



2011 ANNUAL REPORT

CELEBRATING FIVE YEARS

of Innovation, Progress, and Hope

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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!

A handwritten signature in black ink that reads "Josh". The signature is written in a cursive, flowing style.

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](http://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

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.

11 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

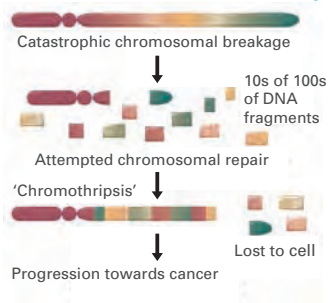
First International Chordoma Research Workshop

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.

Illustration of Chromosome Shattering



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

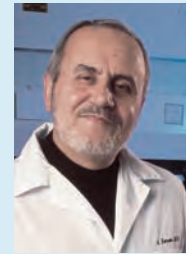
University of Pittsburgh

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.

CONNECTING RESEARCH AND PATIENT COMMUNITIES



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

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

February 2008

National News Debut

Stories about the launch of the Foundation are featured in the Associated Press, NBC's Today Show, and ABC World News Tonight.

April 2008

Second International Chordoma Research Workshop

85 researchers from 32 institutes in 8 countries attend; numerous new discoveries are reported.



THIRD CHORDOMA COMMUNITY CONFERENCE

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



April 2008

First Chordoma Community Conference

Unites more than 100 chordoma patients and family members; connects patient community with leading researchers and physicians.

May 2008



Recognition for Innovation

Foundation co-founder, Josh Sommer, is awarded the prestigious Echoing Green Fellowship for social entrepreneurs.

NEW WEBSITE

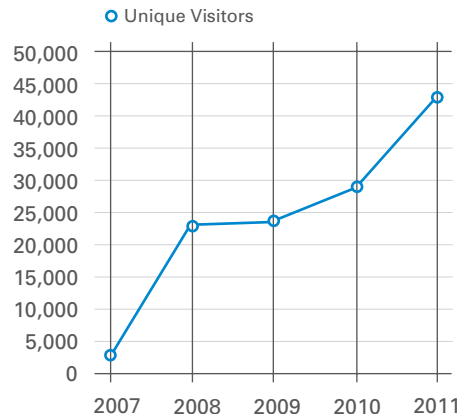
Since the Chordoma Foundation's website first launched in April 2007, it has become the world's leading source of information about chordoma treatment and research for chordoma patients, families, physicians, and researchers alike. To better serve all of our constituents, we re-launched the site with 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



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

WEBSITE TRAFFIC GROWTH



Website traffic up 47% in 2011

August 2008

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.

November 2008

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

Swim for Sue

Susanna Johnson
Woodbridge, VA

4th Annual Bowling Event

Jeff Schilling
Mission, KS

Cell Line Prize Campaign

Malik and Jamellah Ellis
Bowie, MD

3rd Annual Purple Aster Concert

Ian Laird and Ed Les
Calgary, Canada

Texts-4-A-Cause

Zach Daitch
Merrick, NY

2011 Dress Down Days

Lynette Nelson
Clifton, NJ

Poker Tournament

Nadine Cordova
Frisco, TX

Pigeon Auction

Joseph and Christy Nemelka
Salt Lake City, UT

BUPA Marathon

Mark Rayner
London, UK

Bar Crawl

Colleen Riccomini
West Sayville, NY

Auto Museum Tour

Bill Victor

Crushing Chordoma Bowling Invitational

Christa Masters
New Baltimore, MI

2nd Annual Quilt Auction

Karen Hermanson
Knife River, MN

JV Team 5K

Andrew and Jamie Vance
Salt Lake City, UT

Tupperware Party

Debbie Brown
Baltimore, MD

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.

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.



Swim for Sue



Purple Aster Concert



Pigeon Auction



Quilt Raffle

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

July 2009



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.

October 2009



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.



“ 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

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

July 2010

Cell Line Prize Launched

To spur the development of new chordoma cell lines, the Foundation offers a \$10,000 prize for each valid cell line contributed to the Cell Line Repository.

