

**Sharon Berlan**

**“We Are All in This Together”**

**2022 Chordoma Community Conference  
at NYU Langone Health  
October 1, 2022**

(Online version)

While we cannot see the end of our path, embrace the beauty along the way. And the unforeseen challenges too! Walk with me on my own journey...



This was me in 2003 with my parents before any significant symptoms or diagnosis





# “A Lump in My Throat”

My journey over the last 20 years has taken many twists and turns. Let me share briefly some relevant details which are similar to so many chordoma patients



- Primary Care DR sent me to an ENT
- Misdiagnosed in 2003 even with a 2<sup>nd</sup> opinion
- *Correctly* diagnosed in 2004 with **clival** chordoma. New team at Cornell Weill, 3 surgeries 2004-2005
- 2006 new team with Dr. Sen (then at St. Lukes)
- Multiple surgeries (18 total procedures in OR) including reconstruction
- 3 series of radiation, including twice to same spot, from 2007-2020 (MGH PBT; MSKCC SBRT 2X)
- Overall: Clival, cervical, and lung mets 2009-2014
- CSF leak and spinal from spinal meningitis caused by Osteo-Radio Necrosis in both 2012 & 2021 followed by related stroke in 2021

Our wedding in 2007 was postponed due to emergency surgery and radiation. After a lengthy recovery, my husband Rob and I were married on September 14, 2008. Even a hurricane that morning could not dampen celebrating with our families and friends.





## Treatment at MSKCC:

After metastasis to my cervical spine, in 2009 I received SBRT Radiosurgery on an early proto-type machine. I was only the 5<sup>th</sup> chordoma patient treated this way



Sharon with Dr. Yamada (Radiation Oncologist) and Dr. Bilsky (Neurosurgeon)

# Learning to Embrace Survivorship



- In 2007, I stopped working due to permanent effects of medical treatment and abruptly ended a successful career as a retail executive
- Now that I had more free time, I asked my doctors, “[how can I help other patients?](#)”
  - All replied independently, help get patients “[to the experts](#)” up front before any treatment
- Inspired to take action, I dedicated myself to supporting patients and families hoping they could avoid some of the issues I faced

# Learning to Embrace Survivorship



- I co-created the “**Chordoma Survivors**” Facebook group in 2008 which migrated to a private group in 2012
  - FB Group mantra: Get multiple opinions from expert multi-disciplinary teams
- SOCIAL MEDIA has changed EVERYTHING! Now, instead of feeling isolated and perhaps never communicating with another chordoma patient, now we could be in touch often, **from all over the world!!**



# With My Heroes at CF's First Community Conference in 2008



Left to Right: Simone Sommer, Josh Sommer, Heather Lee, Adrian Rothstein, Sharon Berlan, Michael Torrey, Bill Dorland, Candice Owen, Margie Carberry and Lynette Nelson

