Uncommon Cause.
Uncommon Progress.
Uncommon Opportunities.

2012 ANNUAL REPORT
The Uncommon Cause

Chordoma may be rare. But what’s more uncommon than this disease? Our campaign to stop it.

Medical research is producing more breakthrough treatments than ever before. But research for rare cancers like chordoma faces special challenges. As a result, patients are being left behind as medicine advances for more common diseases.

The Chordoma Foundation is attacking this problem with innovative programs that increase the feasibility, speed, and efficiency of chordoma research.

This approach is unleashing a growing community of scientists, doctors, and drug companies focused on developing new treatments for chordoma, and has produced discoveries with important implications for chordoma and other cancers.

Thank you for being part of our team as we accelerate the search for a cure and set a new standard for rare cancer research.

1 in a million
Table Of Contents

3  Letter From The Executive Director

4  Uncommon Progress
   Expanding Access to Materials Needed for Research
   Uncovering Genetic Changes That Drive Chordoma
   Identifying Drugs to Effectively Treat Chordoma
   Accelerating Research Through Collaboration

10  Uncommon Opportunities

11  Accolades

12  Our Community

16  Our Team

17  Donors

20  Financials
Dear Friends,

In 2012, the Chordoma Foundation reached a number of encouraging milestones that make the future increasingly bright for chordoma patients.

Thanks to your support, we:

- Expanded access to chordoma tissue samples and cell lines that are critical for research
- Enabled the discovery of a genetic risk factor shared by nearly all chordoma patients
- Funded a drug repurposing project to identify already-approved drugs that could be effective against chordoma
- Initiated partnerships with three drug companies to search for new chordoma treatments

This progress has created unprecedented opportunities that are attracting more and more researchers and—for the first time—several drug companies to focus on this once-neglected disease. The momentum is electrifying but as the field grows, so too does the need for the Chordoma Foundation—to fund research, to provide critical research materials, and to facilitate coordination and collaboration among doctors, scientists, and drug companies.

With your continued dedication and support, the Foundation is poised to scale up its research-accelerating programs to ensure that life-saving new treatments reach patients as quickly as possible. At the same time, we will remain dedicated to helping patients get the best care possible with the treatments available today.

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,
In 2011, the Chordoma Foundation launched a centralized Biobank to address the unmet demand for high-quality chordoma tumor tissue from the growing field of chordoma researchers.

The Biobank collects tumor tissue from hospitals across the United States and makes it available for research to discover the cause of, and potential treatments for, chordoma. It is also a way for patients to make a meaningful impact on the future of chordoma research by donating excess tumor tissue removed during surgery.

In the year since the launch, 50 patients have contributed tissue to the Biobank, bringing us one quarter of the way to our goal of 200 participants. Though patients can elect to donate tissue regardless of where they have surgery, the Foundation has established partnerships with four hospitals that now routinely save and contribute tissue from chordoma surgeries:

- Barrow Neurological Institute/St. Joseph’s Hospital
- University of North Carolina at Chapel Hill
- University of California San Francisco
- University of Pittsburgh Medical Center

Patients interested in donating tissue can contact the Biobank at 877-230-0164 or at biobank@chordoma.org

Learn more at www.chordoma.org/biobank
Recognized For Innovation

In April 2012, Amy Marcus of the Wall Street Journal reported on the success of the Foundation’s cell line prize – the first time that a prize has ever been used to spur the development of cancer cell lines. The Foundation’s prize set a precedent that is now being replicated by other organizations seeking to develop cell lines for several different types of cancer.

The Chordoma Foundation Cell Line Repository provides validated chordoma cell lines to scientists and companies to enable research critical to identifying new therapies for chordoma.

Cell Lines

The Chordoma Foundation Cell Line Repository provides validated chordoma cell lines to scientists and companies to enable research critical to identifying new therapies for chordoma.

