

Remarkable RESILIENCE



“We all approach our challenges differently, but there are some universals, including the fact that we’re all on a path to get back to who we are—not necessarily who we were, but who we can be.”



ABOVE: Chordoma survivor, writer, and cyclist, Todd Balf

ON THE COVER: Chordoma patient Jeff Schilling and family

Letter from the Executive Director

What’s revealed when “normal” isn’t an option

Life’s curveballs — whether rare like chordoma or universal like a global pandemic — have a way of revealing who we are and what we’re capable of. It’s fitting that 2020 was the year the Chordoma Foundation put resilience front and center with the launch of our Chordoma Survivorship Initiative, which focuses not on returning to life pre-diagnosis but on finding new ways to live well in the midst of our ups and downs and unwelcome changes.

This year also reinforced gratitude as adversity’s antidote. We’re grateful for healthcare workers’ heroic efforts during historic challenges, for our research partners’ extraordinary commitment to continuing their experiments, and for our community’s unshakable support of one another and of our mission.

As you’ll learn in the pages that follow, your steady generosity meant that progress against chordoma hardly missed a beat. Because of you, we’re heading into this next era closer than ever to our shared goals.



Josh

Josh Sommer

Co-Founder and Executive Director
15-year survivor

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Accelerating cures

In 2020, we invested \$1.57M in research, bringing our cumulative research investments to more than \$13M — plus millions more leveraged from the National Institutes of Health, other foundations, and pharmaceutical companies.

Despite 2020's headwinds, our strategic research investments resulted in substantial and measurable progress across multiple priority areas, as described in the following pages. Your support of this research is rapidly changing the outlook for patients.

Currently funded researchers

Our grantees are pursuing top research priorities, including developing drugs that strike at brachyury, the Achilles' heel of chordoma, applying powerful new technologies to harness the immune system to fight chordoma, and systematically identifying existing drugs that can help patients in the near term.

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

Santosh Kesari, MD, PhD
Saint John's Cancer Institute

Michael Lim, MD
Stanford

Cassian Yee, MD*
The University of Texas MD Anderson Cancer Center

Stuart Schreiber, PhD
Broad Institute of Harvard and MIT

Paul Workman, PhD
Institute for Cancer Research, London

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

Publications

Our investments in research culminated this year in six original research publications, which contributed important insights into disease biology, potential therapeutic targets, and treatment approaches.



New understanding of how most chordomas lose a critical break on cell growth

Frequent alterations in p16/CDKN2A identified by immunohistochemistry and FISH in chordoma

From the Flanagan lab at University College London



Clues about how chordomas evade the immune system and what can be done about it

Defective HLA class I expression and patterns of lymphocyte infiltration in chordoma tumors

From the Schwab and Ferrone labs at Massachusetts General Hospital



A new indirect approach to attacking brachyury

Inhibition of histone H3K27 demethylases inactivates brachyury (TBXT) and promotes chordoma cell death

From the Flanagan lab at University College London with collaborators at Oxford University



Circulating tumor DNA can be detected in the blood of chordoma patients

The mutational landscape of spinal chordomas and their sensitive detection using circulating tumor DNA

From the Bettgowda lab at Johns Hopkins Medicine



THE UNIVERSITY
of NORTH CAROLINA
at CHAPEL HILL

New potential combination therapy identified through machine learning approach

Synergistic drug combinations and machine learning for drug repurposing in chordoma

From the UNC Catalyst for Rare Disease at the University of North Carolina at Chapel Hill



