A Decade of Uncommon Progress

Chordoma Foundation
2016 Annual Report
Improving the lives of those affected by chordoma.

Leading the search for a cure.
Table of contents

<table>
<thead>
<tr>
<th>Page</th>
<th>Section</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>Letters from our leadership</td>
</tr>
<tr>
<td>6</td>
<td>What we’ve built together</td>
</tr>
<tr>
<td>12</td>
<td>Developing better treatments</td>
</tr>
<tr>
<td>18</td>
<td>Driving better care</td>
</tr>
<tr>
<td>24</td>
<td>Serving the chordoma community</td>
</tr>
<tr>
<td>30</td>
<td>Looking ahead</td>
</tr>
<tr>
<td>32</td>
<td>Thanks to our supporters</td>
</tr>
<tr>
<td>38</td>
<td>Growth over 10 years</td>
</tr>
<tr>
<td>41</td>
<td>2016 Audited Statement of Activities</td>
</tr>
<tr>
<td>42</td>
<td>Our team</td>
</tr>
</tbody>
</table>

**Our values**

**Patient centricity**

Founded and driven by individuals and families touched by chordoma, we are passionately committed to advancing the interests and well-being of the chordoma patient community.

**Ingenuity**

Succeeding in the fight against an uncommon and under-resourced disease demands a relentless pursuit of efficiency and unconventional approaches that challenge the status quo.

**Urgency**

We know that time is of the essence for everyone affected by chordoma, and we bring that sense of urgency to everything we do, always asking what we can do to move faster.
Dear Friends,

Ten years ago, a small group of chordoma patients and family members started the Chordoma Foundation with an ambitious vision – to create a future in which everyone affected by chordoma would be able to overcome the disease and maintain their quality of life. That future is now within reach.

With your help, the Chordoma Foundation has systematically blazed a path toward better treatments, better medical care, and a better experience for everyone who faces chordoma. And 2016 was, by every measure, our most impactful year yet.

Most notably, our team:

- Supported seven clinical trials bringing promising treatment approaches to patients.
- Launched a first-of-its-kind Drug Screening Program that dramatically decreases the time and cost of testing drugs in preclinical models.
- Exceeded our long-time goal of validating 10 chordoma cell lines, overcoming one of the key obstacles that once stood in the way of research.
- Provided personalized support to more than 500 patients and family members through our Patient Navigation Service.

But what gives us the most hope is that the ground we’ve gained thus far has made it possible for patients to begin benefiting from advances in research in a matter of years rather than decades.

Thank you for believing in us, and for helping us get to this exciting point. Because of you, the future is looking increasingly bright for all of us touched by chordoma.

With deepest gratitude,

JOSH SOMMER
CO-FOUNDER AND EXECUTIVE DIRECTOR
11-Year Survivor
Dear Friends,

Thanks to the generosity of many in our community, 2016 was a year of tremendous growth for the Foundation and the most successful fundraising year in our history. As you will see in the following pages, 2016 also capped a decade of truly astonishing progress, and has created momentum in nearly every aspect of the foundation’s work.

My colleagues and I are bolstered by a growing sense of clarity in the promise of research and the fact that the Chordoma Foundation has an important role to fill in facilitating clinical trials which are bringing new treatments to those affected by the disease. At the same time, we are heartened by the positive impact our Patient Services team is having on the lives of patients and families on a daily basis. The most special part of my involvement is hearing from families who have been helped by our Patient Services team.

The challenge we face together is that many patients are suffering and better treatments are needed urgently. My colleagues and I find it unacceptable to wait another ten years to move promising new treatments into the clinic. To overcome that challenge, we are pushing forward with an ambitious plan to increase the Foundation’s capacity. We know that continued investment will accelerate chordoma research and, ultimately, put an end to this disease.

That dream seems closer by the minute thanks to the growing army of patients, doctors, scientists and philanthropists standing with us in this fight. We are an uncommon community, and, together, I am confident we will succeed.

Thank you most sincerely for your continued commitment to the Chordoma Foundation.

Sincerely,

ANDREW SCHOELKOPF
BOARD CHAIR
Chordoma is a rare and difficult to treat cancer that grows in the bones of the skull and spine, and affects people of all ages.

More effective treatments and a cure are urgently needed.
What we’ve built together

Over the past decade, we’ve created a global movement of patients, families, doctors, and researchers working together to bring about a future in which everyone affected by chordoma is able to overcome the disease and maintain their quality of life.

Historically, the outlook for individuals affected by chordoma was not good. Even with the best care possible, only a minority of patients could be cured, and virtually no research was being done to develop better treatments. Moreover, patients and caregivers faced myriad challenges and had nowhere to turn for support. The Chordoma Foundation was started to change that.