Prior Years

<table>
<thead>
<tr>
<th>Increase in 2012</th>
<th>Prior Years</th>
<th>Goal</th>
</tr>
</thead>
<tbody>
<tr>
<td>3 total</td>
<td>49 total</td>
<td>8 total</td>
</tr>
<tr>
<td>Cell lines in repository</td>
<td>Researchers who have received CF cell lines</td>
<td>Papers reporting discoveries from research utilizing CF cell lines</td>
</tr>
</tbody>
</table>

BEATE RINNER, PHD

The Chordoma Foundation awarded a $10,000 prize to Dr. Beate Rinner of the Medical University of Graz, Austria for successfully developing the world’s third valid chordoma cell line.
Since 2009, the Chordoma Foundation has been investing in the Chordoma Genome Project to catalog all of the changes in the DNA of chordoma in hopes of identifying targets for new treatments.

In 2012, this project produced a breakthrough discovery: an astounding 97% of chordoma patients share an inherited genetic variation (a SNP) in a gene called brachury, and people who have this SNP are five times more likely to develop chordoma than the general population. This provides airtight evidence that brachury plays a critical role in the development of chordoma and could be a target for new treatments.

However, this SNP is also shared by many people who don’t get chordoma, meaning that the SNP alone is not sufficient to cause this rare cancer. Thus, in 2012, the Chordoma Foundation provided funding to search even deeper in the genome – using whole genome sequencing – for additional genetic changes that work with brachury to trigger the disease.

Future Research Priorities:
- Determine how brachury contributes to chordoma development
- Identify additional genetic changes that cooperate with the brachury SNP to cause chordoma
- Develop therapies targeting brachury

“\textit{This discovery is a major step forward in our understanding of how chordoma develops, and can open the door to the development of an effective, targeted treatment.}”
Identifying Drugs to Effectively Treat Chordoma

Approved-Drug Repurposing Project
Through a collaboration with the Chordoma Foundation, National Institutes of Health (NIH) researchers tested all FDA-approved drugs against chordoma cell lines, identifying 40 drugs with the potential to treat chordoma. By the beginning of 2012, Johns Hopkins University researcher Dr. Gary Gallia was ready to test the 10 most promising drugs in newly developed mouse models but $200K was needed to get the project underway.

With the help of a $100K matching gift, nearly 400 donors rallied to meet this funding need. Preliminary results point to a class of cancer drugs that significantly slow the growth of chordoma tumors in mouse models and, based on this data, plans are being made to launch a clinical trial.

Testing Novel Treatments
In 2012, the Chordoma Foundation forged partnerships with three drug companies – Novartis, Sanofi, and H3 Biomedicine – to test drugs currently in development against cell lines provided by the Chordoma Foundation. Additionally, the Foundation successfully lobbied to include three chordoma cell lines in a large-scale, ongoing drug screening initiative at the Broad Institute of Harvard and MIT.

Future Research Priorities:
- Test all 40 promising FDA-approved drugs in chordoma mouse models
- Test promising new treatments from researchers and drug companies in cell lines and animal models

Learn more at http://www.chordoma.org/research/drug-screening-project/
Accelerating Research Through Collaboration

One year after the 2011 International Chordoma Research Workshop, participants reported developing 174 new relationships and 30 new collaborations. Each collaboration represents researchers coming together to accomplish more than they could alone, and each relationship represents the potential for future collaborations or sharing of information and ideas that could lead to new discoveries.

Collaborations: 19%  
Relationships: 65%  
Network Density: 57%

Connections between participants after 2011 International Chordoma Research Workshop
European Expansion

The Foundation has begun expanding its efforts to stimulate research, improve patient care, and organize the chordoma patient and physician communities in Europe. As a first step, meetings for chordoma patients and physicians were held in Amsterdam in June 2012, spearheaded by the Foundation’s volunteer European Liaison and chordoma survivor, Hans Keulen.

European Physician Meeting
Co-hosted with the Istituto Nazionale dei Tumori, Milan, the meeting was attended by over 35 specialists in pathology, orthopaedic surgery, neurosurgery, radiation oncology, medical oncology, and clinical trials methodology. Discussion focused on developing consensus about the optimal treatment of chordoma, forming a “network of excellence” among leading treatment centers in Europe, and developing a multi-institutional registry to study the natural history of chordoma.

