Improving the lives of those affected by chordoma
Leading the search for a cure
Chordoma is a rare cancer that grows in the **bones of the skull and the spine**.

- Strikes people of all ages
- Occupies some of the body’s most valuable real estate: near the brain, spinal cord, nerves, and vital arteries
- Is complicated to remove
- Commonly regrows

Which is why we relentlessly pursue better treatments, better care, and a better experience for all affected.

*We face an **uncommon disease.***

Chordoma patient Madison Jones with her father, Chris, and step-mother, Angela.
Chordoma is one of > 300 rare cancers that, together, account for one quarter of cancer cases and represent the 5th leading cause of death.

Like many rare cancers, chordoma:
- Takes a toll on patients and families
- Poses a major medical challenge
- Lacks adequate treatment

But there’s something different about chordoma ...
We envision a future in which everyone affected by chordoma is able to overcome the disease and maintain their quality of life. To achieve this vision, we invest in three essential and mutually reinforcing program areas:

**RESEARCH**

- to find *better treatments*

**PATIENT SERVICES**

- to create *better experiences*

**HEALTHCARE IMPROVEMENT**

- to drive *better care*

- *ENABLES THE DELIVERY OF BETTER CARE*

- *FOSTERS PATIENT PARTICIPATION IN RESEARCH*

- *CONNECTS PATIENTS WITH RELEVANT STUDIES*

- *ENGAGES PATIENTS IN FINDING SOLUTIONS*

- *DRIVES REFERRALS TO QUALIFIED SPECIALISTS*

- *DEFINE THE TREATMENT GUIDELINES THAT UNDERPIN PATIENT EDUCATION*

An experimental treatment saved the life of Frankie Fernandes, who was diagnosed with chordoma at age five.
Lonely and bewildering journey

Lack of consensus on how to diagnose and treat

Handful of isolated researchers

No companies investing in chordoma

Virtually nothing known about the biology of the disease

2 clinical trials ever

**THEN**

**NOW**

✓ Comprehensive patient services

✓ Published treatment guidelines

≥ 300 researchers studying chordoma

12 companies investing in chordoma

≥ 20 possible drug targets identified

7 NEW clinical trials initiated, 10 by 2020

**at an uncommon pace ...**

Chordoma survivor, CF Community Advisory Board member, and Team Chordoma captain Steve Mandel completes his fourth half marathon. Since 2012, Steve has run to raise awareness about chordoma and funds for chordoma research.
As a neurosurgeon, I’ve cared for chordoma patients for over thirty years. It’s remarkable how dramatically the outlook for these patients has improved over the last ten years since the Chordoma Foundation took up the mantle. To say they’ve taken the bull by the horns would be an understatement.

I’ve not seen anything like this in other diseases.”

- Dr. Chandra Sen, Neurosurgeon, NYU Langone Medical Center, CF Medical Advisory Board
Tens of billions of dollars are spent every year on cancer research. How can a small foundation have any real impact?

In truth, doing business as usual, it can’t.

That’s why the Chordoma Foundation has re-engineered the way research is done, to make the process faster and more efficient.

“*The progress the Chordoma Foundation has catalyzed in the span of 10 years is unprecedented, and is charting a path for other diseases.*

It serves as an example of what’s possible when the right ideas, the right people, and the right resources come together to tackle a rare disease, and it illustrates the power of patient involvement.”

- Dr. Stuart Schreiber, Co-Founder, Broad Institute of Harvard and MIT

**Shared Resources**
We develop and provide easy access to all of the critical tools of cancer research: tumor tissue, cell lines, and mouse models — resources that were once nonexistent for chordoma, and are often surprisingly difficult and costly for researchers to obtain.

**Parallel Processing**
We proactively find or create opportunities to include chordoma alongside other types of cancer in large-scale research projects.

**Focused Investments**
Rather than just passively reviewing an assortment of funding requests — as is typical for research funders — we invest proactively and according to a plan, in projects identified as top priorities by the research community.

**Incentives**
We harness economic incentives to drive investment in chordoma research by scientists (e.g., offering prizes) and companies (e.g., providing a viable path to orphan drug status).

**Economies of Scale**
We centralize commonly performed experiments to eliminate redundant investments across multiple labs, and drive down the time and costs of experiments.

**Collaboration**
We connect doctors, scientists, and companies with complementary interests, capabilities, and resources to carry out projects that none could do alone.
“We have been blown away by the incredible love and support the Foundation has shown us. They have been by our sides throughout this roller coaster, helping us figure out what questions to ask. When Todd’s tumor came back, they helped guide us through the complex medical maze that we faced.”

– Brittany Fuchs, wife of chordoma patient Todd Fuchs, pictured on their wedding day in 2014.

While working to develop better treatments for tomorrow, we are creating a better experience for those living with chordoma today.
We are here to provide:

**Education**
Resources to help understand chordoma, how it is appropriately treated, and how to deal with the consequences of the disease.

**Navigation**
Personalized, one-on-one assistance to find the best treatment options, and overcome barriers to getting appropriate care.

**Support**
Opportunities to connect in-person and online with a supportive community of peers who can illuminate the road ahead and offer a shoulder to lean on along the way.

Listening to the unique needs of our community, we have crafted a suite of continually-improving programs tailor-made to serve patients and families throughout every step of their journey with chordoma.

Chordoma patient, community fundraiser, and CF Community Advisory Board member Jeff Schilling with his daughters Claire and Kate, who helped raise awareness about chordoma at their school.
Imagine a future in which everyone affected by chordoma is able to overcome the disease and maintain their quality of life.

That is our vision. **Perseverance is our promise.**

**Perseverance** was the last word Justin Straus wrote after chordoma robbed him of his voice and before it took his life. It has become the rallying cry uniting our community in the fight against chordoma.
That future is now within reach.

Chordoma research is at a pivotal moment:
A growing number of promising new therapies are reaching human clinical trials, and a strong pipeline of preclinical drug candidates are moving toward the clinic as well. No longer are better treatments decades away - they are now possible within years.

“Chordoma is a solvable problem. It’s not a matter of if, but when. The key variable is who joins with us to be a part of the solution.”

- Josh Sommer, CF Co-Founder and Executive Director
BE A PART OF SOMETHING UNCOMMON.

JOIN US.

Chordoma survivor Matt Myers with his wife Stephanie and their two children at home in Michigan (also pictured on cover).
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