

Going ALL IN



Chordoma Foundation
2019 Annual Report

Improving the lives of those affected by chordoma.

Leading the search for a cure.



ABOVE: Team Chordoma, led by captain Steven Mandel, celebrates their completion of the Brooklyn Half Marathon in May of 2019.

ON THE COVER: Chordoma patient Halle Kraczywk with her mom, Carolyn, at the National Cancer Institute for the first pediatric chordoma clinic.

Letter from the Executive Director



Dear Friends and Partners,

In humanity's long fight against cancer, many have given selflessly to change the odds for those who will come next. But seldom have opportunities arisen that can change the outlook for those currently fighting — for science to outpace the progression of an individual's disease.

So what do you do when such an opportunity emerges?

You seize the moment. You swing for the fences. **You go all in.**

Now is that moment for chordoma.

This annual report details how a confluence of recent research advances have cleared a path to identify existing treatments that could help chordoma patients in the near-term, and, incredibly, created line of sight to the first treatments that strike at the Achilles' heel of chordoma, brachyury (see pages 10–11).

It also tells how many in our community have rallied behind our recently-launched

\$16M ALL IN campaign to bring these unprecedented research opportunities to fruition, while at the same time helping patients and families confront chordoma with confidence and get the best care possible.

I am deeply grateful to everyone who has gone all in with us to create a brighter future for those living with chordoma. Your support made it possible to invest a record \$2.7M in research in 2019 and allowed us to serve more patients in more parts of the world than ever before.

Together, we are going to make chordoma a success story in the fight against cancer. Thank you for being a part of this mission. And thank you for standing with us to bring closer the day when everyone affected by chordoma can overcome their disease and regain the life they love.

Onward!

Josh

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

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ALL IN: A campaign to improve lives and accelerate cures

A confluence of recent advances has created unprecedented opportunities to deliver the first effective treatments to chordoma patients alive today.

Chordoma's Achilles' heel discovered

Scientific breakthroughs have cleared the way for drugs against brachyury, chordoma's greatest vulnerability. If ever there was a shot at potentially curative treatments for a cancer, this is it.

Better treatments may already exist

Researchers have found existing drugs that show efficacy against chordoma in the lab. Bringing them into clinical trials could quickly provide better treatment options.

Ability to make rapid research progress

After recruiting top researchers and building a research-enabling infrastructure, the barriers that typically stifle progress for rare cancers have been overcome.

A united chordoma community

More than 85% of U.S. patients and many more worldwide are now connected through the Foundation, creating opportunities to improve care and learn faster.



Joel S. Beckman

Chordoma Foundation Board Member; Chair, ALL IN campaign

“So much progress has been made in the ten years since I was diagnosed and I’m extremely hopeful about the future. It’s a time of significant momentum for our community, and the ALL IN campaign is harnessing that momentum to improve lives and find a cure.”

For the first time, there is a credible path to new and better treatments for chordoma in our lifetime.

With adequate investment, there is a real chance of enabling individuals facing chordoma today to overcome the disease and maintain their quality of life.

This is a profoundly significant opportunity for all whose lives have been disrupted by chordoma, and one that does not come along often in the world of oncology. It’s an opportunity we know we must seize, which is why in 2019 we publicly launched the ALL IN campaign.

Learn more and follow our progress at chordoma.org/allin.

The campaign seeks to advance five critical areas of opportunity over the next five years:



Brachyury drug discovery

Develop drugs that strike at the Achilles' heel of chordoma



Immunotherapy

Apply powerful new technologies to harness the immune system to fight chordoma



Drug repurposing

Systematically identify existing drugs that can help chordoma patients in the near term



Improving the patient experience

Help patients and their families confidently take on health challenges and get the best care possible

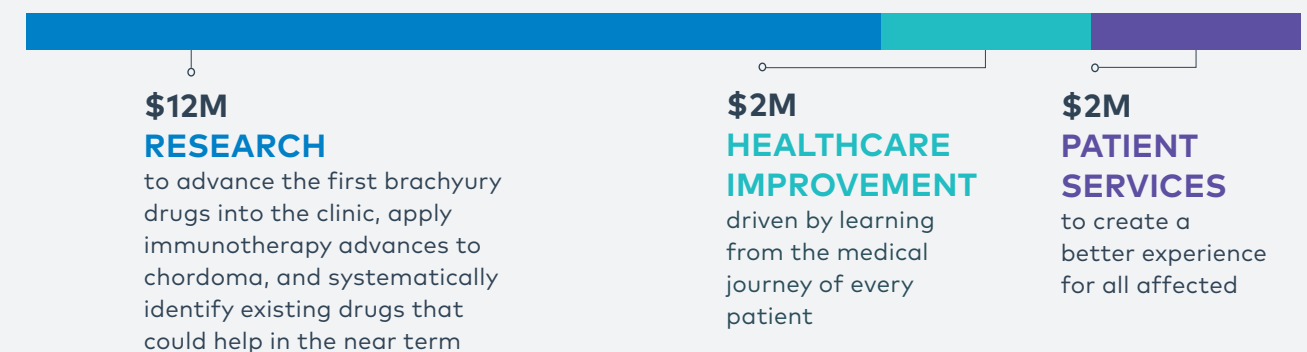


Learning from each patient

Understand which treatments are working and which aren't to continually improve patient care

Realizing these opportunities will require a direct investment of at least \$16M.

