



Participant Profiles

Second International Chordoma Research Workshop

April 3-5, 2008

Team Stats

	<u>2007</u>	<u>2008</u>
Participants	53	80
Countries Represented	5	8
Chordoma Survivors	3	6
Developmental Biologists	1	3
Radiation Oncologists	2	5
Pediatric Oncologists	1	3
Veterinarians	0	2

David Alcorta, Ph.D

Primary Specialty: Molecular Biology

Christopher Austin, M.D.



Primary Specialty: Neurology

Bio

Christopher Austin is Director of the NIH Chemical Genomics Center (NCGC), and Senior Advisor to the Director for Translational Research at the National Human Genome Research Institute (NHGRI). The NCGC, part of the NIH Roadmap Molecular Libraries initiative, develops small molecule probes for biological functions and new paradigms for high-throughput screening, chemistry, and cheminformatics. In his role as

Senior Advisor for Translational Research, he initiated the Knockout Mouse Project, which is producing knockout mice for all mouse genes, and an in-depth transcriptome map of the mouse. Dr. Austin came to NIH from Merck, where he directed research programs genomics-based target discovery, pharmacogenomics, and DNA microarray technologies, with a focus on neuropsychiatric diseases. Dr. Austin received his A.B. from Princeton and M.D. from Harvard. He did clinical training in neurology at Massachusetts General Hospital, followed by a fellowship in genetics at Harvard.

Chordoma Interests

Development and screening of assays relevant to chordoma as a start to drug development

Resources

Well-established pharma-scale center that does assay optimization, HTS, and chemical optimization of chemical probes

Carlos Bagley, MD

Primary Specialty: Neurosurgery

Laurence Baker, DO

Primary Specialty: Medical Oncology

Bio

Laurence H. Baker, DO, is Professor of Internal Medicine and Pharmacology, Departments of Internal Medicine and Pharmacology, Division of Hematology/Oncology, University of Michigan Medical School.

He received his medical degree from the University of Osteopathic Medicine and Surgery at Des Moines, Des Moines, IA, in 1966. After receiving his degree, he did a medical residency at Detroit Osteopathic Hospital which was followed by an oncology fellowship at Wayne State University. He joined the faculty of the Department of Oncology at Wayne State University upon completion of his fellowship in 1972.

In 1987 Dr. Baker became the Director of the Meyer L. Prentis Comprehensive Cancer Center of Metropolitan Detroit where he remained until his recruitment to the University of Michigan in 1994. He served as the Deputy Director and Director for Clinical Research at the University of Michigan until May, 2004.

Dr. Baker has 30 years experience in the treatment of sarcoma and design of clinical trials for new sarcoma therapies. In April, 2005, he became Chairman of the Southwest Oncology Group (SWOG), the largest cancer clinical trials organization in the world after election by the membership. SWOG's membership lists nearly 4,000

of the nation's leading physicians and scientists at 283 institutions in the United States and Canada. Dr. Baker is also the Executive Director of SARC (Sarcoma Alliance for Research through Collaboration), a not-for-profit consortium which advocates for sarcoma medical research and for the conduct of clinical trials studying new treatment for sarcoma. He is a scientific consultant to the National Cancer Institute and several universities, a member of many prestigious organizations, and a nationally recognized expert in sarcoma treatment. He has published extensively in peer-reviewed literature and has authored or co-authored 50 books and/or book chapters, and is regularly invited to speak as a guest lecturer both at the national and international level.

Chordoma Projects

1. Examining inflammatory molecular effect in chordoma invasion
2. Clinical trial with 9NC in chordoma
3. Treated first patient with imatinib

Resources

President, SARC (Sarcoma Alliance thru Research and Collaboration). SARC is developing a multi-institutional clinical trial for chordoma

Fred Barker, MD

Primary Specialty: Neurosurgery

Patrick Boland, M.B. B.Ch. B.A.O., FRSI

Primary Specialty: Orthopedic Oncology

Justin Cates, M.D. Ph.D.

