



More progress, more hope

Improving the lives of those affected by chordoma.

Leading the search for a cure.



ABOVE: Chordoma patient and medical student, Seth Butler with friends and classmates during his Hike for Chordoma fundraiser.

ON THE COVER: Brooke and Carolyn Laney, parents of a pediatric chordoma patient, at the 2018 International Chordoma Community Conference all the way from Australia.

Letter from the Executive Director

Dear Friends and Partners,

Like compounding interest, the accumulated impact of our work together over the past 12 years has made possible more progress on more fronts this year than ever before. And, with that progress, more reasons to be hopeful about the future.

In the pages that follow, you'll see how the pipeline of new treatment options for chordoma continues to grow, from the launch of two new CF-supported clinical trials in 2018 to investments in basic and translational research that are feeding new treatment ideas into that pipeline. You'll read about our first major foray into new drug discovery, and how our research partners are applying innovative and truly remarkable technologies to develop drugs against brachyury

— the Achilles' heel of chordoma. And, you'll learn about valuable new resources we rolled out to help make the journey with chordoma feel less lonely and less bewildering.

But, most importantly, this report is a tribute to you — the volunteers, donors, partners, and advisors who make our work possible and propel our mission forward.

Thank you for being a part of this movement. Thank you for helping to set the bar for catalyzing progress against a rare cancer. And thank you for giving all of us affected by chordoma reasons to hope. Because of you, I know chordoma is a solvable problem, and I look forward to continuing to work with you to solve it.

Onward!



Josh

Josh Sommer
Co-Founder and Executive Director
13-Year Survivor

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Research

Having created a vibrant research ecosystem and attracted some of the brightest minds in science, our search for better treatments is progressing at an unprecedented pace. In 2018, we invested a total of \$1.2M in research, resulting in significant and measurable progress across every stage of our research roadmap.

Resource Development	Target Discovery	Therapeutic Discovery	Preclinical Research	Clinical Research
<p>25 tumors saved for research through our Biobank</p> <p>1 new cell line validated</p> <p>4 new mouse models validated</p>	<p>2 grants awarded to discover new epigenetic drug targets</p>	<p>3 grants awarded to discover drugs targeting brachyury, the Achilles' heel of chordoma</p>	<p>11 drugs tested in mouse models through our Drug Screening Program</p> <p>1 promising drug (cetuximab) nominated for a clinical trial</p>	<p>2 new CF-supported clinical trials launched (afatinib and BN-Brachyury vaccine + radiation)</p>

Most notably, as described in the following pages, we focused on driving progress in four key areas:

- 1

Bringing research advances to **pediatric chordoma**
- 2

Jumpstarting **brachyury drug discovery**
- 3

Expanding the pipeline of **chordoma clinical trials**
- 4

Expanding the **chordoma research network**

Read on to learn more »

Bringing research advances to pediatric chordoma

In 2018, we launched a multi-year Pediatric Chordoma Initiative intended to jumpstart research for this once-neglected subset of the chordoma patient community.



ABOVE
Chordoma survivors, Alli Zellers, Kaitlin Slepian, and Emily Sommer at the 2018 International Chordoma Community Conference.

Seeded with gifts and pledges totaling \$1.3 million, we have already made notable headway:

- **Funded** development of the first pediatric chordoma cell line and PDX model.
- **Tested** eight drugs and combinations in pediatric models through our Drug Screening Program.
- **Ensured** that children 12 and older will be able to participate in forthcoming chordoma clinical trials.
- **Recruited** world class researchers to study pediatric chordoma, including through a breakout session at our biennial International Chordoma Research Workshop dedicated to pediatric chordoma.
- **Worked** with the National Cancer Institute to plan a pediatric and young adult chordoma clinic.



LEFT
Participants at a mini-workshop on pediatric chordoma hosted with the National Cancer Institute.

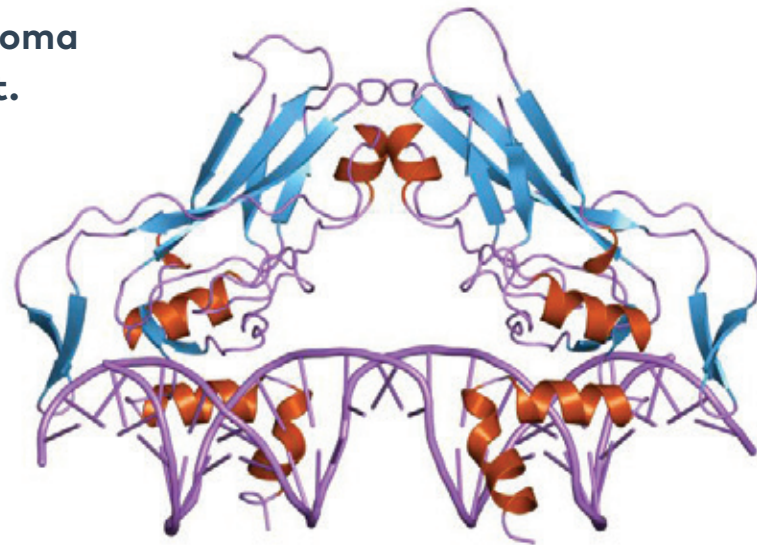
Jumpstarting brachyury drug discovery

The most important insight about chordoma that research has revealed to date is that it has an Achilles' heel: a protein called brachyury. Not only is brachyury the defining feature of chordoma, but chordoma cells cannot survive without it. With no known function in normal cells, **targeting brachyury represents the greatest opportunity to defeat chordoma without harming the patient.**

It also turns out that brachyury plays a role in metastasis in a number of other cancers such as breast, lung, colon, and prostate, so therapies against brachyury could have an impact far beyond chordoma.

