

# Chordoma Foundation Fact Sheet

**Chordoma** is a relentless bone cancer that occurs in the head and spine in people of all ages. 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.

**The Chordoma Foundation** is an innovative 501(c)(3) nonprofit organization uniting patients, doctors, and scientists to accelerate the development of effective treatments for chordoma. It was incorporated in February, 2007 by Simone Sommer, MD, MPH and her son Josh, after he was diagnosed with a chordoma in 2006. Josh volunteered for 2 years in an oncology lab at Duke University to find his own cure until 2008 when he received a two-year Echoing Green Fellowship for Social Entrepreneurs and now serves as the Executive Director. Since its inception, the Chordoma Foundation has launched a coordinated international research effort that has invigorated the field of chordoma research and quickly led to breakthrough discoveries.

**Our approach:** The Chordoma Foundation has been nationally recognized for pioneering an innovative model of patient-driven collaborative research. We take an active role in every aspect of the research process by formulating research priorities, recruiting the best researchers, initiating and funding new projects, brokering collaborations, and breaking down barriers to progress. We have created a vibrant research community, and are empowering scientists and physicians to work hand-in-hand with the chordoma patient community to find a cure.

## Major accomplishments:

1. Initiated over a dozen new research projects in labs not previously studying chordoma.
2. Awarded \$220,000 in research grants to scientists at Duke, Harvard, Johns Hopkins, University of Florida, Instituto Tumori Milan, Italy, the University College London, and the Wellcome Trust Sanger Institute
3. Co-hosted two International Chordoma Research Workshops in May 2007 and April 2008 with the National Institutes of Health (NIH) Office of Rare Diseases (ORD), National Human Genome Research Institute (NHGRI), National Cancer Institute (NCI), and National Institute of Neurologic Disorders and Stroke (NINDS); bringing together over 100 physicians and scientists from eight countries to develop a plan to cure chordoma. This established a vibrant research community to actively work in conjunction with the newly formed Chordoma Community to find a cure.
4. Funded a comprehensive Chordoma Genome Project using an array of cutting edge technologies to discover the molecular underpinnings of chordoma and guide development of new treatments.
5. Initiated first-ever attempts to develop a genetically induced mouse model of chordoma and co-funded a research grant with the Liddy Shriver Sarcoma Initiative to support this exciting research project.
6. Launched the Chordoma Foundation Cell Line Panel and established \$5,000 prize for new cell lines (cancer cells grown in a lab); collected, characterized, and validated all chordoma cell lines in the world; and distributed the only valid chordoma cell line to over a dozen labs not formerly studying chordoma
7. Began process to establish a BioBank and prompted leading surgeons to save and share chordoma tumors
8. Worked with NIH Chemical Genomics Center to screen all 3000 FDA-approved drugs against the only two valid chordoma cell lines and united leading researchers to rapidly translate this data into new clinical trials.
9. Recruited and funded 2/3 salary of a new full-time chordoma research scientist at Duke University to manage the Chordoma Foundation Cell Line Panel, develop new cell lines, and conduct genetic research.
10. Hosted two Chordoma Community Conferences in 2008 and 2009, establishing a cohesive community of patients and families dedicated to finding a cure for chordoma.
11. Created a new online social network for the chordoma community to build supportive relationships and keep loved ones informed of health updates.

## Next Steps

- Establish the Chordoma Foundation BioBank to prospectively collect and distribute chordoma tumor specimens and matched patient registry data to researchers studying chordoma throughout the world
- Launch at least one clinical trial for chordoma treatments with advanced disease
- Expand Chordoma Foundation cell line panel from 2 to 10 within two years
- Complete first-ever comprehensive chordoma genomics project to identify molecular causes of chordoma
- Launch a client navigation program to help guide patients through the complicated treatment process.