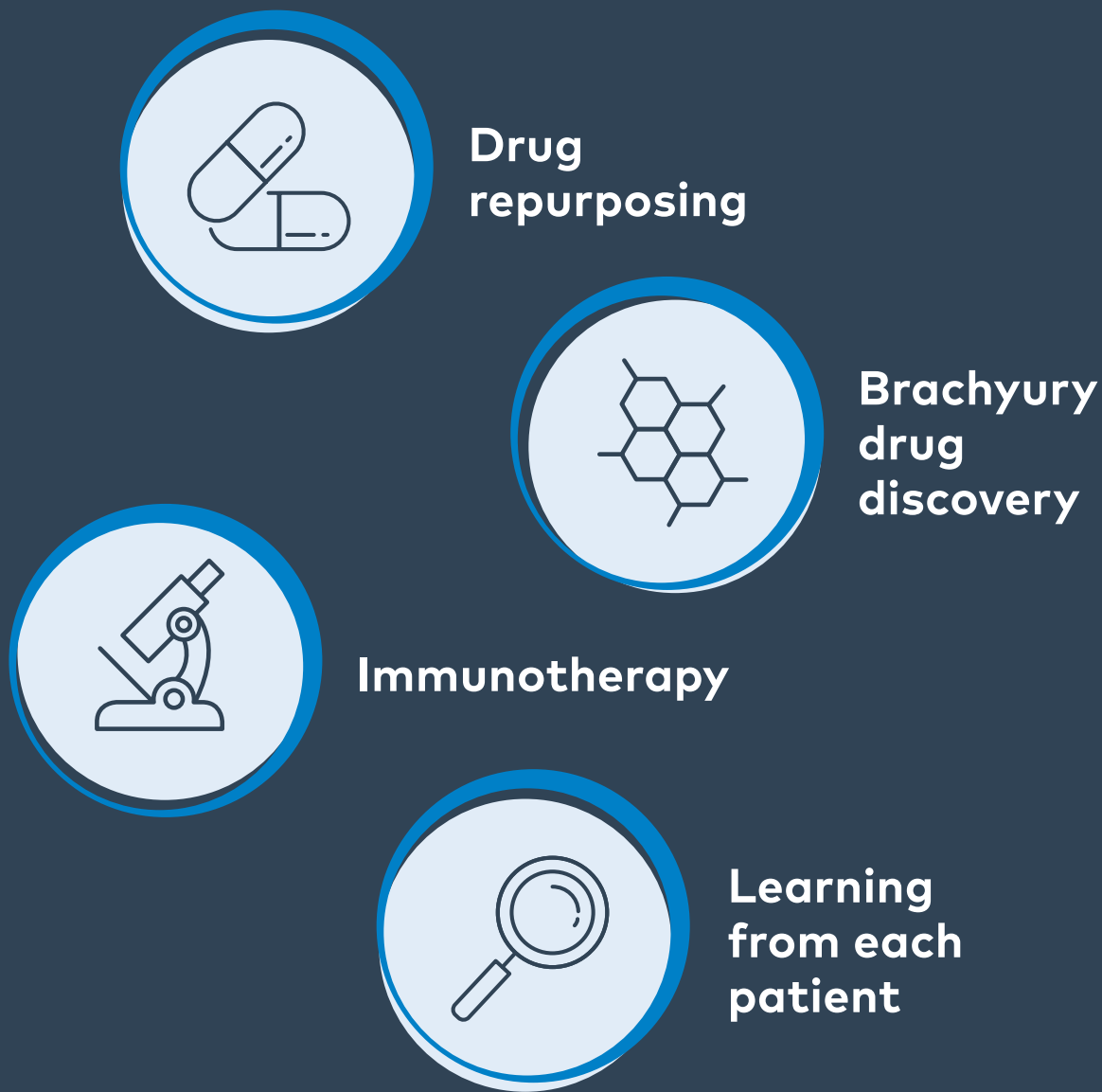
Preclinical evidence for a new potential therapeutic target

Rationale for the advancement of PI3K pathway inhibitors for personalized chordoma therapy