The challenge, however, is that brachyury belongs to a class of proteins called transcription factors, which have historically been considered "undruggable" because they lack the types of nooks, crannies, and crevices to which most drugs bind. Fortunately, several emerging technologies have the potential to overcome this barrier.

RIGHT
Brachyury
protein
structure



“The Foundation’s active role in bringing together research groups with complementary capabilities will probably shorten the time to achieve our goals by at least 50%.”

Opher Gileadi, PhD
University of Oxford

Brachyury drug discovery investments

In partnership with The Mark Foundation for Cancer Research, we awarded pilot grants to support three projects applying cutting-edge technologies to brachyury drug discovery.



In the first year, the goal of these projects is to discover chemical compounds that bind to the brachyury protein — a critical first step in developing drugs that can inhibit or degrade brachyury.

Craig Crews, PhD (*Yale University*)

Identifying brachyury binders through computational modeling, and attempting to eliminate brachyury by harnessing the innate cellular system for destroying faulty proteins, a process called targeted protein degradation.

Daniel Nomura, PhD (*University of California, Berkeley*)

Employing novel chemistry techniques to discover molecules that bind strongly and irreversibly to the brachyury protein, providing a foothold for constructing compounds that either directly inhibit brachyury’s function or trigger its degradation. This work is part of a broader project funded by The Mark Foundation for Cancer Research to target “undruggable” proteins implicated in cancer.

Opher Gileadi, PhD (*Oxford University*)

David Drewry, PhD (*University of North Carolina, Chapel Hill*)

Charles Lin, PhD (*Baylor College of Medicine*)

Developing a high-resolution map of the physical structure of the brachyury protein and constructing drugs based on identifying small chemical structures (“chemical fragments”) that interface with subtle features in the protein.



Craig Crews, PhD



Daniel Nomura, PhD



Opher Gileadi, PhD



David Drewry, PhD

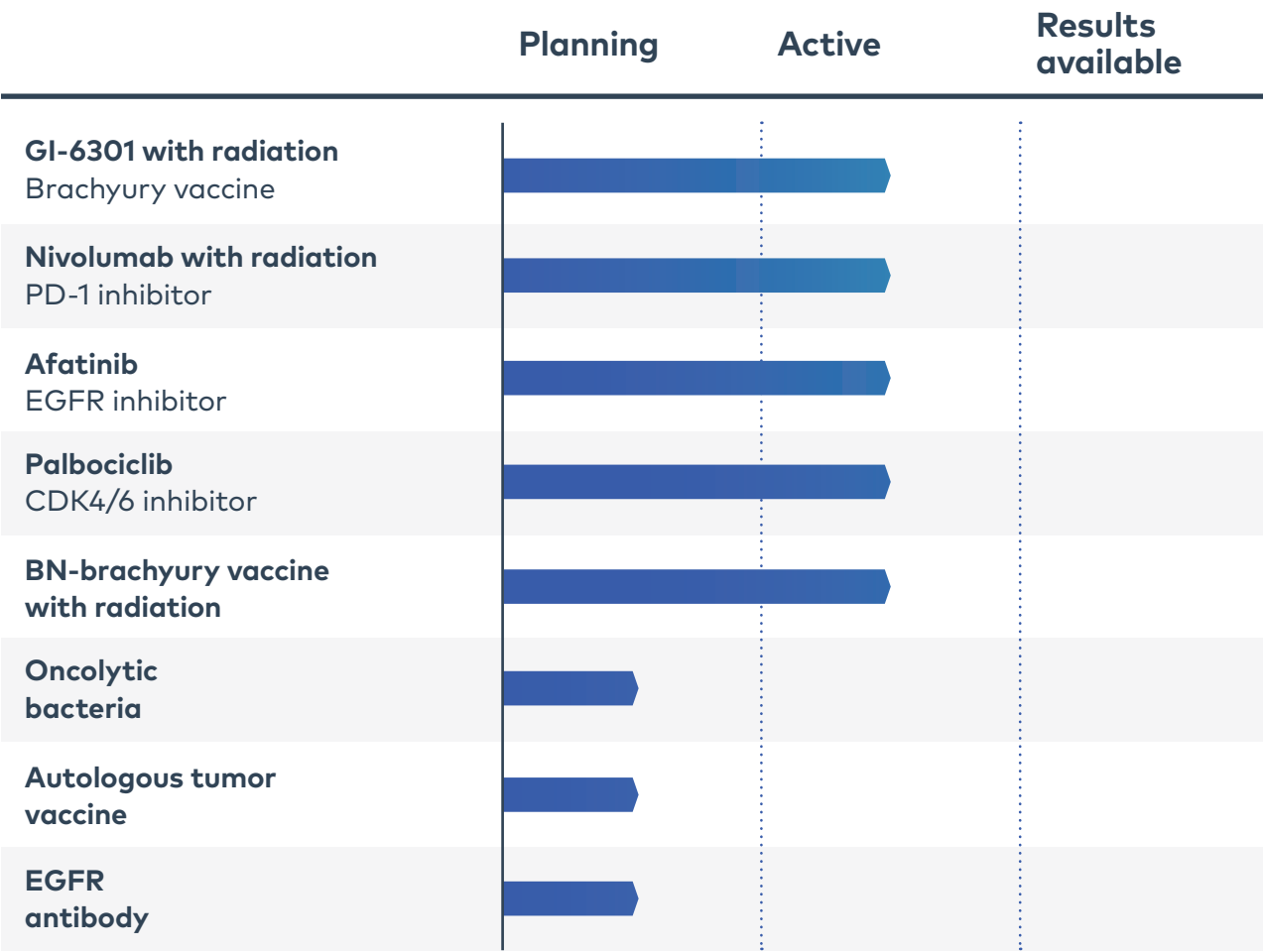


Charles Lin, PhD

Expanding the clinical trials pipeline

Two CF-supported clinical trials opened in 2018, bringing the total number of open trials in our pipeline to five — halfway to our goal of ten by 2020.

