Speakers
2018 International Chordoma Community Conference

Brianne Carter, LCSW, MTS
Brianne is the Co-Director of Wellness and Integrative Care at The Virginia Thurston Healing Garden Cancer Support Center in Harvard, MA. After receiving a Master of Theology from Harvard Divinity School and a Master of Social Work from Smith School for Social Work, Brianne worked in community mental health, with Emerson Hospital, and with the Massachusetts General Hospital Cancer Center at Emerson Hospital-Bethke. Brianne currently leads a number of groups for cancer survivors and caregivers at the Healing Garden. She joined us to lead the caregivers support session at the 2016 International Chordoma Community Conference.

Yen-Lin Chen, MD
Dr. Chen is a board-certified radiation oncologist at Massachusetts General Hospital (MGH). She is a graduate of Vanderbilt University School of Medicine and completed her internal medicine internship at the Brigham and Women’s Hospital and radiation oncology residency at the Massachusetts General Hospital. She has cared for many chordoma patients in her 10 years with the multidisciplinary Stephan L. Harris Center for Chordoma Care at MGH and more recently as a member of the Cancer Survivorship research team at MGH. She is the principle investigator of the MGH Sarcoma Data Repository of more than 13,500 cases, with a focus on sarcoma outcomes, clinical trials, translational research, and survivorship. She also chairs an NCI/CTEP sponsored National Clinical Trials Network trial in intermediate-high risk sarcomas. Her clinical interests include sarcomas, chordoma, proton therapy, novel combinations of sensitizing agents with radiation therapy, intraoperative radiation therapy, and brachytherapy.

Greg Cote, MD, PhD
Dr. Cote is a medical oncologist at the Massachusetts General Hospital Cancer Center in the Henri and Belinda Termeer Center for Targeted Therapies (Phase I), the Center for Sarcoma and Connective Tissue Oncology, and the Stephan L. Harris Center for Chordoma Care. His primary research interest is in developing novel agents for connective tissue malignancies through translational studies and early phase clinical trials. Dr. Cote received his MD and PhD from Boston University School of Medicine, completed his residency at Massachusetts General Hospital and his fellowship at Dana Farber Cancer Institute. In 2017, Dr. Cote was appointed to the Chordoma Foundation’s Medical Advisory Board.

Thomas DeLaney, MD
Dr. DeLaney is a graduate of Harvard College and Harvard Medical School. He trained in radiation oncology at Massachusetts General Hospital (MGH) and spent six years as Senior Investigator at the National Cancer Institute. Since 1992, he has been on staff at MGH where he is the Medical Director of the Francis H. Burr Proton Therapy Center, Co-Director of the Center for Sarcoma and Connective Tissue Oncology, and Co-Director of the Stephan L. Harris Center for Chordoma Care. He is also Andres Soriano Professor of Radiation Oncology at Harvard Medical School. Dr. DeLaney has made important contributions to the treatment of soft tissue sarcomas, bone
sarcomas, and chordomas, as well as the use of charged particle (proton) radiation therapy. His bibliography lists him as lead author or co-author of 135 original articles in peer-reviewed research publications, as well as 83 reviews, chapters and editorials. He is on the editorial boards of the *Journal of Surgical Oncology* and *UpToDate in Oncology* and is a member of the Chordoma Foundation's Medical Advisory Board.

**Bill Dorland**  
As a chordoma patient, Bill has been living with chordoma for more than a decade. He has undergone four surgeries and participated in three clinical trials. With the Chordoma Foundation, Bill initiated and co-sponsored the first conference for chordoma patients in 2008 and continues to support the Foundation’s search for a cure.

**Al Ferreira, RN**  
After graduating from Northeastern University, Al’s 30-year clinical career has included working in critical care, post-anesthesia, perioperative, and orthopedic nursing. In addition, he has worked as a clinical analyst in information systems and as a perioperative informatics consultant for two software firms. After a long career with Massachusetts General Hospital, most recently with the Stephan L. Harris Center for Chordoma Care, Al moved to the David Geffen School of Medicine at UCLA to support the opening of a chordoma center there.