September 2010

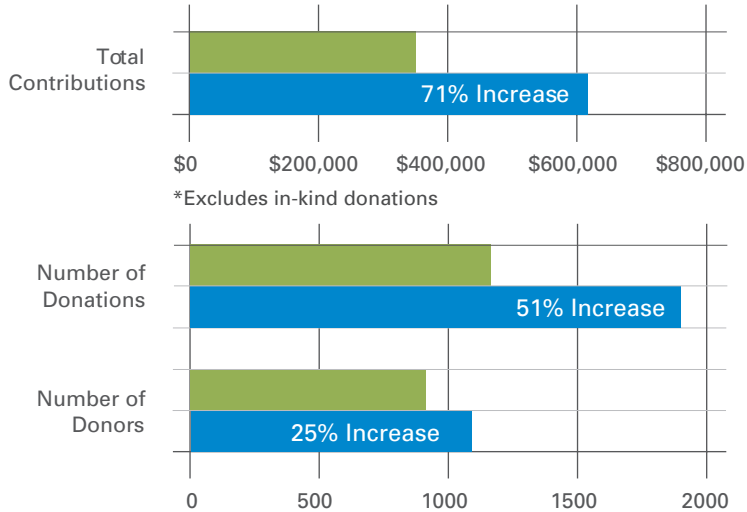
CF Moves to The Research Triangle

The Foundation relocates from Greensboro, NC to its first professional office in Durham, NC.

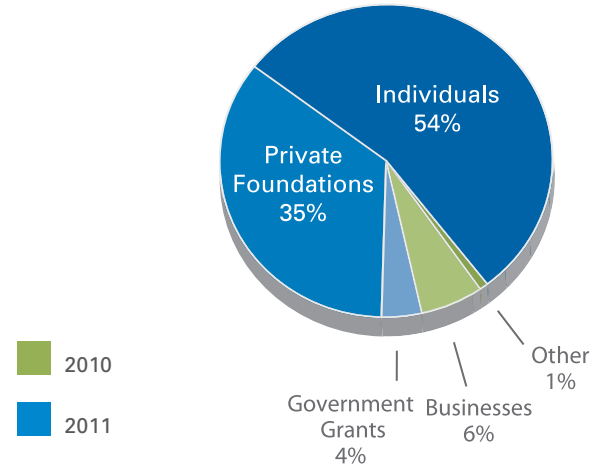


FINANCIALS

Changes In Donor Support



Source Of Funds



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

October 2010



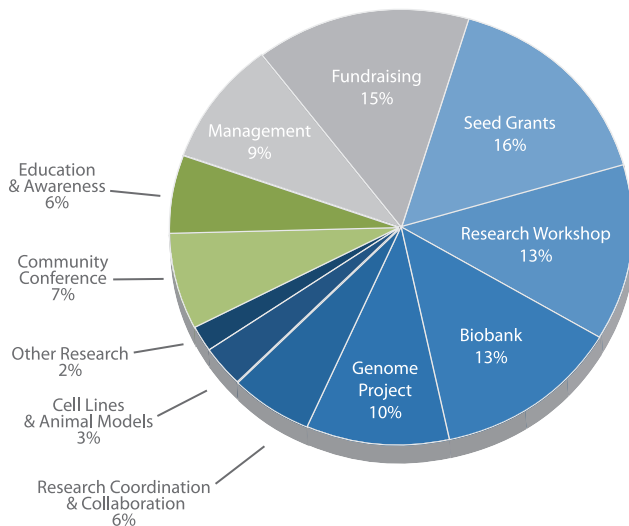
Invalid Cell Lines Revealed
Josh Sommer co-authors a paper reporting that only 2 out of 6 putative chordoma cell lines are actually chordoma, thereby putting an end to the use of invalid chordoma cell lines.

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.

Spending By Program



We value every dollar we receive and strive to allocate donated funds wisely and responsibly. In 2011, 76% of our budget was spent on programs to accelerate chordoma research and help patients get the best care possible.

2011 AUDITED STATEMENT OF ACTIVITIES For The Year Ended December 31, 2011

REVENUE AND SUPPORT

Contributions	\$ 577,425
In-Kind Contributions	163,393
Program Services	26,985
Grants	7,000
Interest	3,820
Total Revenue And Support	778,623

EXPENSES

Program Services	544,264
Management And General	117,518
Fundraising	109,474
Total Expenses	771,256

CHANGE IN NET ASSETS **7,367**

NET ASSETS, BEGINNING OF YEAR **576,239**

NET ASSETS, END OF YEAR **\$ 583,606**

December 2010



First Chordoma Mouse Model

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.

