TABLE OF CONTENTS

LETTER FROM THE EXECUTIVE DIRECTOR ........................................................................................................ 1

ACCELERATING CHORDOMA RESEARCH ........................................................................................................ 2
  Biobank
  Cell Line Repository
  Preclinical Models
  Chordoma Genome Project
  Seed Grants

CONNECTING RESEARCH AND PATIENT COMMUNITIES ................................................................. 5
  Research Workshop
  Community Conference

NEW WEBSITE ................................................................................................................................................ 7

COMMUNITY FUNDRAISING .................................................................................................................... 8
  Community Events
  New Champion Events

LOOKING AHEAD ............................................................................................................................................. 10

FINANCIALS ................................................................................................................................................... 11

OUR TEAM .................................................................................................................................................... 13

DONORS ......................................................................................................................................................... 14
DEAR FRIENDS,

Five years ago, chordoma was just another neglected form of cancer. Treatment options were inadequate. Little was known about the disease. Research was at a near standstill, and major obstacles stood in the way of developing new therapies.

The Chordoma Foundation was started in 2007 to accelerate chordoma research and systematically advance the search for a cure. Since then, with your help, we have overcome many of the barriers that previously hindered progress, and have created the conditions needed for chordoma research to flourish. As a result, dozens more researchers are now studying chordoma, and groundbreaking discoveries have been made that are being translated into new treatments for patients.

Your support of our efforts culminated in significant accomplishments in 2011 - from funding five research grants to launching a national chordoma Biobank. We are excited to share this progress with you and recount the milestones of the Chordoma Foundation’s initial five years in our first Annual Report.

Although the Chordoma Foundation remains an emerging organization by many measures, you have helped it grow into a powerful force for catalyzing research. Your continued support will enable us to build upon the progress of the past five years and seize the extraordinary opportunities that progress has created.

On behalf of the Board of Directors, and all of the patients and families we serve, thank you for being a partner in the search for a cure.

Onward!

JOSH SOMMER
Co-founder and Executive Director
ACCELERATING CHORDOMA RESEARCH

Guided by our Scientific Advisory Board, we are proactively pursuing a comprehensive research strategy to accelerate the development of new treatments for chordoma. In 2011, we made progress on five research priorities:

**BIOBANK**
Chordoma tumor tissue is vital for research. However, most researchers lack the tissue they need to study chordoma. To meet this demand, in 2011, the Chordoma Foundation launched a centralized Biobank that collects chordoma tissue from hospitals across the United States and makes it available to qualified researchers. By providing a reliable source of tissue, the Biobank will enable new research projects around the world and encourage more researchers to bring their expertise to bear on chordoma. The Biobank also gives patients an opportunity to make a meaningful impact on the future of chordoma research by donating their tissue. Learn more at www.chordoma.org/biobank

Contact the Biobank at 877-230-0164 or biobank@chordoma.org

**CELL LINE REPOSITORY**
From 2008 through 2011, the Chordoma Foundation distributed chordoma cell lines to 42 labs around the world, leveraging millions of dollars worth of research on chordoma. In 2011, three publications resulted from research conducted on cell lines provided by the Chordoma Foundation.

42 Number of researchers who have received CF cell lines

I am happy to be able to donate my tissue to the Chordoma Foundation’s Biobank because I know how important it is for researchers in order to develop new treatments for chordoma.

-STEVE KANTER, MD
Sacral chordoma survivor

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**Milestones of Our First Five Years**

Thank you for standing with us as the Foundation got its start over the past five years. In that time, we’ve changed the landscape of chordoma research forever and laid the ground for discoveries that will one day lead to a cure. To commemorate these formative years, here is a look back at some of our most significant milestones.

**February 2007**

Launch of the Foundation
The Foundation is incorporated in North Carolina
PRECLINICAL MODEL DEVELOPMENT
Models, such as cell lines, xenografts, and transgenic animals, help researchers understand the behavior of cancer and provide a means of predicting the effectiveness of potential therapies in humans. The Chordoma Foundation (CF) is working to develop new models and make them available to the researchers who need them.

- **Cell Line Prize**
  In 2011, we awarded a $10,000 prize to researchers at the University of Ulm in Germany for the development of the world’s second valid chordoma cell line, named U-CH2, and added this cell line to the Chordoma Foundation Cell Line Repository.

- **Xenograft Partnership**
  In 2011, CF initiated a collaboration with the University of California San Francisco to develop new xenograft models (human tumors grown in laboratory mice) under an agreement that will make the resulting models easily accessible to the research community.

- **Transgenic Mouse Model**
  Through joint fundraising with the Duke University Cancer Institute, CF directed funding to the lab of Dr. Michael Kelley to develop a transgenic mouse that mimics the genetic alteration in the brachyury gene that Dr. Kelly previously discovered is responsible for causing familial chordoma.