# Early Days of the Chordoma Foundation

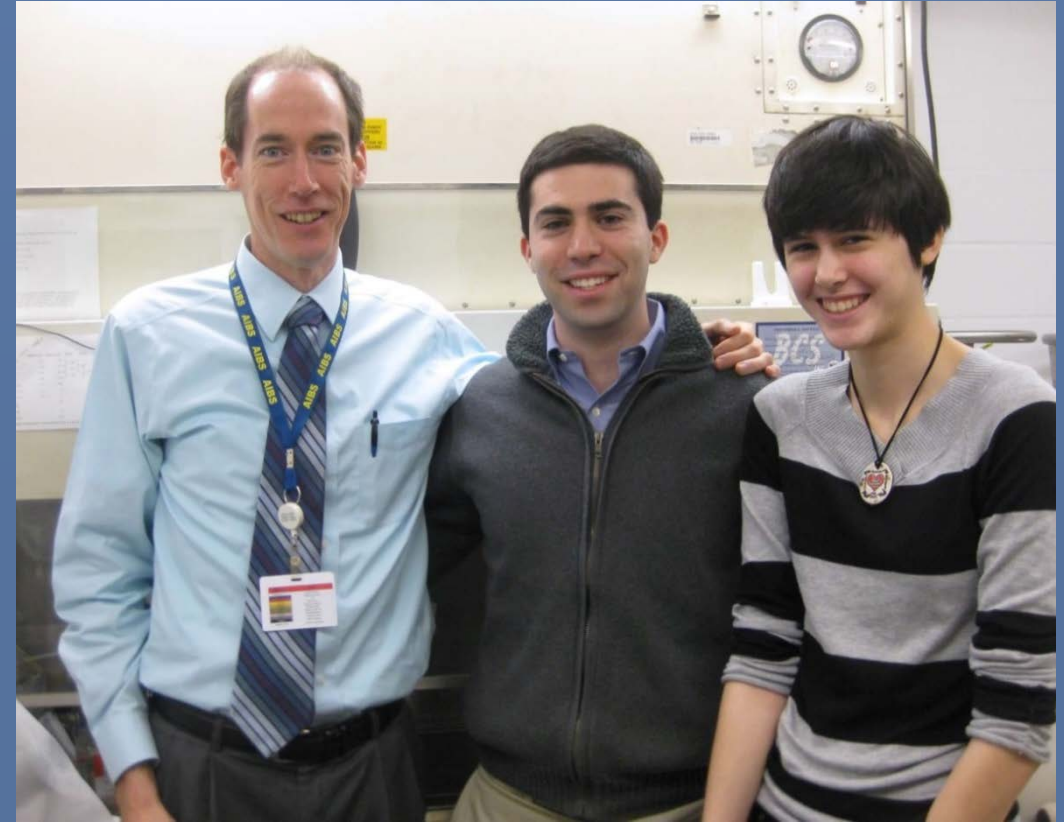
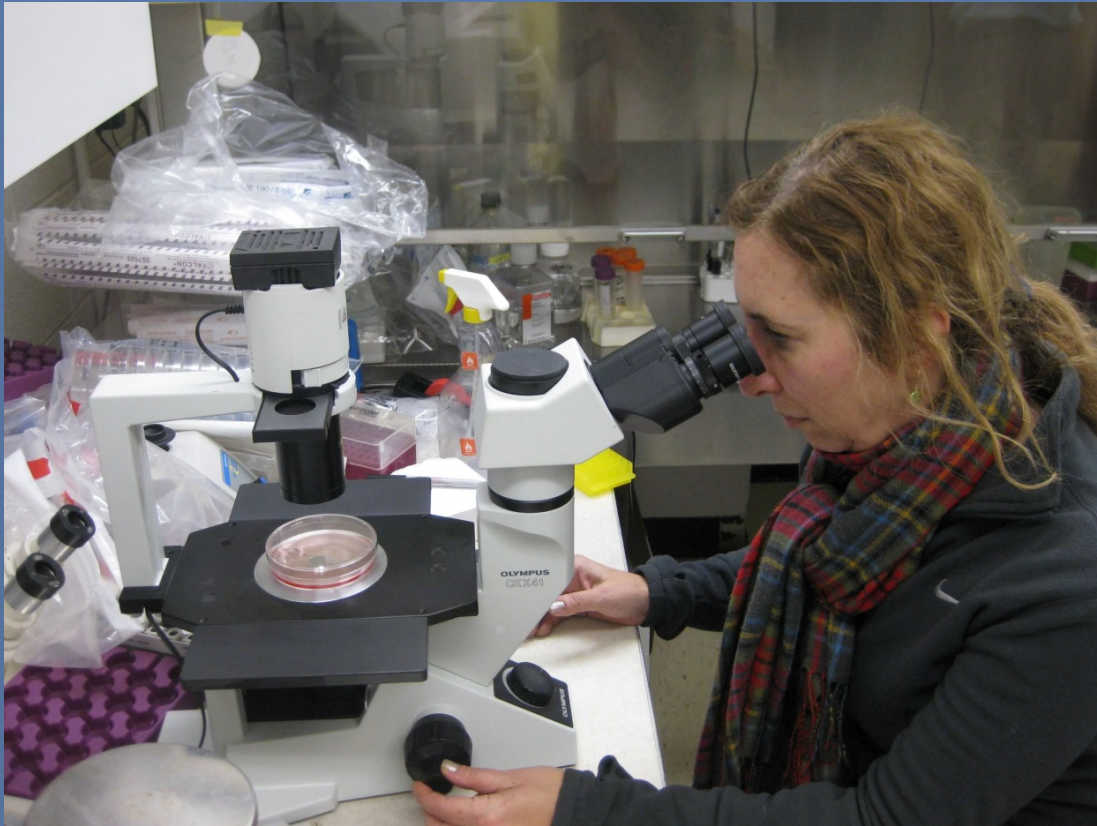
- We have come **so far** within such a short time!
- Everything I would have ever dreamed of for patient support is now thoroughly covered on the CF website.
- Comprehensive resources are all there for any **doctor, patient or caregiver** to view, learn, and act upon!



