

One in
a million,
but not
alone

Chordoma Foundation
2021 Annual Report



15 years of progress, connection, and hope

Fifteen years ago a handful of families affected by chordoma came together with the conviction that the options available to us weren't acceptable. We realized that by teaming up, we'd have a chance of creating a better future for those of us affected by this disease then and everyone who came next.

Today, what began around a dining room table has become an international movement. What started as an uphill battle has given rise to encouraging momentum. And what were once far-off dreams — like clinical trials, treatment guidelines, and access to the accumulated wisdom of fellow patients and leading doctors — have become reality. Together, we've changed much of what it means to face chordoma.

Yet the pressing need remains for better treatments. In the years ahead, our sights are set on treatments that can prevent recurrence, eliminate tumors rather than just

slow their growth, and preserve patients' quality of life. And thankfully, snowballing advances provide ever more tangible reasons to believe this is not only possible but probable.

We're tremendously grateful to those whose encouragement, generosity, and belief in our potential have emboldened us from the beginning, and to those who have joined this quest every day since. Your commitment is bringing our shared vision to life.



A stylized, handwritten signature of Josh Sommer in white ink.

JOSH SOMMER

Executive Director, Co-Founder, and
chordoma survivor

Table of contents

1	Dedication
2	15 years of progress
6	Accelerating cures
13	Improving lives
16	Join Us
17	Financials
19	Donors
24	Champions
25	Team

Dedication

This report is dedicated to the memory of Michael Torrey (1958-2021) whose belief in our collective ability to improve the outlook for all affected by chordoma helped set the Foundation's work in motion and build substantial momentum in our first fifteen years.

Since the Foundation's very first days, Michael's wholehearted support and generosity played an outsized role in our progress and impacted the lives of thousands of fellow patients. Michael is remembered for his big heart, good humor, and infectious optimism. As we continue our urgent mission, we carry with us Michael's determination to create a future in which all those affected by chordoma can get back to the life they love.






15 years of progress

Our vision is to bring about a future in which everyone affected by chordoma is able to overcome the disease and maintain their quality of life. With your help, we've come a long way.

	2007	Today	
<div>Research</div> <div></div>	Virtually no research being done and no infrastructure to enable it	<ul style="list-style-type: none">• Vibrant global research ecosystem• \$15.8M in cumulative research investments, plus \$20M+ leveraged from others• 300+ researchers collaborating toward a cure	<ul style="list-style-type: none">• 30+ high-quality cell and mouse models easily available to scientists• Tumor tissue from 250+ patients banked for research• 25+ disease drivers and therapeutic targets revealed
<div>Treatments</div> <div></div>	No movement toward new treatments	<ul style="list-style-type: none">• Fast-moving therapeutic development pipeline• 6,000 drugs screened against chordoma cell lines	<ul style="list-style-type: none">• 70+ promising drugs and combinations tested in mice through our Drug Screening Program• 7 treatments brought into clinical trials

15 YEARS OF PROGRESS

	2007	Today	
Diagnosis 	Patients frequently misdiagnosed and mistreated due to limited clinical awareness	<ul style="list-style-type: none"> Evidence-based guidelines for medical professionals diagnosing and treating chordoma 	<ul style="list-style-type: none"> 215+ experienced doctors in our Doctor Directory
Support 	Nowhere to turn for support and reliable information	<ul style="list-style-type: none"> 3,000+ families provided with free, personalized Patient Navigation Service to access expert care and get their questions answered 	<ul style="list-style-type: none"> Comprehensive educational resources for patients and caregivers Numerous opportunities for people affected by chordoma to connect with peers
Influence 	No way for those affected by chordoma to change the outlook	<ul style="list-style-type: none"> Multiple ways to participate in research from donating tumor tissue to joining a natural history study or clinical trial 	<ul style="list-style-type: none"> Donations of all sizes can directly advance research and improve patient care

15 YEARS OF PROGRESS

What we've achieved so far is thanks to this unstoppable community. Here are just a few of the countless individuals whose passion and dedication have made a lasting mark on our organization and mission.



What does the
Foundation's
progress mean to me?
It saved my life three
times (so far).
It means my life.”



Bill Dorland
chordoma patient

Accelerating cures

In 2021 we invested in catalyzing progress across the entire spectrum of research needed to bring new therapies to chordoma patients.