CHORDOMA GENOME PROJECT
The Chordoma Genome Project is using next generation DNA sequencing technologies to systematically reveal all of the genetic changes that drive chordoma and identify new targets for treatment.

In 2009, CF funded a pilot project at the Sanger Institute in Cambridge, England to sequence the coding region of the genome (the “exome”) of 10 chordoma tumors. Building on the clues that emerged from the pilot project, in 2011, CF expanded the number of samples to 25 to increase the power of the study.

Since 2008, we have provided seed funding to help start new research projects in 11 labs, two of which have gone on to obtain federal grants to study chordoma.

April 2007
First website, www.chordoma.org
The Chordoma Foundation website becomes the go-to source of reliable information about chordoma, the latest advances in chordoma research, and resources for the chordoma community.

May 2007
First International Chordoma Research Workshop
53 physicians and scientists gather for the first-ever meeting on chordoma, sparking many new projects and collaborations.
**Paradigm-Shifting Discovery**

Early results of the Chordoma Genome Project revealed unusual structural changes in the DNA of some chordoma tumors, which helped lead to the discovery of an entirely new way that cancer can form: through shattering of a chromosome, dubbed “chromothripsis.” This finding, which overturned conventional thinking about how cancer develops, was published in the journal *Cell* in January 2011 and was reported in the New York Times.

**SEED GRANTS**

In 2011, the Chordoma Foundation awarded four $25,000 seed grants to investigators at prominent research institutions to pursue research into new treatment approaches for chordoma. A record 18 applications were received for these grants, reflecting a growing interest in studying chordoma. These seed grants are intended to enable researchers to test ideas and generate data that could help leverage additional funding sources and lead to sustained chordoma research projects in their labs. The four recipients are:

- **Zhenfeng Duan, MD, PhD**  
  Massachusetts General Hospital

- **Soldano Ferrone, MD, PhD**  
  University of Pittsburgh

- **Michael Lim, MD**  
  Johns Hopkins University

- **Alfredo Quinones-Hinojosa, MD, PhD**  
  Johns Hopkins University

“By applying to chordoma what I have been doing for many years with melanoma and breast cancer, we can make quicker and more cost-effective progress.”

-Dr. Soldano Ferrone, MD, PhD

With a CF seed grant, Dr. Ferrone is working to destroy chordoma stem cells using antibodies developed by his lab.

**August 2007**

**Cell Line Repository Launched**

The Foundation obtains rights to distribute the world’s only valid chordoma cell line, called U-CH1, and establishes a repository at Duke University to make this critical scientific resource available to the research community for the first time.

**October 2007**

**Tax-exempt Status Received**

The Foundation is granted 501(c)3 status by the IRS, enabling supporters to make tax-deductible donations.
Workshop Highlights:

- Median survival of US chordoma patients increased from seven to nine years in the past decade.
- Preliminary findings of several studies are beginning to reveal the genetic underpinnings of chordoma.
- Five researchers reported new cell lines and xenograft models that are in development.
- Results were presented from the second and third chordoma clinical trials ever performed.
- Plans for three new clinical trials were announced.

Third International Chordoma Research Workshop

Eighty-five physicians and scientists attended the Third International Chordoma Research Workshop, representing 31 institutions in nine countries, and – for the first time – four pharmaceutical companies. At the workshop, 32 speakers, including six Chordoma Foundation grant recipients, presented new, unpublished data in fields ranging from epidemiology to genomics to clinical trials.

Next Research Workshop:
March 21-22, 2013, Boston, MA
In parallel with the research workshop, we hosted the Third Chordoma Community Conference. More than 70 patients, friends, and family members embraced this opportunity to learn from experts, find resources to help with their treatment, and build supportive relationships with others dealing with chordoma.

Next Community Conference:
March 22-24, 2013, Boston, MA
NEW WEBSITE

Since the Chordoma Foundation’s website first launched in April 2007, it has become the world’s leading source of information about chordoma treatment and research for chordoma patients, families, physicians, and researchers alike. To better serve all of our constituents, we re-launched the site with a great deal of new content and a fresh design intended to make it easy to find the information and resources that are most important to site visitors.

Visit www.chordoma.org

WEBSITE TRAFFIC GROWTH

New home page features portals for Patients and Families, Researchers, and Healthcare Professionals, as well as a guide for newly diagnosed patients.

Website traffic up 47% in 2011

Scientific Advisory Board Formed
Comprised of leading chordoma researchers and physicians, as well as experts in related fields, the SAB is charged with identifying research priorities and shaping the Foundation’s research roadmap.

First Research Grants Awarded
The Foundation awards six grants in 2008 to develop much-needed chordoma cell lines and animal models.
COMMUNITY FUNDRAISING

The Chordoma Foundation relies on the support of individuals to help fund our urgent search for a cure. We are deeply grateful to all the community members who undertook fundraising efforts on our behalf in 2011.