With Deirdre Callahan and Heather Lee at the Foundation's initial Peer Guide training in Durham, NC



# Early Advancements & Research: Cell Lines Research at Duke University Lab





# 2009 and 2011 Conferences – Exciting Breakthroughs, Advancing Treatments and Potential Research!



**Sharon, Steve Straus and Dr. Sen**



**Josh Sommer and Sharon**

# Friendship & Community



Sue & Gerry Fitz-Gibbons started **Chordoma UK** in 2013 to support chordoma research and raise awareness. Their efforts directly contributed to **breakthrough discoveries** at UCL Cancer Institute by Dr. Adrienne Flanagan





# Inspired by These Dedicated Fundraisers Leading Efforts to Support the Chordoma Foundation



**Mick and Noreen Potempa**



**Maureen Schroer**



**Steve Mandell and Sharon**

# Supporting One Another and Still Smiling in the Face of Adversity!



**Lindsay Roman, Sharon  
and Nadine Cordova**

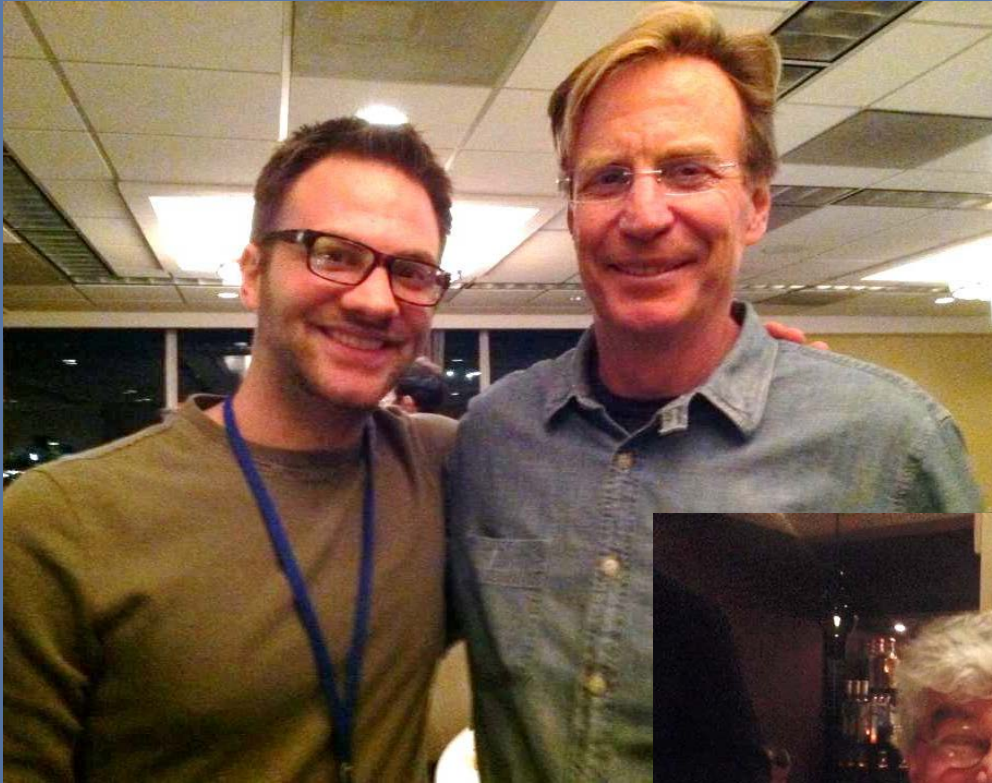


**Barrie Covington, Sharon  
and Felicia Powell**



**John Nelson, Emily Sommer  
and Madison Jones**





**John Nelson and Michael Torrey**



**Josh Sommer and Bill Dorland**



**Hans Kuelen and  
Robinson Strauss**





Sharon and  
Danny Chikva



Carol Crow, Sharon and Allison Roberts



Adriane Rothstein, Judi Novik, Norma Jones

# Finding Inspiration from Fellow Chordoma Survivors

## Jessica McGeever and Aaron McMahon

Jessica lives near Pittsburgh. She often meets and helps patients undergoing treatment at the University of Pittsburgh Medical Center.