**Adrienne Flanagan, MD, PhD**  
Dr. Flanagan received her medical degree from the Royal College of Surgeons in Ireland and undertook her PhD at the University of London in 1990 while she was a Medical Research Council Training Fellow at St. George’s Hospital Medical School in London. She became a senior lecturer and honorary consultant pathologist at Imperial College London, later moved to University College London, and now practices clinical pathology at the Royal National Orthopedic Hospital. Dr. Flanagan was elected as Professor of Musculoskeletal Pathology at UCL’s Cancer Institute in 2004. Dr. Flanagan is the Meeting Secretary of Pathological Society of Great Britain and Ireland, and a trustee or member of various committees including the Sarcoma UK Research Advisory Committee, The Jean Shanks Foundation, the Chordoma Foundation’s Scientific Advisory Board, and the National Quality Assurance Advisory Panel of the Royal College of Pathology. Her research interests focus on reclassifying bone and soft tissue tumors using molecular signatures, which she then translates into clinical practice by stratifying patients for treatment. She is the co-lead of the International Cancer Genome Consortium bone tumor project.

**Paul Gardner, MD**  
Dr. Gardner is Associate Professor of neurological surgery at the University of Pittsburgh School of Medicine and Director of the UPMC Center for Cranial Base Surgery. He specializes in endoscopic endonasal skull base surgery, pituitary tumors, and vascular neurosurgery. Dr. Gardner received his medical degree from the University of Pittsburgh School of Medicine, where he also completed his residency and a two-year fellowship focusing on endoscopic endonasal pituitary and open skull base surgical techniques. His research has focused on evaluating patient outcomes following these surgeries, as well as exploring molecular analysis in rare tumors. Dr. Gardner is a member of the American Association of Neurological Surgeons, Congress of Neurological Surgeons, North American Skull Base Society, and sits on the Medical Advisory Board of the Chordoma Foundation.
Ziya Gokaslan, MD
Dr. Gokaslan is Chief of Neurosurgery at Rhode Island Hospital and Miriam Hospital, Director of the Comprehensive Spine Center at Rhode Island Hospital, Clinical Director of the Norman Prince Neurosciences Institute, and the Neurosurgery Chair at the Warren Alpert Medical School of Brown University. His clinical practice focuses on the surgical treatment of primary and metastatic spinal tumors, sacral neoplasms, and spinal cord tumors, including chordoma. He developed many novel approaches for resection of spinal neoplasms and sacral tumors. Dr. Gokaslan’s research uses animal models to develop local chemotherapeutic delivery systems for primary and metastatic spinal tumors. In addition, he oversees clinical trials assessing the efficacy of surgery and spinal reconstruction for spinal column tumors. He also is a member of the Chordoma Foundation’s Medical Advisory Board.

Chris Heery, MD
Dr. Heery is the Chief Medical Officer at Bavarian Nordic where he oversees preclinical and clinical development of the company’s infectious disease and immuno-oncology portfolio. Prior to joining Bavarian Nordic, Dr. Heery was the Director of the Clinical Trials Group of the Laboratory of Tumor Immunology and Biology at the National Cancer Institute. He is a graduate of Duke University and received his medical degree from East Carolina University Brody School of Medicine. Dr. Heery’s clinical research is focused on the use of novel agents capable of inducing the immune system to recognize and kill cancer cells. Dr. Heery is very interested in the use of these agents in combination with each other as well as conventional cytotoxic therapies in an effort to improve their efficacy. He also has an interest in using these therapies to help patients with the fewest treatment options, including patients with rare diseases. Dr. Heery is a member of the Chordoma Foundation’s Medical Advisory Board.

Debra Jarvis
Debra is an ordained minister and former hospital chaplain for Seattle’s Cancer Care Alliance. She has a BA in communications from U.C. Berkeley, an MA in Christian Arts from New College, Berkeley, and a Master’s in Divinity from Northwest Theological Union. In the past 25 years she has served as a pastoral consultant for volunteer groups caring for people with AIDS and MS, written plays, authored numerous books, and served as writer-in-residence at University Congregational Church United Church of Christ. She has written numerous books about her work supporting patients including, It’s Not About the Hair: And Other Certainties of Life & Cancer, and most recently gave a TED talk titled, "Yes, I survived cancer. But that doesn’t define me."