These funds will help leverage even greater resources from companies, foundations, and government funding agencies.



Research progress

In 2019, we invested a record \$2.7M in research — more than twice the preceding year — resulting in measurable progress along every step of the treatment development process.

Resource Development	Target Discovery	Therapeutic Discovery	Preclinical Research	Clinical Research
<div><div>29 tumors saved for research through our Biobank</div><div>3 new cell lines validated, including 2 pediatric</div><div>2 new mouse models validated, including 1 pediatric</div></div>	<div><div>2 projects funded to discover new therapeutic targets</div><div>2 projects made possible with tumor tissue provided by our Biobank</div></div>	<div><div>9 potential drug binding sites discovered on the brachyury protein by CF grantees</div><div>3 lab consortium funded to develop open source chemical inhibitors of brachyury that attack newly-discovered binding sites</div></div>	<div><div>16 drugs or combinations tested in mouse models through our Drug Screening Program</div></div>	<div><div>6 clinical trials supported</div><div><div>◦ 1 completed enrollment (BN-Brachyury vaccine + radiation)</div><div>◦ 1 new trial launched (pemetrexed)</div><div>◦ 1 trial expanded to a second site (afatinib)</div></div></div>

Currently funded researchers

Our grantees are pursuing top research priorities including discovering drugs against brachyury, uncovering new therapeutic targets, identifying ways to harness the immune system to fight chordoma, and evaluating promising new treatments in clinical trials.

<div><div>Craig Crews, PhD</div><div>Yale University</div></div> <div><div>David Drewry, PhD</div><div>University of North Carolina</div></div> <div><div>Adrienne Flanagan, MD, PhD</div><div>University College London</div></div> <div><div>Hans Gelderblom, MD, PhD</div><div>Leiden University Medical Center</div></div> <div><div>Opher Gileadi, PhD</div><div>Oxford University</div></div> <div><div>Cigall Kadoch, PhD</div><div>Dana-Farber Cancer Institute</div></div>	<div><div>Michael Kelley, MD</div><div>Duke University</div></div> <div><div>Santosh Kesari, MD, PhD</div><div>John Wayne Cancer Institute</div></div> <div><div>Charles Lin, PhD</div><div>Baylor College of Medicine</div></div> <div><div>Michael Lim, MD</div><div>Johns Hopkins</div></div> <div><div>Dan Nomura, PhD*</div><div>UC Berkeley</div></div>	<div><div>Slim Sassi, PhD</div><div>Massachusetts General Hospital</div></div> <div><div>Stuart Schreiber, PhD</div><div>Broad Institute of Harvard and MIT</div></div> <div><div>Paul Workman, PhD</div><div>Institute for Cancer Research</div></div> <div><div>Yoshiya (Josh) Yamada, MD</div><div>Memorial Sloan Kettering Cancer Center</div></div> <div><div>Stephen Yip, MD, PhD*</div><div>BC Cancer Agency</div></div> <div><div>Gelareh Zadeh, MD, PhD*</div><div>University of Toronto</div></div>
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*Funded through partner organization

Current research priorities

Propelled by generous contributions to the ALL IN campaign, we focused on driving progress in three key areas, as described in the following pages.



Drug repurposing



Immunotherapy



Brachyury drug discovery

Drug repurposing

The quickest way to help patients facing chordoma today is to find an effective treatment that already exists.

There are more than 5,000 drugs on the market or under investigation worldwide which could be “repurposed” for chordoma and made available for testing immediately. To enable patients to benefit from these existing drugs as quickly as possible, we are investing in a comprehensive Drug Repurposing Initiative consisting of three stages:



1. Systematically search for vulnerabilities in chordoma that can be targeted with existing drugs

Complementing prior investments to identify drug repurposing candidates, in 2019, we awarded a \$300,000 grant to Dr. Stuart Schreiber and colleagues at the Broad Institute of Harvard and MIT to screen more than 5,000 drugs for activity against chordoma cells. Those that show promising activity in cells will be rapidly tested in mouse models through our Drug Screening Program.



2. Test promising drugs in chordoma mouse models

By the end of 2019, we completed testing of 42 drugs and combinations through our Drug Screening Program, yielding results that have provided rationale for three ongoing clinical trials and two more planned trials. Going into 2020, a dozen more drugs were in the queue for testing.



3. Support well-justified clinical trials to prove the effectiveness of repurposed drugs

Through our Clinical Trials Program we continued facilitating patient participation in five ongoing trials in 2019, and provided a \$140,000 grant to the John Wayne Cancer Institute in Santa Monica, CA to enable the launch of a new trial testing a lung cancer drug called pemetrexed to treat chordoma.

