One in a million, but not alone
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.

JOSH SOMMER
Executive Director, Co-Founder, and chordoma survivor
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.

<table>
<thead>
<tr>
<th>Research</th>
<th>Treatments</th>
</tr>
</thead>
<tbody>
<tr>
<td>2007: Virtually no research being done and no infrastructure to enable it</td>
<td>2007: No movement toward new treatments</td>
</tr>
<tr>
<td>Today: Vibrant global research ecosystem</td>
<td>Today: Fast-moving therapeutic development pipeline</td>
</tr>
<tr>
<td>$15.8M in cumulative research investments, plus $20M+ leveraged from others</td>
<td>6,000 drugs screened against chordoma cell lines</td>
</tr>
<tr>
<td>300+ researchers collaborating toward a cure</td>
<td>70+ promising drugs and combinations tested in mice through our Drug Screening Program</td>
</tr>
<tr>
<td>30+ high-quality cell and mouse models easily available to scientists</td>
<td>7 treatments brought into clinical trials</td>
</tr>
<tr>
<td>Tumor tissue from 250+ patients banked for research</td>
<td>25+ disease drivers and therapeutic targets revealed</td>
</tr>
</tbody>
</table>
## 15 YEARS OF PROGRESS

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>2007</th>
<th>Today</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients frequently misdiagnosed and mistreated due to limited clinical awareness</td>
<td>• Evidence-based guidelines for medical professionals diagnosing and treating chordoma</td>
<td>• 215+ experienced doctors in our Doctor Directory</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Support</th>
<th>2007</th>
<th>Today</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nowhere to turn for support and reliable information</td>
<td>• 3,000+ families provided with free, personalized Patient Navigation Service to access expert care and get their questions answered</td>
<td>• Comprehensive educational resources for patients and caregivers • Numerous opportunities for people affected by chordoma to connect with peers</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Influence</th>
<th>2007</th>
<th>Today</th>
</tr>
</thead>
<tbody>
<tr>
<td>No way for those affected by chordoma to change the outlook</td>
<td>• Multiple ways to participate in research from donating tumor tissue to joining a natural history study or clinical trial</td>
<td>• Donations of all sizes can directly advance research and improve patient care</td>
</tr>
</tbody>
</table>
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.

$2.5M
invested in research in 2021

14
currently funded research teams

9
new research publications

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
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.
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.”
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
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.
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.
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
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](http://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. Pouneh 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+
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
<table>
<thead>
<tr>
<th>Amount</th>
<th>Donors</th>
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<tbody>
<tr>
<td>$250,000+</td>
<td>Beckman Family Foundation, Fleisher Family Foundation, The Marcus Foundation*</td>
</tr>
<tr>
<td>$100,000+</td>
<td>Ciara Arts &amp; Science Foundation, Herbert &amp; Nell Singer Foundation</td>
</tr>
<tr>
<td>$25,000+</td>
<td>Anonymous (3), The Drew Barker-Wright Charity</td>
</tr>
</tbody>
</table>

**$10,000+**
- Shared Health Alliance
- Esperanza
- 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*

**$1,000+**
- 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*
DONORS

Polsinelli
Noreen and Mick Potempa
Colleen and Richard Riccomini
Mark and Laurie Slepian
The Song Family Fund
David and Peggy Tanner Philanthropic Fund
Tricia and Andy Thompson
UK Fund for Charities
Alan and Suzie Wendorf

