

# Chordoma Foundation



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## Mission

The Chordoma Foundation works to improve the lives of those affected by chordoma – a bone cancer of the skull and spine – by accelerating research to develop effective treatments, and ultimately a cure, while helping patients get the information, care and support they need to be well.

## Strategy/Approach

The Chordoma Foundation proactively initiates, orchestrates and funds research with the singular goal of delivering more effective treatments to chordoma patients as quickly as possible. The Foundation's investments in research follow a comprehensive Research Roadmap developed and continually updated with the input of its scientific advisory board. The Foundation catalyzes research in a variety of ways as appropriate, including with grants, contracts, and prizes, as well as by facilitating fruitful collaboration and sharing among researchers or institutions with complementary resources.

## Research Portfolio

The Foundation's Research Roadmap is comprised of the following five initiatives – Resource Development, Target Discovery, Preclinical Evaluation, Drug Discovery, and Clinical Research. Key projects within each initiative are listed below:

### Resource Development

- Cell line and PDX model repositories – collections of well-characterized preclinical models of chordoma available to the research community
- Prizes to incentivize the development of chordoma PDX models and cell lines
- Genetically engineered mouse model and zebrafish model development
- Chordoma Foundation Biobank – a centralized collection of high-quality tumor tissue, blood and clinical data from chordoma patients

### Target Discovery

- Chordoma Genome Project – an ongoing partnership with the Sanger Institute and University College London to comprehensively catalog the genetic and epigenetic landscape of chordoma
- Investigator initiated seed grants – intended to support projects that will uncover or help validate new therapeutic targets

### Preclinical Evaluation

- Preclinical Screening Pipeline – tests drugs contributed by companies and academic labs against panels of chordoma cell lines, PDX models, including “humanized” models suitable for evaluating immune therapies

- Drug Repurposing Project – tested all FDA approved drugs in chordoma cell lines and PDX models

### Drug Discovery

- Brachyury drug discovery project – aims to identify small molecules that inhibit activity of this target

### Clinical Research

- The Foundation works with companies and academic collaborators to initiate and facilitate well-justified clinical trials by recruiting patients, assisting with trial design, and providing funding for non-drug costs as needed.

## Partnership Practices

The Foundation partners with a wide range of academic and government researchers, as well as companies and other nonprofit foundations, to achieve its mission. For example, the foundation partners with ATCC to manage its cell line repository, START to manage its PDX repository and Ohio State to manage its Biobank. It has partnered with organizations such as the Wellcome Trust Sanger Institute and University College London as part of the Chordoma Genome Project, and it has also worked with the NIH Center for Translational Therapeutics as part of its Drug Repurposing Project.

**The foundation partners with biotech and pharmaceutical companies.** It has partnered with a number of companies to screen molecules in preclinical models of chordoma.

## Financials

The Chordoma Foundation is a 501(c)(3) tax-exempt nonprofit organization. The most recent financial information available is from 2013.<sup>1</sup>

Year ending 12/31/13:

- Revenue: \$1,859,476
- Expenditures: \$1,153,605
- Assets: \$1,433,728

## Key Accomplishments

- Executive Director, Josh Sommer, was named to the Forbes “30 under 30” two years in a row.
- Tested all 2,816 FDA-approved drugs in chordoma cell lines and tested top hits in PDX models, identified class of drugs active in both which provided justification for a forthcoming clinical trial.
- Provided seed grants to help start new research projects in over 20 labs.

<sup>1</sup> Information obtained from Chordoma Foundation 2013 Audited Financial Statements

- Results of funded research helped lead to the discovery of an entirely new way that cancer can form through shattering of chromosomes – “chromothripsis” – as well as an inherited genetic alteration shared by 97% of chordoma patients.
- Characterized all published chordoma cell lines, leading to a publication showing that only two were valid, and stopping the future use of invalid cell lines.
- Created the Chordoma Cell Line Repository, a one-stop source of valid cell lines, and distributed cell lines to more than 60 investigators and companies.
- United and expanded the chordoma research community by hosting four international research workshops, which brought together more than 200 physicians and scientists, many of whom were new to the field.

## Leadership

The foundation is governed by a **Board of Directors** and counseled by a **Scientific Advisory Board**.

- **Executive Director:** Josh Sommer, [josh@chordoma.org](mailto:josh@chordoma.org)
- **Chief Development Officer:** Anthony Pulgram, [anthony@chordoma.org](mailto:anthony@chordoma.org)
- **Director of Operations:** Tammy Silverthorne, [tammy@chordoma.org](mailto:tammy@chordoma.org)
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