Tanaz Sharifnia, PhD

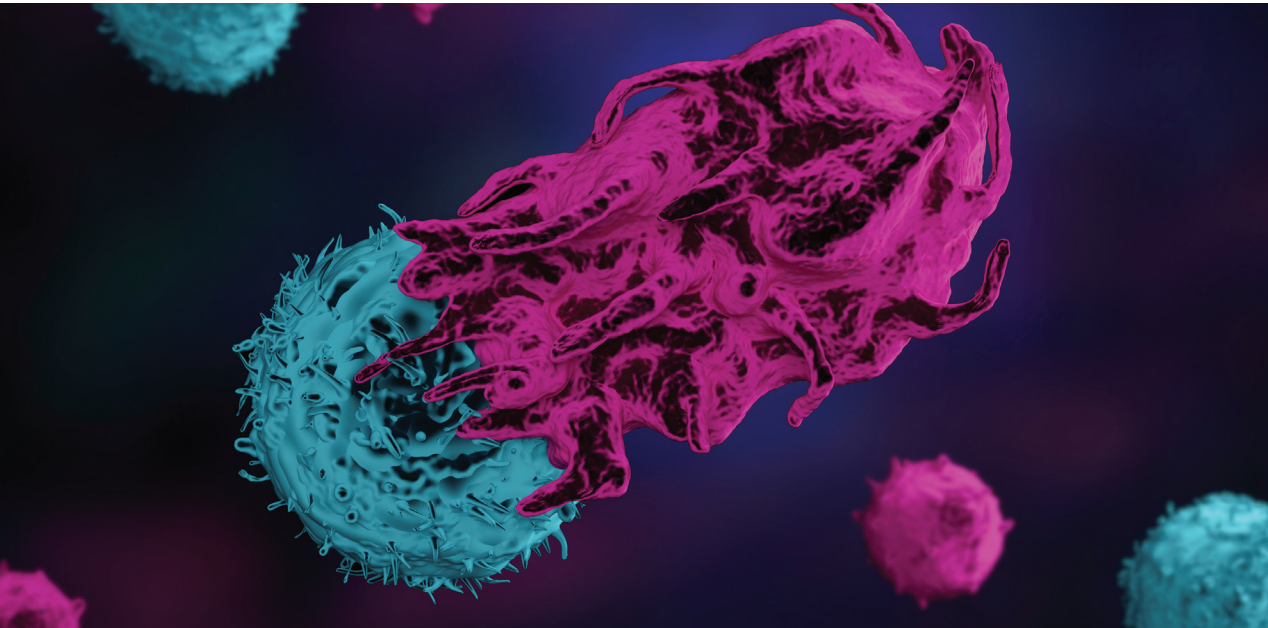
Chordoma Team Lead,
Broad Institute of Harvard
and MIT



“Systematically testing existing drugs offers a promising path to finding viable treatment options for chordoma in the near term. We expect it will uncover several new drug candidates in 2020 which can be rapidly tested in chordoma mouse models through the Foundation’s Drug Screening Program.”

Immunotherapy

There is a growing body of evidence that the immune system has an important role to play in the treatment of cancer. Promising anecdotal responses in chordoma patients treated with various immunotherapies underscore the need for more research in this area.



ABOVE
Immune cell attacking a cancer cell.



In 2019, we partnered with the Cancer Research Institute (CRI) — the pioneer and leader in nonprofit funding of cancer immunotherapy research — to catalyze research needed to bring immunotherapy advances to chordoma. In joining forces with CRI we aim to put chordoma on the radar of the immunotherapy research community and attract leading cancer immunotherapy researchers to turn attention to chordoma.

Together, we will identify and jointly fund high impact, peer-reviewed research projects with grants of up to \$200,000 through CRI’s Clinic and Laboratory Integration Program (CLIP). We received 19 concept submissions in 2019 and will select grants for funding in 2020.

Jill O’Donnell-Tormey, PhD

Chief Executive Officer and
Director of Scientific Affairs,
Cancer Research Institute



Immunotherapy may ultimately be an effective treatment for all types of cancer, but rare cancers are often under-prioritized, despite their potential to teach us important fundamental lessons about how tumors interact with the immune system.

Our partnership with the Chordoma Foundation is an opportunity to fund research capable of bringing the benefits of immunotherapy to patients with this ultra-rare cancer, and informing cancer immunotherapy more broadly.”

Brachyury drug discovery

Breakthroughs by our grantees in 2019 created line of sight to the first drugs against brachyury — the key driver and greatest vulnerability of chordoma.

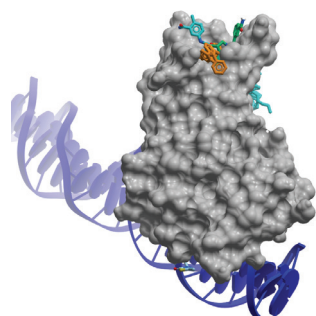
Historically, brachyury and the whole family of proteins to which it belongs, known as transcription factors, have been considered “undruggable” because they lack obvious pockets to which a drug can bind.

But in light of the undeniable importance of brachyury to chordoma and other cancers, in 2018, we partnered with the Mark Foundation for Cancer Research to invest in three pilot projects employing innovative technologies to identify ways to target brachyury.



Given the challenge at hand, these were all high-risk projects with long odds of success.

