

Participant Biographies

Second Chordoma Community Conference

June 26-28, 2009

Daniel K Alter

Daniel is a 24 year old cancer survivor; he was diagnosed with a large clival chordoma nearly 12 years ago, resulting in 36 hours of surgery and 42 proton radiation treatments. A year ago, he graduated from The University of Texas at Austin with degrees in Archaeology and Anthropology. Now he works in Austin for a Jewish non-profit and is contemplating graduate school in the near future. When not at work or enjoying the company of his friends, you can often find Daniel stuck between the pages of a book. He is attending this conference with his mother, Lori.



Lori K Alter

Time stands still when I'm in the garden. If I'm not outside, I can usually be found baking or volunteering. I have been married for 26 years and am the mother to 4 (almost adult) children, 5 dogs and 2 cats. I am attending this conference with my son, Daniel. This summer marks the 12th anniversary of his diagnosis of clival chordoma. At the time of diagnosis, he underwent 36 hours of surgeries and had 42 proton beam treatments. Today, he is doing extremely well. He works in Austin, TX and is contemplating graduate school. I look forward to attending this conference to learn what is on the chordoma horizon and to offer hope to anyone touched by this disease.



Abby Lynn Becherer

I am 18 years old, just graduated from Cardinal Gibbons HS and will be attending UNC Chapel Hill in the fall. I am volunteering at the conference- I am doing this in honor of my brother James' best friend Justin Straus.



Sharon Berlan

I am newly married and just returned from a fantastic honeymoon. I was diagnosed in Feb 04 with Clival Chordoma and have had multiple surgeries and treatments. It has now spread to my Cervical Spine and I am about to be treated for that. I live in NYC and like to walk in Central Park, birdwatch, paint, cook, read and help other Chordoma patients when I can. I am very happy the CF exists and am hopeful they will find a cure.



Douglas A. Berliner

54 year old, father of three, former Marine Helicopter Pilot, former Government Program Manager, 5th Degree Black Belt Judo Instructor. I am a patient, originally diagnosed with clival chordoma in Aug 1997. received trans-sphenoidal partial resection in Aug 1997 and 72 grays of Proton Beam radiation from Dec 1997 thru Feb 1998. No growth for 8 years. Began regrowing Nov 2005. Underwent Gleevec/Hydrea chemotherapy in Jan 2006 that stopped all growth. Underwent trans nasal partial resection in May 2007, continued chemo meds Gleevec/Hydrea. Had to take disability retirement in Oct 2007. No growth until Nov 2008. Underwent 34 grays of Photon Beam radiation and 4 treatments of IV Chem (Cisplatin) in Mar 2009, and placed on new chemo med, Dasatinim, with Hydrea May 2009. Jun MRI showed no growth. Will see doctor, with new MRI, in Jul 2009.



Paul E. Block

I am a 65 year old father of two. I am a pharmacist and currently working for CVS in Cincinnati, OH. I enjoy running, gardening, & working on projects around the house.

Jacquelyn G Britt

I retired two years ago after 30 years in advertising. I'm grateful to be a 22-year chordoma survivor after 9 craniotomies, 1 cervical fusion, halo and all, 4 surgeries to restore my voice, five separate rounds of radiation including experimental highly-charged particle radiation at Lawrence Berkeley Lab in 1987 and three rounds of Cyberknife in Georgetown (yea, Cyberknife!). AND one open heart surgery to remove a metastasized chordoma from the wall of my right ventricle in 2007. Today I am tumor free and a survivor, which is a much better word than patient. There are treatments, and there is hope!



Joseph Carter

Husband of chordoma survivor.

Judith B. Carter

I am a 64 year-old wife, mother, grandmother, and college administration who loves to read, garden, and listen to opera. The chordoma is one of four primary cancers with which I was diagnosed in one 22 month period (other

cancers being endometrial and two separate and distinctly different breast cancers). I was diagnosed with the cervical chordoma in 2003, and had proton beam therapy. The tumor was quiescent for five years and now has begun to grow slightly. I am grateful to the Chordoma Foundation for bringing chordoma, the concerns of patients, and the need for research to the fore.

Steve M Chambers

I am a 58 Year old Married Male with adult children. I am retired from the Army and currently a truck driver driving long haul. I am a Patient at Oregon Health Science University. I have had two surgeries, 1 removing my coccyx and the second removing my lower colon. I received radiation for a third chordoma Aug2008. Recent MRI has shown that chordoma to be reduced in size from previous scans.