5%

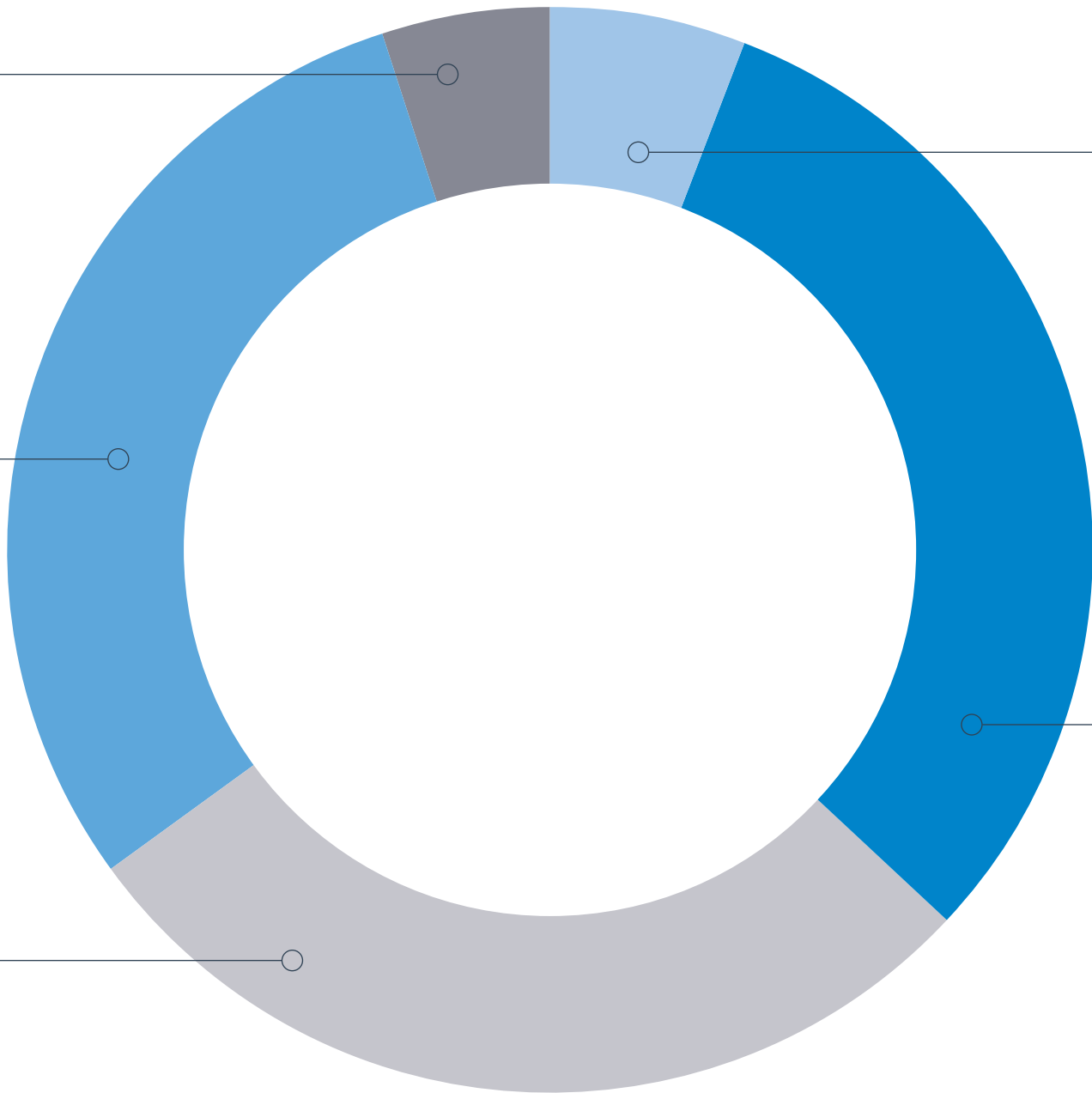
CLINICAL RESEARCH
Cetuximab clinical trial

30%

PRECLINICAL RESEARCH
Testing promising drugs in chordoma cell lines and mouse models

29%

DRUG DISCOVERY
Brachyury drug discovery projects



6%

ENABLING RESOURCES
Tumor tissue / Cell lines and mouse models / Data

31%

TARGET DISCOVERY
Multi-omics projects / Immune biology projects

\$2.5M

invested in research in 2021

14

currently funded research teams

9 *new research publications*

ACCELERATING CURES

Learning from the bigger picture

Like layers of a map, when snapshots of different types of molecules within cancer cells — like DNA, RNA, and proteins — are viewed together, a much more meaningful picture comes into focus. Known as “multi-omics,” this integration of data layers is key to fully understanding what drives chordoma tumors, how tumors differ across individuals, and whether certain patients are likely to benefit from different treatments.