From the Prince and Brenner labs at University of Michigan

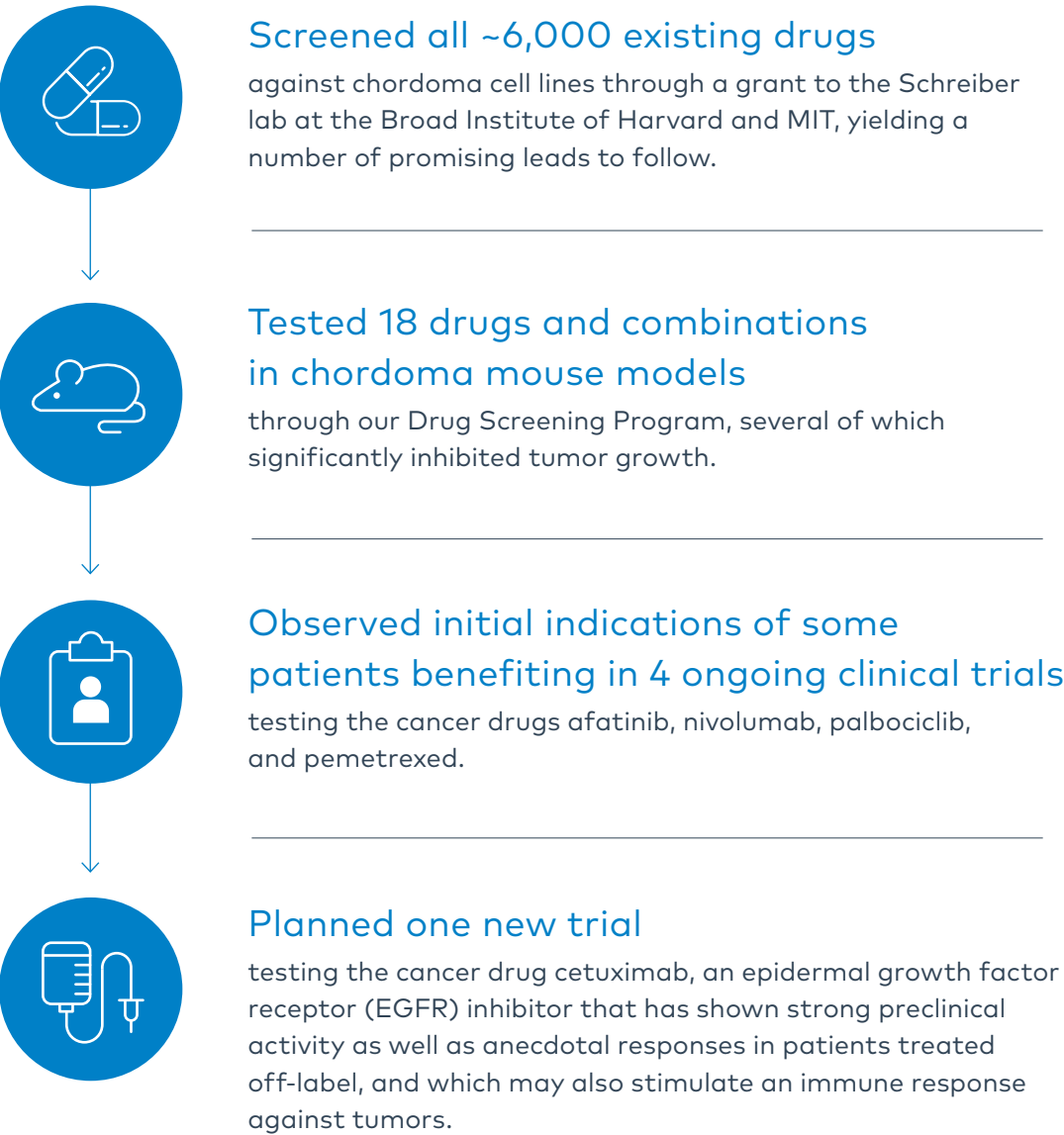
Research priorities

Despite historic challenges this year, our research collaborators and grantees went to great lengths to ensure that progress continued. Their dedication led to significant and tangible progress in each of our four research focus areas.



Drug repurposing

The fastest path to better treatments for chordoma is to find existing drugs that work. In 2020, considerable progress was made towards this goal.



Brachyury drug discovery



Brachyury is the primary driver of chordoma, its greatest vulnerability, and a highly promising therapeutic target. It also plays a role in the progression of numerous other cancers such as breast, lung, and colon. Once thought to be “undruggable,” our research partners made unprecedented progress in the quest for the first brachyury drugs this year.

- **Created new compounds that bind to brachyury** and which could serve as the starting point for multiple classes of drugs, including a new and highly promising type called targeted protein degraders.
- **Demonstrated proof of concept for protein degraders:** in specially engineered chordoma cell lines brachyury degradation permanently stopped cell growth.
- **Developed critical open-access research tools** which enable the evaluation and optimization of emerging brachyury drugs, increasing the feasibility and reducing the cost for all current and future brachyury drug discovery programs.