To achieve this vision, we pursue three core goals:

We drive progress toward these goals by investing in three corresponding program areas:

- Better treatments
- Research
- Better care
- Healthcare Improvement
- Better experience
- Patient Services
Each program area is an essential and mutually reinforcing part of our mission. Progress in each enhances and enables progress in the others. Initially, we focused our resources primarily on laying the foundation for research needed to develop better treatments. In the past four years, however, as research gained momentum and the Foundation’s capacity grew, we began investing more significantly in Patient Services and Healthcare Improvement to ensure that patients would benefit from the latest treatment options.
We’ve come a long way in 10 years

Research
- Created a vibrant research community
- Developed end-to-end research enabling infrastructure
- Revealed key drivers and possible drug targets
- Developed a robust therapeutic development pipeline

Healthcare Improvement
- Developed a collaborative network of leading chordoma specialists
- Created 1st treatment guidelines for chordoma

Patient Services
- Produced reliable educational resources
- Developed robust patient navigation service which helped thousands find and access appropriate care
- Created opportunities for patients and caregivers to develop supportive relationships with peers

Working in Duke lab, Josh Sommer discovered that only 1 of 5 purported chordoma cell lines is valid

Chordoma Foundation started
1st International Chordoma Research Workshop
1st International Chordoma Community Conference
CF Cell Line Repository established
1st research grants awarded
Peer Connect program created

Chordoma Genome Project began
Cell Line Prize launched
Familial chordoma gene, brachyury, discovered
Researchers identified 1st potential therapeutic target

1st chordoma patient derived xenograft (PDX) model developed
1st immunotherapy research grant awarded
All FDA-approved drugs screened against chordoma cell lines

chordomafoundation.org launched
Variation in brachyury gene discovered in 97% of chordoma patients

**CF Biobank launched to collect and supply tumor tissue for research**

1st European physicians meeting

1st European Community Conference
5,000+ users a month accessed chordomafoundation.org

**CF PDX repository established**

Epigenetic and proteomic studies of chordoma began

10 FDA-approved drugs screened in PDX model

Roundtable meeting with FDA about chordoma clinical trial held

1st investment in chordoma drug development by a biopharmaceutical company

10,000+ users a month accessed chordomafoundation.org

**CF Patient Navigation Service (PNS) launched**

Drug Screening Program created

5th International Chordoma Research Workshop
Validated 10th chordoma cell line
5th PDX model developed
Chordoma vulnerabilities identified through CRISPR screening

**10th chordoma cell line validated**

10 FDA-approved drugs screened in PDX model

Roundtable meeting with FDA about chordoma clinical trial held

CF PDX repository established

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5th International Chordoma Research Workshop
Validated 10th chordoma cell line
5th PDX model developed
Chordoma vulnerabilities identified through CRISPR screening

**1st clinical treatment guidelines published in The Lancet Oncology**

Clinical Trials Program developed
1st CF-supported clinical trial launched by Celgene and the NCI
Co-hosted second consensus meeting on best practices for treating recurrent chordoma
100th tumor donated to CF Biobank

1,000+ users a month accessed chordomafoundation.org

10th Chordoma Community Conference held
Research
Developing better treatments

In the span of a decade, chordoma research has advanced dramatically: from knowing virtually nothing about the disease to **7 promising drugs entering clinical trials**.

These advances have been driven by strategic investments in research and research-enabling infrastructure, which have unleashed progress in more than **120 labs across the world**.

Since 2007, we have funded high-impact research in **32 labs worldwide**.

**Currently funded researchers**

- **Cameron Brennan, MD, PhD**
  Memorial Sloan Kettering

- **Gary Gallia, MD, PhD**
  Johns Hopkins

- **Michael Kelley, MD**
  Duke University

- **Michael Lim, MD**
  Johns Hopkins

- **Slim Sassi, PhD**
  Massachusetts General Hospital

- **Stuart Schreiber, PhD**
  Broad Institute of Harvard and MIT

- **Mike Sasner, PhD**
  The Jackson Laboratory

- **Adrienne Flanagan, MD, PhD**
  University College London

We have supported Dr. Michael Lim’s research to harness the immune system to fight chordoma since 2011. With two initial seed grants, Dr. Lim generated preclinical data suggesting that chordomas may benefit from a new class of immunotherapy drugs called immune checkpoint inhibitors. This work will culminate with the launch of a clinical trial at Johns Hopkins and Memorial Sloan Kettering Cancer Center testing a checkpoint inhibitor called nivolumab, together with radiation.
Research enabling infrastructure

In addition to funding research directly, we have also created research-enabling infrastructure that makes it possible for more scientists and companies to bring their expertise and resources to bear on chordoma, and vastly increases the efficiency of research.

