Not if, but when
Improving the lives of those affected by chordoma.

Leading the search for a cure.
“It’s no longer a matter of if we’ll find a cure for chordoma, but when.”

Josh Sommer
Co-Founder and Executive Director, Chordoma Foundation

Our values

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

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

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

For 11 years, your conviction and generosity have fueled progress that is virtually unprecedented for a rare cancer.

In 2017, that progress began making a real impact on the lives of chordoma patients like never before.

Notably, with your support, the Foundation served a record number of patients and caregivers through our Patient Navigation Service, published the first clinical guidelines for management of recurrent chordoma, and supported the launch of two clinical trials for chordoma patients.

At the same time, we laid the groundwork for even greater impact to come by investing in research to discover therapies targeting the Achilles heel of chordoma (brachyury); by recruiting several new, high caliber research groups into the field; and by completing development of new cell lines and mouse models that represent different subtypes of the disease.

Most significantly, we welcomed a seasoned cancer scientist, Dr. Joan Levy, to be our first Director of Research. With nearly 30 years of experience in cancer biology and drug discovery at Yale, Bayer Pharmaceuticals, and the Multiple Myeloma Research Foundation, Joan brings tremendous expertise to our team and has dramatically increased the Foundation’s capacity to initiate and drive research.

Through collaboration and perseverance, our growing team and this community continue to defy the odds, and each day we are getting closer to a future in which everyone affected by chordoma will be able to overcome the disease and maintain their quality of life.

We won’t rest until that vision becomes a reality, and we look forward to forging ahead together.

Onward!

Josh Sommer
Co-Founder and Executive Director
12-Year Survivor
Dear Friends,

In the Chordoma Foundation’s short but momentous history, the field of chordoma has begun a significant transformation, heralding deeply meaningful advances in science and care. The chordoma community is working as a team to drive purposeful change in many lives and the Chordoma Foundation has stepped forward as the agent of that change.

We are inspiring collaboration between top research institutions, hospitals, and companies worldwide and are attracting leading cancer centers and researchers to the study of chordoma. At the same time, we are continuing to grow our clinical trial pipeline, and provide more patients and families with the support and information they need to successfully navigate the disease.

Today, research has reached a tipping point and advancements we could only have dreamed of a few short years ago are now clearly in our field of vision. At the Chordoma Foundation, we are working tirelessly to make that vision a reality.

But curing this disease is a challenge and requires your passionate support. Momentum is on our side, and we have a unique opportunity to positively impact the lives of those who are suffering. Your help can accelerate the pace of change and make a real difference.

Together, we will develop the first effective drug therapies for chordoma, we will help more doctors provide appropriate care for chordoma patients, and we will ensure that every family facing chordoma receives the care and treatment they deserve.

If you carefully review the information contained in this annual report, you will see clearly that the Chordoma Foundation is poised to make significant change.

Thank you for your support and encouragement. Together, we can overcome any challenge.

Sincerely,

Andrew Schoelkopf
Board Chair
A new phase is beginning in our mission to lead the search for better treatments, and ultimately a cure, for chordoma.

After a decade of foundational research, we have built a vibrant chordoma research community, created an end-to-end research-enabling infrastructure, and uncovered promising drug targets. Now, we are beginning to translate those advances into new treatments for chordoma.

2017 Research highlights

2 Chordoma-specific clinical trials opened
14 Drugs tested through our Drug Screening Program
10 New disease models developed

12 Peer-reviewed articles published
320+ Researchers worldwide studying chordoma
2 New tumor donation partner hospitals

To propel this new phase of research forward, we hired a seasoned cancer scientist, Joan Levy, PhD as our first Director of Research. Joan joined our team with nearly thirty years of experience in basic science, drug discovery, and clinical research spanning academic, industry, and nonprofit settings. She is now overseeing all of our investments in research, including our grants portfolio, Drug Screening Program, and Clinical Trials Program. She is also working hand-in-hand with our Research Manager, Patty Cogswell, who continues to oversee our Biobank, model repositories, and model development efforts.
I’ve never felt a greater sense of purpose than when I work directly with patients and caregivers to advance the therapies they need and fight for.