January 2011



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

STAFF

Josh Sommer
Executive Director

Patty Cogswell
Manager of Research Programs

Tammy Silverthorne
Business Manager

Deirdre Callahan
Development Coordinator

CORPORATE OFFICERS

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Bruce Nelson, CPA, Treasurer
John Therien, Esq, Secretary

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John Therien, Esq

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Norma Jones
Heather Lee

SCIENTIFIC ADVISORY BOARD

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Adrienne Flanagan, MD, PhD
University College London

Francis Hornicek, MD, PhD
Massachusetts General Hospital

Michael Kelley, MD
Duke University

Paul Meltzer, MD, PhD
National Cancer Institute

Deric Park, MD
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
Affiliated Foot Surgeons
Mary Margaret Anderton
Burroughs Wellcome Fund
Alfred Liggins
Jennifer Ragonese
The Herbert and Nell Singer Foundation
Heather Lee and Steve Straus
David and Peggy Tanner
Richard and Elizabeth Witten

\$2,500-4,999

William and Laetitia Bourke
Bill and Sarah Dorland
Chris and Kathleen Dubia

Durham Academy
Patrick Jackson
Bobby and Korrel Kanoy
Ed and Nerissa Lawton
Frederic and Marlene Malek
Adriane Rothstein and Mark Billy
Kerry Shad and Julia Walker
Ron and Judy Wenger

\$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.

Roslynne Blake
 Robert and Frances Bridenbecker
 Jacquie Britt
 Consuelo Brown
 Samuel Cohen
 Collins Electric Co.
 Loren Daitch
 Peter and Kathy Davidoff
 Chip Ellis
 Phyllis Ellis
 Patrik Engellau
 Douglas A. and Phyllis G. Smith
 Jeffrey and Marnie Kaufman
 Richard Francis
 David Harrett
 Rich and Tracy Harris
 David Hill
 iContact
 Wesley Jenkins
 Susanna Johnson
 Dana McFerren
 Nancy and Daniel Langsan

Ken and Frankie Lee
 Elizabeth Cullinan
 Kathy Milczarski
 Bernard and Margaret Moulin
 Bradley and Kerry Overman
 Ruth Z. Fleishman Foundation, Inc.
 Jeff and Erin Schilling
 David Small
 Lauren Smith
 Ramona Sonnier Seals
 Lee and Cy Sparkman
 St. Paul's Episcopal Church
 The Clarks Companies
 Royleen Tipton
 Francis and Patti Meyer
 Triangle Community Foundation:
GlaxoSmithKline IMPACT Awards Fund
 United Therapeutics
 Andrew and Jaime Vance
 Nancy Whitney
 Sandy and Jennifer Williams
 Rashida Winslow

\$500-999

Anonymous (2)
 Karthik Balasubramanian
 Stephen and Leslie Beck
 Earl Booker
 John and Jill Boy
 Joni and Michael Claymon
 Louise Coates
 Jane Corder
 Eddie and Nadine Cordova
 Maria Diaz Garcia
 Lorraine Eagan
 Sabriya Ellis
 Ingemar and Diane Lanevi
 Father's Day Council
 Alane Fraser
 Josh Frederick
 Laura Gemme
 Leo and Rita George
 Dahlia Hirsch and Barry Wohl
 Phillip and Marsha Hurt
 Lindy Jones

October 2011



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.

November 2011

Seed Grants

The Foundation awards four seed grants to researchers studying new treatment approaches for chordoma.

John Lazaroff
 Marc Fisher, LLC
 Joe Marfuggi
 James and Lorna Marshall
 Microsoft
 Karissa Nace
 Nassau County Police Activity League, Inc.
 John and Anika Owen
 Research in Motion
 Rick and Colleen Riccomini
 Hans and Mary Lou Saeby
 James and Donna Scancarella
 Rob and Inger Schoelkopf
 Kenneth and Shirley Smith
 Josh Sommer
 Ben and Teresa Spencer
 Michael and Sarah Tonnies
 Chris Trapnell
 Monica Trent
 Ric and Sue Valdez
 William and Patricia Victor
 Matthew Williams
 Mike Williams

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	HR consulting
Jennifer Moyer, BSN, RN	PR consulting

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.

2012



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.



With your continued support, we will bring closer the day when we can declare victory in the fight against chordoma, and people will no longer suffer from this devastating disease. Until then, onward!



Chordoma Foundation
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Durham, NC 27702

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Email: info@chordoma.org

www.chordoma.org



facebook.com/chordomafoundation



[@chordomaFDN](https://twitter.com/chordomaFDN)