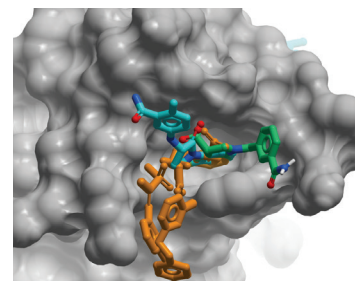
Yet, to our delight, over the course of 2019, **all three pilot projects succeeded in identifying spots on the brachyury protein where chemical compounds could bind** — each representing a possible point of attack against which a drug could be developed.



LEFT

A computer model of chemical compounds (multicolored rings) that were found to bind to the brachyury protein (the gray mass) in multiple spots as it interacts with DNA (in blue double helix)

Brachyury is a protein encoded by the TBXT gene — a gene that everyone has in every cell of their body. The brachyury protein is vitally important during embryonic development, but is normally switched off after birth. However, it gets turned back on in a variety of tumors including breast, lung, colon, and prostate cancers, where it contributes to metastasis and resistance to therapy. In chordomas, brachyury doesn’t just contribute to bad behavior, it is the key driver of the disease — the thing that defines chordoma and that is most critical for their growth.



RIGHT

Close up of chemical compounds fitting within a small crevice in the brachyury protein (in gray)

Building on this year’s breakthroughs, the race is on to develop the first therapies against brachyury. **With adequate investment, these drugs could reach clinical trials in the next five years.**

Using recently-discovered brachyury-binding molecules as starting points, all three teams that we previously supported are poised to use cutting edge approaches to develop drugs that can block or degrade brachyury.

Thanks to the generosity of many in our community and the continued partnership of

the Mark Foundation for Cancer Research, by the end of 2019, we were able to advance the first of these follow-on projects with a **two-year, \$1.4M grant to a consortium of researchers at the UNC Eshelman School of Pharmacy, Oxford University, and the Institute of Cancer Research in London.**



David Drewry, PhD
University of North Carolina



Opher Gileadi, PhD
Oxford University



Paul Workman, PhD
Institute for Cancer Research, London

An open source approach

Rather than the conventional approach of filing patents and keeping data secret, this project will be carried out in the open for other scientists and companies to observe, contribute to, and build upon without delay.

A bigger impact

This project will also yield a set of open-source data and research tools that will bolster other brachyury drug discovery projects and enable research that could expand the understanding of brachyury’s role in many other diseases.

David Drewry, PhD

*Principal Investigator,
UNC Eshelman School of Pharmacy*

This open approach will speed up brachyury drug discovery considerably by allowing researchers to contribute their insights, ideas, and novel compounds to the project. Importantly, it also allows us to share new compounds freely and quickly with any lab interested in studying brachyury inhibition in any disease.”

Patient Services

As always, patients and families affected by chordoma can rely on the Chordoma Foundation to be a source of information, support, and guidance throughout their journey with the disease.

In 2019, we served more people in more ways than ever before:

535

patient navigation cases served

940

members in our online community, Chordoma Connections

2,520

educational materials provided

4

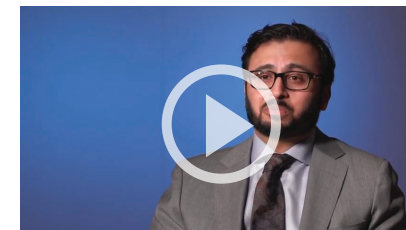
Expert Answers videos released

Newly diagnosed sacral patient

“Your website and Patient Navigator were the best thing for me when I found out about my chordoma. It was exactly what I needed to feel confident in my course of treatment. I also found my surgeon through your [Doctor] Directory and thought all of the resources and videos on your website were so helpful. I am very grateful the Chordoma Foundation is there.”

New educational resources

In 2019, we produced a trove of new educational materials to help arm patients and families with the information and knowledge they need to confidently take on chordoma and make well-informed treatment decisions.

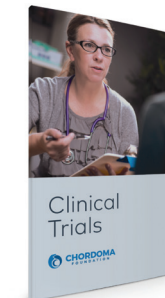


Expert Answers Videos

Our Expert Answers Series provides straightforward answers to some of the chordoma community's most commonly asked questions. New videos added in 2019 include:

- What should chordoma patients know about surgical options?
- How can caregivers and loved ones help?
- What is rehabilitation and how can it help chordoma patients?
- What support is available for mental and emotional health needs?

chordoma.org/expert-answers

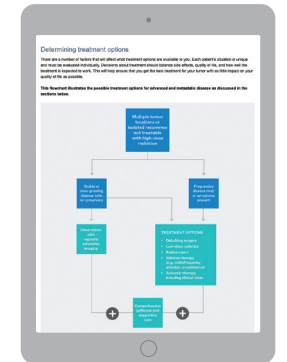


Treatment Information Series

This new series of pamphlets offers easy-to-understand information about the different treatments that may be involved in an individual's chordoma journey. The first two pamphlets cover:

- Clinical Trials
- Systemic Therapy

chordoma.org/educational-resources



Website educational content

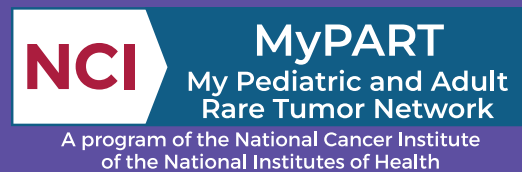
We significantly expanded the educational content on our website and reorganized it so that individuals at any step in their journey with chordoma have easy access to the information they need. New content includes treatment guidelines, questions to ask your care team, decision-making flow charts for managing a recurrence, an interactive glossary, and stories from fellow chordoma patients and families.

chordoma.org

First multidisciplinary clinic dedicated to pediatric chordoma

As part of our ongoing Pediatric Initiative, we were thrilled to partner with the My Pediatric and Adult Rare Tumor (MyPART) Network at the National Cancer Institute to organize the first-ever clinic for pediatric and young adult chordoma patients.