And I’ve never seen progress that matches the scope and speed of what the Chordoma Foundation has accomplished in the past 11 years, especially with a tumor type this rare. It is an honor and privilege to be part of the effort to improve lives and find a cure.”
Investing in a cure

In 2017 we invested in a record amount of research, allocating resources across every step of the treatment development process.

$1.88M
invested in research in 2017

- 29% resource development
- 23% target discovery
- 22% therapeutic discovery
- 13% preclinical research
- 13% clinical research

As part of this investment, we awarded $700,000 in new research grants in 2017 to three labs working to address key priorities identified by our Scientific Advisory Board:

- **Dr. Charles Lin** at Baylor College of Medicine – Exploring the brachyury regulatory network, including how brachyury is regulated, the genes it controls, and the effects of shutting it down.

- **Dr. Slim Sassi** at Massachusetts General Hospital — Identifying small molecules that inhibit the function of brachyury.

- **Dr. Adrienne Flanagan** at University College London — Conducting multi-omic analysis of adult and pediatric chordomas with the goal of better understanding the interplay between genomic and epigenomic alterations in chordoma, and also determining differences between adult and pediatric tumors.

Currently funded researchers

- Cameron Brennan, MD, PhD
  Memorial Sloan Kettering Cancer Center
- Adrienne Flanagan, MD, PhD
  University College London
- Gary Gallia, MD, PhD
  Johns Hopkins
- Hans Gelderblom, MD, PhD
  Leiden University Medical Center
- Michael Kelley, MD
  Duke University
- Michael Lim, MD
  Johns Hopkins
- Charles Lin, PhD
  Baylor College of Medicine
- Slim Sassi, PhD
  Massachusetts General Hospital
- Stuart Schreiber, PhD
  Broad Institute of Harvard and MIT
- Yoshiya (Josh) Yamada, MD
  Memorial Sloan Kettering Cancer Center
Research results

Investments in research have resulted in measurable progress across every stage of our research roadmap. Notable milestones in 2017 included:

<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>Banked 35 tumors</td>
<td>Results of Foundation-funded Chordoma Genome Project published in <em>Nature Communications</em></td>
<td>Awarded 2 grants supporting research to discover therapies targeting brachyury at Massachusetts General Hospital and Baylor College of Medicine</td>
<td>Tested 14 more drugs in mouse models through our Drug Screening Program (26 tested to date), and made results available through a public data repository</td>
<td>Supported launch of 2 chordoma-specific clinical trials – Nivolumab + stereotactic radiosurgery (Phase 1) – Palbociclib (Phase 2)</td>
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<tr>
<td>Validated 6 new cell lines and 4 new PDX models</td>
<td>Funded multi-omic analysis of adult and pediatric tumors at University College London</td>
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<td>Supported planning of 3 more upcoming clinical trials</td>
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<td>Developed the first pediatric cell line and first pediatric PDX model</td>
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Clinical trials pipeline

We aim to initiate at least 10 clinical trials by 2020. At the end of 2017, there were already 7 in the pipeline.

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

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Planning</th>
<th>Active</th>
<th>Complete</th>
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</thead>
<tbody>
<tr>
<td>GI-6301 with radiation</td>
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<tr>
<td>Brachyury vaccine</td>
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<td>Nivolumab with radiation</td>
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<td>PD-1 inhibitor</td>
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<td>Palbociclib</td>
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<td>CDK4/6 inhibitor</td>
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<tr>
<td>Afatinib</td>
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<tr>
<td>EGFR inhibitor</td>
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<tr>
<td>Brachyury vaccine with radiation</td>
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<tr>
<td>Oncolytic bacteria</td>
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<tr>
<td>Autologous tumor vaccine</td>
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</table>
Without the Foundation, our work would not be possible. The funding they provide enables us to study the key genetic driver of chordoma, a protein called brachyury, with the ultimate goal of targeting and turning it off.