Primary Specialty: Anatomic Pathology

Secondary Specialty: Bone and Soft Tissue Pathology

Bio

I am currently a surgical pathologist at Vanderbilt University Medical Center and have subspecialty interests in orthopaedic and molecular pathology. I completed my post-graduate training at Massachusetts General Hospital, including a surgical pathology fellowship in bone and soft tissue pathology.

Chordoma Projects

We would like to apply proteomic technology to the study of chordoma.

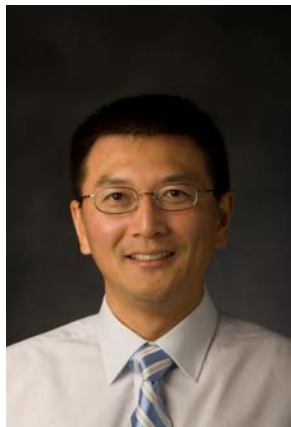
Chordoma Interests

We are interested in the molecular mechanisms of chordomagenesis and the potential application of molecular therapeutics for the treatment of chordoma.

Resources

The Mass Spectrometry Research Center and Proteomics Laboratory at Vanderbilt University has extensive experience in tissue-based techniques such as matrix-assisted laser desorption/ionization mass spectrometry and two-dimensional difference gel electrophoresis.

Wei Chen, Ph. D.



Primary Specialty: Cancer cell signaling

Chordoma Projects

Currently we are studying roles of oncogenic Wnt and Hedgehog signaling pathways in human chordoma U-CH1 cells. We have the following preliminary data. 1) Stimulation of Wnt3A leads to a dramatic increase of endogenous cytosolic beta-catenin, a well-known oncogenic protein, in U-CH1 cells to activate the Wnt signaling pathway, 2) We are developing a novel image based, high throughput screening assay to identify small molecules that inhibit the Wnt pathway, and 3) We are characterizing the Hedgehog signaling in chordoma cells and it appears that this oncogenic pathway seems active because the expression of endogenous Patched (a downstream target of Hedgehog pathway) is quite high as measured by a real time quantitative PCR method. We also have identified about 30 new small molecule inhibitors of the Hedgehog pathway, which may provide a therapeutic benefit.

Chordoma Interest

A goal of my research is to characterize the cellular and biochemical signaling pathways that regulate seven membrane spanning receptor functions in chordoma. These receptors include G-protein coupled receptors, Wnt/Frizzled and Hedgehog/Smoothed and are major drug targets for prescription drugs in the U.S. As a result of our research, we have established a state-of-the-art high throughput, high content screening platform in my laboratory to identify novel small molecules that can be immediately employed in translational research in chordoma since they may provide a therapeutic benefit.

Resources

Cell signaling, Cancer biology, Translational research including development of high throughput screening assays for identification of novel small molecules that inhibit oncogenic signaling pathways.

Dean Chou, M.D.



Primary Specialty: Neurosurgery
Secondary Specialty: Spine Surgery

Chordoma Projects

Dissemination of information so that chordomas are properly managed from the start.

Chordoma Interests

Improving surgical techniques to treat chordoma.

Resources

Potentially establishing cell lines or animal models for chordoma.

Francis Collins, M.D., Ph.D.

Primary Specialty: Genetics

Peter Costantino, MD

Primary Specialty: Otolaryngology
Secondary Specialty: Cranial Base

Michael D. Cusimano, MD, MHPE, FRCSC, PhD

Primary Specialty: Neurosurgery

Bio

Dr. Cusimano received his MD and PhD from the University of Toronto and his Masters degree from the University of Illinois at Chicago. Since completing a Skull Base and Microvascular Fellowship in 1992, Dr. Cusimano has been a Staff Neurosurgeon and a professor of Neurosurgery, Education and Public Health at St. Michael's Hospital, University of Toronto. He is a Fellow of the Royal College of Physicians and Surgeons of Canada, a diplomate of the American Board of Neurological Surgery and a Fellow of the American College of Surgeons. He was the first to describe the dual-nostril technique of endoscopic skull base surgery. Since his first description, the technique has been learned widely and is now used around the world for skull base surgery. He performs surgery and gamma knife radiosurgery on adults and children with skull base tumours and his clinical skill and opinion is sought widely. His research interests are quite varied and include skull base surgery, tumours/aneurysms and lesions that affect the skull base, stem cells, NPH, quality of life, the cerebellum, injury, public health issues, geomatics, knowledge translation and medical education. He is a reviewer for a number of medical journals and has authored over 80 peer-reviewed manuscripts in journals such as The Lancet and Nature. His trainees can be found on every continent except the Antarctica. He has won many awards for his research, his teaching and for his compassion as a doctor.