### COMMUNITY EVENTS

<table>
<thead>
<tr>
<th>Event Name</th>
<th>Organizer(s)</th>
<th>Location</th>
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</thead>
<tbody>
<tr>
<td>Swim for Sue</td>
<td>Susanna Johnson</td>
<td>Woodbridge, VA</td>
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<tr>
<td>Texts-4-A-Cause</td>
<td>Zach Daitch</td>
<td>Merrick, NY</td>
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<tr>
<td>BUPA Marathon</td>
<td>Mark Rayner</td>
<td>London, UK</td>
</tr>
<tr>
<td>2nd Annual Quilt Auction</td>
<td>Karen Hermanson</td>
<td>Knife River, MN</td>
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<tr>
<td>4th Annual Bowling Event</td>
<td>Jeff Schilling</td>
<td>Mission, KS</td>
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<tr>
<td>2011 Dress Down Days</td>
<td>Lynette Nelson</td>
<td>Clifton, NJ</td>
</tr>
<tr>
<td>Bar Crawl</td>
<td>Colleen Riccomini</td>
<td>West Sayville, NY</td>
</tr>
<tr>
<td>JV Team 5K</td>
<td>Andrew and Jamie Vance</td>
<td>Salt Lake City, UT</td>
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<tr>
<td>Cell Line Prize Campaign</td>
<td>Malik and Jamellah Ellis</td>
<td>Bowie, MD</td>
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<tr>
<td>Poker Tournament</td>
<td>Nadine Cordova</td>
<td>Frisco, TX</td>
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<tr>
<td>Auto Museum Tour</td>
<td>Bill Victor</td>
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<tr>
<td>Tupperware Party</td>
<td>Debbie Brown</td>
<td>Baltimore, MD</td>
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<tr>
<td>3rd Annual Purple Aster Concert</td>
<td>Ian Laird and Ed Les</td>
<td>Calgary, Canada</td>
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<tr>
<td>Pigeon Auction</td>
<td>Joseph and Christy Nemelka</td>
<td>Salt Lake City, UT</td>
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<tr>
<td>Crushing Chordoma Bowling Invitational</td>
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**December 2008**

**Chordoma Cell of Origin Discovered**

The Foundation’s first grant recipient, Dr. Brian Harfe at the University of Florida, traces cells of the developing notochord and finds that some become lodged in the vertebral bodies, where they can give rise to chordoma. This discovery paves the way for the development of genetically engineered mouse models of chordoma.

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**June 2009**

**Second Chordoma Community Conference**

Expert physicians answer patient questions and scientists funded by the Chordoma Foundation share how their research could one day lead to new treatments.
Familial Chordoma Gene Discovered

With funding from the Foundation, Duke University researcher, Dr. Michael Kelley, and colleagues at the National Cancer Institute, show that an extra copy of the gene brachyury is the cause of familial chordoma.

NEW CHAMPIONS PAGES

Champions Pages on the CF website give every chordoma patient, and their loved ones, a place to share their story and set a personal fundraising goal. In 2011, we upgraded the software that powers our champion pages to make it easier than ever to track donations, email supporters, and create fundraising events. To support a champion or create a Champion Page of your own, visit http://champions.chordomafoundation.org

Top 10 Champions in 2011

Malik and Jamellah Ellis
Joe and Christy Nemelka
Andrew and Jamie Vance
Marley Jay
Susanna Johnson
Nadine Cordova
Cameron Riccomini
Krista Wolf
James Bell
Heather Burley

$119,738
amount raised by Champions and community events in 2011

Chordoma Genome Project Launched

The Foundation begins sponsoring research by the Sanger Institute in Cambridge, England to uncover all the genetic changes driving chordoma with the goal of identifying new targets for treatment.

Familial Chordoma Gene Discovered

With funding from the Foundation, Duke University researcher, Dr. Michael Kelley, and colleagues at the National Cancer Institute, show that an extra copy of the gene brachyury is the cause of familial chordoma.
LOOKING AHEAD

With your ongoing support, the Chordoma Foundation will continue to strategically pursue the goals set out in our research roadmap, including:

• Expand our model repositories to include 10 cell lines and 10 xenografts
• Fund the development of a genetically engineered mouse model
• Recruit 200 Biobank donors
• Complete the Chordoma Genome Project, including whole genome sequencing
• Finish testing all FDA-approved drugs in chordoma cell lines and mouse models
• Launch at least one clinical trial based on results of approved drug screening project
• Fund additional seed grants to enable researchers to start promising new projects
• Expand the Foundation’s research, education and awareness programs internationally
• Host biennial research workshops and community conferences
• Grow our network of patients, physicians, and researchers

“
It’s hard to put into words what it feels like to know that people’s hard-earned dollars are at this moment funding the cure we know is coming. It’s empowering and encouraging.