And, equally as important, when you have a research and patient community that’s as engaged as the Foundation’s is, forging connections and partnerships with labs around the world becomes easy, and incredibly productive. As a basic scientist, being able to interact with clinicians, patients, and other investigators is incredibly motivating and helps ground our work with a greater purpose.”
Third Chordoma Global Consensus Group meeting

For the third time since 2013, more than 50 leading chordoma physicians from North America, Europe, and Asia gathered in Milan, Italy to codify the most effective, evidence-based treatments for chordoma. Organized by the Istituto Nazionale dei Tumori and sponsored by the Chordoma Foundation, this year’s meeting focused on defining best practices for minimizing the risk of recurrence following surgery and radiation. In particular, the group sought to define more specific recommendations for treating an adequate margin around the tumor to eliminate local micrometastases that are prone to cause recurrence. Building on consensus guidelines published in 2015 and 2017, the output of this year’s meeting is being prepared for publication to help inform the broader medical community and further improve the standard of care.
In 2003, an international team of doctors led by Dr. Griffith Harsh, a skull base neurosurgeon at the Stanford University Medical Center, published Chordomas and Chondrosarcomas of the Skull Base and Spine — the first definitive textbook about chordoma and a related cancer, chondrosarcoma. Since then, the understanding and treatment of chordoma has changed dramatically.

To reflect these recent advances, this year, Dr. Harsh and colleagues published a second edition of their seminal textbook. They assembled, as authors, a remarkable group of experts from top treatment centers throughout the world, representing every specialty involved in caring for patients with chordomas. The result is the most comprehensive reference detailing the current state of the art of diagnosis and treatment for these tumors. We were proud to participate in this effort, including authoring a chapter detailing how the Foundation works with the medical and research communities to accelerate research, improve patient care, and serve the chordoma patient community.

Significant advances have occurred in the last two decades, both in our understanding of the basic pathology and molecular biology of these tumors, and in our clinical approach to diagnosing and treating them. The Chordoma Foundation has played a major role in advancing research and moving us forward together. Much of the progress detailed in the book has happened as a result of their involvement.”
Patient Services

This year, we continued enhancing and expanding the resources and services the Foundation provides to patients and families facing chordoma.

From developing new educational content to increasing our capacity to provide patient navigation and peer support services, we were able to provide more valuable assistance to individuals in need throughout their journey with chordoma. And with this greater depth came greater utilization, including more than a 40 percent increase in the number of individuals served through our Patient Navigation Service.

Moreover, to guide the continued growth of these programs, our Board formed a new Patient Services Committee comprised of four professionals with collective experience in patient navigation, health education, social work, nursing, hospital administration, palliative care, and patient-centered outcomes research. Chaired by our Board member Paula Song, PhD, a health policy researcher at the University of North Carolina, this new committee will oversee the ongoing evaluation and improvement of our service offerings and the implementation of new programs and services in the years ahead.

Throughout 2017, we also worked to build a new online community designed specifically for chordoma patients and family members. Called Chordoma Connections, it is a place where individuals affected by chordoma can come together to exchange information, share experiences, and support one another. The content and conversations shared on the platform will be archived and searchable, providing an important source of information for the chordoma community for years to come.

Learn more and join at community.chordomafoundation.org.
In March 2017, the first ever large-scale analysis of symptoms and life challenges caused by chordoma was published in the journal, *Quality of Life Research*, opening the door to improved understanding and management of the disease. Authored by Paula Song, PhD, a member of the Foundation’s Board of Directors and Chair of our Patient Services Committee, and Josh Sommer, our Co-Founder and Executive Director, this paper is the first to characterize a wide range of medical, emotional, and practical challenges facing chordoma patients and caregivers. Now available in open access format, it is intended to help clinicians better understand and manage patients’ symptoms, to aid in the design of future clinical trials, and to give patients and caregivers a sense of what they might face in their own journey with chordoma.