Chordoma Interest

Interests - Clinical, Surgical techniques, Quality of Life, stem cells. I would like to collaborate with others to do research that improves survival and quality of life for these patients.

Chordoma Projects

Quality of Life in patients with Chordoma and Chondrosarcoma and their Caregivers - results still pending at this time.

Resources

All of the following depend on the availability of funding - Education of Health Professionals (translation of knowledge), Geomatics, quality of Life assessment, stem cell laboratory (if accompanied with funds), cognitive function laboratories (if accompanied with funding) and measurement and evaluation.

Thomas Delaney, M.D.



Primary Specialty: Radiation Oncology

Bio

Dr. DeLaney is currently the Medical Director of the Francis H. Burr Proton Therapy Center at the Massachusetts General Hospital (MGH), Boston. He also is Co-Director of the Sarcoma Center at the hospital, and Associate Professor of Radiation Oncology, Harvard Medical School. His primary areas of clinical and research interest include bone and soft tissue sarcomas and charged-particle (proton) radiation therapy.

Dr. DeLaney was born in Corpus Christi, Texas and grew up in Morristown, New Jersey, in the metropolitan New York City area. He obtained his B.A. degree in history at Harvard College in 1978 and his medical degree from Harvard Medical School in 1982. After completing his internship at the Yale-New Haven Hospital in general surgery, Dr. DeLaney took three years of residency training at MGH in Radiation Oncology, completing training in 1986. He then spent six years as a senior investigator at the National Cancer Institute in Bethesda

MD, where he participated in studies evaluating the treatment of adult and pediatric sarcomas and translational research in photodynamic therapy with light-activated dyes. He returned to Boston in 1992 to become Chief of Radiation Oncology at Boston University Medical Center, where he also established a joint Radiation Oncology residency program in conjunction with MGH. He returned to MGH to head the Sarcoma Service in the Department of Radiation Oncology in 2000, and became medical director of the Francis H. Burr Proton Therapy Center in 2001. He and Hanne Kooy, Ph.D. are editors of the book Proton and Heavier Charged Particle Radiotherapy (Lippincott, 2007). He is on the editorial boards of the Journal of Clinical Oncology and the Journal of Surgical Oncology.

Dr. DeLaney's areas of interest outside of work include his family (wife Linda, sons Alec, 16 and Ian, 13), playing tennis and ice hockey, jogging, and the alto saxophone.

Chordoma Projects

Implementation of intensity modulated proton radiation therapy for spine sarcomas/chordomas.

Evaluation of concurrent targeted therapies (kinase inhibitors, anti-angiogenesis agents) with radiation for unresectable chordomas.

Chordoma Interests

High dose photon/proton radiation therapy +/- surgery for spine chordomas. Completed a prospective trial of this strategy for 50 spine/paraspinal sarcomas in 3/2005, of which 29 patients had chordomas. Local control with a median follow-up of 4 years has been achieved in 26/29 patients and is better in primary than locally recurrent patients.

Resources

1. Charged particle radiation therapy.
2. Member of RTOG Sarcoma Group.
3. Large clinical database of clinical information with access to frozen tissue on many of the patients.

George Demetri, MD

Primary Specialty: Oncology

Secondary Specialty: Internal Medicine

Franco DeMonte, MD



Primary Specialty: Skull Base Surgery

Secondary Specialty: Neurosurgical Oncology

William Dorland, PhD



Primary Specialty: Turbulence, mathematical modeling

Bio

Prof William Dorland is a physicist from the University of Maryland. Relevant interests include statistical analysis tools for rare disease trials and other mathematical aspects of this disease, including analysis of genetic sequences.

Chordoma Projects

I am supporting Chordoma Foundation activities and patient networking.