This year, we supported three complementary multi-omics projects involving teams at New York University, the University of Minnesota, and Germany’s National Center for Tumor Diseases. They’re seeking to identify new therapeutic targets, uncover drivers of metastases, and determine whether there are relevant differences between tumors of various anatomic locations.



MULTI-OMICS
“DATA LAYERS”

What's needed is a comprehensive view into the biology of chordoma tumors and how they vary across patients, and that's what we're aiming to generate. Our vision is to be able to tailor treatment approaches to the unique profile of each patient's tumor."



**Dr. Stefan
Fröhling**

*National Center for Tumor
Diseases, Germany*

ACCELERATING CURES

Targeting chordoma's Achilles' heel

Encouraging progress continued in multiple labs toward the first drugs that strike at brachyury, the main Achilles' heel of chordoma. Notably, our grantees at the University of North Carolina, Oxford University, and The Institute of Cancer Research, London generated compounds that bind to brachyury an order of magnitude more potently than any previous compounds, including some that appear to suppress the brachyury protein in cells. We also initiated two projects applying powerful computational modeling approaches to further improve the potency of these compounds. The next step is to create compounds that can eliminate brachyury in mouse models and serve as a starting point for brachyury drug discovery programs within companies.



Dr. David Drewry

University of North Carolina

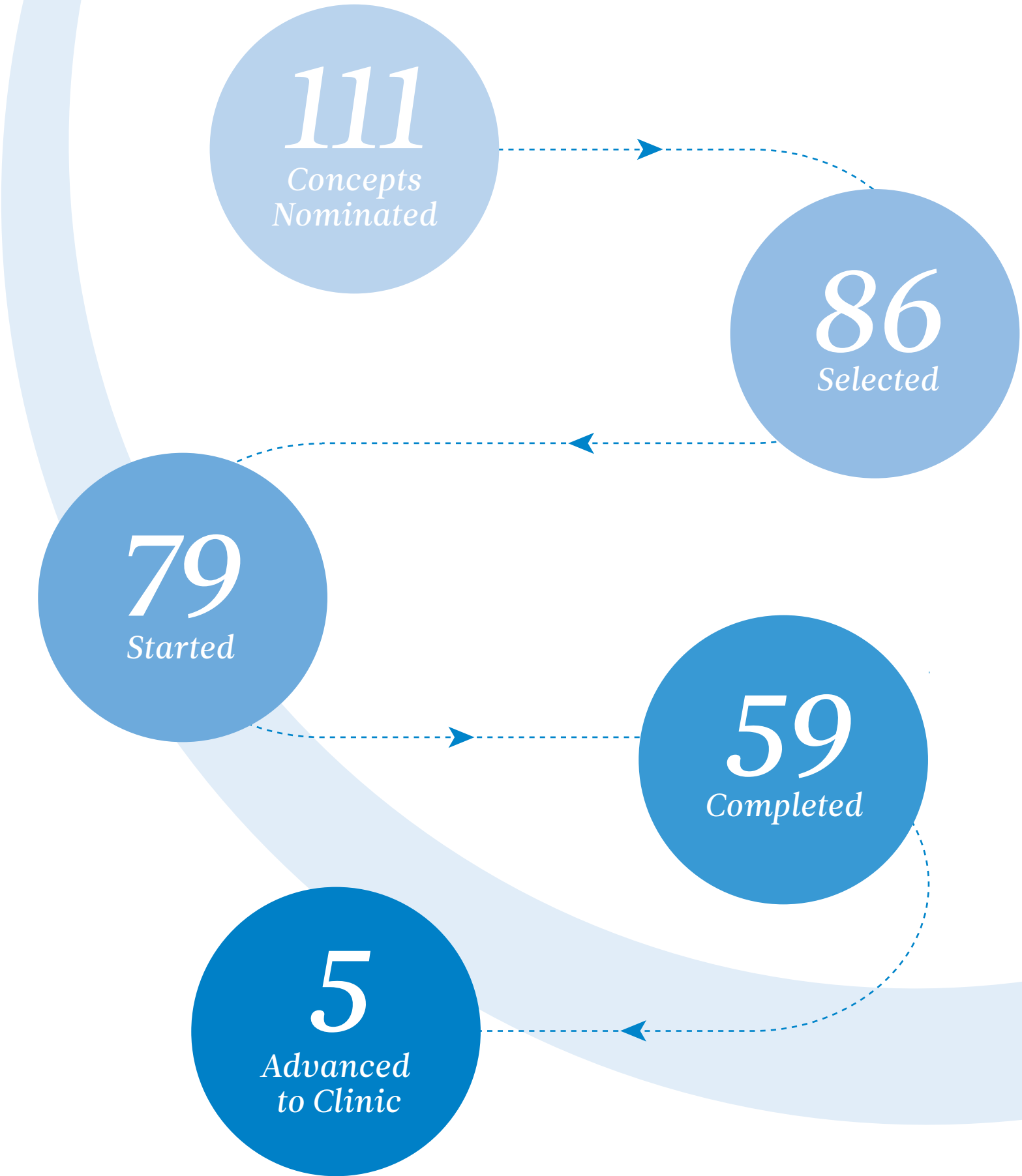
PHOTO BY JEYHOUN ALLEBAUGH/UNC-CHAPEL HILL

ACCELERATING CURES

Better treatments in the near term