**CHORDOMA SYMPTOMS AND LIFE CHALLENGES**

Results of the first large-scale survey to characterize the experience of living with chordoma

**WHO IS REPRESENTED?**

- **50/50 EVEN GENDER DISTRIBUTION: PATIENTS & FRIENDS/FAMILY**
- **72% OF PARTICIPANTS WERE AGE 45 OR OLDER**
- **MOBILE SPINE: 33% SACRAL**
- **56% SKELETAL BASE**

**SYMPTOMS REPORTED**

- ** MOST COMMON SYMPTOMS REPORTED BY ALL PATIENTS WERE:**
  - **38% CHRONIC PAIN**
  - **36% DEPRESSION**
  - **24% SEVERE ANXIETY**
  - **8% DIFFICULTY WALKING**
  - **6% DIFFICULTY SPINNING**

- **SKULL BASE PATIENTS:**
  - **56% DOUBLE VISION**
  - **35% DEPRESSION OR SEVERE ANXIETY**
  - **34% CHRONIC SLEEP PROBLEMS**

- **SACRAL PATIENTS:**
  - **62% DIFFICULTY TANDING**
  - **54% DIFFICULTY WALKING**
  - **51% SWALLOW PROBLEMS**

- **MOBILE SPINE PATIENTS:**
  - **57% CHRONIC PAIN**
  - **40% DIFFICULTY WALKING**
  - **39% CHRONIC FATIGUE**

**CHALLENGES**

- **MEDICAL, EMOTIONAL, AND LOGISTICAL**
- **CAREGIVERS REPORTED EXPERIENCING MANY CHALLENGES AT HIGHER RATES THAN PATIENTS**
- **REDUCED ABILITY TO WORK**
- **LONG-TERM INABILITY**
- **CONFUSION OR LACK OF UNDERSTANDING**
- **LONELINESS**
- **ISOLATION**
- **GRIEF**
- **HELPLSSENCE**

**WHY THIS MATTERS**

1. **HELPS PATIENTS KNOW WHAT TO EXPECT**
2. **HELPS INFORM DESIGN OF FUTURE CLINICAL TRIALS**
3. **HELPS CLINICIANS UNDERSTAND AND MANAGE PATIENTS’ SYMPTOMS**
2017 Chordoma Community Conference

Nearly 60 patients and caregivers from 16 states gathered at our Chordoma Community Conference at the University of Texas MD Anderson Cancer Center in Houston.

They came together to learn about the latest advances in chordoma research and treatment, and connect with others who share similar experiences. Attendees heard presentations from more than a dozen chordoma specialists and researchers on topics that ranged from new surgical and radiation techniques to trends in pain management and rehabilitation to the latest drug development efforts. Videos of the presentations are available on our YouTube channel at youtube.com/chordomafoundation.
I discovered the Chordoma Foundation shortly after being treated for a cervical chordoma, and immediately signed up for the 2013 conference in Boston. I was almost overwhelmed with information and found many new friends who have continued to provide support through my ongoing battle against the disease. The most valuable thing I learned was how much research was being done to treat chordoma.

Since then I have attended most conferences, where I continue to make friends, and especially learn about new treatments and clinical trials. After being told my tumor could no longer receive traditional treatments, with the help of the Foundation, I am currently in a clinical trial which has kept my tumor from advancing. I recommend every chordoma patient attend a Chordoma Community Conference. We all need hope, and that is what the conferences are excellent at providing.”
Thanks to our supporters

We are incredibly grateful to the generous donors who make our work possible. Thank you for helping to improve the lives of those affected by chordoma, and propel research toward better treatments and a cure.

$2.18M raised

14 Community events

1,700+ Donors around the world

35 Online fundraising campaigns
2017 Donors

We’re grateful to the following donors who made our work possible in 2017.

$1M+
The Beckman Family Foundation

$100K–499,999K
Anonymous

$25K–99,999K
Anonymous
Byers Family Trust
The Cedar Street Foundation
Fuchs Family Foundation
Stephanie Neuman
Helen Van Sickle Fund

$10K–24,999K
Anonymous (3)
The Alpert Family Foundation
Stanley & Marion Bergman Family Charitable Fund
Stanley, Marion, Paul and Edward Bergman Family Foundation
Robert Cohen
Charles and Marna Davis Foundation
Hester M. Digges Trust U/A
Lea Glazar
Heather Lee and Steve Straus
Joe McGovern
Stuart and Susan Porter
Chandranath and Sharmila Sen