**Tumor Donation Program**
Enables patients anywhere in the U.S. to donate tumor tissue to research

**Biobank**
Provides a centralized source of high-quality tumor tissue

**Model Repositories**
Provides researchers with easy access to validated chordoma cell lines and mouse models

**Drug Screening Program**
Enables rapid and cost-effective evaluation of promising drugs in cell lines and mouse models

**Clinical Trials Program**
Helps researchers and companies design, launch, and enroll patients in scientifically-sound chordoma clinical trials

$5M+ Invested in research

$20M+ Outside funding leveraged
Research results

 Investments in research have resulted in measurable progress across every stage of the treatment development process.

<table>
<thead>
<tr>
<th>Research Development</th>
<th>Target Discovery</th>
<th>Therapeutic Discovery</th>
<th>Preclinical Research</th>
<th>Clinical Research</th>
</tr>
</thead>
<tbody>
<tr>
<td>200+ tumors banked</td>
<td>Brachyury identified as key driver and prime vulnerability of chordoma</td>
<td>First drugs capable of inhibiting brachyury discovered</td>
<td>All FDA-approved drugs tested against chordoma cell lines</td>
<td>2 clinical trials started</td>
</tr>
<tr>
<td>17 cell lines developed</td>
<td>20+ potential drug targets for chordoma identified</td>
<td>Four-part brachyury therapeutic discovery plan developed</td>
<td>25+ drugs tested in mouse models</td>
<td>5 clinical trials in development</td>
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<tr>
<td>5 mouse models available</td>
<td></td>
<td></td>
<td>5 drug classes found to slow or shrink tumors in mice</td>
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</table>

300+ Researchers around the world now studying chordoma

40 Peer reviewed publications featuring research supported by CF

12 Biopharmaceutical companies investing in chordoma
Clinical trials pipeline

We aim to initiate at least 10 clinical trials by 2020. Already 7 are in the pipeline.

The Chordoma Foundation Clinical Trials Program is designed to eliminate the barriers that typically hinder clinical trials for patients with rare cancers, ensuring that scientifically sound treatment approaches are tested in chordoma patients as quickly as possible.

<table>
<thead>
<tr>
<th>Treatment Type</th>
<th>Planning</th>
<th>Active</th>
<th>Results available</th>
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<tbody>
<tr>
<td>GI-6301 with radiation</td>
<td></td>
<td></td>
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<tr>
<td>Brachyury vaccine</td>
<td></td>
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<tr>
<td>Nivolumab with radiation</td>
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<tr>
<td>PD-1 inhibitor</td>
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<tr>
<td>Afatinib</td>
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<td>EGFR inhibitor</td>
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<tr>
<td>Palbociclib</td>
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<tr>
<td>CDK4/6 inhibitor</td>
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<tr>
<td>Oncolytic bacteria</td>
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<tr>
<td>Brachyury vaccine + PD-L1 inhibitor</td>
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<tr>
<td>Autologous tumor vaccine</td>
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Healthcare Improvement
Driving better care

Over the past decade, we have built a network of more than 400 chordoma specialists across the world, including nearly every leading chordoma treatment team in the U.S. and Europe.

By convening more than a dozen research workshops and physicians’ meetings, we enabled data sharing and discussion among these specialists, helping to push the envelope of state-of-the-art care and clarify treatment best practices.

Our research workshops also provide a unique opportunity for physicians who treat chordoma patients to interact with scientists working in the lab. The exchange of observations and ideas facilitated by these interactions has sparked a number of fruitful research collaborations and informed both patient care and the development of new treatments.

RIGHT
In July of 2016, 115 doctors and scientists from around the world participated in our Fifth International Chordoma Research Workshop, in Boston, MA. This multidisciplinary group represented more than 50 institutions in 11 countries. Pictured: Dr. Paul Gardner, neurosurgeon at the University of Pittsburgh Medical Center, and Dr. Deric Park, neuro-oncologist at the National Cancer Institute.
Consensus guidelines

In partnership with the European Society for Medical Oncology and the Istituto Nazionale dei Tumori in Milan, Italy, we convened an international group of more than 60 leading chordoma physicians to develop consensus about best practices for diagnosing and treating chordoma.

Diagnosis and initial treatment

In 2015, the recommendations developed by this Chordoma Consensus Group were published in The Lancet Oncology, providing an authoritative treatment reference for physicians across the world.

