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 Sommer
Co-Founder and Executive Director
14-Year Survivor
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

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.

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.”
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.

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

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.

Craig Crews, PhD  
Yale University

Michael Kelley, MD  
Duke University

Santosh Kesari, MD, PhD  
John Wayne Cancer Institute

Charles Lin, PhD  
Baylor College of Medicine

Michael Lim, MD  
Johns Hopkins

Dan Nomura, PhD*  
UC Berkeley

Slim Sassi, PhD  
Massachusetts General Hospital

Santosh Kesari, MD, PhD  
John Wayne Cancer Institute

Paul Workman, PhD  
Institute for Cancer Research

Yoshiya (Josh) Yamada, MD  
Memorial Sloan Kettering Cancer Center

Stephen Yip, MD, PhD*  
BC Cancer Agency

Gelareh Zadeh, MD, PhD*  
University of Toronto

*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.

“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.”

Tanaz Sharifnia, PhD
Chordoma Team Lead, Broad Institute of Harvard and MIT
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.

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 underprioritized, 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.

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.

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.

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.

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.

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

David Drewry, PhD
University of North Carolina

Opher Gileadi, PhD
Oxford University

Paul Workman, PhD
Institute for Cancer Research, London
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](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](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](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.

“...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.”

Carolyn Laney
mother of 8-year old chordoma patient

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.

1,733 donors
44 fundraisers
23 countries
$5.1M contributed

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!

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
Team Stephen
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 Bornual
Valencia, CA

Dress Down Day
Lynnette 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

44 donors
1,733 contributed

10th Annual St. Paul’s Michael Galluccio Memorial Golf Outing
Mark Galluccio and Zach Feigman
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Blockbuster Bowling Benefit
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The Skyline Charitable Foundation
Long Island City, NY

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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)

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

$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

$10K–499,999
Anonymous
Roz and Adam Abram
Richard and Susan Friedman
Hirsch Family Foundation
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

$5K–9,999K
Anonymous
Bill and Anne Bachrach Family Fund
Mark Balling
Benevity Causes
Bridenbecker Family Trust
Bright Funds
Brittany Whirle Ball League Charity

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 Barruel
Bob Brown
Charles and Marna Davis Foundation
DC Medical, LLC
Hester M. Digges Trust U/A
Illinois Tool Works, Inc.
George Joseph

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
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
Charity Golf International

$500K+
The Beckman Family Foundation
The Marcus Foundation
The Mark Foundation for Cancer Research
Moira and Gary Sinise

$1M+
The Beckman Family Foundation
The Marcus Foundation
The Mark Foundation for Cancer Research
Moira and Gary Sinise

$500,000–$999,999
The Mark Foundation for Cancer Research
Moira and Gary Sinise

$25K–99,999
Anonymous (2)

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.