$5K–9,999K
Anonymous (3)
Affiliated Foot Surgeons
Mary Margaret Anderton
Andrew Balls
Erwin Bellamy McMerty Foundation
William Bourke
Robert and Frances Bridenbecker
Bright Funds Foundation
Bruns Foundation
William Dorland and Sarah Penniston-Dorland
Patrik and Catherine Engellau
Robert and Joann Fenili
GE Foundation
Goldman Sachs Gives: The Barry and Rochelle Kaplan Fund
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Steven Mandel
Scott and Julie Moller
Bruce and Lynette Nelson
Nikki Nicholau
Renaissance Charitable Foundation, Inc.
Bernard Rothman
SBES Client Consolidated Charitable Foundation, Inc.
Jeff and Erin Schilling
Joel and Christy Shaffer
Douglas and Phyllis Smith
David and Peggy Tanner
Andrew Thomson

$1K–4,999K
Anonymous (5)
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Michael Accurso
Elizabeth Akers
Alaa Alessa
AlixPartners
Yoram Amiga
Artisan Partners
Norman R. and Margaret E. Augustine Bequest Fund
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Oliver Evans
Patrick Fanning
Tinamarie Feil
Richard and Janet Fell
Kathleen Fendler
Frank and Diane Fernandes
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Jeannine Fox
Scott and Cindy Frodle
Chee Fah Fu
Paul Gardner
Radik Gazetdinov
Thomas Given
Lloyd and Mary Gran
Greenberg Traurig
Andrew Greenspan
Elizabeth Gunter
Harcros Chemicals Inc.
Celina Hecht
Mohsen Heshmati
Gary Hulett
Illinois Tool Works
Johnson & Johnson
Judy Johnson
Lance Jones
Danny and Michelle Kalenov
Robert and Korrel Kanoy
Sunny Kantha
Carol Kary
Jeffrey and Marnie Kaufman Fund
Michael Kelley and Elise Hoffman
Michael Knox
Steve and Laurie Krasicky
Robert and Mary Kuhnlein
Kenneth and Frankie Lee
Kara Leibel
Richard and Susan Lichte
Jeanette Loeb
Irene Lowe
Thomas and Holly Lund
Scott Mackin
Leslie and Rhoda Mandel
Scott Mather
Robert and Polly McCrea Family Fund
Mark McDonald
Kristina McVay
Wade and Sally Monroe Family Fund
Thomas Moss and Janie Deal
Alexander Nadaner
Steve Norcross
James and Kathleen Patton
Polsinelli
Michael and Noreen Potempa
Amy Rajan
Steven and Katherine Rhodes
Mark Ricca
Todd Roberts and Arleen Song
Becky Roof
Adriane Rothstein and Mark Billy
RShanahan Recruiting
Maria Pia Ruffilli
Gary and Karen Sain
St. Paul’s Episcopal Church
Sally Sallee
David Sandak
Grace and Andrew Schoelkopf
Robert and Inger Schoelkopf
Dayna Schooley
Kerry Shad and Julia Walker
Madhav Shenoy
Frances Silver
Gregg Slepian
Scott Smaller
Scott Smiley
Bruce Smith
David Bruce Smith
David Smyth and Julie Song
Josh Sommer and Rachel Lichte
Paula Song and Stephen Gazda
Young-dahl and Juliet Kim Song
John Stevenson
Megan and Joseph Stewart
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Robinson Strauss and Sharon Berlan
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Teachers Federal Credit Union
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UK Fund for Charities
Michael Velder
David and Susan Viniar
Shai Waisman
Kathryn Weber
Wells Fargo
Alan and Suzie Wendorf
Terry and Colleen Wilkins
Kevin Scott and Joanne Winters
Susan Woodman
William Yentzen