Jessica was the patient in the NOVA video of a Dr. Sen Surgery which I watched with Lindsay Roman in 2006.

Aaron and his family attended the 2018 Conference in Boston hoping to find new Doctors after being told Aaron had no other treatment options. The CF helped the McMahon's connect with Dr. Gardner at UPMC.





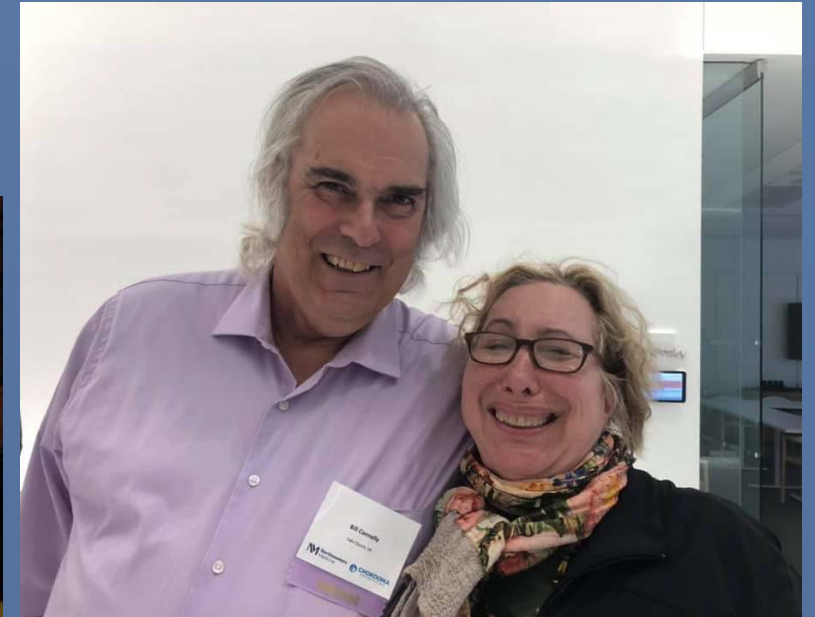
Supporting fellow patients on each other's journeys ...  
has led to so many meaningful friendships!