-JAMELLAH ELLIS,
Wife of chordoma patient Bowie, MD
**Changes In Donor Support**

- **Total Contributions**
  - 2010
  - 2011
  - *Excludes in-kind donations
  - 71% Increase

- **Number of Donations**
  - 2010
  - 2011
  - 51% Increase

- **Number of Donors**
  - 2010
  - 2011
  - 25% Increase

**Source Of Funds**

- **Individuals** 54%
- **Private Foundations** 35%
- **Government Grants** 4%
- **Businesses** 6%
- **Other** 1%

A copy of our 2011 Tax Return (IRS Form 990) and Audited Financial Statement are available online at [www.chordoma.org/financials](http://www.chordoma.org/financials)

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**October 2010**

Invalid Cell Lines Revealed
Josh Sommer co-authors a paper reporting that only 2 out of 6 putative chordoma cell lines are actually chordoma, thereby putting an end to the use of invalid chordoma cell lines.

**November 2010**

All Approved Drugs Tested Against Chordoma
Researchers at the National Institutes of Health screen every drug ever approved by the FDA against 2 chordoma cell lines. At least 40 promising drugs are identified.
With funding from the Foundation, University College London researcher, Dr. Adrianne Flanagan, creates the first successful chordoma xenograft mouse model, a critical tool needed to test new treatments.

First Cell Line Prize Awarded
The Foundation awards a $10,000 prize to Dr. Peter Möller and Silke Brüderlein at the University of Ulm in Germany for contributing the world’s second valid chordoma cell line, U-CH2, to the Foundation’s Cell Line Repository.
OUR TEAM

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Patty Cogswell
Manager of Research Programs
Tammy Silverthorne
Business Manager
Deirdre Callahan
Development Coordinator

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University of Virginia
Neil Spector, MD
Duke University

January 2011
Discovery of a New Way Cancer Can Form
Results from the Chordoma Genome Project help lead Sanger Institute researchers to discover that shattering of chromosomes - a phenomenon they dub “chromothripsis” - can cause cancer, and may play a particularly important role in chordoma.

March 2011
Third International Chordoma Research Workshop and Community Conference
DONORS

Progress toward a cure for chordoma is made possible by the generosity of our donors. We are deeply grateful to all those who contributed to the Chordoma Foundation in 2011.

$100,000+
Anonymous

$25,000-99,999
Joel and Shari Beckman
Gary and Karen Sain

$10,000-24,999
Clayman Family Foundation
Charles and Marna Davis
Malik and Jamellah Ellis
Buddy and Bobbie Johnson
Steve Kanter
Bruce and Lynette Nelson
Joe and Christy Nemelka

$5,000-9,999
Anonymous
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Kerry Shad and Julia Walker
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$1,000-2,499
Anonymous
Suhail Afzal
Paul and Brenda Allen
Auto Museum
Baco Che-Na-Wah Bazaar Foundation
Tsion Bensusan
Bill and Melinda Gates Foundation

June 2011
Chordoma Genome Project Doubled in Size
Building on initial success, the Foundation awards a grant to the Sanger Institute to increase the number of chordoma tumors in the Chordoma Genome Project to 25.

September 2011
Peer Connect Program Begins
In partnership with the Cornucopia Cancer Support Center, the Foundation trains members of the chordoma community as peer guides to provide quality support and information to fellow patients, family members, and caregivers.
Chordoma Biobank Launches
The Foundation begins collecting chordoma tumor samples from patients across the US, establishing the first centralized source of chordoma samples available to the research community.

Seed Grants
The Foundation awards four seed grants to researchers studying new treatment approaches for chordoma.
Drug Screening Begins in Mouse Models
To determine if any already-approved drugs could effectively treat chordoma, the Foundation funds Dr. Gary Gallia at Johns Hopkins University to test the top 10 compounds identified by the NIH drug screen in two newly-developed mouse models.

IN-KIND DONORS
Donations of in-kind services from the following companies and professionals were critical to the Chordoma Foundation’s operation in 2011. Your generosity enabled us to spend more of our budget directly on programs to advance chordoma research and improve the lives of chordoma patients.

Smith Anderson Law Firm  Legal services
CapStrat  Communications services
Salesforce.com  Database
Capitol Broadcasting Company  Office space
Innocentive  Cell line prize administration
Kathy Corley, SPHR  PR consulting
Jennifer Moyer, BSN, RN

We greatly appreciate every donation; however, due to space limitations, this list reflects donors who contributed $500 or more in 2011. For a complete list of donors visit www.chordoma.org/donors

We have made every attempt to ensure the accuracy of our donor list, and we regret any errors or omissions that may have occurred. Please contact us at: feedback@chordoma.org to correct any inaccuracies.