Take action! Lunch discussion

At this year’s Chordoma Community Conference, we want to make it possible for you to learn how to get involved with the Chordoma Foundation and stay connected with others in our community. Stop by one or more of these tables during lunch to learn about community fundraisers, connect with others, and hear how you can support chordoma research.

Tables 1 and 2: The Chordoma Foundation Peer Connect program is a free, confidential peer-to-peer support program that connects anyone touched by chordoma with another person whose experiences with chordoma are similar. Trained Peer Guides are available to support patients who are newly diagnosed, in active treatment, survivors, caregivers, family members, or friends. Come chat with trained Guides about what the program offers, how to become a Guide, and to say hi to a Peer Guide you have already connected with!

Table 1: Susan Garbett (Sarasota, FL) was diagnosed with a sacral tumor in 2009. She has been a Peer Guide since 2016 and has supported numerous patients since then. Susan also wrote a book, Confronting Chordoma Cancer: An Uncommon Journey, in 2015 to chronicle her treatment and recovery. Sharon Berlan (New York, NY) was first diagnosed with a clival tumor in 2004. She was one of the first to be trained as a Peer Guide in 2011. Sharon also co-moderates the Chordoma Survivors group on Facebook. In these roles she has provided support to countless chordoma community members.

Table 2: Chris Jones (Simi Valley, CA) is the parent of a patient. He was trained as a Peer Guide in 2016, and he co-moderates the Chordoma Survivors group on Facebook. Kris Stahl (Menasha, WI) is the wife of a patient. She was also trained as a Peer Guide in 2016, and is one of the moderators of Chordoma Connections, the Foundation’s online community. Kris and Chris, as caregivers themselves, provide support to other caregivers who request to be matched with a Peer Guide.

Table 3: The CF Tumor Donation Program accepts donations of chordoma tumor tissue into our Biobank, to be used to support chordoma research efforts. More than 200 people have donated tissue in the past 7 years. Come hear about donating tissue and how this is instrumental in furthering chordoma research.

Patty Cogswell manages the Foundation’s Biobank, cell line and animal model repositories, and prizes. She works with patients to donate their tumor tissue following surgery, and to arrange legacy tumor donations.

Table 4: Chordoma Connections is the Foundation’s online community, where chordoma patients and family members around the world can connect to share information and support one another. Stop by and meet some of the community moderators.

Maureen LaForge (Campbell River, BC, Canada) is the parent of a patient and one of the moderators of Chordoma Connections. Shannon Lozinsky and Chase Hinnant are the Patient Services team at the Foundation. They created Chordoma Connections as a resource for the chordoma community, and are moderators of the community along with Maureen LaForge, Kris Stahl, and Sue Brenneman.
Table 5: Our keynote speaker, **Debra Jarvis** (Seattle, WA), will be available to talk and answer questions about her experiences supporting cancer patients and what she’s learned on her own cancer journey.

Tables 6-12: **Chordoma Foundation Fundraisers** turn their passion into action by fundraising to improve the lives of those affected by chordoma and lead the search for a cure. As a patient driven organization, our success depends on the initiative of supporters like you. Each dollar that you raise helps the Chordoma Foundation accelerate the development of new treatments and provide vital information to chordoma patients and their families. Join one of seven different fundraisers to learn about how they have made a difference!

**Table 6: Athletic Events – Running. Steve Mandel** (London, England) is a patient, member of the Board of Directors, and this year’s Uncommon Champion Award winner. He is the captain of #TeamChordoma and has run annual half-marathons supporting the Foundation since 2014, raising more than $250,000.

**Table 7: Athletic Events – Hiking. Ed Les** (Calgary, Canada) is a patient and the Medical Liaison to the Community Advisory Board. In the fall of 2017 he hosted the inaugural *Climb for Chordoma*, a 16-kilometre round-trip hike to the top of Centennial Ridge in Alberta, the highest maintained trail in the Canadian Rockies, raising more than $60,000 to further chordoma research in Canada.

**Table 8: Musical events. Steven Golick** (Toronto, Canada) is a chordoma patient, retired lawyer, and musician. In November 2017 Steven hosted *Chords for Chordoma*, a jazz concert bringing together many of North and South America’s top jazz musicians, to raise a record breaking $315,000 to further research in Canada.

**Table 9: Cocktail Party Events. Beth Cullinan** (Boston, MA) is a patient and former Uncommon Champion Award winner. She has hosted several parties, rallying hundreds in her network to help create a better future for chordoma patients and their families, raising more than $56,000 for the Foundation. In addition, she has also participated in the Cycle for Survival fundraiser, bringing in more than $12,000 to support chordoma research at Memorial Sloan Kettering Cancer Center.

**Table 10: Writing campaigns. Joel Beckman** is a chordoma patient, vice-chair of the Board of Directors, and this year’s Perseverance Award winner. Each year since 2015, he has conducted annual email campaigns soliciting support from his network of coworkers, friends, and family, raising tens of thousands of dollars.

**Table 11: Champion pages. Rachel Lichte** (Durham, NC) is the wife of our very own Josh Sommer and a social impact consultant. At the end of 2017 she surprised Josh by creating a Champion page and raising more than $30,000 for his 30th birthday.

**Table 12: Unique events. Gene and Sue Brenneman** (Lancaster, PA) are the parents of a patient and live in a lovingly restored colonial era house. Since 2016 they have opened up their home and hosted guided Christmas-time tours, complete with colonial era garb and period refreshments such as hot buttered rum, shrub, and wassail. Their efforts have raised several thousand dollars!