The first trial is testing the effectiveness of the FDA-approved targeted therapy afatinib, which blocks a protein called EGFR that plays an important role in driving chordoma. The second is evaluating the effectiveness of an experimental cancer vaccine called BN-Brachyury, which is designed to harness the immune system to attack cells in which brachyury is produced.



Looking for a clinical trial that may be right for you?

Our Clinical Trials Catalogue lists all chordoma-specific trials as well as all other trials deemed relevant to chordoma patients by our Medical Advisory Board (MAB). It currently includes information on 17 trials worldwide.

chordoma.org/clinical-trials

Chris Heery, MD

Chief Medical Officer,
Bavarian Nordic



“The challenges of doing research in rare cancers often deter companies from investing in developing drugs for these patient populations, despite the significant unmet need. But the Chordoma Foundation has made it feasible for companies like ours to pursue drug development for this rare tumor type. Working with the Foundation was critical to enabling us to open and quickly enroll patients into the BN-brachyury vaccine trial.”

Expanding the chordoma research network

After more than a decade of cultivating interest in chordoma and attracting researchers into the field, today, we are grateful to be working with a network of more than **350 research collaborators and 12 pharmaceutical and biotech companies**. And, as the bleeding edge of chordoma research continues to expand into new areas, we are working proactively to recruit the most talented scientists in those areas to turn their attention to chordoma.



ABOVE
We hosted an immune roundtable to define research priorities and recruit new investigators into the field.

Expanding chordoma research in Canada



Through a joint grants program with the Canadian Cancer Society, we awarded two \$150,000 grants in 2018 to outstanding physician scientists whose work is breaking new ground in understanding chordoma biology and identifying new treatment approaches.

- **Dr. Stephen Yip, MD, PhD (BC Cancer Agency)** is working to identify epigenetic drugs that can make chordoma more susceptible to immune attack and thus make immunotherapies more effective.
- **Dr. Gelareh Zadeh, MD, PhD (University of Toronto)** is undertaking the largest study to-date to characterize epigenetic alterations in chordoma and identify new epigenetic targets.



Dr. Stephen Yip, MD, PhD



Dr. Gelareh Zadeh, MD, PhD

Currently funded researchers

Cameron Brennan, MD, PhD Memorial Sloan Kettering Cancer Center	Opher Gileadi, PhD* Oxford University	Slim Sassi, PhD Massachusetts General Hospital
Craig Crews, PhD* Yale University	Michael Kelley, MD Duke University	Stuart Schreiber, PhD Broad Institute of Harvard and MIT
David Drewry, PhD* University of North Carolina	Michael Lim, MD Johns Hopkins	Yoshiya (Josh) Yamada, MD Memorial Sloan Kettering Cancer Center
Adrienne Flanagan MD, PhD University College London	Charles Lin, PhD* Baylor College of Medicine	Stephen Yip, MD, PhD*+ BC Cancer Agency
Hans Gelderblom, MD, PhD Leiden University Medical Center	Dan Nomura, PhD*+ UC Berkeley	Gelareh Zadeh, MD, PhD*+ University of Toronto

*2018 Grantees
+Funded through partner organization

Uniting the global chordoma community

In March, a record number of participants joined us in Boston for the sixth International Chordoma Research Workshop (ICRW) and International Chordoma Community Conference (ICCC).

Together, these two conferences serve as the principal gathering points for the worldwide chordoma research and patient communities, providing a unique opportunity to forge relationships and share the latest research and treatment advances. Hosted back to back, they also serve as an important bridge between the researchers working to find better treatments and the individuals who stand to benefit from their work.

140 100

doctors and scientists

patients and caregivers

10

countries

70

institutions

International Chordoma Research Workshop

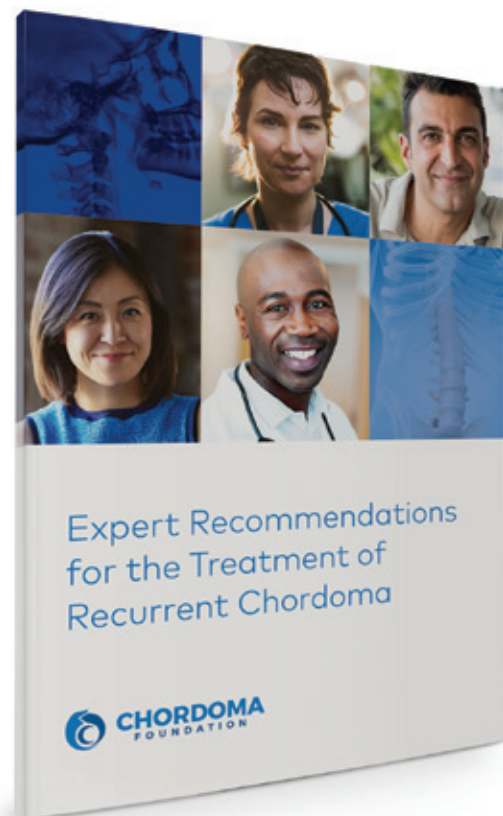


International Chordoma Community Conference



Patient Services

This year, a record number of patients and families turned to the Foundation for information, guidance, and support through their journey with chordoma. To better meet their needs, we developed a host of new educational resources and launched a new, private online community called Chordoma Connections to facilitate more peer-to-peer knowledge sharing and support among patients and caregivers.



