

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 Simone Sommer, MD, MPH and her son Josh, after he was diagnosed with a chordoma in 2006. After he was diagnosed, Josh has volunteered for 2 years in an oncology lab at Duke University to find his own cure. Currently, we operate with seven volunteer board members, numerous scientific and medical advisors, and two part-time staff. Our dedicated board members have extensive experience in medicine, public health, nonprofit management, venture capital, technology transfer, and law. Our Scientific Advisory Board is comprised of esteemed scientists and physicians from Duke, Harvard, National Cancer Institute, University College London and the University of Pittsburgh.

Our approach: 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. In addition to 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 have created a vibrant research community where none existed before, and are empowering scientists and physicians to work hand-in-hand with the newly-formed Chordoma Community of patients, family members and friends to find a cure.

Major accomplishments:

1. Co-hosted the First International Chordoma Research Workshop (ICRW) in May 2007 and the Second ICRW in 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
2. Hosted First Chordoma Community Conference (CCC) and Chordoma Youth Conference in 2008, establishing a cohesive community dedicated to finding a cure for chordoma. The Second CCC will be held in Bethesda, MD June 26-28, 2009
3. Created a new online social network for the chordoma community to build supportive relationships and keep loved ones informed of health updates. Visit Champions.ChordomaFoundation.org for more information
4. Awarded \$157,500 in research grants to scientists at Duke, Harvard, Johns Hopkins University of Florida, Instituto Tumori Milan, Italy and the University College London.
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. Began process to establish a BioBank and prompted leading surgeons to save and share chordoma tumors
7. Recruited a Director of Research to run the Chordoma Foundation BioBank and coordinate multiple research collaborations
8. Launched the Chordoma Foundation Cell Line Panel and established \$5,000 prize for new cell lines; 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
9. Worked with NIH Chemical Genomics Center to screen all FDA-approved drugs against the only two valid chordoma cell lines and united leading researchers to rapidly translate this data into new clinical trials
10. 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 and lead the development and characterization of new cell lines
11. Josh Sommer was awarded a prestigious two-year social entrepreneurship fellowship from the Echoing Green Foundation to serve as the full-time Executive Director of the Chordoma Foundation.

Near-term goals: **Raise \$1 million in 2009 to continue the work above and fund the projects below**

- 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.

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