$500–999
Anonymous (3)
John Amato
Kourtney Anderson
Anheuser Busch Companies
Peter Antoszyk
Kurtis Bachman
Balbach Family Foundation
Al and Ruth Baldwin
Laura Barton
Sharon Berry
Peter and Alyssa Blume
Robert and Teresa Boccanfuso
Dusty Bowenkamp
Gene and Sue Brenneman
Burgaw Rotary Club
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Peter and Sharon Catto
Murray Chidester
Jeffrey Concepcion
Karen Cox
Patricia Cullinan
James Cunningham
Stephen Darr
Thomas and Linda DeLane
Alfredo del Valle
Daniel Dempsey
Stephen Deshaies
Edward Devlin
Tom Doar III
Alison Dorsey
Sue Dorsey
William and Deborah Duensing
Steve and Melodi Dunn
Thomas and Diane Dutil
Enterprise Bank & Trust
Lynn Etheredge Fund
John Euston
Evan Flaschen
Cheryl Fromhold
Gregory and Diane Fuchs
Hiranya and Saraswathi Gowda
Richard and Gillian Gregory
William and Beverly Griffin
Tim Gu
Susan Hall
Sandy Haymann Marks
Robert and Julie Hertzberg
Mary Jo Heston
Hewlett Packard Enterprise
Geoffrey Hobart
Melissa Hoffman
Intel Corporation
Scott Jenkins
Steve Johnson
Vivek Krishnappa
Jerald and Albertina Kuhn
Joshua Kutilek
Tzuchin Lee
Ken and Jacqueline Lefkowitz
Lexis Nexis
James Long
John and Lorelie Lynn
MarksNelson LLC
George Masnick and Reisa Kahn
Cynthia McAfee
Amy Mcdowell
Mat McKitterick
Microsoft
Monsanto Matching Gift Program
Arlynn Muckey
Edward Mulloy
Dennis Murphy
Joe Nezewk
Leon and Sharon Oberlander
Louis Parrillo
Michael and Gillian Parrish
John and Joyce Penniston
Diane Pitt
Jennifer Purvis
Anthony Quirarte
Mark and Alicia Reid
Kenneth Remsen
Dietmar and Dorothy Riccomini
Richard and Colleen Riccomini
William and Laurel Roebuck
Richard and Stacy Rosenthal
Sayville Union Free School District
Robert Scheibe
Theodore and Katherine Shults
Skinner Family Charitable Fund
Kimberly Smith
Travis Smith
Bradley W. Snyder
Charitable Fund
Barbara Spina
Zinia Santeliz Splendoria
A C Sreeram
Stalter Foundation
Jeremy Stalter
Derrick Strupp
Takeda Pharmaceuticals NA, Inc.
Employee Giving Program
William Thompson
Margaret Tritschler
Stephen Tully
Andrew and Bridgett Turner
Ricarte and Susan Valdez
Joe and Allison Villinski
Mike and Linda Waldschmidt
David and Toni Walton
Claus Werner
William and Heather Wiggins
Jessica Wolters
Barbara Wortman

We have made every attempt to ensure the accuracy of our donor list and we regret any errors or omissions. Please contact us at feedback@chordoma.org to correct any inaccuracies.

ABOVE
Board member, Christy Shaffer, PhD, and Medical Advisory Board member, Paul Gardner, MD, support our mission not only with their time and expertise, but with generous philanthropic contributions as well.
Champion story: Steven Golick

Steven Golick was always a force of nature. A restructuring lawyer, musician, volunteer, and family man in Toronto, Canada, he was used to being in constant motion, and loved the energy of his multi-faceted life.

Then, in September of 2012, Steven noticed that he couldn’t walk in a straight line – despite not drinking a drop. Although he had no other symptoms, he and his wife Greta soon found themselves sitting across from a shocking diagnosis; Steven had a massive skull base chordoma.

Forced to hit pause on his other commitments, Steven applied the same rigor and passion he had always put toward his professional and cultural pursuits to tackling his disease and improving his health. His treatment included a 12-hour surgery, multiple rounds of radiation, and a long rehabilitation. With outstanding medical care and a community of family and friends encircling him with love, Steven made a full recovery and — so far — his chordoma has not come back.

BELOW
Performers and concertgoers enjoy Chords for Chordoma: A Pan-American Jazz Event and fundraiser in Toronto, Canada
But he knows he’s one of the lucky ones, and is aware that someday it might return. That’s why Steven added tireless chordoma advocate to his already impressive resume, to help improve the odds for everyone facing this devastating disease.

