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 Kraczyw with her mom, Carolyn, at the National Cancer Institute for the first pediatric chordoma clinic.
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.

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.

- **$12M RESEARCH**
  to advance the first brachyury drugs into the clinic, apply immunotherapy advances to chordoma, and systematically identify existing drugs that could help in the near term

- **$2M HEALTHCARE IMPROVEMENT**
  driven by learning from the medical journey of every patient

- **$2M PATIENT SERVICES**
  to create a better experience for all affected
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></td>
</tr>
<tr>
<td>2 new mouse models validated, including 1 pediatric</td>
<td></td>
<td></td>
<td></td>
<td></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

David Drewry, PhD  
University of North Carolina

Adrienne Flanagan, MD, PhD  
University College London

Hans Gelderblom, MD, PhD  
Leiden University Medical Center

Opher Gileadi, PhD  
Oxford University

Cigall Kadoch, PhD  
Dana-Farber Cancer Institute

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

Stuart Schreiber, PhD  
Broad Institute of Harvard and MIT

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.
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.

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.

**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**  
*University of North Carolina*

**Opher Gileadi, PhD**  
*Oxford University*

**Paul Workman, PhD**  
*Institute for Cancer Research, London*

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.

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.

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 Borruel  
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  
Crushing Chordoma With Coach  
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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  
Pub Crawl for Chordoma  
Colleen Riccomini  
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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

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

$25K–99,999K
Anonymous (2)

$100,000–$499,999
Anonymous
Roz and Adam Abram
Richard and Susan Friedman
Hirsch Family Foundation
Steven F. Kanter, MD
Stephanie and Herbert Neuman

$1M+
Anonymous (2)
The Beckman Family Foundation
The Marcus Foundation

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

$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

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.

$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)

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The Beckman Family Foundation
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$500,000–$999,999
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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

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 Borruel
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

$1K–4,999K
Anonymous (6)
Patricia and Randy Akers
AmazonSmile Foundation
American Express Foundation
Ameriprise Financial

$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 Viniar Family Foundation

Yoram Amiga
AMP Charitable Fund
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David Biondi
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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
John Golfinos
The Goodman-Lipman Family Foundation, Inc.
Mary and Lloyd Gran
Carolina and Salvatore Grandinetti
Bobbi Gruwell
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 Kanoy
Jeffrey and Marnie Kaufman Fund
The Robert and Sydney Kindler Foundation
Loida and Michael Knox
KPMG
Mary and Robert Kuhnlein
Ira and Lillian Langsan Fund
Frankie and Ken Lee
Kit and Bob Lennon
JonathonLeonhardt
Holly and Thomas Lund
Terri and John Mainey
Makioka Foundation
Malkani 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 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

20 CHORDOMA FOUNDATION
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.
2019 Financials

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

<table>
<thead>
<tr>
<th>Revenue and support</th>
<th>Total</th>
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<td>Contributions</td>
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<td>In-kind contributions</td>
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<td>Interest</td>
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<tr>
<td>Total revenue and support</td>
<td>$ 5,283,092</td>
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<table>
<thead>
<tr>
<th>Expenses</th>
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<tbody>
<tr>
<td>Program services</td>
<td>$ 3,147,693</td>
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<tr>
<td>Management and general</td>
<td>431,597</td>
</tr>
<tr>
<td>Fundraising</td>
<td>465,150</td>
</tr>
<tr>
<td>Total expenses</td>
<td>$ 4,044,440</td>
</tr>
</tbody>
</table>

| Change in net assets                     | 1,216,884 |
| Change in value of foreign currency pledges | (21,768)  |
| 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

- **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
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

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.

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

**Scientific Advisory Board**
David Drewry, PhD  
Adrienne Flanagan, MD, PhD  
James W. Hodge, PhD, MBA  
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  
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

*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.
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