



Welcome to the First Chordoma Community Conference

As all of us whose lives have been affected by chordoma know, it is a challenging, confusing, lonely, and sometimes frightening disease. It is a disease that has, until recently, received little public attention, and was barely known to the medical and research community.

Despite the rarity and complexity of this disease, a small but dedicated group of highly skilled physicians have chosen to specialize in saving or extending the lives of chordoma patients. Nearly all of us have traveled great distances in search of these doctors, and to many of us they are our saviors, our heroes, and our friends. These doctors would like to offer more treatment options to their patients and many of them have funded research in hopes of uncovering clues that could lead to more effective treatments. However, just as being a chordoma patient can be a lonely journey, so too is being a chordoma researcher. For years, a handful of scientists studied chordoma in isolation, often unaware of other researchers who shared their interest in this unusual disease, and hindered by poor access to funding and vital scientific resources like tissue and cell lines.

When we started the Chordoma Foundation in February, 2007, our first goal was to build a chordoma research community from the ground up by connecting, for the first time, the doctors and scientists studying chordoma, and recruiting top cancer researchers into the newly formed field. Last May we brought together fifty-three of these researchers at this hotel in Bethesda for the First International Chordoma Research Workshop. Most had never met one another, yet by the end of the workshop a vibrant community had coalesced around a shared mission to find a cure. New bonds had formed between surgeons, cancer biologists, oncologists and geneticists; collaborations had been initiated between top medical centers in the US and abroad; and most importantly a path towards a cure was developed for the chordoma research community to follow.

Now, less than a year later the chordoma research community has broadened even further, and exciting new data about the molecular and genetic events that underlie chordoma has opened up new possibilities for precise and effective treatments. The incredible progress of the past year has proven that by working together towards a common goal researchers are more productive than they could possibly be working alone.

We believe that the same is true of the patient community; together, we are stronger than the sum of our parts. That you have traveled here for this landmark event is a testament to the strength and determination of chordoma patients and their families. Every single one of us hopes, prays, and dreams for a cure to this terrible disease. Now, working together, we finally have the power to turn our dreams into reality.

At this conference the chordoma patient community has the chance to join the chordoma research community in a quest for the cure. We all have something to offer to this effort and much to gain. The researchers need our encouragement, our participation in their studies, and most importantly our financial support. We, the patient community, need compassion and understanding, superb clinical care,

and progress towards more effective treatments. At the nexus of these two communities lies the Chordoma Foundation. We serve as a link between all stakeholders: patients, families, physicians, scientists, government agencies, and drug companies. In this role we inject a sense of urgency into research process and serve as the engine to drive forward the development of new treatments.

Our mission is to rapidly develop effective treatments and ultimately a cure for chordoma, while improving the diagnosis, treatment, and quality of life for all of us who have been affected. We appreciate your support and are honored to work with you towards these goals. This conference is a opportunity for the Chordoma Foundation to learn how to best meet the needs of the community that we serve, and it is also an opportunity for the community to understand how best to support the Foundation.

This inspiring event would not be possible without the dedication and leadership of Chordoma Foundation Board Member, Heather Lee. Heather has worked tirelessly to make this event a success while juggling commitments with work and taking care of her son Justin, who continues to battle a recurrent clival chordoma. Working closely with the Chordoma Foundation, Carolyn Rubenstein, president of Carolyn's Compassionate Children, selflessly devoted herself to creating an uplifting and empowering Chordoma Youth Conference which will take in parallel to the CCC. In addition, we would like to recognize Bill Dorland, for his dedication to the chordoma community, his vision to have this gathering and for securing significant financial support from the University of Maryland. Finally, we thank our volunteers and sponsors for their generous contributions, and all the members of the coordinating committee for their input and support.

We are excited to meet so many of you for the first time, and hope that each one of you will leave this conference optimistic about what the future holds. Together we will cure chordoma!

Warm regards,

Simone & Josh Sommer