Held at the National Institutes of Health Clinical Center, the two-day clinic provided 12 patients and their families an opportunity to meet with some of the world's most experienced chordoma doctors and get a full, multidisciplinary work-up and treatment recommendations. In addition to offering medical insights and guidance, the clinic also gave the families a chance to foster close personal bonds with one another and to enroll in a natural history study conducted by the National Cancer Institute that seeks to learn from their experience.



Carolyn Laney

mother of 8-year old chordoma patient

“We found the whole experience of the clinic to be positive. It was wonderful to sit with neuro-oncology, endocrine, and genetic specialists and be able to discuss [our daughter]. We had many questions answered and learned some things to ask our doctors back at home.”

2019 Chordoma Community Conference

More than 90 patients and caregivers from 21 states joined us in Chicago for the latest Chordoma Community Conference (CCC) hosted in partnership with Northwestern Medicine.

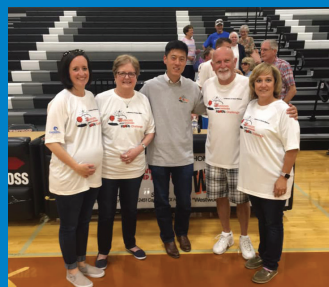


Held at the beautiful Shirley Ryan AbilityLab at Northwestern, participants heard from leading chordoma experts about the latest treatment approaches and had the opportunity to get their questions answered during a live Ask the Experts panel. As always, this year's conference also provided an invaluable opportunity to meet others who share similar experiences and connect with friends new and old.



Thanks to everyone who makes our progress possible

Your contributions provide a lifeline to those confronting chordoma and are fueling research advances that are changing the way chordoma is treated.



A groundswell of support for our newly launched ALL IN campaign propelled contributions past \$5M for the first time, enabling us to invest a record amount in research in 2019, and setting the stage for growing momentum in the coming years.

Sincere thanks to everyone standing with us during this exciting time and for being a part of this increasingly powerful movement!

1,733
donors

44
fundraisers

23
countries

\$5.1M
contributed

2019 Online fundraisers

Ellis Bell

Matt Berger

Sharon Berlan

Dusty Bowenkamp

**Sue and Gene
Brenneman**

**Christopher and
Stephen Capuzzi**

Nicholas Carr

Alex Chen

Kenny Li is Getting Old
(Which is Great)

Kate Church

Beth Cullinan
Team Beth

Christine Ciocca Eller
Team Ciocca

Jill Engstrom
Youth Entrepreneurs
Employees

William Farris

**Paul and Maria
Feldman**

Stephanie Finley

Catherine Fuentes

Jared Gentry

Jordan Giallanzo

Aimee Howell
TeamStephen

Maureen LaForge

Steven Mandel

Lorraine Martin
Beloved Bill

Colleen Riccomini
Collecting donations in
memory of her son

Maureen Schroer

Emily Sommer

**Steve Straus and
Heather Lee**

Julie and Jeremy Trask

Gennady Voldz

2019 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
Brooklyn, NY

**Chloe's 3rd Birthday
to Fight Chordoma**
The Finley Family
Philadelphia, PA

**Crushing Chordoma
With Coach**
Tim Borrue
Valencia, CA

Dress Down Day
Lynette Nelson
Clifton, NJ

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

One in a Million Benefit
Noreen and Mick Potempa
Libertyville, IL

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

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

Shop Night
Megan and Joe Stewart
Brookhaven, GA

**Skyline's 11th Annual
Charitable Gold
Classic**
The Skyline Charitable
Foundation
Long Island City, NY

**Warriors Against
Chordoma Golf
Challenge**
John Mainey
Austin, TX

**Warriors Against
Chordoma Hoops
Challenge**
John Mainey
Austin, TX

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

2019 Donors

We are deeply appreciative of the following individuals, families, and organizations who made our work possible in 2019.

\$500K+

The Beckman Family Foundation
The Marcus Foundation
The Mark Foundation for Cancer Research
Moira and Gary Sinise

\$100K–499,999K

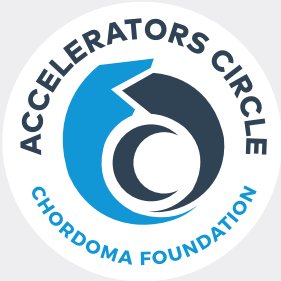
Hirsch Family Foundation
Stephanie and Herbert Neuman

\$25K–99,999K
Anonymous (2)

Stanley, Marion, Paul and Edward Bergman Family Foundation
The Cedar Street Foundation
Robert Cohen
Facebook
Illinois Tool Works, Inc.
George Joseph

Accelerators Circle

Special thanks to members of our Accelerators Circle whose gifts of \$25,000 or more over a 3-year period have sustained and accelerated our mission. Your consistent generosity has enabled us to make multi-year investments needed to achieve meaningful long-term impact.