Lynda Chambers

I am the wife of 30 years to Steve Chambers, a 7 year chordoma survivor. I am a city counselor for the city of Brownsville, Or., and raised three daughters.

Sergio Cuesy

I am a 48 year old male. Originally from Mexico. Married and father of two wonderful kids, ages 7 and 4. Business executive. Used to love to travel, these days love to spend time with my kids, and when I can, I love to read books and watch movies.

I am a chordoma patient. My first tumor was discovered on July 15th, 2007, kind of by accident. It was at the T11 vertebra. I had a total resection of the T11 vertebra and fusion of T10-T12 at Jackson Memorial Hospital in Miami FL. Afterwards, I had IMRT and Proton Beam radiation at MGH. On Jan 22, 2009 I was diagnosed with a recurrence. It came back with a vengeance: 2 posterior tumors from T12 to S3 in soft tissue, one anterior tumor in soft tissue at T9 -unoperable-, two mid size tumors in soft tissue in the left paraspinal area, One small tumor in the left lung, two small tumors in the pleura. My Drs at Miami and Boston told me they could not do anything for me. I looked for a 2nd opinion at Sloan Kettering in New York where they are now treating me. I had surgery on March 20, 2009 to remove the two tumors from T12-S3. I had IGRT radiation there as well to treat the tumor at T9 on April 21st, 2009. I started Gleevec on April and Cisplatin (IV) on May, 2009. I can not go for additional radiation (for the surgical bed and the two mid size tumors in paraspinal area) because one of my kidneys would be in danger. If things don't work out with Chemo, maybe they will add Rapamycin. My treatments are still being evaluated.

Kathy Davidoff

43 year old mother of three, nurse, spouse

Peter Davidoff

53 years old, father of 3, Marina owner, love to sail

Diane Evia-Lanevi

I am a volunteer with the Foundation. My daughter, Sammy, was a friend of Justin Straus. When Justin passed away, I vowed to help the Foundation in any way I could.

Peter Gerhard

52 year old male whose daughter has a tumor which was operated on twice and has gone thru proton radiation for 2 months. 40% of the tumor was removed and at this moment it is dormant. I and my work have donated to the foundation.

LaDonna L Hoyt

53 years old, mother of 2 and grandmother of 9, soon to be 10. Diagnosed w/clival chordoma in Sept 2002, surgery Nov 2002 and radiation at Loma Linda in early 2003. Currently on Social Security Disability. Part of the tumor still remains but no recurrences yet. Member of the Chordoma Support Group. Also, a participant in the NIH Cancer Institute's Familial Chordoma Study, working with Dr Parry.

Steven F Kanter

60 year old, father of three, grandfather of one, physician entrepreneur

Warren P Kearns

I am a 42 year old father of 6 Children age 5-19 yrs. After weeks/ months of pain and his head progressively tilting backwards, our 3 year old son, Ben, was given an MRI scan on 1 June 2007, which revealed a large clival tumour. A further CT scan revealed multiple tumours to his lungs. A biopsy was carried out, through the roof of his mouth and the diagnosis in Belfast was uncertain. We only got a diagnosis of a chordoma Poorly

dedifferentiated type in January 2008, from MGH Boston. In the mean time Ben underwent extensive chemo for 6 months, which reduced his primary tumour and cleared the tumours in his lungs. This was followed up by 2 months PBT along with less intensive chemo at PSI in Switzerland in Feb/Mar 08; after which Ben had 2 weeks photon radiation to his lungs in Belfast and a further 6 months chemo. Ben's latest MRI of his skull shows residual tumour, which is, if anything, slightly smaller than the last scan. His lung CT scan is booked for 2/July/2009. Previous scans show his lungs to be clear. Ben is now a happy active 5 year old who loves running around and playing. He is crazy about lego building and transformers. He is due to start school in September. He has been home schooled for the past year and his teacher says he is extremely bright

Catherine M Kearns

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Ian H Laird

My role at the conference is that of former caregiver, now widower. My wife, Alison, was diagnosed with chordoma in July 2000; T8 - T9 region. She endured several surgeries, and some specialised radiation treatment (Cyberknife). Her mobility was progressively compromised and eventually became immobile. She passed from this life on 12 June 2008 at age 60 years.



Samantha Lanevi

I was a good friend of Justin Straus at Durham Academy. I'm entering 8th grade at DA. I want to help at the conference in his memory.