European Patient Meeting
This meeting united over two dozen patients and family members from France, Germany, the Netherlands, Portugal, Spain, and the UK. It provided an opportunity for participants to learn about chordoma, build connections with others who share similar experiences, and discuss how to join forces to support research and help improve access to appropriate care for chordoma patients in Europe.
Uncommon Opportunities

The progress of the past year has created unprecedented opportunities to accelerate the search for a cure while continuing to help patients get the best care possible. With your ongoing support, the Chordoma Foundation will:

- Enable more top scientists to apply their expertise to chordoma by:
  - Increasing funding for Seed Grants to start new projects
  - Growing the Biobank to include samples from 200 chordoma patients
  - Expanding the Cell Line Repository from 3 to 10 valid chordoma cell lines
  - Developing a Mouse Model Repository with 10 chordoma patient-derived xenograft models
- Determine whether any already-approved drugs could help chordoma patients by completing our Approved-Drug Repurposing Project, and launch at least one clinical trial based on the results
- Set up a centralized Drug Screening Pipeline to continuously test promising new drugs in chordoma cell lines and mouse models
- Uncover all of the genetic changes driving chordoma by completing whole genome sequencing through the Chordoma Genome Project
- Facilitate the development of treatments that target the brachyury gene
- Help more chordoma patients access appropriate care by increasing investments in patient outreach and support programs
- Invest in fundraising capacity to provide the funds necessary to accomplish all of the above and ensure the long-term success of our mission

“We are grateful to know that families who face a diagnosis of chordoma today will have a much better chance and much more support than even we did in 2006.”

TANYA SADAGOPAN, wife of chordoma patient Sriram Sadagopan
Accolades

The Foundation continues to be recognized for its innovative approach to accelerating rare cancer research. In 2012, stories about the Foundation’s work appeared in:

Forbes
The Wall Street Journal
The Seattle Times
VentureBeat
Xconomy

“The Chordoma Foundation [is] one of the forces pushing academics and drug companies to start sharing more data in the hopes of speeding up medical innovation” - Forbes

FORBES 30 UNDER 30
Executive Director Josh Sommer was named by Forbes to its list of “30 Under 30”—30 rising stars under the age of 30 who are poised to change the world. Josh, representing the Science & Healthcare field, was highlighted in a video interview on the Forbes website and in Forbes Magazine.

Watch the video at www.chordoma.org/30-under-30/

Read the stories at www.chordoma.org/cf-in-the-news/
Our Community
Our strength comes from the community of dedicated partners who stand with us in the search for a cure. This community is critical to everything we do: from guiding patients to the best care possible, to recruiting patients for clinical trials, to raising the funds needed to fuel chordoma research. In 2012, our community grew faster than ever before.

<table>
<thead>
<tr>
<th>Patients</th>
<th>Family Members</th>
<th>Friends of Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>↑28%</td>
<td>↑41%</td>
<td>↑170%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Donors</th>
<th>Facebook Fans</th>
</tr>
</thead>
<tbody>
<tr>
<td>↑27%</td>
<td>↑124%</td>
</tr>
</tbody>
</table>
The Chordoma Foundation relies on the support of dedicated champions across the world to raise the funds needed to pursue our urgent search for a cure. In 2012, community fundraisers brought in over $178,000, funding over one quarter of our total budget for the year.

Because our community is not large, everyone’s fundraising efforts – no matter how big or small – are critical to our success. To get started with a fundraiser of your own, contact Deirdre at 919-809-6779 or deirdre@chordoma.org

