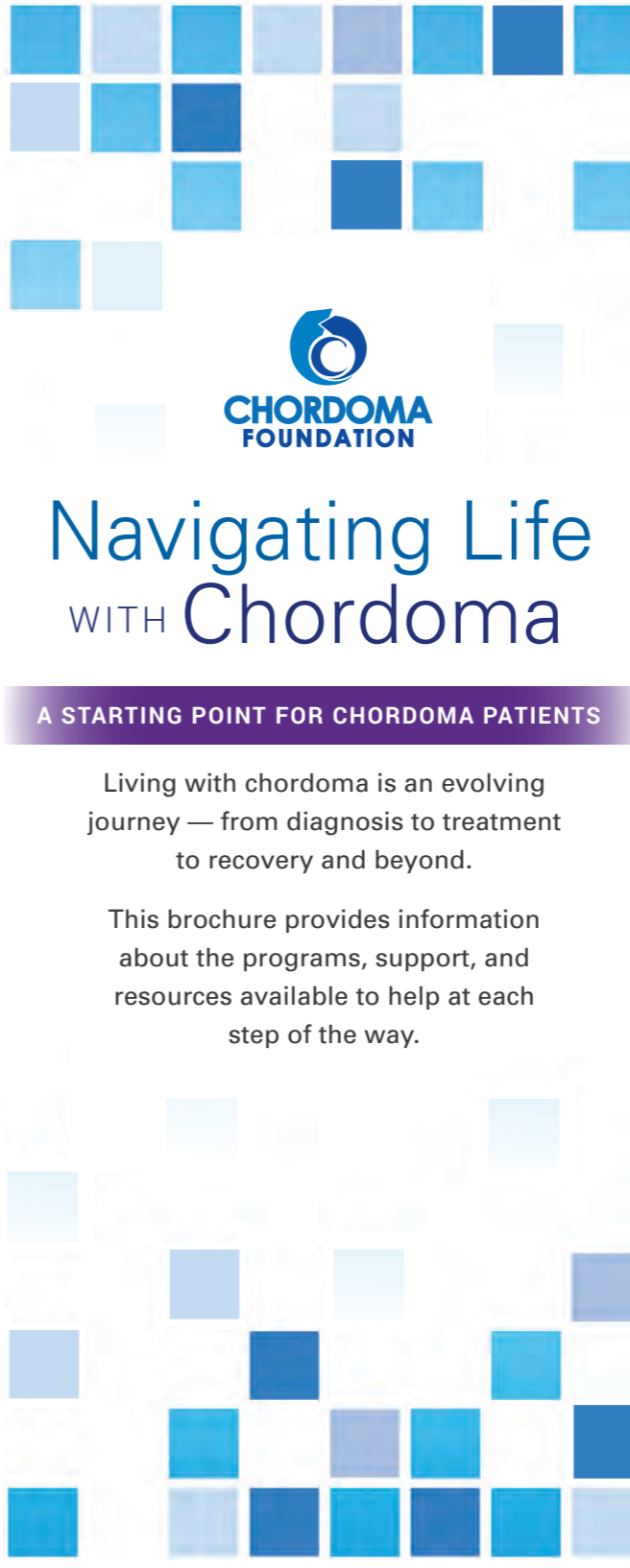
### WHAT IS THE PROGNOSIS?

With appropriate treatment, many chordoma patients can live for a decade or more, and some can be cured. The majority of patients eventually experience recurrences of their tumor after treatment, and studies have indicated the average survival after diagnosis is approximately 7–9 years. However, every patient's case is unique, and treatment techniques continue to improve.

### HOW COMMON IS CHORDOMA?

One person in every million is diagnosed with chordoma each year. Approximately one in 125,000 people are living with chordoma at any given time.

For more information about chordoma, visit [chordoma.org/understanding-chordoma](http://chordoma.org/understanding-chordoma)



## Navigating Life WITH Chordoma

### A STARTING POINT FOR CHORDOMA PATIENTS

Living with chordoma is an evolving journey — from diagnosis to treatment to recovery and beyond.

This brochure provides information about the programs, support, and resources available to help at each step of the way.

## For Newly Diagnosed Patients

If you or someone you care about has recently been diagnosed with chordoma, you are not alone. The Chordoma Foundation is here to help you through your journey with this disease. 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. Get help from a Patient Navigator at [chordomafoundation.org/requesthelp](http://chordomafoundation.org/requesthelp)

For important information about steps you can take to get the right treatment, visit [chordomafoundation.org/newly-diagnosed](http://chordomafoundation.org/newly-diagnosed)

## Treatment

In most cases, the main treatment for chordoma is surgery. The goal of surgery is to remove as much of the tumor as possible without causing harm.

For some patients, radiation therapy before and/or after surgery can reduce the chance that the tumor will grow back and may prolong survival. When surgery is too risky or not possible, radiation therapy is sometimes used as the main treatment. Even after these treatments, chordomas tend to return in the same location or in the areas around the original tumor. If this happens, or if the tumor spreads to other areas of the body, certain drug therapies may slow or temporarily stop the progression of the disease.

For more information about treatment options, get our *Expert Recommendations for the Diagnosis and Treatment of Chordoma* booklet at [chordomafoundation.org/expert-recommendations](http://chordomafoundation.org/expert-recommendations)

### SETTING YOURSELF UP FOR TREATMENT SUCCESS

#### 1 Find Experienced Doctors

Treating chordoma involves complex procedures that require extensive training and experience to master. It is very important to be treated by doctors who routinely care for chordoma patients, and who do so as part of a multi-disciplinary team of specialists.

#### 2 Get Multiple Opinions

Different doctors may have different opinions about the best course of action and may be able to offer different treatment options. Good doctors are not offended when a patient gets a second opinion. This reasonable step is standard practice, especially for complex and rare diseases like chordoma.

#### 3 Make Informed Decisions

The doctors and treatment plan you choose will have a major impact on your outcome, so it is important not to rush to make a decision without understanding your options. In most cases, patients have time to gather information and seek multiple opinions. Ask your doctors how soon you need to be treated, and do not delay treatment if you are advised it would be unsafe to wait.

A list of doctors who routinely treat chordoma patients is available at [chordomafoundation.org/doctor-directory](http://chordomafoundation.org/doctor-directory) or you may contact a Chordoma Foundation Patient Navigator for assistance identifying medical specialists.

## Patient Navigation Service

If you or someone you care about is dealing with chordoma, our Patient Navigation Service can answer your questions, explain treatment options, help you find qualified doctors, and more. For a personal consultation with a Patient Navigator, call (888) 502-6109 or visit [chordomafoundation.org/requesthelp](http://chordomafoundation.org/requesthelp)



Shannon Lozinsky, MSW  
Patient Services Manager

## Emotional Support

Dealing with chordoma can be a lonely and challenging journey. Sometimes talking with someone who has been there can make all the difference. If you need support, we can match you with a trained Peer Guide who shares similar experiences with chordoma. To learn more, visit [chordomafoundation.org/peer-support](http://chordomafoundation.org/peer-support)

## Helpful Resources

Our website provides an extensive list of programs, services, and materials to assist chordoma patients and their families including:

- > Financial assistance
- > Prescription assistance
- > Housing
- > Transportation
- > Family and caregiver support

You can find these resources at [chordomafoundation.org/helpful-resources](http://chordomafoundation.org/helpful-resources)



## Educational Materials



Learning about chordoma and treatment options is an important part of managing the disease no matter where you are in your journey. For reliable, up-to-date information, visit [chordomafoundation.org/educational-materials](http://chordomafoundation.org/educational-materials)