In 2021 our Drug Screening Program shined as a powerful tool for accelerating promising therapies from the lab into the clinic. Based on compelling drug screening data generated previously, we funded a clinical trial at the University of Texas MD Anderson Cancer Center testing the cancer drug cetuximab. In parallel, we continued searching for additional options by testing a record 25 treatment concepts in mice, on behalf of 10 researchers or companies. Several of these concepts dramatically decreased tumor growth and have strong potential to move into clinical trials. Looking to the future, we invested in expanding our drug screening capabilities so we can identify markers that could predict response to various therapies, as well as start testing promising immunotherapies preclinically.

Drug repurposing progress through 2021



ACCELERATING CURES

Jumpstarting pediatric chordoma research

Pediatric chordoma may differ in important ways compared to the disease in adults, so we're working to better understand its potentially unique biology and determine the best treatment approaches for children. To that end, we're collecting precious pediatric chordoma tumor samples, testing drugs against pediatric chordoma models, and looking for new vulnerabilities to target.



Sloane Swanton

In 2021, Sarah and Mat Swanton suffered the devastating loss of their daughter Sloane to chordoma. Her bright light shines on through the Sloane Swanton Research Fund, which supports our work to ensure far better outcomes for future pediatric chordoma patients.

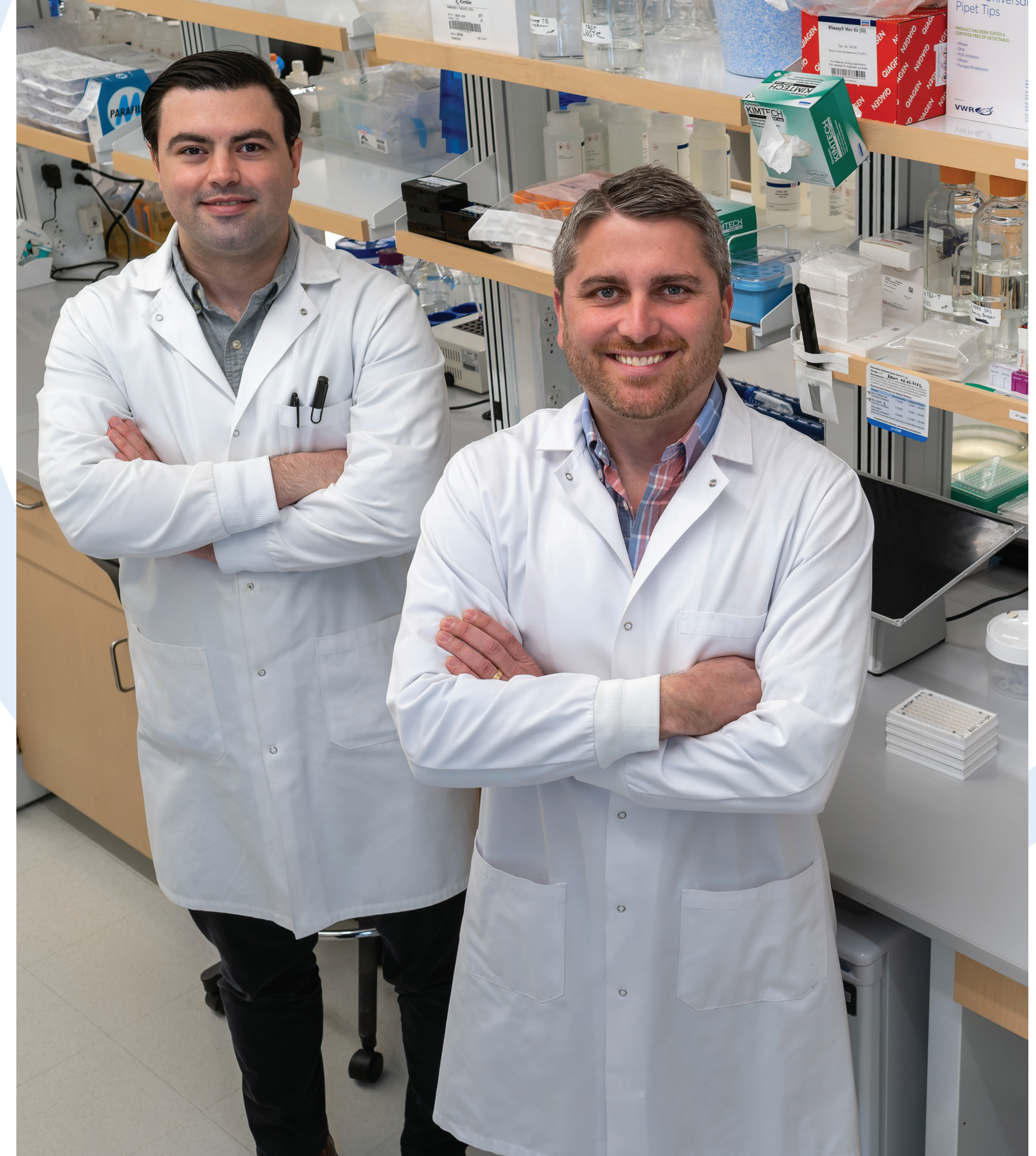
To learn how to set up a named fund to support any of our research initiatives, contact development@chordoma.org.