Becky Bish, PhD

Head of Discovery and Preclinical Research, The Mark Foundation for Cancer Research



“There is growing evidence that developing drugs against brachyury could be beneficial not just for chordoma but for other cancers in which it appears to play a role as well.”

Ryan Schoenfeld, PhD

Chief Scientific Officer, The Mark Foundation for Cancer Research



“Bringing these drugs to fruition will set an important precedent for how emerging technologies can be applied successfully to the most challenging targets in oncology.”

Immunotherapy

Extraordinary advances are being made in the development of therapies that harness the immune system to fight cancer. Our goal is to ensure that chordoma patients everywhere benefit from these powerful new treatment approaches as quickly as possible. Key milestones in 2020 included:



Development of the first cell based therapy for chordoma

initiated by immunotherapy pioneer Dr. Cassian Yee and colleagues at The University of Texas MD Anderson Cancer Center. This research is made possible by a \$200,000 grant co-funded by the Chordoma Foundation and Cancer Research Institute, the world’s leading nonprofit funder of cancer immunotherapy research.



Identification of new potential targets for immunotherapy

by the Kislinger lab at the University of Toronto, presented during our virtual International Chordoma Research Workshop.



Cassian Yee, MD
*The University of Texas
MD Anderson Cancer Center*

Cell-based therapies have shown they can shrink or eliminate various types of tumors. Endogenous T Cell (ETC) therapy, in particular, can be developed and tested in clinical trials faster than certain other forms of cell therapy. Applying these approaches to chordoma represents one of the most promising paths to better treatments and, if successful, could lead to a clinical trial for patients within two to three years.”

Learning from each patient

Knowledge about how chordomas behave over time is critical for improving care, designing future clinical trials, and getting new treatments approved.

To generate this knowledge, we’ve partnered with the U.S. National Cancer Institute (NCI) to include chordoma patients within their ongoing Natural History Study of Rare Solid Tumors. Designed in consultation with our Medical Advisory Board and other leading chordoma clinicians, this study seeks to determine:

- **How chordoma progresses** in patients with various clinical profiles
- **Clinical and biological factors** associated with better or worse outcomes
- **Treatments** that are benefitting chordoma patients

Chordoma patients anywhere in the world can take part in advancing this important research.



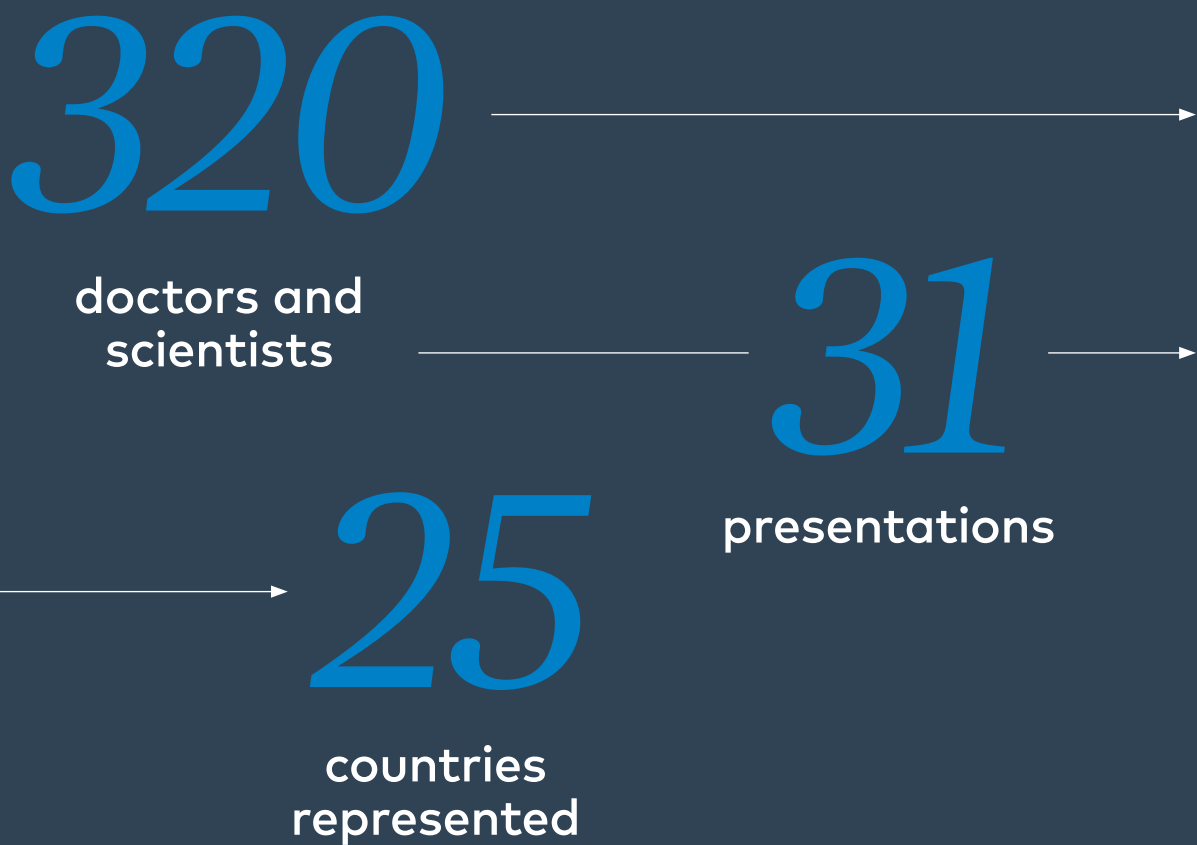
Brigitte C. Widemann, MD
*Chief of Pediatric Oncology,
NCI’s Center for Cancer
Research*