Edward F Lawton

59 years old, w/m/married/19+ yr survivor of recurring sacral chordoma; Attendee as patient, would not mind speaking of personal experiences; have received multiple surgeries, proton beam radiation, (beta) medicine treatments



Heather Lee

Mother of Justin Straus, clival chordoma diagnosed in 2002, died in 2008 after multiple surgeries, radiation and chemotherapy. Determined to find a cure as a part of his legacy.



Jacob E Les

42-year old pediatrician and clival chordoma patient, diagnosed 2 1/2 years ago, stable residual disease. Father to 3 little girls.

Deborah L MacDonald

I am a 46 year old chordoma patient/survivor, happily married to my husband Darryl. We have no children, but a lovable English Bulldog Max. Enjoy pontoon boat rides on our beautiful lake, spending time with family and friends, raising awareness and money for the foundation, and reading. I was diagnosed in April 2006 with a thoracic chordoma (T-12). In 2006 I had 3 surgeries and proton/photon radiation treatments at Mass General in Boston. I've been very fortunate with no recurrence in 2-1/2 years. The Chordoma Foundation is a blessing to all of us. My family and I have been working to raise money this past year to support research. I'm also honored to be part of the conference Planning Committee this year.

Cecilia Maldonado

I am a caregiver for Abel. He is one of the most important reason of my life! it has been difficult to face the fact. I keep trying to do my best for him!

Liliana Martire

Father had cervical chordoma, with 3 partial resections followed by two months of proton beam radiation with Dr. Liebsch. He has been in remission since 2006.

Marysia H. Marts

Marysia Marts has been married to Greg for nearly 25 years and is a mother of two teenage sons, Timothy (18) and Thomas (14). Marysia has been working for the Chordoma Foundation since October 2007. She wears many hats, but her title is staff assistant. She enjoys her work with Simone, Josh, Laura, and Michelle and counts it a privilege to work for the Chordoma Foundation. Marysia is looking forward to putting faces to the names she sees in the office on a daily basis as she works along side of Laura at the CCC.

Abel Muniz

While i was studying my first year at UNSW in Sydney, Australia, i was diagnosed Clival chordoma at the age 18 year. Last september, i had a real pain in the neck again since i was 12 years old, which my GP dismissed at that time. Suddenly, i had a deviation of my tongue. After a CT scan and a MRI scan, I had a huge clival meningioma. I have had 3 extremely high risk surgeries, and then other complication: meningitis.

At the moment, I am in Boston under Proton Radiation therapy; which is really hard to handle. I really enjoy traveling. And, I love to go to rock concerts.

Shawn Owenburg

My name is Shawn Owenburg, I am a divorced father of two beautiful girls. In September 2004 I injured my back on a construction site. After a year of physical therapy, the doctors decided to do surgery to repair two blown discs. During surgery the doctors discovered tumors on my lower spine and sacrum. After testing the biopsies the doctors realized I had Sacral Chordoma. Over the past three years I have gone through two different oral chemotherapy trials and numerous scans. In July 2008 I started getting severe headaches, after undergoing an MRI and a Myelogram the radiologist discovered tumors from my C1 down to C7. The Chordoma had spread. I underwent surgery on September 19, 2008 at Memorial Sloan Kettering to remove tumors from my C3 to C5. After surgery the headache wasn't as bad. In November 2008 I started to have pins and needles on the right side of my face. The doctors were concerned but not sure what to make of it. Over the next five months I started to have word finding issues and speech problems. Then in April I developed double vision with depth perception difficulty. After many tests and looking back at my September scans the doctors realized I was dealing with Leptominigile disease. They saw plaques on the meninges of my brain. My oncologist started me on a chemo pill while waiting to hear about a trial she thought would be helpful. This disease is usually caused by a primary cancer, in my case

Chordoma. Very rare with Chordoma. On May 27th I underwent surgery to remove a piece of tumor to test to see if I qualified for this trial. After two weeks of waiting, I received the call letting me know I qualified. I was so thankful, I was given a chance, just what I needed. Shortly after getting the news I met with Dr. Kim Kramer, who is running the trial. I am scheduled to have an Omia, (shunt) implanted to the right side of my head for the injections on chemo. So on Friday June 19th I will have this Omia implanted and will hopefully start my chemo injections next week.

I am so thankful for my family and my fiancé Kim. They have been so supportive, and I know without them I would never make it through this terrible time in my life. As for my daughters, they are my world. They are the reason I fight so hard and will never give up. I am so thankful to the Chordoma Foundation and I know, "Together We Will".

