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

Leading the search for a cure.

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“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

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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

Letter from the Executive Director

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

Letter from the 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.”

Joan Levy, PhD
Director of Research, Chordoma Foundation
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
- 13% preclinical research
- 23% target discovery
- 22% clinical research
- 13% therapeutic discovery

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

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

- **Banked 35 tumors**
- **Validated 6 new cell lines and 4 new PDX models**
- **Developed the first pediatric cell line and first pediatric PDX model**
- **Results of Foundation-funded Chordoma Genome Project published in Nature Communications**
- **Funded multi-omic analysis of adult and pediatric tumors at University College London**
- **Awarded 2 grants supporting research to discover therapies targeting brachyury at Massachusetts General Hospital and Baylor College of Medicine**
- **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**
- **Supported launch of 2 chordoma-specific clinical trials**
  - Nivolumab + stereotactic radiosurgery (Phase 1)
  - Palbociclib (Phase 2)
- **Supported planning of 3 more upcoming clinical trials**
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.

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Charles Lin, PhD
Assistant Professor, Molecular and Human Genetics, Baylor College of Medicine (Pictured on cover)

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.”
Healthcare Improvement

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.

Updating the definitive textbook on chordoma

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.”

Griffith Harsh, MD
Professor of Neurosurgery, Stanford University Medical Center
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.

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.

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.

Chordoma symptoms and life challenges survey

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 male to female gender ratio
31% of respondents were married
31% of respondents were single

72% of respondents were white
1 in 5 patients reported having cancer

SYMPTOMS REPORTED

56% at skull base
54% at sacral
57% at mobile spine

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

CHALLENGES

Musculoskeletal
Sensory, cognitive, functional
Fatigue, depression, mood swings
Illness, pain
Fatigue, sleep, depression
Planning, travel, financial

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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.”

Dusty Bowenkamp
Chordoma patient and Community Conference attendee
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

$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
Byers Family Trust
The Cedar Street Foundation
Fuchs Family Foundation
Stephanie Neuman
Helen Van Sickle Fund

$10K–24,999K
Anonymous
Byers Family Trust
The Cedar Street Foundation
Fuchs Family Foundation
Stephanie Neuman
Helen Van Sickle Fund

$10K–24,999K
Anonymous
Byers Family Trust
The Cedar Street Foundation
Fuchs Family Foundation
Stephanie Neuman
Helen Van Sickle Fund

$1K–4,999K
Anonymous
Byers Family Trust
The Cedar Street Foundation
Fuchs Family Foundation
Stephanie Neuman
Helen Van Sickle Fund

$5K–9,999K
Anonymous
Byers Family Trust
The Cedar Street Foundation
Fuchs Family Foundation
Stephanie Neuman
Helen Van Sickle Fund

2017 Donors

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

Erwin Bellamy McMerty Foundation
William Bourke
Robert and Frances Bridenbecker
Bright Funds Foundation
Bruns Foundation
William Darland and Sarah Penniston-Darland
Patrik and Catherine Engellau
Robert and Joann Fenili
GE Foundation
Goldman Sachs Gives: The Barry and Rochelle Kaplan Fund
Bruce Laxer
Steven Mandel
Scott and Julie Moller
Bruce and Lynette Nelson
Nikki Nicholau
Renaissance Charitable Foundation, Inc.
Bernard Rothman
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Norman R. and Margareta E. Augustine Bequest Fund
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Denham Capital Management LP
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Frank and Diane Fernandes
Fidelity Brokerage Services LLC
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Scott and Cindy Frodle
Chee Foh Fu
Paul Gardner
Radik Gazetdinov
Thomas Given
Lloyd and Mary Gran
Greenberg Traurig
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.
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.

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 Licht 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
Lourl and Bill Roebuck have continued to collect donations in memory of their son
Miss Caylee Saati* Since 2012
Cathy Sapeta Since 2015
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

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 Yarkarth, UK
Chords for Chordoma Steven Galick Toronto, CA
Chords 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

Revenue and support
- Contributions $1,978,835
- In-kind contributions $194,215
- Program service revenue $4,345
- Interest $3,685

Total revenue and support $2,181,080

Expenses
- Program services $2,255,403
- Management and general $258,280
- Fundraising $510,759

Total expenses $3,024,442

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

Sources of funding

- 61% Private Foundations
- 28% Individuals
- 10% Businesses
- 1% Other

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

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.”

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.
Our team

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

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

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David Drewry, PhD
Shreyas Patel, MD
David Sandak
Christy Shaffer, PhD
Josh Sommer
Paula Song, PhD

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William Phelps, PhD
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John Therien, JD

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Mrinal Gounder, MD
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Silvia Stacchiotti, MD
Katie Thornton, MD
Josh Yamada, MD

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Brittany Puchis
Susan Garbett
Chris Jones
Steven Mandel
Jeffrey (Jeb) Nadaner, PhD
Jeff Schilling
Tim Zellers

ABOVE
Joan Levy, PhD and David Drewry, MD

*Through December 2017
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.