Harnessing his extensive skills and network for the cause, Steven became one of the key architects behind a new partnership between the Chordoma Foundation and the Canadian Cancer Society (CCS) designed to rally the Canadian chordoma community and jumpstart chordoma research in Canada. And in November, he organized and hosted Chords for Chordoma, a remarkable concert at the Toronto Centre for the Arts which brought together some of North and South America’s top jazz and latin musicians to build awareness and raise funds for research. The event, Steven’s way of giving back to other Canadians with chordoma and their circles of love, was attended by more than 550 people and raised an incredible $320,000.

“This is a rare diagnosis, which affects one in a million people per year, so it’s important to build the community and collaborate across borders. Getting involved with the Chordoma Foundation is a fantastic opportunity for Canadian patients and their families.

We know Josh and his team are the right ones to shepherd this effort forward. Our mission has been to find a way to expand the Foundation’s reach here, and create opportunities for more Canadian researchers, chordoma patients, and their families to become involved.”

Steven Golick
Chordoma patient
2017 Online Fundraising Champions

Anonymous
Since 2012

Daniel Baroff
Since 2017

Ryan Benevides
Since 2017

Sharon Berlan
Since 2008

Dusty Bowenkamp
Since 2013

Christopher Capuzzi
Since 2017

Nadine Cordova
Since 2010

Carol Crow*
Since 2013

Beth Cullinan
Since 2012

Connie de Pan
Since 2011

Jon and Noa Denning
Since 2014

Mike Etchamendy
Since 2014

Jess and Jake Gorelick
Since 2017

Nathaniel Hamlett
Since 2013

Bobbi Antonazzi Jensen
Since 2013

Norma Jones
Since 2009

Rachel Lichte
Since 2017

Debbie MacDonald
Since 2008

Steven Mandel
Since 2012

James and Elisa McBratney
Since 2016

Brea McCormley
Since 2017

Kathleen Milczarski
Since 2010

Facebook Milestones
Since 2015

Ross and Ally Parks
Since 2017

Michael Potempa
Since 2013

Colleen Riccomini
Since 2008

Collecting donations in memory of her son

David Roebuck*
Since 2013

Laurel and Bill Roebuck have continued to collect donations in memory of their son

Miss Caylee Saati*
Since 2012

Cathy Sapeta
Since 2016

Matt and Danielle Sauerhoff
Since 2016

Andrew Schoelkopf
Since 2017

Maureen Schroer
Since 2013

Tammy Silverthorne
Since 2015

Luc Tremblay
Since 2010

Randi Windt
Since 2014

*Indicates those who have passed

2017 Community fundraising events

Bake Sale and Lemonade Stand
Stewart Family
Brookhaven, GA

Blockbuster Bowling Benefit
Jeff Schilling
Kansas City, MO

Brooklyn Half Marathon
Steve Mandel
London, UK

Cardiff Half Marathon
Melanie Barker-Wright
Talgarth, UK

Chordoma Necklace Sale
Stephanie Mulry
East Meadow, NY

Chords for Chordoma
Steven Golick
Toronto, CA

Climb for Chordoma
Ed Les
Calgary, CA

Hike for Chordoma II
Nat Hamlett
Little Valley, NY

Olde Colonial Home Tour
Gene and Sue Brenneman
Kinzers, PA

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

Pub Crawl for Chordoma
Colleen Riccomini
West Sayville, NY

Sayville Cares Basketball Tournament
Colleen Riccomini
West Sayville, NY

Swing Fore the Cure
Jeff Schilling
Kansas City, MO

The Trouble With Flight EP Release
Ryan Van Slooten
Andover, MN
## Financials

### Audited statement of activities for the year ended December 31, 2017

<table>
<thead>
<tr>
<th>Revenue and support</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contributions</td>
<td>$1,978,835</td>
</tr>
<tr>
<td>In-kind contributions</td>
<td>194,215</td>
</tr>
<tr>
<td>Program service revenue</td>
<td>4,345</td>
</tr>
<tr>
<td>Interest</td>
<td>3,685</td>
</tr>
<tr>
<td><strong>Total revenue and support</strong></td>
<td><strong>$2,181,080</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Expenses</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Program services</td>
<td>$2,255,403</td>
</tr>
<tr>
<td>Management and general</td>
<td>258,280</td>
</tr>
<tr>
<td>Fundraising</td>
<td>510,759</td>
</tr>
<tr>
<td><strong>Total expenses</strong></td>
<td><strong>$3,024,442</strong></td>
</tr>
</tbody>
</table>