Chordoma Interests

I was diagnosed with a sacral chordoma in 2004, and subsequently treated at JHH and MGH.

Resources

I have good connections to mathematically sophisticated graduate students with interests in nonlinear problems. I can provide high-quality computing cycles to scientists working on chordoma research.

John Ferguson, MD

Primary Specialty: neurology

Soldano Ferrone, PhD, MD



Primary Specialty: Immunology

Chordoma Interest

development of antibody-based immunotherapy for chordoma

Chordoma Projects

Antigenic profile of chordoma lesions. Expression of high molecular weight-melanoma associated antigen in about 50% of chordoma lesions.

Adrienne Flanagan, MB BCH BAO FRCPath PhD

Primary Specialty: Histopathologist

Secondary Specialty: Bone and soft tissue pathologist

Chordoma Projects

to identify the molecular genetic basis of this disease

Chordoma Interests

I am a pathologist with a specialist in bone and soft tissue tumours. A few years ago with my team I identified that brachyury was highly sensitive and specific for the diagnosis of chordoma. Since then we have identified that chordomas (brachyury and CK19+ tumours) also occur in soft tissue and in skeletal extra-axial sites. We are: 1. studying what effect brachyury mediates on mesenchymal stem cells 2. studying how to maintain chordoma cell lines and 3. attempting to identify if there are biomarkers for clinical progression.

Jane Fountain, Ph.D.

Primary Specialty: Cancer Geneticist

Joseph Fraumeni, M.D.

Primary Specialty: cancer epidemiology

Sherri Gibbons, M.D.

Primary Specialty: Obstetrics/gynecology

Alisa Goldstein, PhD

Primary Specialty: Genetic Epidemiology

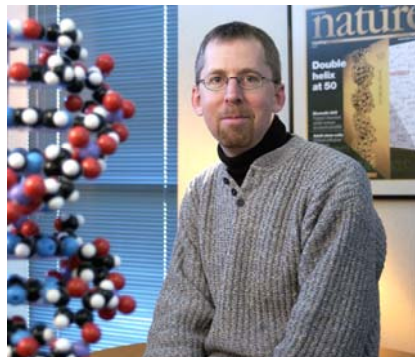
Chordoma Interests

Mapping and identifying major susceptibility genes for familial chordoma

Rashmi Gopal-Srivastava, PH.D.

Primary Specialty: Molecular Biology

Eric Green, M.D., Ph.D.



Primary Specialty: genomics

Bio

Eric D. Green, M.D., Ph.D. is the Scientific Director of the National Human Genome Research Institute (NHGRI) at the National Institutes of Health (NIH) in Bethesda, Maryland, a position he has held since 2002. In addition, he serves as Chief of the NHGRI Genome Technology Branch (since 1996) and Director of the NIH Intramural Sequencing Center (since 1997). Dr. Green received his B.S. degree in Bacteriology from the University of Wisconsin-Madison in 1981, and his M.D. and Ph.D. degrees from Washington University in 1987. Since the early 1990s, Dr. Green's research program has been at the forefront of efforts to map, sequence, and understand eukaryotic genomes. His work included significant, start-to-finish involvement in the Human Genome Project. More recently, Dr. Green established a program in comparative genomics that involves the generation and comparative analyses of sequences from targeted genomic regions in multiple evolutionarily diverse species. His laboratory has directly utilized its own mapping and sequence data to identify and characterize several human disease genes, including those implicated in certain forms of hereditary deafness, vascular disease, and inherited peripheral neuropathy.

Steve Groft, Pharm.D.

Primary Specialty: Pharmacy

Brian Harfe, Ph.D.