Sasha Knowlton, MD
Dr. Knowlton is an instructor and the Assistant Director of Cancer Rehabilitation in the Department of Physical Medicine and Rehabilitation at Spaulding Rehabilitation Network/Harvard Medical School. She received her medical degree at the George Washington University School of Medicine and Health Sciences. She attended residency in physical medicine and rehabilitation at Spaulding Rehabilitation Network/Harvard Medical School, where she served as Chief Resident, followed by a fellowship in Cancer Rehabilitation at Memorial Sloan Kettering Cancer Center. Dr. Knowlton is board certified in physical medicine and rehabilitation. Her clinical and research interests are in cancer rehabilitation, with the goal of improving the function and quality of life of cancer patients during all aspects of cancer treatment and survivorship.
**Edward Les, MD**

Ed is a pediatric emergency medicine physician in Alberta, Canada and a clival chordoma survivor. A former CF Board member, Ed now serves as the Medical Liaison on the CF Community Advisory Board (CAB), acting as a link between the CF Medical Advisory Board (MAB) and the CAB. In this role, Ed brings important questions, issues, and concerns of the chordoma patient community to the MAB and helps the staff relay insights and recommendations from the MAB to the patient community.

**Joan Levy, PhD**

Joan joined the Chordoma Foundation as Director of Research in June 2017 with 30 years of experience in oncology research in academic, pharmaceutical, and disease foundation settings. In the 10 years prior to joining the Foundation, Joan led a variety of research programs at the Multiple Myeloma Research Foundation (MMRF) ranging from spearheading different grant programs to working closely with their affiliate research consortium on large genomics projects and coordinating early clinical trials between consortium sites and industry partners. Prior to joining the MMRF, Joan was responsible for coordinating an oncology pipeline of early drug discovery projects at Bayer Pharmaceuticals. Joan brings to the Foundation extensive knowledge ranging from therapeutic target identification and preclinical drug screening approaches to driving the results into meaningful clinical studies. At the Chordoma Foundation, Joan is responsible for oversight of research activities with particular focus on programs involving identification of new therapeutic targets, further development of the Drug Screening Program, and advancement of new drugs and combination approaches into the clinic. Joan has a passion to interact directly with patients and caregivers and works closely with her colleagues at the Foundation to identify new treatments as well as improve medical care and experiences for chordoma patients. Joan has a BS in Biology from the State University of New York at Stony Brook and a PhD in Biochemistry from the University of Vermont.

**Marcia Lewin-Berlin, LICSW, ACHP-SW, Reiki Master**

Marcia is the Co-Director of Wellness and Integrative Care at The Virginia Thurston Healing Garden Cancer Support Center in Harvard, MA. She is a psychotherapist specializing in loss, bereavement, and life altering issues for individuals and their families. Marcia is a home-based Hospice Social Worker with advanced certification in Hospice and Palliative Care. For more than twenty-five years, she has been both in practice as a group facilitator with training in dreamwork, mindfulness, Reiki, and family systems work. At the Healing Garden she leads a variety of groups for patients, caregivers, and parents of patients.

**Leora Lowenthal, LICSW, OSW-C, MPA**

Leora is a Senior Clinical Social Worker at Boston's Beth Israel Deaconess Medical Center, where she leads the social work program for a satellite cancer center in Needham, MA. Leora's education includes master's degrees in Social Work and Public Administration respectively, and a postgraduate certificate in Bioethics and the Medical Humanities. In addition to her clinical work she has served on several boards, including three years as Education Director for the Association of Oncology Social Work. Leora currently serves on the Board of Directors for the Board of Oncology Social Work Certification and is a member of the Medical Advisory Council for the Cutaneous Lymphoma Foundation.
Shannon Lozinsky, MSW
Shannon joined the Chordoma Foundation in 2014 and now serves as Director of Patient Services. Shannon has been in the fields of social work and education for more than 15 years and has a Master of Social Work from the University of North Carolina at Chapel Hill. She has worked for a number of public and private social service organizations and spent time in private practice providing mental health services to children, adults, and families. Shannon is passionate about educating patients and family members on chordoma, helping patients get the best possible care, and providing ways for the chordoma community to come together to support one another.