Champions

Community Events

**Half Marathon**
Kaitlin Thaney, London, UK

**T-Shirt and CD Sale**
Marley Jay, New York, NY

**Dress Down Day**
Lynette Nelson, Clifton, NJ

**Pub Crawl**
Riccomini Family, West Sayville, NY

**Evening of Magic**
Doug and Julie Booth, Petaluma, CA

**Quilt Auction**
Karen Hermanson, Knife River, MN

**Horse Show**
Kears Family, Derry, UK

**Magnabilities Online**
Kim Swierpel, Livonia, MI

**Durham Academy Cav Dome**
Samantha Lanevi, Durham, NC

**Justin’s Buddies Porch Party**
Tillman & Lanevi Families, Durham, NC

**Purple Aster Concert**
Laird Family, Calgary, AB

**2012 Bowlathon**
Jeff Schilling, Kansas City, MO

**Macy’s Shop-for-a-Cause**
Jennifer Swierpel, Farmington Hill, MI

**Holiday Letter Campaign**
Nelson Family, Clifton, NJ

**Weight Loss Challenge**
Kathy Milczarski, Farmington Hills, MI

**Team Beth Boston**
Elizabeth Cullinan, Boston, MA

**2012 Michael Galluccio Golf Outing**
St. Paul’s Episcopal Church, Glen Cove, NY
Champions’ Pages

Champions’ Pages give every member of the chordoma community a place to share their story and invite family and friends to help reach a personal fundraising goal. To support a champion or to create a page of your own, visit:

http://champions.chordomafoundation.org

Top 10 Champions of 2012

- Elizabeth Cullinan
- The Riccomini Family
- Douglas and Julie Booth
- The Nelson Family
- The Kearns Family
- Debbie MacDonald
- Joe and Christy Nemelka
- Kurt Stevens
- Steven Mandel
- Kaitlin Thaney

JEFF SCHILLING
Chordoma survivor, 5 time Kansas City Bowlathon organizer

“Don’t be afraid to start your own fundraiser... the benefits are huge to see some money go to the foundation that ultimately can change your life. You’re not donating or raising money for anything else but you!!!”
Our Team

Staff
Josh Sommer
Executive Director
Patty Cogswell
Manager of Research
Tammy Silverthorne
Director of Operations
Deirdre Callahan
Development Coordinator
Jenae Logan
Research and Administrative Associate

Board of Directors
Chair: Heather Lee, PhD, SPHR
President: Josh Sommer
Secretary: John Therien, JD
Adam Abram
Benjamin Abram
Joel Beckman
Andrew Schoelkopf
Chandranath Sen, MD

Research Committee
David Cocchietto, PhD, RPh
Jeff Collins, PhD
Fran Meyer, PhD
Bill Phelps, PhD
Chandranath Sen, MD
Josh Sommer
John Therien, JD

Education & Outreach Committee
Sharon Berlan
Norma Jones
Hans Keulen
Heather Lee
Andrew Schoelkopf
Josh Sommer

Development Committee
Adam Abram
Ben Abram
Joel Beckman
Heather Lee
Andrew Schoelkopf
Josh Sommer

Finance Committee
Adam Abram
Ingemar Lanevi
Heather Lee
Josh Sommer

Scientific Advisory Board
Tom DeLaney, MD
Massachusetts General Hospital
Adrienne Flanagan, MD, PhD
University College London
Fran 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
Donors

Our accomplishments are only possible with the support of our many generous donors. We are deeply grateful to all who contributed in 2012.

$100,000+
- Anonymous

$25,000-99,999
- Adam and Roslind Abram
- Ryan Allis
- Joel and Shari Beckman
- Steve Kanter
- Van Sickle Donor Advised Fund

$10,000-24,999
- Anonymous
- Clayman Family Foundation
- Elizabeth Cullinan
- Charles and Marna Davis

$5,000-9,999
- Genentech
- Heather Lee and Steve Straus
- Ed and Sherri Les
- Bruce and Lynette Nelson
- Chandra and Sharmila Sen

$2,500-4,999
- Debra Beltrami
- Eugene and Gay Crowley
- Bill and Sarah Dorland
- Maciej Grabski
- Vilma Hernandez
- Bobby and Korrel Kanoy
- Hans Keulen and Marja Musson
- Dorothy Riccomini
- Maria Pia Ruffilli
- Schwab Charitable Fund
- Ray Underhill Foundation, Inc.