ACCELERATING CURES

Introducing CF Labs: our most powerful tool for accelerating chordoma research

In the past fifteen years, we've greatly increased the pace of progress by playing a more hands-on role in creating a productive research ecosystem. But it's also become clear that to truly make research move at a pace consistent with the urgent needs of patients, a further leap in speed and efficiency is needed. To make that happen, this year we launched the first lab 100% dedicated to chordoma research. It vastly increases the breadth of experimental capabilities we can offer to the global research community and the questions we can answer. With the unprecedented nimbleness CF Labs provides, our next chapter promises to be one in which our yearning for better treatments is finally matched by our ability to influence their discovery. Learn more:

chordoma.org/CFLabs



NINDO PUNTURI AND DR. DAN FREED AT CF LABS

Improving lives

We're here to support patients and families at all stages of their experience with chordoma.
In 2021, that included:

15,695

*views of our Doctor
Directory*

1,800+

*educational materials
accessed*

1,300+

*members in Chordoma
Connections, our online
community*

537

*families given free,
personalized support from our
Patient Navigation Service*

This year also saw a significant expansion of our international outreach efforts: We grew our team of volunteer Ambassadors outside the U.S. and provided key educational resources in seven languages. Better serving patients everywhere is among our top priorities in the year to come. View our growing number of international resources at chordoma.org/international.

Expanding opportunities to learn and connect

The ongoing pandemic provided an opportunity to further expand our free virtual programs, making support and connection more accessible than ever.

Through five webinars accompanied by detailed new content, we shared hope, knowledge, and solutions for common physical, emotional, and practical quality of life challenges. In addition, we launched professionally facilitated monthly virtual support groups, a place to share and be encouraged by peer experiences.

These offerings are part of our [Chordoma Survivorship Initiative](#), which supports the overall health and wellbeing of chordoma patients and families beyond the initial diagnosis and treatment period. We'll continue to expand the Initiative in 2022 through a greater number of survivorship topics and virtual groups.



Dr. Pounesh Fazeli

*Neuroendocrinologist at
University of Pittsburgh and a featured
expert in our 2021 webinars*

We're not meant to do life alone. Each time I participate in a virtual group, I walk away encouraged. It's amazing to connect with people around the world who share similar struggles and experiences with chordoma. The group helps me overcome feelings of isolation and hopelessness. I feel so blessed to have connected with it."



Shari Grueninger

*chordoma survivor
(pictured here
with spouse, Jim)*

Join Us

Peer Guides

Life-changing relationships

Peer Guides connect one-on-one with individuals affected by chordoma. By providing empathy and wisdom to others, you'll form close personal ties that ease loneliness and stress. Our self-paced, online training program makes it easy to get started.

Ambassadors

Local support, global reach

Our Ambassadors help chordoma patients and families outside the U.S. connect with local resources — and each other. You'll also help distribute educational materials to medical centers and identify chordoma-experienced doctors in your country.

Contact support@chordoma.org to volunteer as a Peer Guide or Ambassador.