560+

Patient Navigation cases served

6,300+

views of our Doctor Directory

200K

views of "Living with chordoma" section of our website

Expert Recommendations for the Treatment of Recurrent Chordoma

Our newest educational booklet helps patients and caregivers facing a recurrence learn about and act upon evidence-based treatment guidelines developed by top chordoma experts.

chordoma.org/educational-materials

Aaron's story

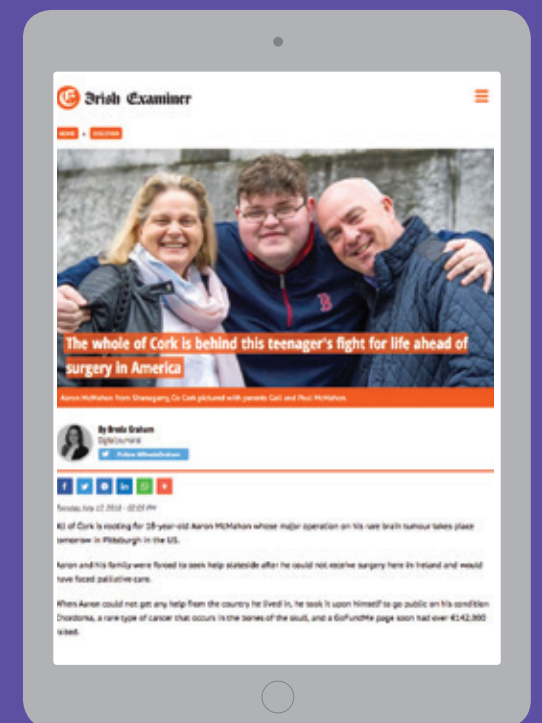
Aaron McMahon, a sports-loving teen from County Cork, Ireland, was diagnosed with a skull base chordoma in March of 2017 at just 16 years old.

After undergoing surgery in Ireland and radiation in Germany, Aaron and his family were optimistic chordoma would be behind them. So, when, just a few months later, his tumor started growing again, they were devastated. Aaron's doctors told the family there was nothing more they could do.

But at 16 years old, with his whole life ahead of him, **Aaron and his parents refused to give up hope.** Instead, they made contact with our Patient Navigators who helped the family understand their treatment options, connect with fellow patients, and meet Dr. Paul Gardner, a neurosurgeon and chordoma expert at the University of Pittsburgh Medical Center (UPMC).

After learning that he was, in fact, a candidate for surgery, Aaron and his family were elated. They felt as if he had been granted a second chance. **Aaron's whole community rallied behind him, launching an all-out fundraising campaign to get him the care he needed.** Through fundraisers, personal donations, and even a music video, they raised over €100,000 within a matter of months to send Aaron to Pittsburgh.

In June of 2018, Aaron underwent surgery at UPMC to remove the tumor that his local doctors told him was inoperable. **Amazingly, they were able to remove the entire tumor, and Aaron made it through surgery with flying colors.** Following surgery, Aaron's diagnosis was revised to chondrosarcoma, a tumor for which chordoma is often misdiagnosed. Thanks to the help he received, Aaron is now back in Ireland preparing to start college and looking forward to a bright future.



ABOVE
Aaron McMahon with Dr. Paul Gardner at the University of Pittsburgh Medical Center; Article about Aaron and his family in the Irish Examiner

Kris Stahl

Chordoma Foundation Peer Guide and co-moderator of Chordoma Connections



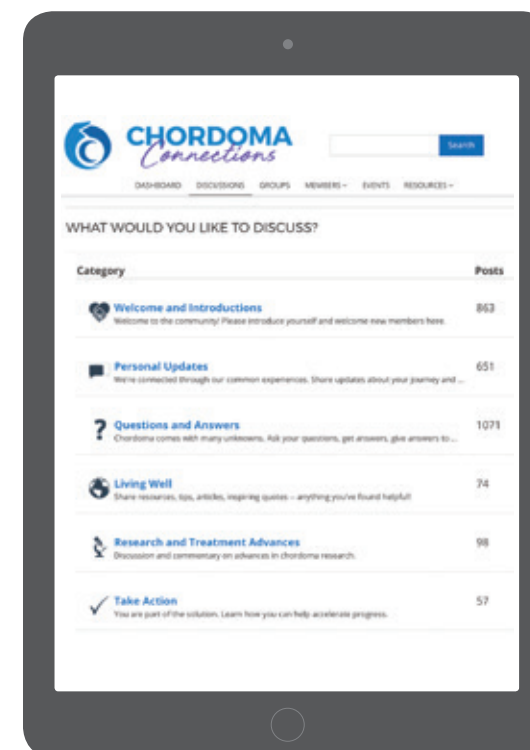
I am so proud of the Foundation's work to build this community and so grateful for the opportunity to serve as a moderator. Though it may seem like that role is about helping others, I have found that it is helping me, too. After losing my husband to chordoma, it has been a privilege to share connections with others who have experienced some of the same things I have, and help each other move forward together."



Since launching in January, more than 650 patients and caregivers worldwide have joined the conversation in Chordoma Connections, the Foundation's private online community. They come from many different backgrounds, countries, and cultures, but they all share one thing in common — the experience of having had their lives forever changed by chordoma.

Chordoma Connections offers a space where individuals affected by chordoma can turn to ask questions, share experiences, and get support from others who understand and have walked their same path. From insights on pain management, systemic therapy, side effects of treatment, or how to cope with survivorship, it's all there.

community.chordoma.org



650+
members

36
states in the U.S.

50
countries

300+
discussion threads

8
private groups

Uncommon Awards

Our Uncommon Awards recognize members of our community who exemplify the qualities necessary for success in the fight against chordoma.