Shreyaskumar Patel, MD
Dr. Patel is a professor of medicine and holds the Robert R. Herring Distinguished Professorship in Cancer Research at The University of Texas MD Anderson Cancer Center. He is also the Medical Director of the Sarcoma Center and Deputy Chairman of the Department of Sarcoma Medical Oncology at MD Anderson. Dr. Patel has been a part of the Foundation’s Medical Advisory Board since its inception, and in May 2017 he was appointed as Chair. He graduated from Baroda Medical College in Baroda, India and did his medical oncology training at the Mayo Clinic in Rochester, Minnesota. Dr. Patel has authored or co-authored more than 200 articles in various journals and has been section editor for the sarcoma section of Current Oncology Reports since 2000. He has also authored or co-authored 30 book chapters. His clinical research interests include systemic therapy for sarcomas, GISTs, and other tumors originating in bone and soft tissues. He is a past President of CTOS, a member of the Executive Committee and Chair of the Clinical Research Committee of SARC, and has served as the past Program Chair for CTOS and the Sarcoma Track for ASCO.

Lisa Ruppert, MD
Dr. Ruppert is a physiatrist at Memorial Sloan Kettering Cancer Center, specializing in evaluating cancer patients and cancer survivors who have neurological and musculoskeletal impairments related to cancer and its treatment. She is a graduate of Ross University School of Medicine and New York-Presbyterian Hospital/Columbia University Medical Center. She did her residency at Weill Cornell Medical Center and was fellowship trained at the Rehabilitation Institute of Chicago/Northwestern University-Feinberg School of Medicine. Dr. Ruppert is board certified in spinal cord injury medicine and physical medicine and rehabilitation. Her clinical interests include the care of patients with neurological impairments secondary to primary and metastatic tumors of the spine, spinal cord, and brain, as well as neurological impairments that can develop as a result of cancer.

Andrew Schoelkopf
Andy is a partner at Menconi & Schoelkopf Fine Art, a leading private art dealer located in New York City that specializes in American paintings, drawings, and sculpture of the eighteenth-, nineteenth-, and early twentieth-centuries. Andy was raised in a family of art dealers, the son of Robert and Jane Schoelkopf, who ran the prestigious Robert Schoelkopf Gallery in New York until Robert’s death in 1990. Working at the gallery until its close in 1991, Andy then joined Christie’s, where he rose to head of the American Paintings Department. Andy holds a bachelor’s degree from Denison University and a Master of Business Administration from Fordham University Graduate School of Business. Andy is a past board member of the Private Art Dealers Association, of which his gallery is a member. After his brother Rob Schoelkopf was diagnosed with chordoma in 2010, Andy joined the Chordoma Foundation’s Board of Directors, of which he is now the Chair.
Josh Sommer

Josh was diagnosed with a skull base chordoma in 2006. Unwilling to accept the limited treatment options available to chordoma patients, he joined the lab of Dr. Michael Kelley at Duke University, where he spent the next two years studying chordoma. There he experienced the very practical challenges faced by virtually all would-be chordoma researchers — insufficient funding; scarcity of tissue, cell lines, and animal models needed for experiments; and isolation from others studying the disease. To solve these problems and proactively advance the search for a cure, Josh co-founded the Chordoma Foundation in 2007. Under his leadership, the Foundation has united and expanded the chordoma research community and vastly accelerated the pace of chordoma research. As Executive Director, Josh works with the Foundation’s research partners, advisors, and supporters to design, execute, and fund research initiatives focused on developing new treatments for chordoma.

Yoshiya (Josh) Yamada, MD

Dr. Yamada received his medical degree from the University of Alberta, with residency at Princess Margaret Hospital and fellowship training at Memorial Sloan Kettering Cancer Center. He is a board-certified radiation oncologist at Memorial Sloan Kettering Cancer Center with expertise in treating cancers, including chordoma, with brachytherapy (radiation placed inside of tumors) and image-guided radiation therapy (using advanced medical imaging technology to deliver precise beams of radiation to safely destroy tumors). He has particular expertise in caring for patients with spine tumors, primary brain tumors, metastatic brain tumors, and prostate cancer. He is also involved in clinical research that involves using image-guided technologies to treat tumors in all sites of the body, including adult brain and spine tumors, as well as liver tumors. He is a member of the Chordoma Foundation’s Medical Advisory Board.