

# Chordoma Foundation Fact Sheet

**Chordoma** is a slow growing, relentless bone cancer that occurs in the head and spine in people of all ages, from infants to the elderly. Chordoma is typically resistant to chemotherapy and radiation, and is prone to multiple recurrences. The average survival after diagnosis is 7 years; a statistic we are determined to improve.

**Our Mission** is to rapidly develop effective treatments and ultimately a cure for chordoma, while improving the diagnosis, treatment and quality of life for people affected by this devastating bone cancer. We serve as a bridge between patients, doctors, researchers, drug companies, government and funding agencies, representing the interests of those with chordoma, and instilling a sense of urgency in the treatment development process.

## Who we are

The Chordoma Foundation is the only 501(c)(3) nonprofit organization dedicated to curing chordoma. It was incorporated in February, 2007 by Dr. Simone Sommer, and her son Josh, after he was diagnosed with a chordoma in 2006, during his freshman year at Duke University. Since his diagnosis, Josh has worked in an oncology lab at Duke to find his own cure. Currently, we operate with seven volunteer board members, numerous scientific and medical advisors, and the support of many volunteers. Our dedicated board members have extensive experience in medicine, public health, nonprofit management, entrepreneurship, venture capital, technology transfer, disease advocacy, and law.

## Our approach

We take a big-picture, systems-based approach to the problem of curing chordoma, ensuring that time and resources are focused to achieve maximum results as quickly as possible. With the input of a diverse group of experts from around the world, we have created a roadmap for developing new effective treatments for chordoma, and serve as the engine to drive this plan forward. Beyond awarding grants, we take an active role in every aspect of the research process by formulating research priorities, recruiting the best researchers, initiating new projects, brokering collaborations, and breaking down barriers to progress. We are working to overcome major research obstacles by 1) fostering communication and collaboration among and between physicians and scientists 2) providing access to chordoma tissue and cell lines, and 3) securing funding for research.

## Major accomplishments

- Co-hosted the First International Chordoma Research Workshop (ICRW) with the National Institutes of Health, bringing together over 50 physicians and scientists from around the world to develop a plan to cure chordoma.
- Formed a multidisciplinary network of physicians and researchers at numerous institutions, and initiated eleven new collaborative chordoma research projects
- Began process to establish a BioBank and prompted leading surgeons to save and share chordoma tumors
- Convened Chordoma Clinical Management Committee to develop recommendations for the optimal diagnosis and treatment of chordoma patients, and initiated development of chordoma pathology guidelines
- Raised over \$250,000, plus secured NIH funding for the First ICRW in May 2007, and the Second ICRW, in April 2008
- Collected all known chordoma cell lines, distributed cell lines to multiple labs not formerly studying chordoma, created the first ferret chordoma cell line, and initiated the first attempts to create a chordoma animal model
- Worked with oncologists at Memorial Sloan Kettering Cancer Center to initiate a clinical trial using Sutent® for chordoma patients with advanced or metastatic disease – only the second chordoma clinical trial in US history

## Near-term goals

- Prevent chordoma tissue from being unnecessarily discarded and make tumor specimens, vital for research, available to the scientific community by establishing a tissue and cell line repository (BioBank)
- Create a comprehensive chordoma patient registry, and ongoing tracking system for epidemiological research
- Fund the development of model systems including new chordoma cell lines and animal models
- Expand targeted treatment development using the latest technologies including: gene expression analysis, genotyping, genetic sequencing, functional proteomics, predictive algorithms, and drug screening
- Co-host the Second International Chordoma Research Workshop with over 80 leading physicians and scientists
- Host the First Chordoma Community Gathering, uniting chordoma survivors and their loved ones
- Expand board, hire staff including patient navigation services coordinator, recruit more volunteers
- **Raise an additional \$250,000 by April 2008 and \$3 million by December 2009 to fund the projects above**

02/19/08