Participant Biographies

Third Chordoma Community Conference

March 18 – 20, 2011

Edward Lawton

I'm a sacral chordoma survivor, having become symptomatic in the Spring of 1990 and being diagnosed in October 1990. I've experienced extensive medical surgeries; radiation treatment and numerous radiological tests used to manage and monitor my circumstances. I've been using something called Erlotinib since mid-2005 to control the growth of the existing tumor and amazingly, it has worked quite well. I say prayers daily due to my survivability and manage my future one day at a time. I'm quite sure my strong positive attitude and faith coupled with the faith and strength of my wife, family and friends has all contributed to my longevity and I'm grateful to say so.

Jacquelyn Britt

I am turning 57 this weekend! And never imagined I would be here 23 years ago when first diagnosed with clival chordoma. But with surgical and radiological advances over those 23 years - and brilliant, kind doctors willing to make "curing chordoma" THEIR goal - I'm here today, and their work continues. I am forever grateful.

Adriane Rothstein

Educator (independent schools), wife (he's a good guy), mom (daughter age 12) chauffeur (see previous), loves Labradors, yoga, reading, politics, old movies, and travel seeks: (now, it gets interesting) people who will not give up, who live courageous lives, who give and foster support, and finally, who will fight to find a cure for chordoma. It is an honor to be on the Steering Committee for this conference, and an honor to be with so many good people.
Earl Underwood

I am 67 years old and married. Laura and I have a son who is married and we have one grandson. I retired from full time ministry after 41 years in 2006. My main avocations are genealogy and travel. During 2008 I had a lot of pain in the tailbone region and eventually a tumor was located and a biopsy was done which showed Chordoma on the Sacrum. On February 19, 2009 wide margin surgery was done at Mayo Clinic in Rochester, MN. I remained at St. Marys Hospital for 28 days and then returned to Nebraska. I continue to have check-ups and have had no recurrence to this point. I am interested in others who have the same disease and want to support others who are diagnosed.

Renee Butler

49 year old mother of two, Personal Fitness Trainer, Marathon runner. Parent of patient who was diagnosed with clival chordoma on 3/24/07. Treatment was surgery and then proton beam radiation.

Stephen Dunn

Father of Tyler, 4 year old diagnosed with a Clival Chordoma at age 2. He's undergone two surgeries, nine rounds of chemotherapy and proton beam radiation. Currently monitoring clival area with MRIs every three months.

Penny Halling

I have lived with this diagnosis for 22 years, although at first I was misdiagnosed. I have 2 daughters and 3 grandchildren. Initially, I was treated by surgical procedures, but then went out to Loma Linda, CA for proton radiation treatments. Currently, I am followed at the Mayo Clinic in Rochester, MN. I love to help other people, volunteer at the school, and to play cards.

Stacy Halling

My mother was diagnosed when I was an infant, so she has lived with this my whole life.

Mohammad Khanichehri

I was diagnosed with sacral chordoma in Oct. of 2009. I am married to my lovely wife (Zohreh) and have two beautiful children. This is my first time at the Chordoma Conference and I appreciate the opportunity to be with individuals who are experiencing my current situation.
Susanna Johnson

40 years old, married with 3 children (ages 9, 6, and 3), stay-at home mom, former Army Officer, military dependent, we move around a lot! Patient, diagnosed in Nov 08, L3 laminectomy, partial resection and reconstruction surgery in Dec 08, IMRT in Feb 09-Apr 09, member of the Chordoma Foundation.

Kathleen Milczarski

I was a 51 year old who enjoyed running (including marathons) with my three sisters and friends until I was diagnosed with chordoma of the upper cervical spine (C2, C3) on February 18, 2009. The local surgeon was only able to remove a portion of the extensive tumor and recommended proton therapy to follow. The week before I was to begin radiation in May 2009, my treatment was postponed due to staffing issues. This actually turned out to be for my good (really, it was a miracle!) as I then found Dr. Liebsch at Massachusetts General Hospital who recommended state of the art surgery in Switzerland. After quite a team effort just to obtain approval from the insurance company, surgery was scheduled for December 8 and December 10, 2009. The surgery was HUGE but very successful as this superb surgeon was able to remove ALL of the tumor and keep me fully intact. The experience was difficult but my family and I had the prayers and support of many and, by the grace of God, we all made it (my sister and parents were with me for almost 2 months). In the spring of 2010, I had 2 months of radiation (photon and proton) in Boston and now there is no more tumor and no more treatment and I have returned to work. I have so much to be thankful for and although I can no longer run, I am very happy that I can walk!

Mari Musson

My name is Maria Musson, I am 52, mother of three and living in a small town near Eindhoven in the Netherlands. I am a registered nurse and have been working in ER for more than 30 years. Starting 2011 I've decided to quit my job in the hospital and started to give courses in intuitive drawing. From 2007 my husband started developing several clinical symptoms. After visiting many doctors he finally was diagnosed with a severe clival chordoma in 2009. He had surgery in the US (UPMC) and things went well for a short time but in 2010 a chordoma related cyste started to develop in his brainstem.
Cary Tennis

I'm a 57-year-old advice columnist for Salon.com. I live in San Francisco. I am at the conference as a patient. I had a sacral chordoma diagnosed in November 2009 and had a sacral resection at the University of California at San Francisco Medical Center in December 2009, and proton beam radiation at Loma Linda Medical Center in June and July 2009. I'm recovering well from surgery and have no sign of recurrence.