Primary Specialty: Developmental Biology

Bio

My undergraduate degree is from the University of Glasgow in Glasgow, Scotland. After having a lot of fun traveling all over Europe I returned to the United States and began my Ph.D. at The Johns Hopkins University in 1993. My Ph.D. thesis was on muscle development in the nematode *C. elegans* in the laboratory of Dr. Andrew Fire (2006 Nobel Prize winner for his discovery of RNAi). After obtaining my Ph.D. in 1998, I moved to Emory University and began my first postdoctoral position in the laboratory of Dr. Sue Jinks-Robertson working on DNA damage pathways in yeast. In 2000, I moved to Boston where I began my second postdoctoral position in the laboratory of Dr. Cliff Tabin at Harvard Medical School working on the molecular pathways responsible for limb formation using the mouse and chick model systems. Since 2003, I have been an Assistant Professor in the Molecular Genetics and Microbiology Department at the University of Florida College of Medicine in Gainesville, Florida.

Chordoma Projects

To generate a mouse model of chordoma.

Chordoma Interests

My lab has performed a detailed fate map of the mouse notochord at the single cell level in order to study intervertebral disk development. We found that the notochord forms the entire nucleus pulposus of the intervertebral disk. In the course of this work I noticed that there were always a few cells that did not make it into the disks but got stuck in the vertebrae between each disk. At the time, I ignored these cells since the goal of the project was to figure out how the nucleus pulposus formed.

However, after having these cells keep appearing in all experiments and confusing my very simple interpretation of what happens to the mouse notochord, I decided that we should figure out what they were. Based on their location and lineage, it appears that we may have stumbled upon the elusive notochordal remnants. Currently, we are attempting to express genes in notochordal remnants to model chordoma using conditional mouse alleles and cre driver lines.

Resources

My lab uses the mouse and chick model systems to investigate any area of development that either I, or someone in the lab finds interesting. In mice, we extensively use and make conditional alleles and cre lines to remove gene function from specific tissues in the embryo. In chick, we mis-express proteins using viruses and classical tissue manipulations.

Carolyn Hoban, DSc

Primary Specialty: Translational medicine

Francis Hornicek, MD, PhD

Primary Specialty: Orthopaedic Oncology

Bio

Chief of Orthopaedic Oncology Service and Co-Director of the Center for Sarcoma and Connective Tissue Oncology at the MGH. He is associate Professor at Harvard Medical School and focuses his clinical practice in the treatment of primary tumors of the pelvis/axial skeleton.

Wesley Hsu, M.D.

Primary Specialty: Neurosurgery Resident

Yang Huilin, MD

Primary Specialty: Spine surgery

Tadashi Kamada, MD

Primary Specialty: Radiation oncology

Steve Kanter, M.D.

Primary Specialty: Administrative Medicine

Secondary Specialty: Anesthesiology

Chordoma Interests

I am a patient who had a sacral chordoma surgically removed on 02/07/06, followed by proton beam radiation therapy (microscopic chordoma protocol) and several complications, most notably: fractured S1 vertebra requiring ORIF with 2 titanium screw fixation on 12/27/06; and radiation proctitis.

Resources

As a physician and patient, I can use my experiences to help guide clinical matters.

Amin Kassam, MD



Primary Specialty: Neurosurgery

Bio

Amin Kassam, MD, completed his medical and undergraduate education at the University of Toronto and his residency and fellowship training at the University of Ottawa. Dr. Kassam pursued additional post-graduate training in epidemiology and clinical outcomes. Dr. Kassam joined the faculty of the Department of Neurological Surgery at the University of Pittsburgh in February of 1998. He spent the next year focusing on microvascular surgery. Dr. Kassam has performed over 1,000 microvascular decompression procedures for cranial nerve neuropathy and has provided a unique perspective by using the endoscope to visualize and enhance difficult regions. Since his appointment, he has also focused on building a collaborative center to provide comprehensive care for complex pathology of the skull base. This center builds on the strength of combining the talents of surgeons from

multiple specialties. This allows for the use of proven conventional approaches in conjunction with new minimally invasive endoscopic approaches to provide safe and effective treatment for patients. This has culminated in the development of the multidisciplinary Minimally Invasive Neurosurgical Center (MINC). Dr. Kassam along with Carl Snyderman, MD, and Ricardo Carrau, MD, were directly involved with the development of the Expanded Endonasal Approach (EEA). This approach represents an entirely new paradigm to remove complex lesions of the skull base and brain without incisions. The center, under the direction of Dr. Kassam, has

pioneered and developed much of the technology and instrumentation used during the EEA surgeries. With continued research and experience, he now uses the EEA surgery for most tumors affecting the skull base. Dr. Kassam has performed over 3,000 neurosurgical procedures including over 700 minimally invasive endoscopic procedures. In July 2006, Dr. Kassam was named Interim Chairman of the Department of Neurological Surgery. Dr. Kassam has over 80 peer reviewed publications, an additional 11 book chapters currently published or in press, and is funded by both industry and the NIH. He lectures extensively nationally and internationally on surgery of the cranial nerves, skull base and on minimally invasive endoscopic techniques.