Uncommon Action

Chris Jones

For his consistent teaching, guidance, and support of fellow patients and caregivers as a Peer Guide, a moderator of the Chordoma Survivors group on Facebook, and Chair of our Community Advisory Board.

“While my daughter’s disease ultimately ran its course, it didn’t need to – or at least not so soon – had it been properly diagnosed initially. I remain committed to the Chordoma Foundation and to helping them improve the lives of people impacted by chordoma, and provide patients and families with support in navigating this challenging journey.”



Uncommon Champion

Steven Mandel

For his extraordinary fundraising efforts through #TeamChordoma, which have raised nearly \$300,000 for the Foundation since 2014.

“Five years ago, when we started our half marathon fundraiser, it was just me and four friends. Today, we have more than 60 runners on #TeamChordoma. This event has become a staple at the Foundation, and I hope it serves as a grassroots model for many others in the community to kick-start their own #TeamChordoma fundraiser.”



Uncommon Champions

Team Fat Boys
Slim Sisters

For raising more than \$300,000 in honor of one of their own – chordoma survivor Todd Balf – to support cutting edge chordoma research in the lab of Cigall Kadoch at Dana-Farber Cancer Institute.

“Although I joked that having chordoma was proof of what I’d always maintained – that I was one in a million – the recovery was harder than I could have ever imagined. In addition to my family, one of the things that most motivated me in my recovery was to try to get back on the bicycle and ride again. Being on the bike, surrounded by the whole team, felt like the best normal ever. To have that kind of support was incredible, and something I’ll never forget.”

— Todd Balf,
chordoma survivor



Uncommon Collaboration

Ulm and Heidelberg
Chordoma
Research Teams

For working together to make great strides in chordoma research, including the discovery of a new therapeutic target, and, most recently, launching a clinical trial for chordoma patients.

“I am truly amazed by the collaborative spirit that the Foundation fosters in this field. Our team in Heidelberg is happy to be a part of it, and we look forward to continuing to make progress with our friends and colleagues at Ulm University.”

— Stefan Fröhling, Heidelberg
University Chordoma
Research Team



Uncommon Insight

Opher Gileadi,
Oxford University

For solving the crystal structure of brachyury, a vital step both toward understanding how brachyury drives chordoma and developing new therapies that target brachyury.

“Normally, this type of discovery would take months to reach publication, and then maybe years to be exploited. But with the help of the Foundation, we immediately formed a network of collaborating experts in chemistry, cell biology, crystallography, and disease biology, and we’re already moving forward to discover inhibitors of brachyury.”



Uncommon Perseverance

Joel Beckman

For his extraordinary contributions to the Foundation as a leader on the Board of Directors, Chair of the Development Committee, mentor and guide to fellow patients, successful fundraiser, and transformational donor.

“Chordoma has been a major battle for me and I’m incredibly happy to be here nine years after being diagnosed, during which time I have seen both of my sons married and my two grandchildren born. The Chordoma Foundation is saving lives and improving the lives of so many individuals confronting the disease. I’m truly amazed when I look at the progress the Foundation has helped to achieve in such a short time. And I’m so proud that I’m able to play a role in such an extraordinary organization.”

Thank you for your support

We are filled with gratitude for all you have done for chordoma patients and families over the past year. You gave your time, your money and your heart to this uncommon community, creating a great and lasting impact.