Irene Badura

*Ambassador to Germany and
grandmother of patient*

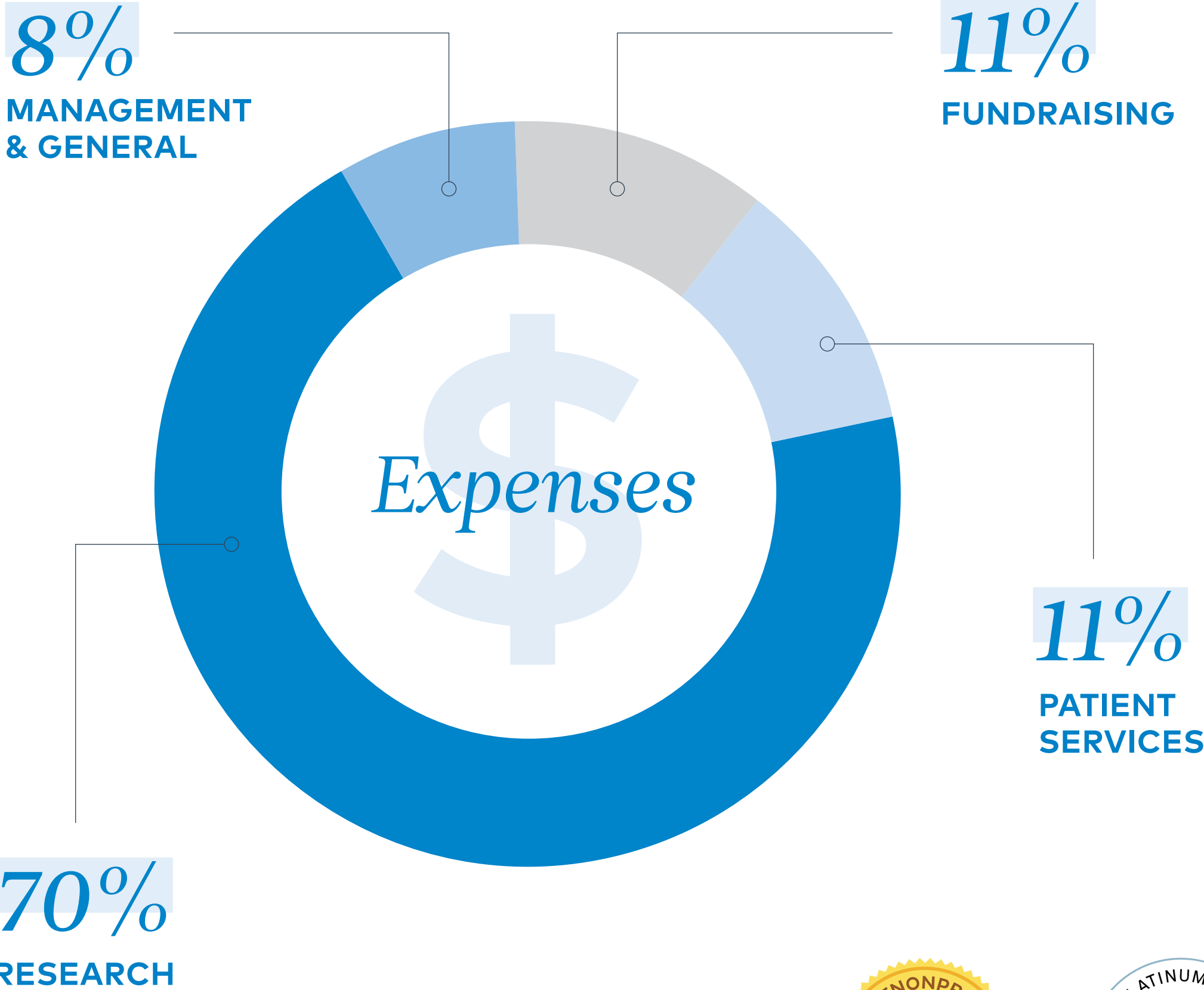
Financials

REVENUE AND
SUPPORT
\$3,257,137

EXPENSES
\$3,543,567

NET ASSETS,
BEGINNING OF YEAR
\$4,697,761

NET ASSETS,
END OF YEAR
\$4,398,031



Our 2021 IRS Form 990 and audited financial statements are available at chordoma.org/financials.



I’ve had the honor of serving on a number of different boards and committees over my 40 years as a partner in a large CPA firm, and the Chordoma Foundation team members have all demonstrated a high degree of professionalism and dedication to our vital cause. It is comforting to know that the Foundation is in a well-run, secure financial and administrative position.”