Managing recurrence

Subsequently, the Chordoma Consensus Group published a second set of recommendations in Annals of Oncology outlining best practices for the management of recurrent chordoma.
“With a rare cancer like chordoma, it is very important to have doctors who are willing to improve their knowledge and find a common language across medical specialties so they can work together.”

SILVIA STACCHIOTTI, MD
Sarcoma medical oncologist
Istituto Nazionale dei Tumori / Milan, Italy

A member of the Foundation’s Medical Advisory Board, Dr. Stacchiotti has been a key partner in unifying the chordoma physician community in Europe and spearheaded an international effort to develop the first two consensus guidelines for the diagnosis and treatment of chordoma.
Serving the chordoma community

We are here to help.

In our first 10 years, the Foundation has become a trusted resource for thousands of chordoma patients and their caregivers across the world.

With a growing suite of services designed to meet the unique needs of the chordoma community, we seek to help individuals facing chordoma avoid and overcome challenges throughout their journey with the disease.

2016 INTERNATIONAL CHORDOMA COMMUNITY CONFERENCE

More than 120 patients and caregivers from five countries and 21 states gathered in Boston for the 2016 International Chordoma Community Conference. Twenty speakers presented on topics ranging from the latest advances in chordoma research to the status of new therapy development.
“When you’re diagnosed with cancer or any type of debilitating disease, you can feel like you’ve lost control over your life. But giving of yourself to others can be rewarding—helping others so that they can learn the lessons that you know.”

NORMA JONES
Chordoma survivor and Peer Guide / Alabama

Norma was one of the first chordoma patients to be trained as a Peer Guide in 2011, and has been involved with the Foundation’s education and outreach efforts since the beginning. A counselor by profession and a survivor herself, Norma has been a source of comfort for numerous patients and families at all stages of the disease.
Thousands of patients and caregivers around the world have benefited from our Patient Services over the years.
Patient Services
10-year milestones

**Patient Navigation Service**
Personalized assistance from a trained patient navigator to help find and access appropriate care

1,200
Individuals served

**Doctor Directory**
Vetted list of experienced chordoma specialists who meet criteria set by the Foundation’s Medical Advisory Board

150
Vetted doctors

**Clinical Trials Catalogue**
A curated list of all chordoma-specific clinical trials, as well as other relevant trials recommended by the Foundation’s Medical Advisory Board

15
Vetted clinical trials

**Community Conferences**
Gatherings that provide an opportunity to learn about the latest research and treatment advances, connect with peers, and gain practical advice about living with chordoma

12
Community conferences

**Peer Connect**
Emotional support from a trained Peer Guide who has been through a similar experience

11
Trained Guides

**Educational Content**
Online, print, and video content designed to provide actionable information about chordoma and treatment options

15,000+
Users per month
On Christmas Eve, Monica Cruz-Diaz started to feel sick. She initially dismissed the aches and nausea as holiday excitement, but as the weekend went on her symptoms got worse, and a trip to the emergency room revealed the shocking news that the clival chordoma she overcame as a child more than 20 years prior had returned. An MRI confirmed that the tumor was wrapped around her brain stem, and would require a risky surgery to remove.

After seeing four doctors in four weeks, none of whom felt they could safely perform the surgery she needed, Monica began to feel afraid. Her legs, arms, and face were constantly tingling, and she was finding it harder to speak and walk. Overwhelmed with questions, Monica and her family reached out to the Chordoma Foundation’s Patient Navigators for answers.

“I was hopeful, but scared. I needed information and advice; someone who understood chordoma and could help me think through all of the choices I had to make. I called the Foundation, and within a day they had sent me a list of top doctors and surgeons to reach out to, explained different treatment options, and answered countless questions about what to expect. With their help, I got connected to the specialist who performed my surgery, and today, even the calcified remnants of the old tumor are gone.”
Looking ahead

With your help, in the span of 10 years, the outlook for the chordoma community has changed dramatically.

More than 300 researchers and a dozen companies are now studying chordoma, and a growing pipeline of new treatments are moving from the lab into clinical trials. The first comprehensive treatment guidelines have been published, helping to ensure that more patients receive high-quality care. And, individuals facing chordoma now have a place to turn for information and support throughout their journey with chordoma.

The confluence of these advances is beginning to make a meaningful impact in people’s lives, and it has laid the groundwork for even greater progress to come.

Based on the opportunities that lie ahead, better patient outcomes are no longer decades away—they are now possible within years.

To accelerate the timeline, we plan to more than double our annual investment in Research, Healthcare Improvement, and Patient Services over the next three years.
Current priorities

Research

1 Initiate and fund a “Brachyury Drug Discovery Initiative” to create the first drugs capable of targeting brachyury—a gene revealed to be the key driver and prime vulnerability of chordoma. Importantly, if successful, this would result in new therapies that could be used for more common cancers in which brachyury is also implicated.