\$2.5M
contributed



18
community
fundraising events



1,870+
donors around
the world



37
online fundraising
campaigns

2018 Online Fundraising Champions

Gail Baker
Since 2018

Daniele Bananto
Since 2018

Matt Berger
Since 2018

Sharon Berlan
Since 2008

Dusty Bowenkamp
Since 2013

**Sue & Gene
Brenneman**
Since 2018

Seth Butler
Hike to Find A Cure For
Chordoma
Since 2018

**Christopher &
Stephen Capuzzi**
Since 2017

Nicholas Carr
Since 2018

David Drewry
Since 2018

Christina Ciocca Eller
The Henry G. Ciocca
Champion Fund
Since 2018

Stephanie Finley
Since 2018

Aimee Howell
#TeamStephen
Since 2018

Norma Jones
Since 2009

Vanessa King
Christmas Surprise for
Best Friend
Since 2018

Maureen LaForge
Since 2018

Samuel Leinoff
Since 2018

Rachel Lichte
30-for-30 Birthday
Challenge!
Since 2017

John Mainey
Since 2018

Steven Mandel
Since 2012

Lamia Mandy
Since 2018

Chris McCormley
Since 2018

Facebook Milestones
Since 2015

Ross and Ally Parks
Since 2017

Michael Potempa
Since 2013

Justin Remsen
Since 2018

Colleen Riccomini
Since 2018
Collecting donation
donations in memory of
her son

Bart Salant
Since 2018

Jaclyn Salant
Since 2018

Matt Sauerhoff
Since 2016

Dan Sauerhoff
Since 2018

Maureen Schroer
Since 2013

Robin Seitz
Since 2018

Emily Sommer
Since 2018

Kristin Stahl
The Marty Stahl Champion
Fund
Since 2018

Julie and Jeremy Trask
Since 2018

**Jaclyn Weissman &
Zach Grauman**
Since 2018

2018 Community Fundraising Events

**10th Annual St. Paul's
Michael Galluccio
Memorial Golf Outing**
Mark Galluccio and Zach
Feigman
Glen Cove, NY

**Blockbuster Bowling
Benefit**
Jeff Schilling
Kansas City, MO

**Brooklyn Half
Marathon**
Steven Mandel
London, UK

**Dawson's Circle of
Hope 5K**
Susan Creager
Geneva, FL

Dress Down Day
Lynette Nelson
Clifton, NJ

**Hike To Find A Cure
For Chordoma**
Seth Butler
Pownal, ME

**Infinity Fitness Day
After Thanksgiving
Workout**
April Wallace
Scottsdale, AZ

**Make Mr. Whelan
Look Silly**
Marciszewski Family
Baltimore City, MD

No Shave November
Nicholas Carr
Williamstown, NJ

**Olde Fashioned
Colonial Christmas
Home Tour**
Gene and Sue Brenneman
Kinzers, PA

**Operation Support &
Recover Ride**
Rik Karena
Queensland, AU

Pan-Mass Challenge
Todd Balf
Beverly, MA

**Pub Crawl for
Chordoma**
Colleen Riccomini
West Sayville, NY

**Riccomini Dodgeball
Tournament**
Colleen Riccomini
West Sayville, NY

**Skyline's 10th Annual
Charitable Gold
Classic**
The Skyline Charitable
Foundation
Long Island City, NY

**Spirit Night Jess's
Battle Against
Chordoma**
Jessica McGeever
West Mifflin, PA

**Swing For a Cure in
Honor of Hank Ciocca**
Ciocca Family
New York, NY

Swing Fore the Cure
Jeff Schilling and Maggie
Bates
Kansas City, MO

Accelerators Circle



Formed in 2018, the Accelerators Circle recognizes donors who make a gift of \$25,000 or more over a 3-year period to speed the pace of progress.

We are deeply grateful to the following individuals, families, and organizations who joined the Accelerators Circle in 2018:



Megan Stewart
Wife of chordoma patient Joe Stewart

The Chordoma Foundation was a voice in the wilderness for our family after my husband Joe was diagnosed.

We benefited so much from their information and encouragement – especially their help finding experienced doctors, which made all the difference in Joe's outcome and recovery. Getting that help at such a frightening time gave us hope, and hope and gratefulness are powerful motivators. That's why we joined the Accelerator's Circle. Because we know that a strong Chordoma Foundation means a stronger and healthier chordoma community. And that's an investment worth making."

Leader

\$500,000+

Anonymous (3)
 The Beckman Family Foundation

Benefactor

\$250,000 – \$499,999

Mark Foundation for Cancer Research

Patron

\$100,000 – \$249,999

Anonymous
 Richard and Susan Friedman
 Esta Stecher

Supporter

\$50,000 – \$99,999

Anonymous
 Joe and Christine McGovern
 Grace and Andrew Schoelkopf

Friend

\$25,000 – \$49,999

Anonymous (2)
 The Alpert Family Foundation
 The Cedar Street Foundation
 Celgene
 Dawson's Circle of Hope
 The Drew Barker-Wright Charity
 The Orokawa Foundation Inc.
 Michael and Noreen Potempa
 Megan and Joe Stewart
 Helen Van Sickle Fund
 Richard and Karen Westin

2018 Donors

We're grateful to the following donors who made our work possible in 2018.

\$250K+

Anonymous
 The Beckman Family Foundation
 Mark Foundation for Cancer Research

\$100K–249,999K

Anonymous (3)
 Richard and Susan Friedman
 Esta Stecher

\$25K–99,999K

Anonymous (4)
 The Alpert Family Foundation
 The Drew Barker-Wright Charity
 The Cedar Street Foundation
 Celgene
 Dawson's Circle of Hope
 Joe and Christine McGovern
 The Orokawa Foundation Inc.
 Michael and Noreen Potempa
 Grace and Andrew Schoelkopf
 Megan and Joe Stewart
 Helen Van Sickle Fund
 Richard and Karen Westin

\$10K–24,999K

Anonymous (2)
 Bavarian Nordic A/S
 John and Myrna Blume
 Boehringer Ingelheim
 Sherry Brown-Marfuggi
 Chordoma Foundation Europe
 Charles and Marna Davis Foundation
 Hester M. Digges Trust U/A
 Illinois Tool Works

Goldman Sachs Gives: The Barry and Rochelle Kaplan Fund
 The Robert and Sydney Kindler Foundation
 Heather Lee and Steve Straus
 Steven Mandel
 Massachusetts General Hospital Cancer Center
 SBES Client Consolidated Charitable Foundation, Inc
 Chandranath and Sharmila Sen

\$5K–9,999K

Anonymous
 Affiliated Foot Surgeons
 Arthur and Karen Pappas
 Norman R. and Margareta E. Augustine Bequest Fund
 Robert and Frances Bridenbecker
 Bright Funds Foundation
 Burroughs Wellcome Fund
 Richard and Ann Citarella
 Richard and Janet Fell
 G1 Therapeutics, Inc.
 Lea Glazar
 Global Genes - Allies in Rare Disease
 Gary and Andrea Gold
 Hughes Hubbard & Reed
 Brooke and Carolyn Laney
 Irene Lowe
 Scott Miller
 Stuart and Susan Porter
 Drew Regitz
 Renaissance Charitable Foundation, Inc.
 Jeff and Erin Schilling
 Mark and Laurie Slepian
 David and Peggy Tanner

Teachers Federal Credit Union
 Andrew Thomson
 UPMC Center for Skull Base Surgery

\$1K–4,999K

Anonymous (5)
 AmazonSmile Foundation
 American Century Investments
 Ameriprise Financial
 Yoram Amiga
 Victoria Anderson
 The Norman and Mary Anderton Charitable Fund
 Shelba Barnes
 Jaynee and Eric Beckman Family Fund
 Benevity Community Impact Fund
 Berg Family Fund
 Stanley, Marion, Paul and Edward Bergman Family Foundation
 Bespoke Partners, Inc.
 David Biondi
 Steve and Erin Bishop
 Baltimore County Employees Federal Credit Union Board of Directors
 Robert and Teresa Boccanfuso
 Gene and Sue Brenneman
 John and Renee Butler
 Douglas and Jen Call
 Ann Marie Castenfelt
 John Cochrane
 Kenny and Mona Cohen
 Samuel Cohen
 Collins Electric Co.
 William and Sharon Connelly
 Robert and Maureen Cooper
 Frank Courtney