\$1M+

Anonymous (2)
The Beckman Family Foundation
The Marcus Foundation

The Herbert and Nell Singer Foundation
Esta Stecher

\$25,000–\$99,999

Anonymous (6)
The Alpert Family Foundation
The Drew Barker-Wright Charity
Bavarian Nordic
The Becherer Family Charitable Giving Fund
Stanley, Marion, Paul and Edward Bergman Family Foundation
Boehringer Ingelheim
Shawn and Brook Byers
The Cedar Street Foundation
Celgene
Robert Cohen
Lorna and Stuart Cook

Charles and Marna Davis Foundation
Dawson's Circle of Hope
Hester M. Digges Trust U/A
Illinois Tool Works, Inc.
George Joseph
Christine and Joe McGovern
The Orokawa Foundation Inc.
Noreen and Mick Potempa
SBES Client Consolidated Charitable Foundation, Inc.
Erin and Jeff Schilling
Grace and Andrew Schoelkopf
Sharmila and Chandranath Sen
Megan and Joe Stewart
Heather Lee and Steve Straus
Helen Van Sickle Fund
Karen and Richard Westin

\$500,000–\$999,999

The Mark Foundation for Cancer Research
Moira and Gary Sinise

\$100,000–\$499,999

Anonymous
Roz and Adam Abram
Richard and Susan Friedman
Hirsch Family Foundation
Steven F. Kanter, MD
Stephanie and Herbert Neuman

Includes giving from 2017 through 2019. In accordance with Generally Accepted Accounting Principles, the full amount of multi-year gifts is recognized in the year they are pledged.

The Orokawa Foundation, Inc.
Erin and Jeff Schilling
The Herbert and Nell Singer Foundation
Karen and Richard Westin

\$10K–24,999K

Anonymous
The Drew Barker-Wright Charity
Bavarian Nordic
The Becherer Family Charitable Giving Fund
Jaynee and Eric Beckman Family Fund
Boehringer Ingelheim
Donna and Timothy Borrueel
Bob Brown
Charles and Marna Davis Foundation
DC Medical, LLC
Hester M. Digges Trust U/A
Alisa and Daniel Doctoroff
Paul and Maria Feldman Charitable Foundation
Janet and Richard Fell
Marion and John Johnson
Tina and Steven Price Charitable Foundation
Wendy and Neil Sandler
SBES Client Consolidated Charitable Foundation, Inc.
Eric Schwartz
Sharmila and Chandranath Sen
Christy and Joel Shaffer
Cody Smith
The Song Family Fund
The Stecher Family Fund
The Tres Chicas Foundation

\$5K–9,999K

Anonymous
Bill and Anne Bachrach Family Fund
Mark Balling
Benevity Causes
Bridenbecker Family Trust
Bright Funds
Brittany Whiffle Ball
League Charity

Anne Noel and Robert Alec Dawson
J. Gary Dean
G1 Therapeutics
The GE Foundation
Lea Glazar
Irene Lowe
Cathi Luski
McCanna Foundation
Julie and Scott Moller
Nuventra
Polsinelli
Noreen and Mick Potempa
Reinhardt Family Trust
Paul Savarino
Shinchon, LLC
Steve Straus and Heather Lee
Teachers Federal Credit Union
The Vinjar Family Foundation

\$1K–4,999K

Anonymous (6)
Patricia and Randy Akers
AmazonSmile Foundation
American Express Foundation
Ameriprise Financial

Yoram Amiga
AMP Charitable Fund
John Bane
Shelba Barnes
Berg Family Fund
David Biondi
Julia Bridgewater
Julie Brooks
Florence Cahill Charitable Trust
Elizabeth and William Case
David Cenaiko
Charity Golf International
Chordoma Foundation Europe
Cink Fundraising
Clayman Family Foundation
Mona and Kenny Cohen
Samuel Cohen
Cheryl Colleluori
Collins Electric Co.
Lois and Linc Cornell Giving Fund
Frank Courtney
Susan Creager
Beth Cullinan Giving Fund
Daniel Dempsey and Barbara Seneca



ABOVE
Longtime supporters, Andy Schoelkopf and Shari and Joel Beckman at the Menconi + Schoelkopf art gallery in New York City for the Speeding the Path fundraiser celebrating Joel's 10 years of survivorship