2 Initiate and fund a “Chordoma Immunotherapy Initiative” to bring the latest advances in cancer immunotherapy to chordoma.

3 Launch 10 clinical trials testing the most promising new treatment approaches for chordoma with the goal of identifying the first effective drug therapy.

Healthcare Improvement

1 Develop and support a “Chordoma Learning Network” comprised of leading chordoma treatment centers to optimize treatment techniques with a particular focus on improving patient quality of life.

2 Continue to refine and disseminate treatment guidelines to help specialists who encounter chordoma patients outside of top treatment centers accurately diagnose chordoma and provide best-practice treatment.

Patient Services

1 Develop and distribute an actionable set of educational resources tailored to the unique needs of caregivers and patients representing every disease status, tumor location, and treatment history.

2 Provide individualized healthcare navigation assistance to 2,000 patients to help them overcome barriers to care and get the best treatment possible.

3 Facilitate peer-to-peer support and knowledge-sharing through community conferences, a new online community, and our Peer Connect program.
Thanks to our supporters

Your support is making a real difference in the lives of individuals affected by chordoma, and propelling research toward better treatments for this disease.

Transformative contributions

We gratefully acknowledge the following families and organizations whose extraordinary contributions in excess of $400,000 over the past decade have made a transformative impact on the Foundation. Their dedication and vision has been integral to building the Foundation into a powerful catalyst for progress.

Anonymous
Anonymous
Anonymous
Adam and Rosalind Abram

The Beckman Family Foundation
Smith, Anderson, Blount, Dorsett, Mitchell & Jernigan, LLP
Young-dahl and Juliet Kim Song

LEFT
Team Chordoma completes the Brooklyn Half Marathon on May 21, 2016, raising over $40,000 for chordoma research.
10-year donors
It is with great pleasure and gratitude that we recognize the following individuals for their continuous support of the Foundation over the last ten years.

Vincent and Mary Ann Bush
John and Renee Butler
Kenny and Mona Cohen
Steve Kanter
Robert and Barbara Kehler
Bruce and Lynette Nelson
Daniel and Dawn Pratt
Bernice Samuels
Patsy and Sandra Sinisi
Josh Sommer and Rachel Lichte
Steve Straus and Heather Lee
Michael Torrey and Cheryl Kugel-Torrey

2016 donors
We’re grateful to the following donors who brought us closer to a cure in 2016.

$1M+
Anonymous
Anonymous
Anonymous

$100K–249K
The Beckman Family Foundation

$25K–99,999K
The Cedar Street Foundation
Celgene
Hirsch Family Foundation
Steve Kanter
Stephanie Neuman
Helen Van Sickle Fund

$10K–24,999K
Anonymous
Michael Bluhm
Bristol-Myers Squibb
Charles and Marna Davis
Denham Capital Management LP
Hester M. Digges Trust U/A
Lea Glazar
Illinois Tool Works

$5K–9,999K
Elizabeth Akers
Mary Margaret Anderton
Anonymous (2)
John and Patti Becherer
Michael Beltrami
John and Myrna Blume
William and Laetitia Bourke
Robert and Frances Bridenbecker
Burroughs Wellcome Fund
Covidien
G1 Therapeutics
GE Foundation
Hughes Hubbard & Reed

$I. & B. Neuman Foundation, Inc.
Goldman Sachs Gives:
The Barry and Rochelle Kaplan Fund
Steven Mandel
Medtronic
MGH Cancer Center
Scott and Julie Moller
Edoardo Moretti
Benjamin and Kelly Navarro
Bruce and Lynette Nelson
Richard and Colleen Riccomini
Kerry Shad and Julia Walker
Andrew Thomson
UPMC Center for Skull Base Surgery