Studies like these are crucial to our understanding of how rare cancers progress and in building the scientific foundation upon which drug development programs are formed. All chordoma patients, including those in active treatment, are welcome to participate in the Natural History Study from the comfort of their home. They are also welcome to come to the NCI to meet with our experts directly.”

Keeping information flowing

Our biennial International Chordoma Research Workshops enable the rapid exchange of unpublished data, surface new research ideas and opportunities, and facilitate coordination and collaboration among researchers.

Adapting in the face of the pandemic, what would have been our seventh in-person gathering of the international chordoma research community turned into our first fully online research workshop.



International Chordoma Research Workshop



A silver lining of holding the event online was that it enabled many more investigators to participate: more than twice the number we've ever had in person and six times the number at the first workshop 13 years ago. We're heartened to watch the field continuing to grow and to see the level of dedication and intellectual investment in our disease by so many talented physicians and scientists.

Improving lives

Managing life in a pandemic is challenging for everyone, but for those touched by chordoma, the worries are multiplied. We faced unknowns, asked tough questions, and wondered if things were going to be okay. Many patients and families turned to one another and to the Foundation as a source of support and guidance, and we were here to help address new needs and navigate new challenges.

1,165

members in Chordoma Connections,
our online community

1,425

educational materials
provided

584

responses to the Chordoma
Survivorship Survey

498

patient navigation
cases served

5

new Peer Guides
trained

3

educational
webinars held

2nd

NCI MyPART Clinic
(held virtually)

Daniel Nagridge

*Chordoma patient
and Peer Guide*



I knew as soon as I got my diagnosis that one of the things I wanted to do was help others struggling with chordoma. When I became a patient, I had to teach myself how to become comfortable accepting help, but learning that skill has been a gift. It's critical for someone like me who is currently going through a recurrence, and for all of us in this pandemic."

Chordoma Survivorship Initiative

Quality-of-life challenges are common for all those affected by chordoma: patients, survivors, caregivers, and co-survivors. Our Chordoma Survivorship Initiative, launched in 2020, is helping members of the chordoma community learn about these challenges and find ways to manage and overcome them. We do this by providing:



Information

Including guidelines for follow-up care after treatment, information on survivorship care plans, and guidance on managing quality of life issues such as pain and fatigue.



Resources

Including a Survivorship Specialist Directory within our online community, Chordoma Connections, which helps people find care to address the medical, emotional, and practical needs that may arise following treatment.



Support

A discussion forum in Chordoma Connections focused on quality of life and access to Peer Guides with shared experiences.