Christopher Cracchiolo
Beth Cullinan
Virginia Daly
Thomas and Linda DeLaney
Denham Capital Management LP
William Dorland and Sarah Penniston-Dorland
David and Roberta Drewry
Patrik and Catherine Engellau
Feldmann Family Fund
Fidelity Brokerage Services LLC
Stephen and Carol Finley
The Karen and Edward Friedman Family Fund
Adam Frieman
Scott and Cindy Frodle
GE Foundation
Lloyd and Mary Gran
Bobbi Gruwell
Dave Hagar
Janet Halfar
Timothy and Susan Hall
Harcros Chemicals Inc.
Michael Hatfield
Mohsen Heshmati
Andrew Hirsch
Geoffrey Hobart
Sarah Hoit
Judy Johnson
Robert and Korrel Kanoy
Carol Kary
Ken and Cathy Katz Foundation
Jeffrey Kaufman
The Judy Kirkland and James Kenneth Wilson Family Foundation in Memory of George and Muriel Kirkland
Michael and Loida Knox
KPMG
Ingemar and Diane Lanevi
Ira and Lillian Langsan Fund
Kenneth and Frankie Lee
Robert and Kit Lennon
Irene Loeb
Lucey Charitable Foundation
Thomas and Holly Lund
Leslie and Rhoda Mandel

Maryland Proton Treatment Center
Cynthia McAfee
Linda Mirels
Alexander Nadaner
Bruce and Lynette Nelson
Victor and Denise Nesi
Northwestern University Feinberg School of Medicine
Daniel and Jane Och Charitable Trust
Michael and Gillian Parrish
James and Kathleen Patton
Polsinelli
Michael and Jo-Ann Rapaport
Ray Underhill Foundation, Inc.
Maria Pia Ruffilli
Gary and Karen Sain
Robert and Inger Schoelkopf
Madhav Shenoy
Sherwood Forest Boys & Girls Summer Camp
The Skyline Charitable Foundation Inc.
Gregg Slepian
David Smyth and Julie Song
Josh Sommer and Rachel Lichte
Young-dahl and Juliet Kim Song
Paula Song and Stephen Gazda
Judith Sprague
Steve and Kimberli Sterling
Robinson Strauss and Sharon Berlan
The Steve Sullivan and Erin McKean Fund
Barry Swidler
John and Heather Therien
Claudio and Mirna Umaschi
University of Florida Proton Therapy Institute
University of Pennsylvania Health System
University of California Los Angeles Health
Nicholas Vantzelfde and Lauren Erb
Veritas Foundation Fund
Joe and Allison Villinski
Terry and Colleen Wilkins

\$500-999

Anonymous (5)
Randy and Patricia Akers
American Express Foundation
Michael Aresco
Thomas and Nicole Armentrout
Kurtis Bachman
Paul and Karen Baer
Walter Bananto
Scott Barber and Jennifer Schwartz
Warren Barrett
Scott Bartholow
David and Laura Barton
Michele Barton
Karen Barwick
Jonathan and Margaret Bates
Mindy Berry
Sharon Berry
Dusty Bowenkamp
Alicia Brown
Nancy Buckman
Carol Bunt
Kelly Campbell
Peter Casanave and Naomi Nemtzow
Peter and Sharon Catto
Yen-Lin Chen
Michael Ciocca
Rita Ciocca
Cohen Feeley Altermose & Rambo, P.C.
Karen Cox
Daniel Dempsey and Barbara Seneca
Kate Egan
Marjory Eller
Enterprise Bank & Trust
Lynn Etheredge Fund
Oliver Evans
Peter Fang
Russell and Virginia Flaum
Jeannine Fox
Gregory and Diane Fuchs
Cink Fundraising
Joan Funk

Andrew Gaasch
John Gally
William and Beverly Griffin
Arthur Hagar
Celina Hecht
Jeff and Diana Hewitt
Infinity Fitness AZ, LLC
Julia Jernigan
The Suzanne Nora Johnson & David G Johnson Foundation
Jeremy Johnson
Mark Konnick
Adalbert Koth
Jerald and Albertina Kuhn
Tzuchin Lee
Kara Leibel
Levy Holm Pellegrino & Drath LLP
Kenny Li
Richard and Susan Lichte
Andrew Little
MarksNelson LLC
Dolores Martinez
Jordan Marye
George Masnick and Reisa Kahn
Brea and Chris McCormley
Robert and Polly McCrea
Family Fund of the Minneapolis Foundation
Merck Foundation
Francis J. and Mary A. Meyer Charitable Fund
Emery Miller
Monsanto Matching Gift Program
Victoria Moran
Thomas Moss and Janie Deal
Arlynn Muckey
Christine Newfrock
Nancy Prendergast and Augusto Pichard
Red Top Foundation
Alicia Reid
J. Robert and Nora Reinhardt
Scott Renner
Dietmar and Dorothy Riccomini
James Rittinger
Richard and Stacy Rosenthal
Adriane Rothstein and Mark Billy

Hans and Mary Lou Saeby
Sayville Union Free School District
The Shepard Broad Foundation, Inc.
Theodore and Katherine Shults
Scott Silverthorne
Gary Simon
Scott Smiley
Bruce and Maureen Smith
Matthew and Laura Soule
Mike Staveris
Strategic Enhancement Group Inc
Robert Switzer

Takeda Pharmaceuticals NA, Inc. Employee Giving Program
Jeffrey and Janis Tillman
Andreas Timm
Jeremy and Julie Trask
University of New England
Patty Vaughn
David and Toni Walton
Scott and Joanne Winters
Susan Woodman

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.