Joyce Reichel

After graduating from Glenbard High School in a Chicago suburb in 1958, I enjoyed college, graduating from Southern Illinois University in Carbondale, IL, in 1962 with a degree in Marketing and a minor in Education. The SIU years were very enjoyable and many of my sorority sisters are still good friends today. I began doing market research with Proctor & Gamble following graduation. The training program was in Cincinnati; upon its completion new employees traveled throughout the U.S. doing market research on products like Pampers, Folgers, and Duncan Hines. I had a new location assignment each week, so I saw a great deal of the U.S. that I had never seen before. This was exciting and it was fun working with other new marketing graduates.

I left Proctor & Gamble after a year to work near Dayton, OH, where Ken Reichel was stationed with the Air Force. I taught high school business for the next year, and Ken & I were married at Christmas break in 1963. We stayed another two years while Ken continued his time in the Air Force, and had a baby girl. After his discharge, Ken started his lifetime career in electronics with a microphone company. We bought a house in Evanston, IL, and our son was born. We lived there for 8 years and 5 years in Barrington, IL, where I worked for a local attorney. After 13 years we moved to Connecticut for a new career opportunity. We thoroughly enjoyed that time, although it lasted only 4 years.

Our fifth move took us to Hudson, OH, where we remained for 25 years! Our daughter, Tammi, was a senior in high school, and our son, Scott, a freshman when we moved there. We loved it: lots of activities, work, friends, and fun for all four of us, including tennis and bridge and working for a local attorney again. Later, when our children had graduated and we were empty nesters, I became the Registrar at the private school they had attended. This was most rewarding and enjoyable. After 9 years I retired to be able to travel with my husband on numerous international business trips, which took us to presidential debates, political conventions, and summer and winter Olympics.

During the 2002 Winter Olympics in Salt Lake City it was discovered I had a chordoma brain stem tumor. Fortunately, it was accurately diagnosed while in Salt Lake City. We went back to the Cleveland Clinic (in Ohio) for surgery and then to Boston for proton radiation at Mass. General Hospital under the care of Dr. Norbert

Leibsch. The care was amazing. My biggest residual problems are fatigue, complete loss of hearing in the left ear and partial loss in the right ear, and random memory loss; otherwise my quality of life is quite good.

This is especially true since we moved to Richmond, VA in 2004 and are within a couple of miles of our four grandchildren, daughter, son-in-law (a German native), and our son. The grandchildren were all born in Germany, are multilingual, and (of course) brilliant! So say Grandma and Grandpa!

Colleen E Riccomini

I am a 37 year old mother of 2 boys, Conor is 9 years old and Cameron is 7 years old. I enjoy spending time with my family.

I am attending the conference as a parent and caregiver to Cameron. He was diagnosed with clival chordoma in February 2008. Cameron has had 4 surgeries, chemotherapy, and 43 sessions of proton beam radiation. Recurrence of the tumor happened 5 weeks after his initial surgery. Cameron gets rechecked in August 2009 to see how the proton beam radiation did.

My husband and I are attending the conference to learn more about the cure for chordoma, to meet other families effected by chordoma, and to help raise more awareness.

Richard G Riccomini

I am a 38 year old father of two boys, Conor is 9 years old and Cameron is 7 years old. I enjoy spending time with my family.

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Tina Phyllis Rosen

60 year old mother of 2 sons, teacher, retailer, ski instructor. I am a survivor of a clival chordoma excized at Columbia/Cornell in NYC on 11/30/06. 3 months later completed full regimen of proton beam radiation therapy at Mass General under Dr. Leibsch. Fortunately, no recurrences as I come upon my 3rd year anniversary in Nov. '09. I attended last years conference and am looking forward to this one.

Karen Sain

My husband and I live in western NC where we own and operate an independent pharmacy. We both attended the University of North Carolina School of Pharmacy but actually met playing tennis! We have a 20 year old son who is a junior at NC State. He is an avid cyclist and is a member of the NC State Cycling Team. Gary and I also cycle. Our older son Aaron was diagnosed with a clival chordoma in 1997. He was eleven years old at the time. After many surgeries, proton beam radiation and various treatments, Aaron died in Aug. 2004. My husband and I have become involved with the CF to help ensure that a cure will be discovered for this challenging tumor. We attended the conference last year and found the experience invaluable. I am honored to be a part of the planning committee for this year's conference and look forward to seeing everyone again.

Robert N Schils

I am a 67 year old husband, father of four, grandfather of four, and great grandfather of six. I am still working as a lighting technician (gaffer) for film and video productions in upstate New York. I enjoy fly fishing, hunting, and yard work. I was diagnosed with chordoma in C-2 on May 12, 2009. I am presently researching doctors and hospitals for treatment.