$1K–4,999K
Natale and Sylvia Aiello
Lola Anderson
Anonymous (5)
Norman R. and Margareta E. Augustine Bequest Fund
Kurtis Bachman
Jamie Barber
Shelba Barnes
Melissa Batz
Eric and Jaynee Beckman
David Biondi
BP Foundation, Inc.
Gene and Sue Brenneman
Ally Bulley
Kenny and Mona Cohen
Samuel Cohen
Collins Electric Co.
Frank Courtney
Allen Cragin
Eugene and Gay Crowley
Beth Cullinan
Virginia Daly
Peter and Kathy Davidoff
Betty Davis
Robert Alec and
Anne Noel Dawson
Thomas DeLaney
James De Long
Tom Doar
William Dorland and Sarah
Penniston-Dorland
Steve and Melodi Dunn
Patrik and Catherine Engellau
Lynn Etheredge Fund
Oliver Evans
Family Heritage Life Insurance
Company of America
Richard and Janet Fell
Fercap Management Ltd.
Frank and Diane Fernandes
Fidelity Brokerage Services LLC
Scott and Cindy Frodle
Chee Fah Fu
Stephen Gazda and
Paula Song
Greg Gliner
Mary Gran
Elizabeth Gunter
Amanda Hager
Harcros Chemicals Inc.
Geoffrey Hobart
Intel Corporation
James Porto Photographer Inc.
The Suzanne M. Nora Johnson
& David G. Johnson Foundation
Judy Johnson
Johnson & Johnson
K Foundation
Danny and Michelle Kalenov
Robert and Korrel Kanoy
Bradley and Belinda Karp
Jeffrey and Marnie Kaufman
Michael Knox
Jerald and Albertina Kuhn
R.L. and Mary Kuhnlein
Joshua Kutilek
Ira and Lillian Langsan Fund
Kenneth and Frankie Lee
Lisa and Michael Leffell
Foundation
Irene Loeb
Christopher Long and Marie
Hatem
Thomas and Holly Lund
Leslie and Rhoda Mandel
Joe Marfuggi
Dana McFerran
Thomas Moss and Janie Deal
Arlynn Muckey
Michele Muska
Alexander Nadianer
Daniel and Jane Och
Charitable Trust
Pacific Neuroscience
Institute, LLC
Arthur and Karen Pappas
Josh Parker
James and Kathleen Patton
Polisnelli
Michael and Noreen Potempa
Pete and Carmen Ramirez
J. Robert and Nora Reinhardt
Todd Roberts and Arleen Song
Gwilym Roddick and Anat Or
Timothy Rodell
Maria Pia Ruffilli
Gary and Karen Sain
Sally Sallee
Saugus VFW Men’s Auxiliary
Madhav Shenoy
The Shepard Broad
Foundation, Inc.
Robert and Hazel Shinholt
Michael Sirchio
Gregg Slepian
Scott Smaller
Bruce Smith
Douglas and Phyllis Smith
David Smyth and Julie Song
Josh Sommer and
Rachel Lichtte
Young-dahl and
Juliet Kim Song
Stalter Foundation
James Stotz
Strategic Enhancement
Group Inc
Robinson Strauss and
Sharon Berlan
Mark Struznik
David and Peggy Tanner
John and Heather Therien
Thrivent Financial
Jeffrey and Janis Tillman
Claudio Umaschi
United Way of Snohomish
County
University of Florida Proton
Therapy Institute
The Viniar Family Foundation
Ryan Wiebe
Terry and Colleen Wilkins
Jim and Judy Wilson
Susan Woodman

$500–999
Anonymous
C and T Aiello
Randy and Patricia Akers
Allan Myers MD, Inc.
John Amato
AmazonSmile Foundation
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.
Chordoma Champions

We are inspired by the Chordoma Champions across the world who have organized fundraisers that advance our shared cause.

Their tireless efforts have raised a collective $565,000, and have been instrumental to fueling advancements in chordoma science, unearthing new treatment possibilities, and expanding support for everyone affected.

CLOCKWISE FROM TOP LEFT
Michael and Noreen Potempa, Todd and Brittany Fuchs, Maureen Schroer and family, Daniel Kalenov and family
### 2016 Online Fundraising Champions