One-on-one navigation

Individualized assistance for survivorship needs through our Patient Navigation Service.

Ed Les, MD

*Chordoma survivor and
Chordoma Foundation
Board member*



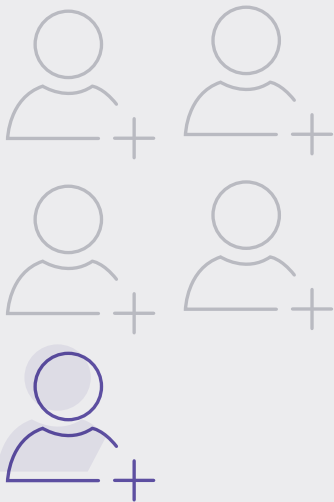
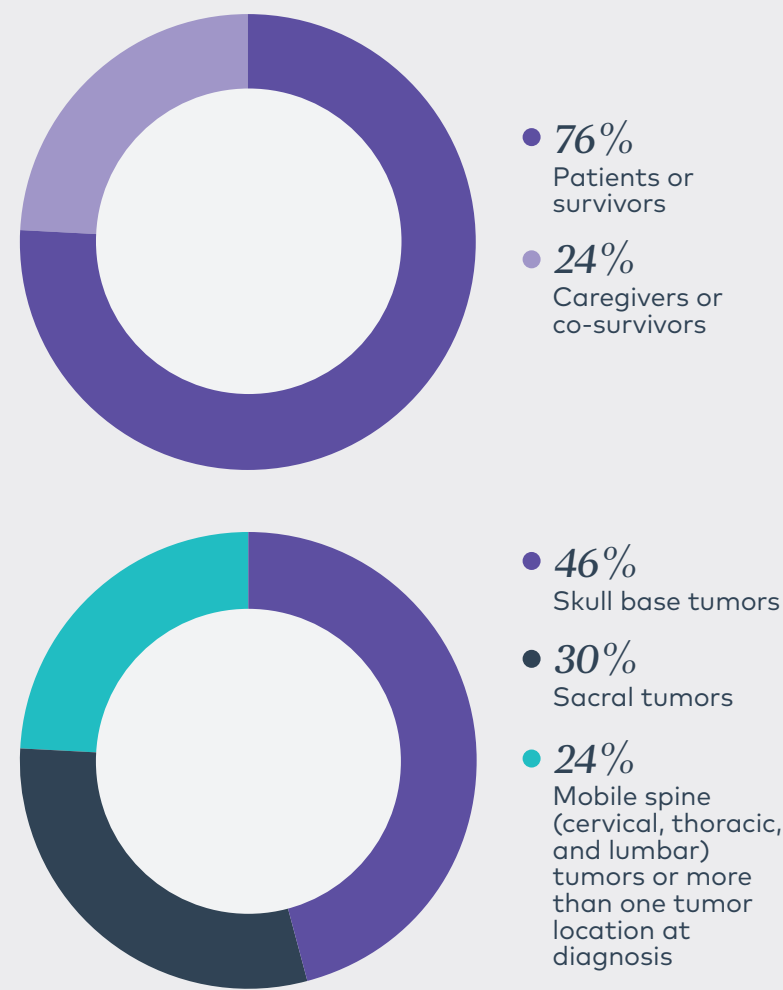
The launch of the Chordoma Survivorship Initiative is tremendous news for the chordoma community. It’s bringing dedicated focus to helping chordoma survivors live well — physically, mentally, emotionally, financially — after their initial intense battle with the disease and as they grapple with the reality of their diagnosis and all that it means.”

Listening to our community

We conducted the Chordoma Survivorship Survey to capture the physical, emotional, social, and practical experiences of our community members, including both survivors and co-survivors.

An incredible 584 individuals in 34 countries participated, contributing to the most extensive collection of chordoma patient experiences ever gathered. The following figures put into numbers what many affected by chordoma already know: major gaps remain in survivorship care. We'll use what we've learned to guide the expansion of our survivorship offerings.

Who responded?



1 in 5 respondents were in active treatment

Experience with survivorship care planning

Only 7% of survivors and 5% of co-survivors say that a survivorship care plan was given when the patient completed their most recent treatment.