Leslie Adler, CPA

chordoma patient

Donors



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

\$1M+

The Marcus Foundation

\$500,000+

Beckman Family Foundation

The Mark Foundation for Cancer Research

Moira and Gary Sinise

\$100,000+

Stanley, Marion, Paul and Edward Bergman Family Foundation

Cedar Street Foundation

Ciara Arts & Science Foundation

Fleisher Family Foundation

Lynette and Foster Friess

Hirsch Family Foundation

George Joseph

Kenneth Koza

Stephanie Neuman

Herbert & Nell Singer Foundation

Triad Foundation

\$25,000+

Anonymous (6)

Roz and Adam Abram

The Drew Barker-Wright Charity

The Becherer Family Charitable Giving Fund

Michael Bluhm

Bruns Foundation

Robert and Louise Cohen

Cracchiolo Family

Charles and Marna Davis Foundation

Dawson’s Circle of Hope

Hester M. Digges Trust

Janet and Richard Fell

Robert Greenebaum

Bob & Dolores Hope Foundation

Illinois Tool Works Foundation

Michael Torrey and Cheryl Kugel-Torrey

Kit and Bob Lennon

John Lewis

Christine and Joe McGovern

The Orokawa Foundation, Inc.

Susan Pence

Reinhardt Family Trust

SBES Clients Consolidated Charitable Foundation

Erin and Jeff Schilling

Grace and Andrew Schoelkopf

Christy and Joel Shaffer

Sarah and Matthew Swanton

Tres Chicas Foundation

TrueScripts Foundation Fund

Tully Family

The Van Sickle Fund

Mark and Maria Velleca

Karen and Richard Westin

DONORS

\$250,000+

Beckman Family Foundation
Fleisher Family Foundation
The Marcus Foundation*

\$100,000+

Ciara Arts & Science Foundation
Kenneth Koza
Herbert & Nell Singer Foundation

\$25,000+

Anonymous (3)
The Drew Barker-Wright Charity

Stanley, Marion, Paul and Edward Bergman Family Foundation
Cedar Street Foundation
Cracchiolo Family
Bob & Dolores Hope Foundation

Richard Horvitz and Erica Hartman-Horvitz Foundation
George Joseph
Steven Kanter*
Christine and Joe McGovern*

The Orokawa Foundation, Inc.
Reinhardt Family Trust
Erin and Jeff Schilling
Grace and Andrew Schoelkopf*

Shared Health Alliance
Esta Stecher*
Sarah and Matthew Swanton
Triad Foundation
Tully Family*
Maria and Mark Velleca

\$10,000+

Anonymous (2)
Alpert Family Foundation*
Bill and Anne Bachrach Family Fund
The Becherer Family Charitable Giving Fund
Better Than Ezra Foundation
Bright Funds
Robert Cohen*

Lorna and Stuart Cook
Charles and Marna Davis Foundation
Dawson's Circle of Hope
Abby Donnell
Janet and Richard Fell
Joanne Fournier
Janie and Adam Frieman
Robert Greenebaum
Aaron and Maggie Hayek
Illinois Tool Works Foundation
Michael Torrey and Cheryl Kugel-Torrey
Maria and Steven Mandel

Christy and Joel Shaffer*
Cody Smith
Tres Chicas Foundation
TrueScripts Foundation Fund

\$5,000+

Anonymous
Amy Adams
American Online Giving Foundation
Betsy Blackwell and John Watson
Michael Bluhm
Rosalynn Bonamusa
Bridenbecker Family Trust
Beth Cullinan

DC Medical LLC
Fayetteville Fallen Heroes, Inc.
Paul and Maria Feldman Charitable Foundation
Lea Glazar
Bobbi Gruwell
Andrew Hettinger
Gary Hulett
David Hunt
Maine Community Foundation
Bruce Marcus
Julie and Scott Moller
Robert and Antoineta Neff
Brian O'Sullivan
Point of Grace Christian

DONORS

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The Song Family Fund	Annika Folcker Aschan	Elizabeth and William Case	Daniel Dempsey	Colleen Honan	Carol Lippoli
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Alan and Suzie Wendorf	Benevity Causes	Charity Golf International	Juan Garcia	Jeffrey and Marnie Kaufman Fund	Bianca Mancinelli
\$1,000+	BEP Organization	Ann and Richard Citarella	Peter Gerhard	Judy Kirkland and James Kenneth Wilson Family Foundation	Rhoda and Leslie Mandel
	Charitable Gift Fund	Mona and Kenny Cohen	Ruhma Ghazi	KPMG	Michelle Matthews
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	David Biondi	Collins Electric Co.	Greater Twin Cities United Way	Kirsten Larsen	Catherine McGowan
Anonymous (8)	Myrna Blume	Theresa Cooney	Jackie and Damian Green		Joseph Meyerowitz
Hans Aagaard	Jeremy Boreing		John Guckert		Michael Munro
					Sally and Ron Munro

DONORS

Dennis Murphy	Pfizer	J. Martin Smiley	Veritas Foundation Fund	Jaynee and Eric Beckman	Raven Chong
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				Edward Chaloner	Joan Funk
					Robert Gavin
					Kate and Steve Gill

DONORS

Kerry and Eddie Gilmartin	Michelle and Danny Kalenov	Mandelbaum Family Fund	Bailey Munro	Adam Reeves	Mary Taylor
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David Johnson		Ann Beth and Ed Mulloy	Michael Potempa, Jr.		Susan Witek
Jeffrey Jones					

We sincerely appreciate every gift and regret any errors or omissions that we may have made to the above list. Contact development@chordoma.org with questions or corrections.