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 Peniston-Dorland
Sue Dorsey
Catherine and Patrik Engellau
Anika Fisker Aschan
GPH Office Realty, LLC
Wayne Goldstein and Tara Slone
Goldstein Family Fund
John Golfinos
The Goodman-Lipman Family Foundation, Inc.
Mary and Lloyd Gran
Carolina and Salvatore Grandinetti
Bobbi Grunwell
Janet Halfar
Kimberly Hamer
Harcros Chemicals Inc.
Celina Hecht
John Hedley
Patricia and James Heery
The Steven M. & Anita C. Heller Family Foundation
Geoffrey Hobart
Susan and Alan Hock
Gary Hulett
Johnson & Johnson
The Suzanne Nora Johnson & David G. Johnson Foundation
JustGiving
Michelle and Danny Kalenov
Korrel and Robert Kanay
Jeffrey and Marnie Kaufman Fund
The Robert and Sydney Kindler Foundation
Laida and Michael Knox
KPMG
Mary and Robert Kuhnlein
Ira and Lilian Langsan Fund
Frankie and Ken Lee
Kit and Bob Lennon
Jonathan Leonhardt
Holly and Thomas Lund
Terri and John Maney
Makioka Foundation
Malkini Family Fund
Maria and Steven Mandel
Rhoda and Leslie Mandel
Mark McDonald
William McLoughlin
Mcloughlin Plumbing & Heating Co.
Monsanto Matching Gift Program
Nick Mullane
Dennis Murphy
Thomas Murphy
Alexander Nadaner
Lynette and Bruce Nelson
Network for Good
Northeastern Operating Engineers FCU
Daniel and Jane Och
Charitable Trust
Bennett Pagano
Susan Palermo
Louis Parrilla
Gillian and Mike Parrish
Kathleen and Jim Patton
Andrea and Michael Pell
Maria Pia Ruffilli
Karen and Gary Sain
Allegra and David Sandak
SC McFie Family Foundation
Maureen Sexton
The Skyline Charitable Foundation Inc.
Scott Smaller
J. Martin Smiley
David Smyth and Julia Song
Ellen Saltow
Josh Sommer and Rachel Lichte
Judith Sprague
St. Paul’s Episcopal Church
Robinson Strauss and Sharon Berlan
Steve and Kimberly Sterling
James Statz
Barry Swidler
Takeda Pharmaceuticals
Employee Giving Program
David and Peggy Tanner
Philanthropic Fund
Heather and John Therien
Thrivent Financial
Tom Thust
Mira and Claudio Umaschi
Nicholas Vantselfide and Lauren Erb
Verris Foundation Fund
Barry & Teri Volpert Foundation
Stephanie Wilcox
Coleen and Terry Wilkins
Judy Kirkland and James Kenneth Wilson Family Foundation
Jessica Walters
YourCause
$500–999
Anonymous (2)
Kurt Bachman
Barrie Bergman
Mark Billy and Adriane Rathstein
Teresa and Robert Boccanfuso
Dusty Bowenkamp
Sue and Gene Brenneman
Jennifer Cahill
Peter Casanove and Naomi Nemtzow
Sharon and Peter Catto
Thelma Chubbuck
Cohen Feeley Altermoser & Rambo, P.C.
Barbara Collie
Mark Condic
Christopher Cracchiola
Mary and Peter Cullinan
Custamink, LLC
Virginia Daly
M. Susan Ditzler
Kyle Dumas
Lari Espe
Lynn Etheredge Fund
Carol and Stephen Finley
Michelle Finley
Angelette and Brian Finzen
Joan Funk
Karyl Grasso
Gray Market, LLC
Gillian Gregory
Frances Hamacher
Margaret Harris
Mohnen 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 Ingerman Lanevi
Richard Lebowitz
J. Lee
Jacqueline and Ken Lefkowitz
Eleanor and Richard Leong
Edward Les and Sherri Gibbons
Jordan and Charles Lin
Kathleen Laeb-Schwab
Lois and Marc Lust
Sandra and Kenneth Lyles
George Massnick 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
Sharon and Leonard Oberlander
Josh Parker
Hollis Parks
Kalmow 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 Schoekopf
Shakou, LLC Series Barrington
Katherine and Theodore Shults
Silver Linings
J. David Small
Laura and Matthew Soule
James Strygle
St. Casimir Catholic School
C. Donald Stanger
Mike Stavens
Heidi and Scott Steffen
Jinda and Kevin Stoll
Robert Switzer
Chad Thompson
Tritscher 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

<table>
<thead>
<tr>
<th>Total</th>
<th></th>
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<tbody>
<tr>
<td><strong>Revenue and support</strong></td>
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<tr>
<td>Interest</td>
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<td><strong>Total revenue and support</strong></td>
<td>$ 5,283,092</td>
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<tr>
<td><strong>Expenses</strong></td>
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<td>$ 3,147,693</td>
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<tr>
<td>Management and general</td>
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<td>Fundraising</td>
<td>465,150</td>
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<td><strong>Total expenses</strong></td>
<td>$ 4,044,440</td>
</tr>
<tr>
<td>Change in value of foreign currency pledges</td>
<td>$(21,768)</td>
</tr>
<tr>
<td>Change in net assets</td>
<td>1,216,884</td>
</tr>
<tr>
<td>Net assets, beginning of year</td>
<td>3,486,695</td>
</tr>
<tr>
<td><strong>Net assets, end of year</strong></td>
<td>$ 4,703,579</td>
</tr>
</tbody>
</table>

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

Sources of funding

- **68%** Private Foundations
- **26%** Individuals
- **5%** Businesses
- **1%** Other

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
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 team

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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

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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 Schoellkopf

Christy Shaffer, PhD

Josh Sommer
John Therien

Our team

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

Yen-Il 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 Schoellkopf

Joe Villinski

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 Kooi

Maureen LaForge

Heather Lee, PhD

Steven Mandel

Joe McGovern

Jeff Schilling

Tim Zellers

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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.”

Sharon Berlan
chordoma survivor