Marley Seaman

I am the 27 year old journalist writing about health care business for the Associated Press in NYC. In December 2006 I learned that my brother Tyler had a clival chordoma. It was removed in January 2007 with three days of surgeries. After two months of setbacks and surgical procedures, he was released to physical therapy for one month. He received proton beam radiation from June to August 2007. In August 2008 another tumor was found between the muscle and skin of his neck, which was treated with chemotherapy and another two months of radiation. I am currently editing a book that I wrote with Tyler about our family and about his illness, recovery and brave attitude during this crisis.

Diane L. Seaman

I am the mother of three sons. In December 2006 we learned that my 16 year old son Tyler had a clival chordoma. It was resected in January 2007. After many surgical procedures and setbacks he was released to rehab in March 2007 where he spent one month. Tyler had proton beam radiation from June through August 2007. In August 2008 another tumor was found in the surgical pathway between the muscle and skin of his neck. He had chemotherapy from November 2008 through January 2009 and another round of proton beam radiation which ended May 2009. We will return to Boston for MRIs in September.

Sue Shimer

I am a happily married to my husband Dan and am the mother of two beautiful, and very active 11 year old twin boys and a Shichon doggy Harley Peter. I work part-time as a Pharmacist, volunteer at my son's school, and love to do anything that sparks my creativity. I also enjoy spending time with family and friends, attending my son's baseball and soccer games, and gardening. My sister Debbie is a thoracic Chordoma survivor. I am very passionate about raising awareness and money for research.

Ellen Soltow

Patient. 54 years old. Single mother of 2 elementary-aged kids. Two-time cancer survivor (also had breast cancer). Sacral chordoma. Surgery in 2004. 8 months of recuperation. No radiation or chemo. Clean bill of health since surgery. Took early retirement and moved back to hometown in Ohio to concentrate on healthy, low-stress living. I would like to provide encouragement and hope to others.

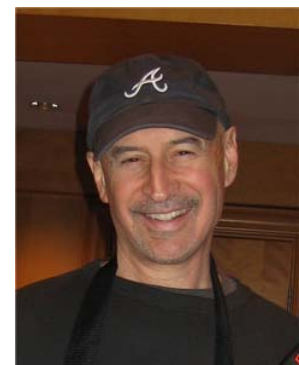


Elise Stoll

I learned about the Chordoma Foundation from the Straus/Lee family. Heather who is on the Chordoma Foundation board and her husband Steve are my second parents. Their son Justin was like a brother to me. Since the disease has directly impacted my family, it is very meaningful for me to give back to the Chordoma community any way that I can. I volunteered at the conference in 2008 and am eager to help again this year.

Steve K Straus

Father of Justin Straus, clival chordoma diagnosed in 2002, died in 2008 after multiple surgeries, radiation and chemotherapy. Found his voice at First Chordoma Conference and committed to keeping his messages alive: 1) Researchers and physicians must collaborate, 2) Support the Chordoma Foundation, 3) Persevere, 4) Always have hope



Michael J Torrey

51 father of two girls. Custom Home Designer and Builder. Love to spend time with family and friends. biking and Sailing. Coming to participate and volunteer

Thomas L Toynton

I am a 41 year old college professor in the NY/NJ metro area. My interests are physical fitness, games, science, and individual sports. I was diagnosed with Chordoma on April 1st 2003. The tumor resided at L4 and was removed along with the vertebrae and replaced with hardware after 3 operations. A second tumor appeared in the same region last year and was removed on January 2nd. In April and May I underwent 7 weeks of Tomotherapy radiation treatment as a preventative measure.



Craig S Tunks

I am a Director of Technology for a public school system. I am attending the conference as a caregiver. In 2003 my life partner, Tom, was diagnosed with Chordoma cancer. It was located in his L4 vertebrae. In 2008 he experienced pain in his lower back again and after a few months of testing was diagnosed again that the cancer had returned. He went through another surgery, his fourth since his original diagnosis, to remove the cancer. He recently completed 7 weeks of Tomo radiation treatment.



We are new to the foundation and created our champion pages this year and are participating in this conference. We are hoping to become more involved in the future.

Candice O Walsh

After losing my mother and grandfather to cancer, I began to realize at a young age that I was destined to fight cancer. As a friend and admirer of the Straus family, I am here at the conference not only as a volunteer, but as an individual, a friend, and a team member of this big fight...I am persevering for you all, persevering towards a cure!

