

International Chordoma Community Conference

July 14-15, 2023 | Cambridge, MA

Friday, July 14

	Welcome sessions: Meet fellow attendees	
4:30 PM	Skull base & cervical patients and caregivers <i>Discovery Room</i>	Hosted by Mick Potempa, Noreen Potempa, and Joan Funk
	Mobile spine & sacral patients and caregivers <i>Endeavor Room</i>	Hosted by Megan Stewart, Donna DiMuro, and Darcia Medoway
6:00 PM	Welcome reception <i>Grand Foyer</i>	
7:00 PM	Uncommon Awards dinner <i>Salon 4</i>	

Saturday, July 15

7:00 AM **Registration and breakfast**
Grand Foyer

Morning sessions in Salon 3

8:00 AM	Welcome Survivorship Initiative updates	Shannon Lozinsky Chordoma Foundation
8:20 AM	A survivor's story: Chordoma as a manageable chronic condition	Susie Rinehart Cervical chordoma survivor, author, life coach
8:40 AM	The path to cures: Chordoma research updates	Josh Sommer Chordoma Foundation
9:00 AM	Chordoma Foundation Labs	Dan Freed, PhD Chordoma Foundation
9:15 AM	Natural History Study of Rare Solid Tumors	Liny John, MD National Cancer Institute and Children's National Hospital Mary Frances Wedekind, DO National Cancer Institute
9:30 AM	BREAK	

10:00 AM	<p>Ask the experts panel</p> <p>Moderator: Christopher Heery, MD</p>	<p>Shaan Raza, MD MD Anderson Cancer Center</p> <p>Shannon MacDonald, MD Mass General Cancer Center</p> <p>Joe Schwab, MD, MS Mass General Cancer Center</p> <p>Yen-Lin Chen, MD Mass General Cancer Center</p> <p>Shreyas Patel, MD MD Anderson Cancer Center</p>
11:30 AM GROUP PHOTO AND LUNCH		
Breakout sessions: Living with chordoma		
Session 1: Managing side effects (choose one session)		
12:45 PM	<p>Clival & upper cervical side effects <i>Salon 3</i> Learn about side effects like double vision, hormone imbalances, and speech and swallowing difficulty as well as ways to manage them.</p> <p>Mobile spine & sacral side effects <i>Salon 1</i> Learn about side effects like mobility, bone fractures, and bowel and bladder incontinence as well as ways to manage them.</p>	<p>Lisa Nachtigall, MD Endocrinology, Mass General</p> <p>Dean Cestari, MD Neuro-ophthalmology, Mass Eye and Ear</p> <p>Chloe Slocum, MD, MPH Physiatry, Spaulding Rehabilitation Network</p> <p>Joel Lee, PA-C Urology, Mass General</p>
Sessions 2 & 3: Living well (choose one session during each time block)		
2:00 PM (Session 2)	<p>Dealing with pain <i>Salon 3</i> The majority of chordoma survivors experience pain and neuropathy. Learn about ways to manage pain and how to find a pain specialist.</p> <p>Nutrition and cancer <i>Salon 2</i> It's important to have a healthy diet when dealing with an illness like cancer. Find out more about how to do that in this session.</p>	<p>David Hao, MD Anesthesiology, Mass General</p> <p>Carol Sullivan, MS, RD, CSO, LDN Nutrition Services, Mass General Cancer Center</p>
2:45 PM (Session 3)	<p>Advocating for your care <i>Salon 1</i> Patients with rare diseases like chordoma often have to learn to advocate for themselves during and after treatment. These patient advocates can help you strengthen your advocacy skills.</p>	<p>Nancy Forte Spouse of clival survivor; Patient Advocate</p> <p>Megan Stewart Spouse of sacral survivor; Patient Advocate</p>

3:30 PM	BREAK	
Session 4: Supporting one another (choose one session)		
We are so pleased to have our monthly virtual support group leaders join us in person! Come meet them during these sessions and talk with each other about your experiences with chordoma.		
	Patients and survivors <i>Salon 6</i>	Jennifer Bires, LCSW
3:45 PM	Caregivers and co-survivors <i>Salon 7</i>	Megan Whetstone, LCSW
	Adolescents and young adults <i>Salon 5</i>	Kaitlin Slepian
5:00 PM	Closing: Going forward with hope	Kaitlin Slepian Cervical chordoma survivor

Thank you for joining us!

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