<table>
<thead>
<tr>
<th>Name</th>
<th>Since</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anonymous</td>
<td>2012</td>
</tr>
<tr>
<td>Bobbi Antonazzi Jensen</td>
<td>2013</td>
</tr>
<tr>
<td>Andy Bartaletti*</td>
<td>2008</td>
</tr>
<tr>
<td>Matthew Berger</td>
<td>2016</td>
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<td>Sharon Berlan</td>
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<td>Christine Bowenkamp</td>
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<td>Nadine Cordova</td>
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<td>Joey Cross</td>
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<td>Beth Cullinan</td>
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<td>Lee Gryll*</td>
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<tr>
<td>Tiffany Hanke-Benner*</td>
<td>2013</td>
</tr>
<tr>
<td>Danny Kalenov</td>
<td>2016</td>
</tr>
<tr>
<td>Danielle Krinsky</td>
<td>2016</td>
</tr>
<tr>
<td>Steven Mandel</td>
<td>2012</td>
</tr>
<tr>
<td>Daryl Marciszewski</td>
<td>2009</td>
</tr>
<tr>
<td>James and Elisa McBratney</td>
<td>2016</td>
</tr>
<tr>
<td>Facebook Milestones</td>
<td>2015</td>
</tr>
<tr>
<td>Makenna Muska</td>
<td>2016</td>
</tr>
<tr>
<td>Greg Ostrofsky</td>
<td>2016</td>
</tr>
<tr>
<td>Elisa Pennetti</td>
<td>2016</td>
</tr>
<tr>
<td>Michael Potempa</td>
<td>2013</td>
</tr>
<tr>
<td>Justin Remsen</td>
<td>2016</td>
</tr>
<tr>
<td>Allison Roberts</td>
<td>2013</td>
</tr>
<tr>
<td>Jaclyn Salant</td>
<td>2016</td>
</tr>
<tr>
<td>Dan Sauerhoff</td>
<td>2016</td>
</tr>
<tr>
<td>Matthew Sauerhoff</td>
<td>2014</td>
</tr>
<tr>
<td>Maureen Schroer</td>
<td>2013</td>
</tr>
<tr>
<td>Jessica Spiesman</td>
<td>2016</td>
</tr>
<tr>
<td>Lisa Vanelli</td>
<td>2010</td>
</tr>
<tr>
<td>Jaclyn Weissman</td>
<td>2016</td>
</tr>
<tr>
<td>Grace Wen</td>
<td>2016</td>
</tr>
<tr>
<td>Randi Windt</td>
<td>2014</td>
</tr>
<tr>
<td>Geraldine Yu</td>
<td>2016</td>
</tr>
</tbody>
</table>

*Indicates those who have passed

### 2016 Community fundraising events

<table>
<thead>
<tr>
<th>Event</th>
<th>Organizer</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blockbuster Bowling Benefit</td>
<td>Jeff Schilling</td>
<td>Kansas City, MO</td>
</tr>
<tr>
<td>Brooklyn Half Marathon</td>
<td>Steve Mandel</td>
<td>London, UK</td>
</tr>
<tr>
<td>Conor Riccomini Dodgeball Tournament</td>
<td>Colleen Riccomini</td>
<td>West Sayville, NY</td>
</tr>
<tr>
<td>Dress Down Day</td>
<td>Lynette Nelson</td>
<td>Clifton, NY</td>
</tr>
<tr>
<td>Home Tour</td>
<td>Gene and Sue Brenneman</td>
<td>Kinzers, PA</td>
</tr>
<tr>
<td>One in a Million Benefit</td>
<td>Mick and Noreen Potempa</td>
<td>Libertyville, IL</td>
</tr>
<tr>
<td>Riccomini Pub Crawl</td>
<td>Colleen Riccomini</td>
<td>West Sayville, NY</td>
</tr>
<tr>
<td>Surprise Birthday Party</td>
<td>Michelle Kalenov</td>
<td>San Diego, CA</td>
</tr>
<tr>
<td>Swing Fore the Cure</td>
<td>Jeff Schilling</td>
<td>Kansas City, MO</td>
</tr>
</tbody>
</table>

*Collecting donations in memory of her son*
Since the Foundation’s inception, we have pursued our goals with intentionality, focusing our efforts on achieving the greatest possible impact with available resources.

This has resulted in significant progress toward better treatment, better patient care, and a better patient experience, and has positioned the Foundation to achieve an even greater impact in the years ahead.

Our progress over the past 10 years has reflected the steady growth of our revenue and organizational capacity. Though our mission has remained constant, revenue growth over time has enabled us to expand the scope of our work each year.
Donors from 43 countries have contributed and pledged more than $12 million and counting over the last 10 years to improve the lives of those affected by chordoma and lead the search for a cure.

Cumulative investments made over the last 10 years

We ended 2016 on a high note, with three, generous $1M gifts that will propel our work forward over the coming years.
“In many ways, the Chordoma Foundation operates more like an investor than a traditional charity. Every donation has an outsized impact on advancing research and care, and patients like me are already seeing the benefits. Its collaborative, mission-driven approach to finding and supporting best-in-class science and patient services makes the Foundation not just an engine of innovation in chordoma, but a model for how to tackle other rare diseases as well.”