Fewer than half

of survivors report that their doctors discussed current or possible quality of life issues, including how to seek care for those issues, at the end of their last treatment.

1 in 4 say that their chordoma doctor provided them with information about chordoma to give their primary care provider.



Ability to access care

Over 75% of survivors experience 5 or more quality of life challenges, such as fatigue, fear of recurrence, depression, pain, inability to go to work or school, etc.



But only 62%

of those who do experience challenges say they accessed care for those needs.

And just 41%

say that their needs were met by that care.

Expanding Peer Connect

Launched in 2011, the Peer Connect Program is a free, confidential peer-to-peer support program that connects anyone touched by chordoma with another person whose experiences are similar.

Over nearly a decade, it's fostered hundreds of matches and cultivated life-changing relationships between affected individuals, including patients, caregivers, family members, or friends seeking to reduce feelings of isolation and stress.

In 2020, we introduced a new online training program designed to make the process of becoming a Peer Guide more accessible.



Become a Peer Guide or be matched with one

If you're interested in talking to someone who has been through a similar chordoma journey or providing support for others, visit chordoma.org/peer-support or contact support@chordoma.org.



Susan Hall

*Chordoma survivor
and Peer Guide*



My Peer Guide was by far the greatest source of hope and comfort to me when I was first diagnosed. If I can provide even a fraction of that relief to other people experiencing chordoma, it will have been worth it. And I was pleasantly surprised at how much I got out of the training personally and professionally. The skills it focuses on, listening and empathizing, can be applied to many different types of relationships.”

Thank you for your support

Our progress is possible thanks to your generosity, which was especially inspiring this year, and enabled our mission to continue uninterrupted despite the tremendous collective challenges we all faced.

2020 Fundraising Champions

We're grateful to the many Chordoma Champions who rallied their personal networks to fundraise for the Foundation, finding creative ways to raise funds in a socially distanced world. To learn how to become a Chordoma Champion, contact development@chordoma.org.

Wendy Abbott

Leslie Adler

Irene Badura

Sharon Berlan

Sue and Gene Brenneman

Renée Butler

Tracy Clifford

Millie Cowles

Dawson's Circle of Hope

Melodi Dunn

Peter Ernharth

Crystal Feldman

The Finley Family

Wanda Fuller

Robin Ho

John Mainey

Steven Mandel

Alexandra Muckey

Shyla Nash

Ruth O'Brien

Kimberly Ochs

Noreen and Mick
Potempa

The Riccomini Family

Jeff Schilling, Maggie
Bates, and Priscilla
McInnes

Maureen Schroer

Joyce Spiegel

Team Mac

Todd Vallie

Hannah Wilson



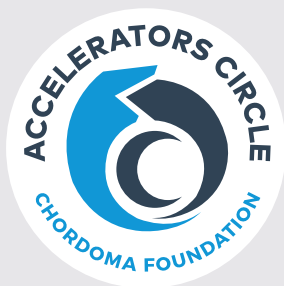
Renée Butler

*Ultrarunner and mom of
chordoma survivor*

Fundraising for the Chordoma Foundation is such a meaningful opportunity. It's easy, fulfilling, and so much fun. You feel like you're changing the world."

Accelerators Circle

Special thanks to the members of our Accelerators Circle whose gifts of \$25,000 or more over a period of up to three years accelerate our mission and make possible the multi-year investments needed to achieve meaningful long-term impact.



\$1M+

The Beckman Family Foundation
The Marcus Foundation

\$500,000-999,999

The Mark Foundation for Cancer Research
Moirra and Gary Sinise

\$100,000-499,999

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The Cedar Street Foundation
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Hirsch Family Foundation
George Joseph
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Heather Lee and Steve Straus
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TrueScripts Foundation Fund
The Helen Van Sickle Fund
Karen and Richard Westin

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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.