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

Champions

We're grateful to our Chordoma Champions, who rallied their personal networks to fundraise for the Foundation, giving their family, friends, and colleagues the opportunity to be part of our shared quest.

Darya Alexander
Irene Badura
Sharon Berlan
Sue Brenneman
Kenny Brighton
Renée Butler
Lilly Caro
Erik Clark
Kathy Flores and family
Paul Herrick

Daniel and Michelle Kalenov
Janice Kennedy
Campbell Krotee
Kim Mahr
John Mainey and friends
Kate Mason
Tim McCormack
Michael Munro and family
Noreen and Mick Potempa
The Riccomini family

Marcelina and Martin Schiele
Jeff Schilling, Maggie Bates,
and Priscilla McInnes
Maureen Schroer
Sarah and Mat Swanton
Team Mac
Mark and Jenna Thompson
Wally van Laarhoven and
David Andrewartha

I've met many doctors who've said that patient participation through the Chordoma Foundation is unusual — and wonderful. This disease is so rare; it falls to us to help find new treatments and a cure. If not us, who? If not now, when? We've made progress, but we're not there yet."

**Sharon
Berlan**

*chordoma survivor,
pictured here with
husband Rob Strauss*



Team

We know chordoma is a solvable problem. How fast it gets solved depends on the contributions of every one of us affected: whether by donating, hosting a fundraiser, participating in research, or supporting others in the same boat. Our new staff members, Sara Nick and Kimberley de Haset, are here to help you propel our shared mission forward, and to share the progress that results.

Staff

Josh Sommer
Co-Founder and Executive Director

Kenny Brighton
Head of Philanthropy

Daniel Freed, PhD
Head of Target Discovery and Translational Research

Larry Gottschalk
Operations Coordinator

Kimberley de Haset
Program Manager

Diane Ignar, PhD
Head of New Drug Development

Andrea Locke
Patient Navigator

Shannon Lozinsky, MSW
Director of Patient Services

Sara Nick
Head of Engagement

Tammy Silverthorne
Director of Operations

“The many examples of participation I’ve seen in this community are inspiring and energizing. I’m honored to work with families touched by chordoma to turn hope for a better future into tangible progress.”

Sara Nick

Head of Engagement

Get in touch with Sara
about taking action.



TEAM

In 2021, we added marketing leader Alicia Jeffreys (pictured with her family on the cover) to our Board of Directors and CPA Leslie Adler to our Finance Committee. Their collective expertise is allowing us to reach our goals more quickly than ever.

Board of Directors

David Sandak
Chair

Ingemar Lanevi
Treasurer

Julie Song
Secretary

Paul Feldman, PhD

Steven Golick

Christopher Heery, MD

Alicia Jeffreys

Ed Les, MD

Sue Mahony, PhD, MBA

Steven Mandel

Shreyas Patel, MD

Christy Shaffer, PhD

Josh Sommer

John Therien

We're also fortunate to benefit from the talents of dozens within our six [Board committees](#); our [Medical](#), [Scientific](#), and [Community](#) Advisory Boards; and our [Ambassadors](#) and [Peer Guides](#).

*Heartfelt
thanks this
year to Andy
Schoelkopf*



for completing eight years of extraordinary service on our Board of Directors. During his tenure — including five years as Board Chair — Andy played leading roles in the launch of our Patient Services department, our \$16M ALL IN campaign, and in the continued growth and professionalization of the organization. We're deeply grateful to Andy for the enduring impact he's made on the organization, and all that he's done and continues to do to support our mission.

When our daughter Kaitlin was diagnosed with chordoma at age 17, our world as we knew it fell apart. Thankfully, the guidance and sense of community provided by the Chordoma Foundation became the glue that slowly pieced our world back together. We're forever indebted to them for their unyielding perseverance toward a cure. They deliver families' most critical element: hope.”



Dr. Mark Slepian

pictured here with spouse, Laurie; and daughter and chordoma survivor, Kaitlin



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