$1,000-2,499
- Kerry Shad and Julia Walker
- Timothy Van Dyck
- Susan and Victor Woodman
- Am Mahalingham Prof Corp
- Karthik Balasubramanian
- Lee Ann Bartoletti
- Bellmore-Merrick Central High School
- Bethlehem Pharmacy, Inc.
- William and Laetitia Bourke
- John and Jill Boy
- Robert and Frances Bridenbecker
- Bringing Joy Fund
- Bristol-Myers Squibb
- Joni and Michael Claymon
- Samuel Cohen
- Collins Electric Co.
- Nancy Cooper
- Frank Courtney
- Frank Crowley
- Kevin and Candy Crowley
- Durham Academy
- Pauline Ekwalanga
- Patrik and Catherine Engellau
- Lauren Erb
- Fluor Canada Ltd.
- Elizabeth Morse Genius Foundation
Mary Gibbons
Halaby Family
Harcros Chemicals Inc.
Carolyn Harley
Geoffrey Hobart
iContact
Jeffrey and Marnie Kaufman
Wil Keenan
Ian Laird
Ruth Laurie
Gary and Bernice Lebin
Ken and Frankie Lee
Howie Liu Fund
Cindy Lo
Holly Lund
Joe Marfuggi
Dana McFerran
Jennifer and Matthew McGinnis
Microsoft
Christopher Mitchell
Joseph and Christine Morena
Mary Cannon Morris Charitable Foundation
Bernard and Margaret Moulin
Norampac-Lithotech
James and Kathleen Patton
Michael Quinn
Raymond Riccomini
Rick and Colleen Riccomini
Brian Sauer
Jeff and Erin Schilling
Andrew and Grace Schoekopf
Dudley Smith
Josh Sommer
Brian and Tamela Staple
Thomas and Dee Stegman
Jane Sterkenburg
Sweet Frog Sayville
Craig and Rebecca Tester
Andy Thomson
Jeff and Janis Tillman
Royleen Tipton
Ouynh Tran
Mike and Linda Waldschmidt
Myles Wittenstein
Barbara Wortman
Fanny Yeung

Bernstein and Pinchuk LLP
Christine Botica
Jacquie Britt
Britten Banners Inc.
Cheryl Bumphrey
Michael and Sarah Burdick
Brindisi Chan
Frank Chauner
Heather Cheyne
Louise Coates
Creative Innovations and Design
Michael Curran
Tim and Kristen Delay
James DeLong
Stephen Deshaies
Chris Dewhurst
John and Joan Dickson
Steve and Melodi Dunn
Lynn Etheredge
Matthew and Lisa Ewend
Robert and Joann Fenili
Theresa Foudy
Fox 50
Philip and Joan Galbo
Claudia Gibson
Kirsten Hadley
Joseph and Julie Harris
Warren and Helen Herz
Dahlia Hirsch and Barry Wohl

$500-999

Brett Arnol
Luke Atkinson
Darlene Bargiel
Mike and Kay Bartoletti
John and Patti Becherer
Michael Beheshti
Barrie and Arlene Bergman
Robinson Strauss and Sharon Berlan
Daniel and Karen Berman
In-kind donors

Donations of goods or services from the following companies and professionals were critical to the Foundation’s operations in 2012:

- Smith Anderson Law Firm – Legal services
- Salesforce.com – Database
- Capitol Broadcasting Company – Office space
- Innocentive – Cell Line prize administration
- Jennifer Moyer BSN, RN – PR Consulting

We greatly appreciate every donation. Visit www.chordoma.org/donors for a complete list of donors.

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

We value every dollar we receive and strive to allocate donated funds wisely and responsibly. In 2012, 74% of our budget was spent on programs to accelerate chordoma research and help patients get the best care possible.

Sources of Funding

- **Individuals**: 64%
- **Businesses**: 20%
- **Private Foundations**: 15%
- **Other**: 1%

A copy of our 2012 Tax Return (IRS Form 990) and Audited Financial Statement are available online at www.chordoma.org/financials.
2012 Audited Statement of Activities
For The Year Ended December 31, 2012

REVENUE AND SUPPORT

- Contributions: $775,081
- In-Kind Contributions: 111,825
- Program Services Revenue: 6,400
- Interest: 1,075

Total Revenue And Support: 894,381

EXPENSES

- Program Services: 538,212
- Management and General: 83,395
- Fundraising: 128,523

Total Expenses: 750,130

CHANGE IN NET ASSETS: 144,251

NET ASSETS, BEGINNING OF YEAR: 583,606
NET ASSETS, END OF YEAR: $727,857