**Sharon and Tamara Weinstein**



**Margie Carberry and Sharon**



**Bill Connelly and Sharon**



**Sharon and Irith Abada**



**Adriane Rothstein, Sharon and Michael Torrey**



**Chris Jones and Sharon**





**Alicia Nieves and Sharon**



**Sharon and Chris Forman**



**Sharon and Bobbi Antonazzi**



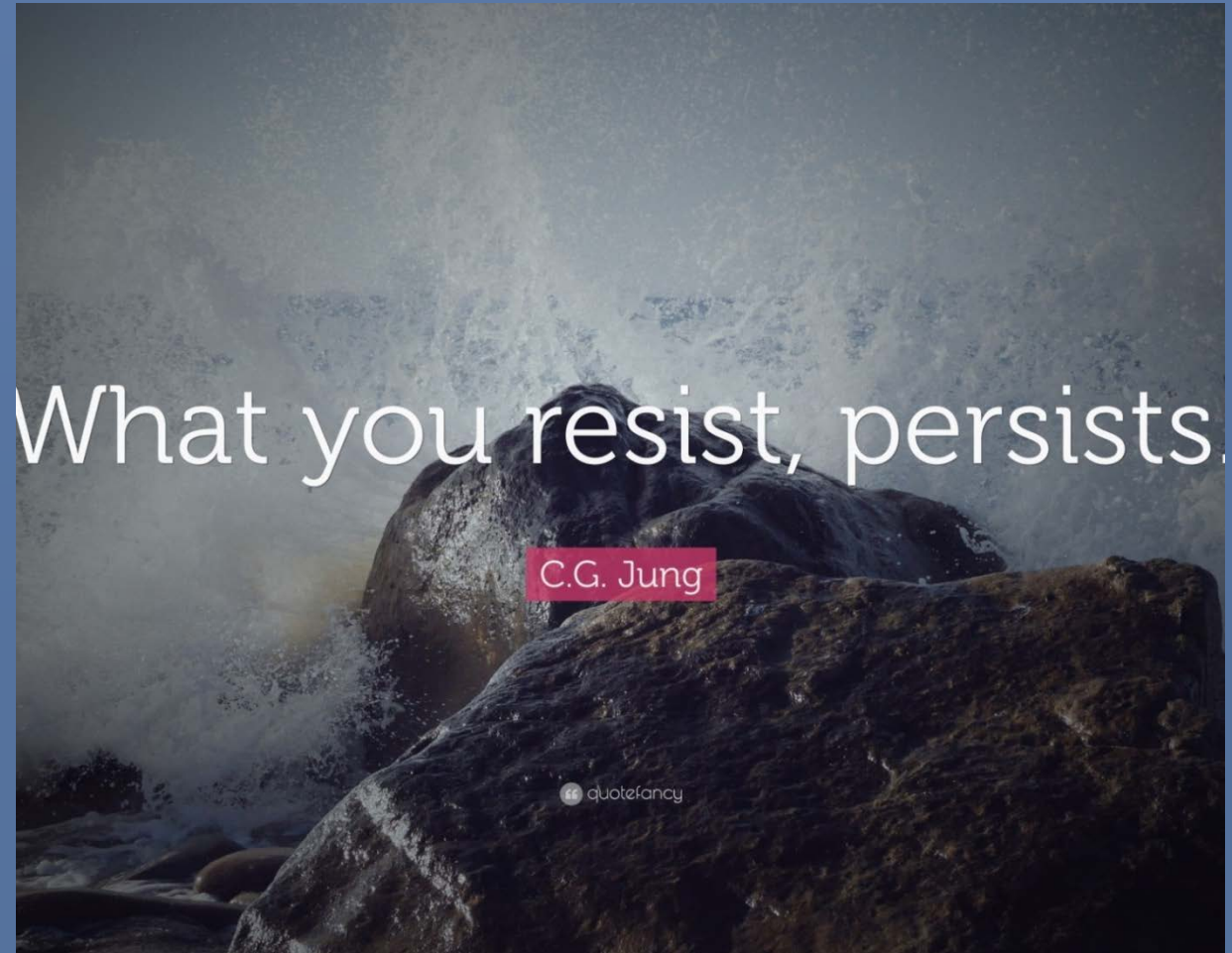
## Doctors from *Within* the Chordoma Community

Jake Griner, co-survivor and aspiring liver cancer immunologist;  
Ryan Kiser, survivor and practicing vascular neurologist.



# My Approaches to Persevering Through Challenges

- Picture salmon moving against the stream with water ...fighting vs going with the flow
- Easier to ride the horse in the direction that its going
- In hindsight: I'm grateful for the free time I have had; less stress and my disability has had a positive side
- A silver lining is concentrating on me vs work/politics, can do what I want when I want – even when to take a much needed nap!
- I think my outcome has been much better than I might have otherwise had if I were still working



# My Approaches to Persevering Through Challenges

- We have the power to attract positive or negative energy
- **Power of visualization:** During MRIs, imagining the treatment is working
- Reminds me to look at the bright side!