$1,000+
Anonymous (8)
Hans Aagaard
Patricia and Randy Akers
AmazonSmile Foundation
American Express Foundation
William Andrews
Annika Folker Aschan
Irene Badura
Shelba Barnes
Warren Barrett
Benevity Causes
BEP Organization Charitable Gift Fund
Sharon Berlan and Robinson Strauss
Ed Bernero
David Blondi
Myrna Blume
Jeremy Boreing
William Buhrman
Debra Burlingame
Harold Carlson
Ronni and Scott Carpenter
Elizabeth and William Case
Anita Cassarino and Steve Carboni
David Cenaiko
Monica Cepin
Charity Golf International
Ann and Richard Citarella
Mona and Kenny Cohen
Samuel Cohen
Michael Colbert
Collins Electric Co.
Theresa Cooney
Frank Courtney
Clara Cracchiolo
Mary and Peter Cullinan
Robert Cutts
Daniel Dempsey
Terri Emmett
Jack Fife
Cindy and Scott Frodle
Juan Garcia
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Ruhma Ghazi
Mary and Lloyd Gran
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Jackie and Damian Green
John Guckert
Marc Gurvitz
Camille Harris
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Mary and Robert Kuhnlein
Ira and Lillian Langsan Fund
Kirsten Larsen
Frankie and Ken Lee
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Terri and John Mainey
Bianca Mancinelli
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Michelle Matthews
MaxiVAX SA
McCanna Foundation
Catherine McGowan
Joseph Meyerowitz
Michael Munro
Sally and Ron Munro
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Alexander Nandaner
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Janet Nolan
Kathleen Parker
Kathleen and Jim Patton
Sarah Penniston-Dorland and William Dorland
Kip Perry
Perry Lodge No. 1851 BPOE
Kristiina Perttila and Louis Parrillo
Pfizer
Pinnacle Charities
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Adriane Rothstein and Mark Billy
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Carol Siedhoff
Robert and Mylles Sinise
The Skyline Charitable Foundation Inc.
J. Martin Smiley
Doug Smith
Josh Sommer and Rachel Lichte
Julie Song and David Smyth
James Srygley
Joseph Stanley Charitable Trust
Karen and Robert Stanuch
Kimberli and Steve Sterling
Barry Swidler
Elliott Tarson
Jon Tennyson
Heather and John Therien
Lawrence Tistaert
Veritas Foundation Fund
Catherine Villinski
Joseph and Allison Villinski
Colleen and Terry Wilkins

$500+
Anonymous (8)
Leslie Adler
Brian Allen
Robert Allen
American Century Investments
American Express Company
Amgen
David Andrewartha
Jaynee and Eric Beckman
The Daniel and Karen Berman Foundation
Teresa and Robert Boccanfuso
Millicent Bogert
Dusty Bowenkamp
Jay Brantley
Sue and Gene Brenneman
Kenneth Brighton
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Raven Chong
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Barton Couch
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Armand Dhamo
Annie Dietzen
Thomas Doar
Michael Dairon
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Barrett Ethridge
Russell and Virginia Flaim
Simona Frateschi
Lynn Etheredge Fund
Joan Funk
Robert Gavin
Kate and Steve Gill
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Anita Gupta
Janet Halfar
Andrew Hamilton
Darlene Hanes
Robert Harris
Jeremy Hart
Courtney Hatch
Aaron House
Andrew Huggett
Lisa Jaubert
David Johnson
Jeffrey Jones
Michelle and Danny Kalenov
Joseph Kane
Pamela Kindler
Amy and Shane Knee
LeAnn Kroll
Celine Bourke Kuhn and J.C. Kuhn
Eleanor and Richard Leong
Susan and Richard Lichte
Amir Lozani
Sandra and Kenneth Lyles
Debbie Mainey
Mandelbaum Family Fund
Andrea Mandell
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Dolores Martinez
Cynthia McAfee
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Ellis and Darci Medoway
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Bailey Munro
Patricia Munro
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Stacy Neir
Naomi Nemtzow and Peter Casanave
Rob and Jean Normandy
Leen and Sharon Oberlander
Gillian and Mike Parrish
Eric Perrotta
Ashley Pert
Diane Pitt
Martin Porter
Michael Potempa, Jr.
Adam Reeves
Dorothy and Dietmar Riccomini
Raymond Riccomini
Kieran Sharpe
Gregg Slepick
J. David Small
Scott Smaller
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Shaun Southall
Mike Staveris
Michael Swift
Phyllis Tanaka
Mary Taylor
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Janis and Jeffrey Tillman
Diana Tischer
Pat and Jane Tracy Fund
Margaret and Mark Tritschler
Cuneyt Vanli
James Waide
Rebecca Weaver and Curtis Croley
Robert Wellstein
Claus Werner
Kenneth Wilson
Susan Witek

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 Haseth, are here to help you propel our shared mission forward, and to share the progress that results.

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 Haseth
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.
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.

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.
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.”