JOEL BECKMAN
Chordoma survivor
Vice Chair, Board of Directors

Our commitment to excellence in financial management and transparency has been recognized by Charity Navigator and Guidestar.
## 2016 Audited Statement of Activities

For the year ended December 31, 2016

<table>
<thead>
<tr>
<th>Revenue and support</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contributions</td>
<td>$ 4,117,928</td>
</tr>
<tr>
<td>In-kind contributions</td>
<td>165,700</td>
</tr>
<tr>
<td>Program service revenue</td>
<td>15,044</td>
</tr>
<tr>
<td>Interest</td>
<td>439</td>
</tr>
<tr>
<td><strong>Total revenue and support</strong></td>
<td><strong>$ 4,299,111</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Expenses</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Program services</td>
<td>$ 2,020,302</td>
</tr>
<tr>
<td>Management and general</td>
<td>189,031</td>
</tr>
<tr>
<td>Fundraising</td>
<td>278,732</td>
</tr>
<tr>
<td><strong>Total expenses</strong></td>
<td><strong>$ 2,488,065</strong></td>
</tr>
</tbody>
</table>

| Change in net assets | 1,811,046   |
| Net assets, beginning of year | 2,267,108  |
| **Net assets, end of year** | **$ 4,078,154** |

A copy of our 2016 IRS 990 and Audited Financial Statement are available at chordoma.org/financials

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### Spending by program

- Research: 62%
- Patient Services: 19%
- Fundraising: 11%
- Management: 8%

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### Sources of funding

- Individuals: 59%
- Private Foundations: 32%
- Businesses: 8%
- Other: 1%
Our Team

TOP
Chordoma Foundation staff at 2016 Board Retreat. Not pictured, Joan Levy.

Our staff

Josh Sommer
Executive Director

Daniel Baroff
Development Coordinator

Patty Cogswell
Manager of Research

Larry Gottschalk
Operations Coordinator

Megan Hohenstein
Education and Outreach Coordinator

Joan Levy, PhD
Director of Research

Shannon Lozinsky, MSW
Patient Services Manager

Breanna McCormley
Director of Development

Jennifer Roeder
Marketing and Communications Manager

Tammy Silverthorne
Director of Operations

Gillian Parrish
Communications Consultant

Board of Directors

Andrew Schoelkopf
Chair

Joel Beckman
Vice Chair

Ingemar Lanevi
Treasurer

Kerry Shad, JD
Secretary

David Drewry, PhD

Shreyas Patel, MD

David Sandak

Chandra Sen, MD*

Christy Shaffer, PhD

Josh Sommer

Paula Song, PhD

*Completed term
Board committees*

FINANCE
Ingemar Lanevi
Chair
Mark Ricca
Andrew Schoelkopf

RESEARCH
Kurt Bachman, PhD
Jeffrey Collins, PhD
David Drewry, PhD
Shreyas Patel, MD
William Phelps, PhD
David Sandak
Chandra Sen, MD
John Therien, JD

PATIENT SERVICES
Paula Song, PhD
Chair
Karen Cox, PhD, RN
Vickie Leff, LCSW
Mike O’Brien, MSW, LICSW

DEVELOPMENT
Joel Beckman
Chair
Andrew Schoelkopf
Joe Villinski

NOMINATING
Kerry Shad, JD
Chair
Joel Beckman
Edward Les, MD
Andrew Schoelkopf
Christy Shaffer, PhD

EXECUTIVE
Andrew Schoelkopf
Chair
Joel Beckman
Ingemar Lanevi
Kerry Shad, JD

Scientific Advisory Board
David Drewry, PhD
Adrienne Flanagan, MD, PhD
Fran Hornicek, MD, PhD
Michael Kelley, MD
Paul Meltzer, MD, PhD
Deric Park, MD

Medical Advisory Board
Chandra Sen, MD
Founding Chair
Shreyas Patel, MD
Incoming Chair, 2017
Greg Cote, MD, PhD
Tom DeLaney, MD
Paul Gardner, MD
Hans Gelderblom, MD, PhD
Ziya Gokaslan, MD
Mrinal Gounder, MD
Christopher Heery, MD
Fran Hornicek, MD, PhD
Silvia Stacchiotti, MD
Katie Thornton, MD
Josh Yamada, MD

Community Advisory Board
Heather Lee, PhD
Chair
Edward Les, MD
Medical Liaison
Nadine Aoun-Cordova
Brittany Fuchs
Susan Garbett
Chris Jones
Steven Mandel
Jeffrey (Jeb) Nandaner, PhD
Jeff Schilling
Tim Zellers

*Our Executive Director Josh Sommer is an ex officio member of all Board committees.
“It has been an honor to work with such a dedicated and talented group of colleagues on the Chordoma Foundation’s Medical Advisory Board. The work we’ve done together has helped the Foundation pave the way for patients to get better care and for new treatments to reach the clinic. I look forward to seeing the impact that these new therapies have in the lives of chordoma patients.”

DR. CHANDRA SEN
Neurosurgeon, NYU Langone Medical Center
Medical Advisory Board, Founding Chair
Chordoma patient Frankie Fernandes is visited by Gus, a therapy dog at the University of California San Francisco, while getting treatment there in 2012.