LEFT TO RIGHT
Foundation supporters Jeff Collins, Terri Mainey, Rose Mills, and John Mainey at our 2018 Board Retreat and appreciation dinner.

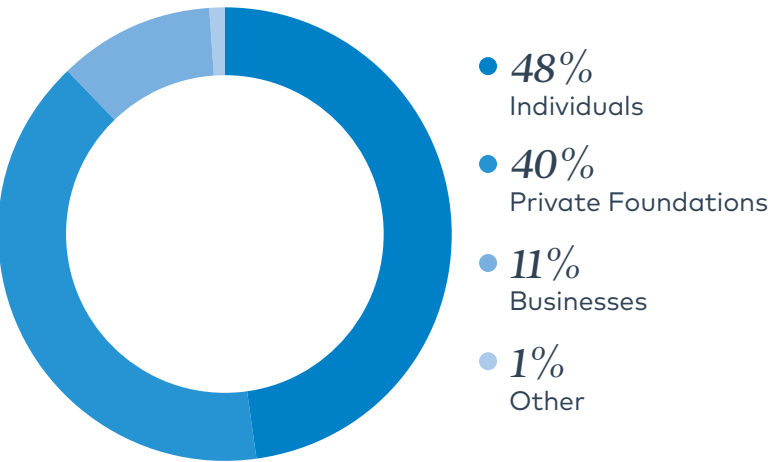
Financials

Audited statement of activities for the year ended December 31, 2018

	Total
Revenue and support	
Contributions	\$ 2,314,783
In-kind contributions	166,405
Program service revenue	11,150
Interest	4,180
Total revenue and support	\$ 2,496,518
Expenses	
Program services	\$ 1,666,722
Management and general	306,030
Fundraising	439,268
Total expenses	\$ 2,412,020
Change in net assets	\$ 51,711
Net assets, beginning of year	3,434,984
Net assets, end of year	\$ 3,486,695

A copy of our 2018 IRS Form 990 and audited financial statements are available at chordoma.org/financials

Sources of funding




Looking ahead

Thanks to your investment and support, we're on the cusp of some really big steps forward, particularly in the development of new therapies.


A growing pipeline of better chordoma treatments is on the way, and those facing the disease today now have a deep trove of trusted resources and support systems to aid in the journey.

But we won't rest until everyone affected by chordoma is able to overcome the disease and maintain their quality of life. Here's our plan of attack for 2019:

2019 Priorities



More support for patients and families, including new educational content, new translations to reach more people worldwide, and more in-depth support from our Patient Navigation Service.



Greater progress in clinical trials, including increasing patient participation, completing enrollment milestones for ongoing CF-supported trials, and launching at least one new trial.



Expanded investment in brachyury drug discovery, including follow-on funding for current collaborators whose research has proven successful, and new grants for pre-vetted, high-impact proposals.



New investments in cutting-edge science aimed at attacking chordoma through epigenetics and immunotherapies.

We look forward to working with you to make this progress possible!

Our team



LEFT
Members of our Board of Directors, staff, and special guests at our 2018 Board Retreat.



ABOVE
Josh Sommer and Andy Schoelkopf at our 2018 Board Retreat.

Our staff

- Josh Sommer**
Executive Director
- Daniel Baroff**
Development Manager
- Patty Cogswell**
Manager of Research
- Larry Gottschalk**
Operations Coordinator
- Chase Hinnant**
Patient Services Coordinator
- Joan Levy, PhD**
Director of Research
- Shannon Lozinsky, MSW**
Director of Patient Services
- 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
- David Drewry, PhD**
- Steven Mandel**
- Shreyas Patel, MD**
- David Sandak**
- Christy Shaffer, PhD**
- Kerry Shad, JD***
- Josh Sommer**
- Paula Song, PhD**

*Through November 2018

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****
- Michael O'Brien, MSW, LICSW**

DEVELOPMENT

- Joel Beckman**
Chair
- Anne Noel Dawson**
- Steven Mandel**
- Andrew Schoelkopf**
- Joe Villinski**



LEFT
Our staff outside the Broad Institute in Cambridge, MA. Not pictured: Larry Gottschalk and Jennifer Roeder.

NOMINATING

- Joel Beckman**
Chair
- Edward Les, MD**
- Andrew Schoelkopf**
- Christy Shaffer, PhD**
- Andrew Schoelkopf**
Chair
- Joel Beckman**
- Ingemar Lanevi**
- David Sandak**
- 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

- Shreyas Patel, MD**
Chair
- 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**
- Chandra Sen, MD**
- Silvia Stacchiotti, MD**
- Katie Thornton, MD**
- Josh Yamada, MD**

Community Advisory Board

- Chris Jones**
Chair
- Edward Les, MD**
Medical Liaison
- Sue Brenneman**
- Susan Garbett**
- Steven Golick**
- Caroline Kooy**
- Maureen LaForge**
- Heather Lee, PhD**
- Steven Mandel**
- Joe McGovern**
- Jeff Schilling**
- Tim Zellers**

*Through November 2018
**Through June 2018

Susan Garbett

chordoma survivor



I have been so impressed with what the Chordoma Foundation and the chordoma community have accomplished together. It gives me great hope that the years ahead will be even more promising.”



CHORDOMA
FOUNDATION

PO Box 2127 Durham, NC 27702
(919) 809-6779 • chordoma.org