*Indicates a payment on a pledge made in a prior year

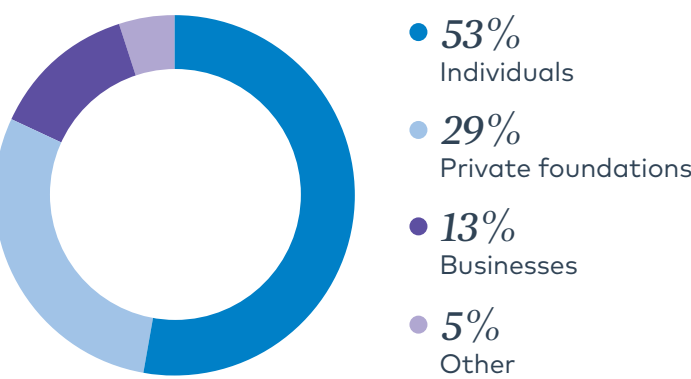
Financials

Audited statement of activities for the year ended December 31, 2020.

	Total
Revenue and support	
Contributions	\$ 2,334,581
In-kind contributions	205,352
Paycheck Protection Program proceeds	120,400
Interest	5,729
Program service revenue	1,775
Total revenue and support	\$ 2,667,837
Expenses	
Program services	\$ 2,003,515
Management and general	276,469
Fundraising	412,693
Total expenses	\$ 2,692,677
Change in value of foreign currency pledges	\$ (19,022)
Change in net assets	-\$24,840
Net assets, beginning of year	\$ 4,703,579
Net assets, end of year	\$ 4,697,761

A copy of our 2020 IRS Form 990 and audited financial statements are available at chordoma.org/financials.

Funding sources



Onward

Chordoma is a solvable problem. Your support accelerates our focused quest for solutions. Our current priorities include:



Brachyury drug discovery

Developing drugs that strike at the Achilles' heel of chordoma

- The moment we've been waiting for: Begin first preclinical efficacy studies of emerging brachyury drug candidates
- Begin studying safety of therapies targeting brachyury



Immunotherapy

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

- Initiate and fund projects addressing top immunotherapy research priorities



Drug repurposing

Identifying existing drugs that can help chordoma patients in the near term

- Complete testing of all approved drugs in chordoma cells
- Initiate and support new drug repurposing clinical trials
- Identify new treatment approaches that show strong preclinical efficacy to pave the way for future clinical trials



Patient experience

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

- Start new virtual support groups for patients and caregivers
- Host virtual community conference series focused on addressing quality of life issues
- Develop and translate educational materials addressing key questions identified by our community



Clinical learning

Understanding how different treatments impact patient outcomes to continually improve patient care

- Surpass 100 patients enrolled in the Natural History Study of Rare Solid Tumors

Team

To keep pace with rapid advances and the growing set of opportunities in chordoma research, in 2020, we made several key additions to our research team. Dr. Dan Freed joined the Foundation as our new Head of Target Discovery and Translational Research, and Dr. Diane Ignar joined us in a consulting capacity as our Head of New Drug Development. Dan and Diane’s work at the Foundation builds upon the many achievements of Dr. Joan Levy, our former Director of Research, who moved on to an exciting new role and remains involved as an advisor. We also welcomed drug discovery and development leaders Dr. Paul Feldman and Dr. Sue Mahony onto the Board of Directors and brachyury expert Dr. Charles Lin to our Scientific Advisory Board.

Additionally, to bolster our ability to serve the full spectrum of needs within the chordoma community — particularly around survivorship — Andrea Locke joined us as our Patient Navigator, and caregiver and board-certified patient advocate Megan Stewart joined our Community Advisory Board.

Staff

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This year also marked longtime director Joel Beckman’s retirement from the Board after 10 years. His dedication, leadership, and wisdom have left a lasting positive mark on our organization and on many in the chordoma community. We are deeply grateful to Joel for all that he has done and continues to do to support our mission.

Joe Stewart

*Chordoma survivor,
pictured here with wife
Megan Stewart, member of
the Chordoma Foundation's
Community Advisory Board*



The Chordoma Foundation was instrumental in my treatment. When I was diagnosed five years ago, it was through the help of the Foundation's Patient Navigators that I was able to receive excellent care from chordoma experts. My family and I are forever grateful for the work of the Foundation in working towards a cure. They offer a wealth of information to those diagnosed with chordoma and are invaluable in helping us understand how this disease can be managed. Ultimately, the Foundation gave us tools, and those tools gave us hope.”



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