Michael Torrey

Father of two girls, custom home designer and builder. Love to pray, sail, ski and bike. Grateful for everyday!

Molly Buss

I am 59 years old, mother of twin girls. I am a hairdresser and own a salon in Iowa. I love people and life. I am a patient who was diagnosed in Nov. 2009 with a clival chordoma. I had surgery in Feb 2010 and proton therapy in July 2010. I had my first MRI since radiation in February 2011. I am a member of the Chordoma Foundation.

Pedro Reis

I am 54 years old, father of three (two sons and one daughter) and an occupational health physician in Portugal. I had a clivus chordoma diagnosed in December 1982, submitted to surgery and radiotherapy. After returning to Portugal, I started taking vitamin D and calcium supplements in an attempt of calcification of the remaining tumor, which somehow happened, and I have had no recurrences ever since. My relationship with the Chordoma Foundation began at the first conference.

Karen and Gary Sain

Our son Aaron was diagnosed with a clival chordoma in 1997 when he was eleven years old. After numerous surgeries and proton beam radiation therapy at Loma Linda, he enjoyed several years of "remission" but in 2001 the tumor recurred. In spite of all of this, Aaron played on his high school tennis team and graduated with honors in May of 2004. Aaron died in August of 2004 at the age of eighteen. It is in memory of Aaron's positive, hopeful and courageous attitude that we dedicate ourselves in seeking to find a successful treatment for chordoma. We are honored to support the Chordoma Foundation.
Jamellah Ellis

I am the spouse of Malik Ellis a chordoma patient.

Malik Ellis

I am a 39 year old lawyer/real estate developer and father of 3. I am a patient that was originally diagnosed with a Chordoma in my C-Spine in 2007 and a recurrence in 2009. I had surgery again in Nov 2010 and radiation in Jan-Feb 2011. I have also been exploring both traditional and naturopathic approaches to treating chordoma.

Joyce Reichel

I'm a 70 year old mother of two, grandmother of four, retired registrar and financial/legal secretary. I was diagnosed with a chordoma in Feb 2002, had surgery the following month, then proton radiation therapy with Dr. Liebsch at Mass. General and have had no new growth since then. I have attended both the previous conferences with my husband (who died in October).

Sharon Berlan

I was misdiagnosed in 2003 and correctly in 2004. I have had multiple surgeries for residuals/recurrences for Clival and now also have a cervical chordoma. I have had Proton Beam in Boston and IGRT at MSKCC in NY. I live in NYC and am active with the CF and try to guide patients found on internet to the right care and throught the process. We are all in this together!

Nadine Cordova

On September 11, 2010, I was diagnosed with a Cervical Chordoma on my C2 vertebra. At the age of 35, I never thought I would hear the word Cancer. I am a mother of two beautiful boys. I traveled from Frisco, TX to New York, NY to be treated as MSKCC. There I received IGRT Radiation Treatment (single high dose). I joined the Chordoma Foundation so that others can be aware of this rare disease and get educated about it as I did by joining. Without the foundation, I would have been another test subject to a non-experienced in Chordoma surgeon.
Judith Carter

I am a 66 year-old mother of two with two grandsons. I love music, reading, gardening and my job as a financial aid director (until I retired on December 31). Now I hope to love retirement and spend more time with my family.

My cervical chordoma was discovered 8 years ago in the same month I was diagnosed with breast cancer, and was the third of four primary cancers diagnosed in less than two years. Given all of the surgeries and treatments for the other cancers, I opted for Proton Beam radiation as my only treatment for chordoma. So far, there has been little or no growth of the tumor. The physicians thought my MRI of about 2 1/2 years ago might have shown slight growth, but none of my recent tests have suggested any increase. Many thanks to my husband, Joe, who has been wonderfully helpful and supportive throughout.

Joseph Carter

I am a retired English Professor/Academic Dean and caregiver for my wife, Judy.

Marley Jay

I'm a writer and journalist living in New York City, and my hobbies include comedy and playing guitar and bass. I'm coming to the conference to represent my family and my youngest brother, Tyler. Tyler was diagnosed with a clival chordoma in December 2006, when he was 14. He was treated with surgery and radiation, and had a recurrence in 2008 that was treated with chemotherapy and radiation. He completed high school and agreed to attend the University of Florida to work on chordoma research with Dr. Brian Harfe. When a new recurrence was discovered in August, he opted against further treatment. Tyler died on the evening of October 29, surrounded by his family. Since then we've been paying tribute to him and searching for meaning.

J. Small

Brother of Joyce Reichel, chordoma survivor

Theresa Gallagher

Before being diagnosed with a Clival Chordoma in July of 2009 at age 39, I was a Special Education Teacher for 16 years. I spent most of those years teaching Emotionally Disabled Students from K -12 grades. I also taught general education 6th grade for a time. I have no children of my own but between my nieces, nephews and students, I have hundreds of kids. I had surgery in Aug. '09 and Proton Radiation at MPRI in Bloomington, IN from Dec. '09 to Feb. '10.
Becky Baldwin

I am a nurse and my sister is Molly Buss who has a clival chordoma.

Robert Schoelkopf

Professor of physics and chordoma survivor