| Change in net assets                 | $−643,170   |
| Net assets, beginning of year        | 4,078,154   |
| **Net assets, end of year**          | **$3,434,984** |

Our 2017 IRS Form 990 and audited financial statements are available at chordoma.org/financials

### Sources of funding

- **61%** Private Foundations
- **28%** Individuals
- **10%** Businesses
- **1%** Other
Looking ahead

Today, many of the obstacles that once stood in the way of realizing our vision of better treatments, better care, and a better experience for everyone affected by chordoma have been alleviated.

Promising experimental therapies are creating more options for patients, and outcomes for those facing chordoma around the world are improving.

But even though much ground has been gained, a cure is still urgently needed, and we won’t rest until everyone facing chordoma has one. To realize that future, we will focus our efforts and investments on five strategic priorities over the next three years.

Develop the first therapies capable of targeting brachyury

Bring the latest advances in cancer immunotherapy to chordoma

Accelerate clinical trials for promising therapies

Help more doctors appropriately care for chordoma patients

Help more patients and families overcome barriers to care and get the best treatment possible
Our commitment to excellence in financial management and transparency was recognized once again by both of the nation’s leading charity ratings agencies, Charity Navigator and GuideStar.

“

What has impressed me the most about the Chordoma Foundation is the speed at which it has funded and advanced exemplary science from the lab to the clinic.

Importantly, this unparalleled research model has attracted over a dozen industry partners to co-invest in a diverse set of clinical programs. As a scientist and investor, I believe they have made monumental progress since I joined the board in 2016.”

— Christy Shaffer, PhD
Hatteras Venture Partners
Member, Chordoma Foundation
Board of Directors
Our team

Our staff

Josh Sommer
Executive Director

Daniel Baroff
Development Coordinator

Patty Cogswell
Manager of Research

Larry Gottschalk
Operations Coordinator

Chase Hinnant
Patient Services Coordinator

Megan Hohenstein*
Education and Outreach Coordinator

Joan Levy, PhD
Director of Research

Shannon Lozinsky, MSW
Patient Services Manager

Breanna McCormley
Director of Development

Jennifer Roeder
Marketing and Communications Manager

Tammy Silverthorne
Director of Operations

Gillian Parrish
Communications Consultant

*Through December 2017

Board of Directors

Andrew Schoelkopf
Chair

Joel Beckman
Vice Chair

Ingemar Lanevi
Treasurer

Kerry Shad, JD
Secretary

David Drewry, PhD

Steven Mandel

Shreyas Patel, MD

David Sandak

Christy Shaffer, PhD

Josh Sommer

Paula Song, PhD

LEFT
Chordoma Foundation team at a 2017 staff retreat
Not pictured: Joan Levy, PhD and Chase Hinnant

ABOVE
Director of Research Joan Levy, PhD and Board Member David Drewry, PhD
Board committees

FINANCE
Ingemar Lanevi
Chair
Mark Ricca
Andrew Schoelkopf

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

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

DEVELOPMENT
Joel Beckman
Chair
Anne Noel Dawson
Andrew Schoelkopf
Joe Villinski

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

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

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

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

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

LEFT
Patient Navigators
Chase Hinnant and
Shannon Lozinsky
In 2017, Dan and Brittany Johnson, pictured opposite, shared with our community the story of Dan's six-year battle with chordoma. In January 2018, we lost an incredibly strong, brave, and kind member of our community when Dan passed away.

We’re grateful to Dan and Brittany for allowing us to share their story and we will continue to fight every day — on behalf of Dan and everyone whose life has been taken by chordoma — until everyone facing this devastating disease has a cure.