The Dogwood Fund
William Dorland and Sarah Penniston-Dorland
Sue Dorsey
Catherine and Patrik Engellau
Annika Folcker Aschan
GHP Office Realty, LLC
Wayne Goldstein and Tara Slone Goldstein Family Fund
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The Goodman-Lipman Family Foundation, Inc.
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The Robert and Sydney Kindler Foundation
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KPMG
Mary and Robert Kuhnlein
Ira and Lillian Langsan Fund
Frankie and Ken Lee
Kit and Bob Lennon
Jonathon Leonhardt
Holly and Thomas Lund
Terri and John Mainey
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Malkani Family Fund
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Mark McDonald
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McLoughlin Plumbing & Heating Co.
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Nick Mullane
Dennis Murphy
Thomas Murphy
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Lynette and Bruce Nelson
Network for Good
Northeastern Operating Engineers FCU
Daniel and Jane Och Charitable Trust
Bennett Pagano
Susan Palermo
Louis Parrillo
Gillian and Mike Parrish
Kathleen and Jim Patton
Andrea and Michael Pell
Maria Pia Ruffilli
Karen and Gary Sain
Allegra and David Sandak
SC McAfee Family Foundation
Maureen Sexton
The Skyline Charitable Foundation Inc.
Scott Smaller
J. Martin Smiley
David Smyth and Julie Song
Ellen Soltow
Josh Sommer and Rachel Lichte
Judith Sprague
St. Paul's Episcopal Church
Robinson Strauss and Sharon Berlan
Steve and Kimberli Sterling
James Stotz
Barry Swidler
Takeda Pharmaceuticals Employee Giving Program
David and Peggy Tanner Philanthropic Fund
Heather and John Therien
Thrivent Financial
Tom Tlusty
Mirna and Claudio Umaschi

Nicholas Vantzelfde and Lauren Erb
Veritas Foundation Fund
Barry & Teri Volpert Foundation
Stephanie Wilcox
Colleen and Terry Wilkins
Judy Kirkland and James Kenneth Wilson Family Foundation
Jessica Wolters
YourCause

\$500-999

Anonymous (2)
Kurtis Bachman
Barrie Bergman
Mark Billy and Adriane Rothstein
Teresa and Robert Boccanfuso
Dusty Bowenkamp
Sue and Gene Brenneman
Jennifer Cahill
Peter Casanave and Naomi Nemtzow
Sharon and Peter Catto
Thelma Chubbuck
Cohen Feeley Altermose & Rambo, P.C.
Barbara Collie
Mark Condic
Christopher Cracchiolo
Mary and Peter Cullinan
Customink, LLC
Virginia Daly
M. Susan Ditzler
Kyle Dumas
Lori Espe
Lynn Etheredge Fund
Carol and Stephen Finley
Michelle Finley
Angelete and Brian Finzen
Joan Funk
Karlyn Grasso
Gray Market, LLC
Gillian Gregory
Frances Hamacher
Margaret Harris
Mohsen Heshmati
Michael Hollander

Veronica and Harry Hoplamazian
Aaron House
Aimee Howell
Judy Johnson
Robert J. Katz Charitable Fund
Albertina and Jerald Kuhn
Ian Laird
Diane and Ingemar Lanevi
Richard Lebowitz
J. Lee
Jacqueline and Ken Lefkowitz
Eleanor and Richard Leong
Edward Les and Sherri Gibbons
Jordan and Charles Lin
Kathleen Loeb-Schwab
Lois and Marc Lust
Sandra and Kenneth Lyles
George Masnick and Reisa Kahn
Molly Maxwell
Christine and Joe McGovern
Philip McHugh
Matt McInnes
Robert McLoughlin
Jean and Brendan McPherson
William Meyer
Karen and Michael Mitchell
Sally Morgan
Arlynn Muckey
Brian J. Mullins
Christine Newfrock
Aaron Niskode-Dossett
Sharon and Leon Oberlander
Josh Parker
Hollis Parks
Kalmon Post and Linda Farber Post
Gus Raptis
Rasmussen Family Foundation
Red Top Foundation
Kenneth Remsen
Dorothy and Dietmar Riccomini
Raymond Riccomini
Timothy Rodell
Steven Rolston
Mary Lou and Hans Saeby
Sayville Union Free School District
Grace and Andrew Schoelkopf

Shakou, LLC Series Barrington
Katherine and Theodore Shults
Silver Linings
J. David Small
Laura and Matthew Soule
James Srygley
St. Casimir Catholic School
C. Donald Stanger
Mike Staveris
Heidi and Scott Steffen

Jinda and Kevin Stoll
Robert Switzer
Chad Thompson
Tritschler Family Fund
Marita and Francis Truax
Patrick Welde
Joanne and Scott Winters
WireCo WorldGroup
Susan Woodman

We sincerely appreciate every gift and regret any errors or omissions that we may have made to the above list. Please contact us at development@chordoma.org with questions or to correct any inaccuracies.