**THOUGHTS  
ARE THINGS**

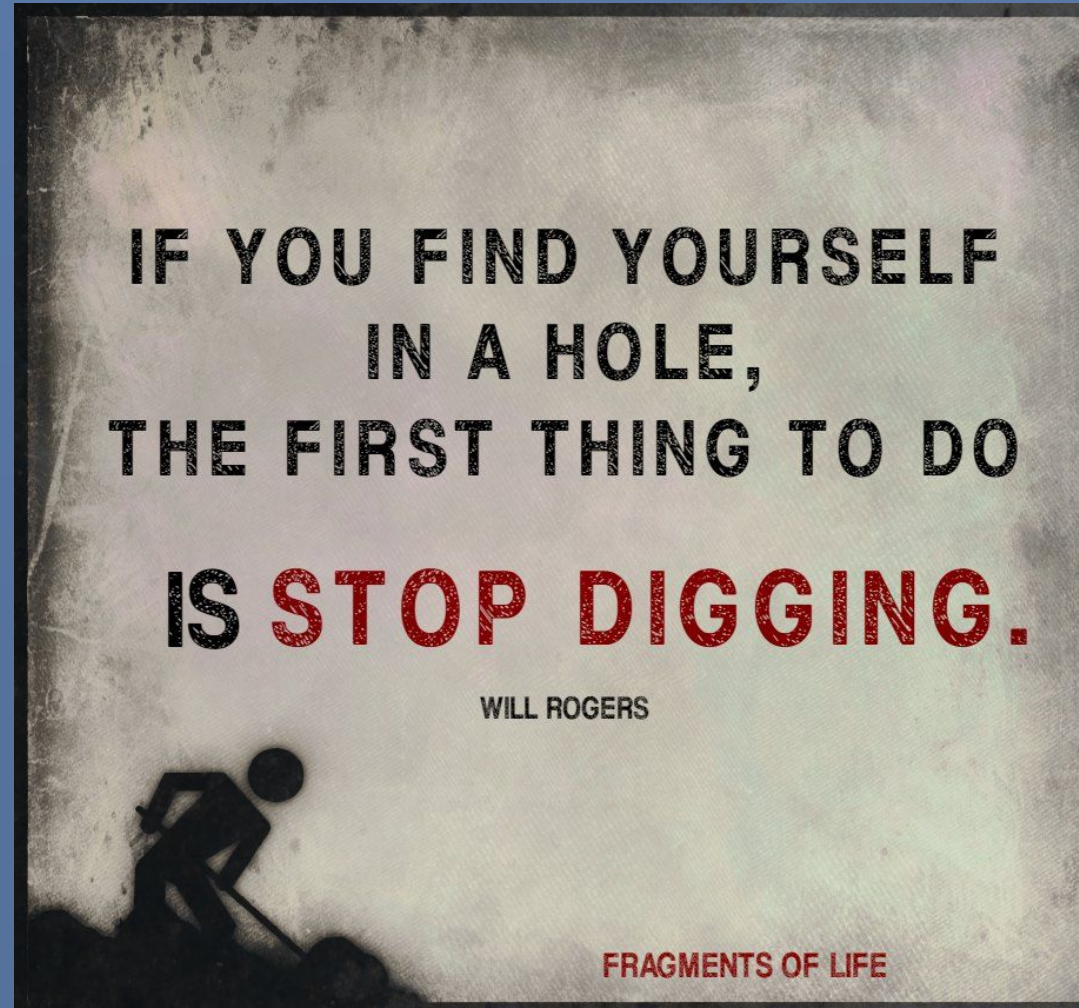


# Kick the Can Down the Road



- Manage our care to buy time for all of us
- For new discoveries and new treatments

# Drop the Shovel





# You CAN do it!



Whether you think you can  
or you can't, you're right.

Henry Ford

quote fancy



# MSKCC Art Show 2019: Fundraiser for the CF

## Silver Linings

Artwork by  
Sharon Berlan



### ON DISPLAY

**March 14, 2019 to June 13, 2019**

Charles Hallac Patient Recreation Center (M-15)

Open daily, 9:00 AM – 7:30 PM

### ARTIST RECEPTION

**Thursday, March 21 | 6:00 PM – 7:30 PM**

#### ART EXPRESSIONS AT MSK

This exhibit's featured artist, Sharon Berlan, has participated in a variety of Art Expressions workshops over the past several years.

Art Expressions workshops are taught by volunteer artists and are available to current and

# Supporting the Chordoma Foundation in Any Way Possible

- My email signature contains a link to my CF Champions Page. This is my subtle way to spread awareness. I update my status on this page
- I donate to the CF to honor others on special occasions such as birthdays and holidays
- I remember those who have passed with donations
- I ask for no physical gifts. Even at our wedding, we asked for donations only!
- The CF is the only non-profit I support financially
- If not us, who?  
If not NOW, when?

CHORDOMA FOUNDATION

SEARCH SHARE MANAGE

Sharon Berlan

\$60,012 Raised \$60,000

DONATE

Welcome to Sharon Berlan's Champion Page

STORY UPDATES 0

CF Champions \$2,566,770 / \$3,000,000



# Expressing Gratitude to CFDs: Chordoma Fighting Doctors!





# Continuing to Live Life and Celebrate Survivorship and Co-Survivorship



Celebrating 4th of July, 2022

*Thank you* to the **Chordoma Foundation** including the Medical, Scientific and Community Advisory Boards.

*Special and Eternal Thanks* to **Josh Sommer** for starting the Foundation, for his hard work and perseverance all these years. Your unwavering commitment is truly inspiring!

*Thanks to Heather Lee* for commanding the volunteers through the first decade of the Foundation. I know it wasn't always pretty or easy!

*Thanks to Shannon Lozinsky and Andrea Locke* for their work with Survivors and Co-Survivors!

The Foundation remains our primary hope to find a cure.  
We really are all in this together!