ABOVE
Participants at the All In for a Cure fundraiser in Durham, NC

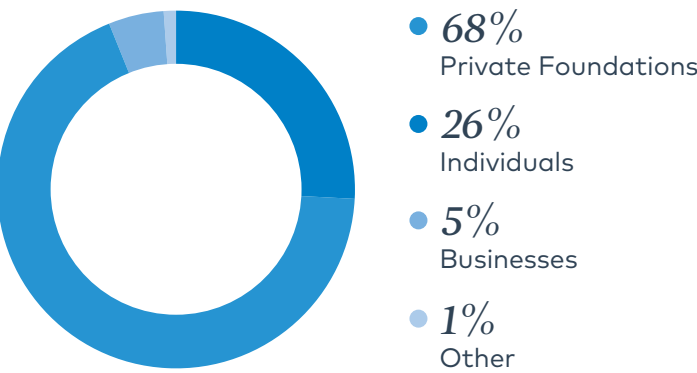
2019 Financials

Audited statement of activities for the year ended December 31, 2019

	Total
Revenue and support	
Contributions	\$ 5,120,316
In-kind contributions	159,215
Program service revenue	2,512
Interest	1,049
Total revenue and support	\$ 5,283,092
Expenses	
Program services	\$ 3,147,693
Management and general	431,597
Fundraising	465,150
Total expenses	\$ 4,044,440
Change in value of foreign currency pledges	\$ (21,768)
Change in net assets	1,216,884
Net assets, beginning of year	3,486,695
Net assets, end of year	\$ 4,703,579

A copy of our 2019 IRS Form 990 and audited financial statements are available at chordoma.org/financials

Sources of funding



Looking ahead

Our current focus is on pursuing the following five priorities of our ALL IN campaign.



Brachyury drug discovery

1. Launch repositories of key brachyury-related research tools
2. Support discovery of the first compounds that inhibit brachyury in cells
3. Facilitate investment in brachyury drug discovery by companies



Immunotherapy

1. Support discovery of a chordoma-specific cell surface marker that could be a target for immunotherapy
2. Support research to identify predictors of response to immune checkpoint inhibitor drugs
3. Co-fund high-impact immunotherapy grants with the Cancer Research Institute



Drug repurposing

1. Screen all existing drugs in chordoma cell lines
2. Test the most promising drugs and drug combinations in chordoma mouse models
3. Initiate at least one new clinical trial



Improving the patient experience

1. Better understand the survivorship needs and experiences of our community
2. Produce new educational content geared toward these survivorship needs
3. Provide greater support and more valuable resources to patients after treatment



Learning from each patient

1. Establish a way for patients to contribute medical records to research
2. Facilitate collaboration among leading treatment centers to identify patterns of response to radiotherapy

Our team

In 2019, we made significant additions to our Board with the appointment of Steven Golick, Chris Heery, and Julie Song as new directors, and were delighted to welcome back early Board members Ed Les and John Therien who rejoined after a hiatus. Additionally, longtime Board members Paula Song and David Drewry completed their terms and departed the Board. On the staff, we welcomed our new Head of Philanthropy, Kenny Brighton, and bid farewell to our team members Breanna McCormley and Chase Hinnant. We are deeply grateful to all of our departing Board and staff members for their service and for all that they did to propel our mission forward.

Our staff

- Josh Sommer

Executive Director
- Daniel Baroff

Development Manager
- Kenny Brighton

Head of Philanthropy
- Larry Gottschalk

Operations Coordinator
- Joan Levy, PhD

Director of Research
- Shannon Lozinsky, MSW

Director of Patient Services
- Jennifer Roeder

Marketing and Communications Manager
- Tammy Silverthorne

Director of Operations
- Patty Cogswell

Research Consultant
- Gillian Parrish

Communications Consultant



ABOVE
Shannon Lozinsky and Joan Levy, at a fundraising event in New York City

Board of Directors

- David Sandak

Chair
- Joel Beckman

Vice Chair
- Ingemar Lanevi

Treasurer
- Julie Song

Secretary
- Steven Golick
- Christopher Heery, MD
- Edward Les, MD
- Steven Mandel
- Shreyas Patel, MD
- Andrew Schoelkopf
- Christy Shaffer, PhD
- Josh Sommer
- John Therien

Includes staff and Board and committee members as of January 1, 2020.

Board committees

- FINANCE**

Ingemar Lanevi

Chair

Mark Ricca

David Sandak
- RESEARCH**

Kurt Bachman, PhD

David Drewry, PhD

Shreyas Patel, MD

William Phelps, PhD

David Sandak

Chandra Sen, MD

John Therian, JD
- PATIENT SERVICES**

Edward Les, MD

Chair

Yen-lin Chen, MD

Karen Cox, PhD, RN

Al Ferreria, RN

Sasha Knowlton, MD

Paula Song, PhD
- DEVELOPMENT**

Joel Beckman

Chair

Anne Noel Dawson

Steven Mandel

Andrew Schoelkopf

Joe Villinski
- NOMINATING**

Joel Beckman

Chair

Edward Les, MD

David Sandak

Andrew Schoelkopf

Christy Shaffer, PhD
- EXECUTIVE**

Joel Beckman

Ingemar Lanevi

David Sandak

Julie Song



LEFT
Chuck Garbett, Edward Les, and Susan Garbett at the 2019 Chordoma Community Conference in Chicago, IL. Ed and Susan are both chordoma survivors and members of our Community Advisory Board.

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
- Shaan Raza, MD
- Joe Schwab, MD
- 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

Sharon Berlan

chordoma survivor



“Because of the Chordoma Foundation, I feel hopeful. When I was diagnosed there was no research or new treatments. We have come so very far and I trust we are close to significant progress for treatments. I am going ALL IN for chordoma because now is the time. We are finally within sight of a cure, which we desperately need.”



CHORDOMA
FOUNDATION

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