Michael Kelley, MD

Primary Specialty: Medical Oncology

Secondary Specialty: Molecular Biology

Bio

I am a graduate of University of Michigan School of Medicine (MD, 1985), completed Internal Medicine Residency training at Duke University (1988), and completed training at National Cancer Institute including post-doctoral work in the laboratory of Stuart Aaronson and a clinical fellowship in Medical Oncology. I am currently Associate Professor of Medicine at Duke University and Chief of Hematology/Oncology at the Durham Veterans Affairs Hospital.

Chordoma Interest

My interest in chordoma began more than a decade ago in collaboration with Dilys Parry and others in pursuit of familial chordoma gene(s).

Daniel Kelly, M.D.

Primary Specialty: Neurosurgery

Ed Les, MD,DVM

Primary Specialty: Pediatric Emergency Medicine

Bio

Initially trained as a veterinarian (DVM '91); almost five years of private veterinary practice. Back to medical school (MD '98) then pediatrics residency followed by emergency medicine fellowship. Currently attending physician at Alberta Children's Hospital in department of emergency medicine and clinical assistant professor at University of Calgary. Diagnosed with large clival chordoma January 2007, have had several surgeries followed by proton beam radiation.

Chordoma Interests

I am a physician afflicted with a clivus chordoma. I am still recovering from treatment, but intend to lend my efforts to the chordoma foundation, possibly acting as a facilitator between the medical and veterinary communities (i.e. maximizing the supply of ferret chordoma tissue).

Resources

As a patient, physician, and veterinarian I can bring a unique perspective to the table.

Frank Lieberman, MD

Primary Specialty: Neurooncology

Bio

Dr. Lieberman is currently the director of the adult neurooncology program at the University of Pittsburgh Cancer Center and Associate Professor of Neurology and Medical Oncology. He served his neurology residency at the University of Chicago, where he subsequently completed a neuroimmunology fellowship.

He has been a faculty member in the Departments of Neurology at Memorial Sloan-Kettering Cancer Center and Mt. Sinai School of Medicine prior to joining the University of Pittsburgh in 1999. Dr. Lieberman is a member of the CNS Tumor Committee of Radiation Therapy Oncology Group, the Neurooncology Section of the American Academy of Neurology, institutional PI for UPSOM participation in the North American Brain Tumor Consortium, and served on the American Academy of Neurology committee creating the neurooncology subspecialty certification examination. His primary research interests are molecularly targeted drug therapies for malignant gliomas, meningiomas, and chordoma, as well as neurotoxicities of cancer therapies and the immunobiology and treatment of paraneoplastic neurologic disorders.

Norbert Liebsch, M.D., Ph.D.

Primary Specialty: Radiation Oncology

Secondary Specialty: Diagnostic Radiology

David Loeb, MD, PhD

Primary Specialty: Pediatric Oncology

Lilia Loreda, MD.

Primary Specialty: Radiation Oncology

Bio

Graduated from Loma Linda University Medical School in 1984 and from Radiation Oncology Residency in 1988. I have been involved in the treatment of Chordomas with proton beam radiotherapy since 1992.

Chordoma Projects

Improve on the dosage and decrease further the side effects.

Chordoma Interests

We have published our experience with Chordomas of the base of skull and cervical spine.

Pending publications of Chordomas in the pediatric population and of the sacrum.

Susan Mackem, MD, PhD

Primary Specialty: Developmental Biology

Bio

I am an investigator in the Laboratory of Pathology in NCI and my primary area of research is in the regulation of embryonic development. I have studied early embryo mesoderm formation, particularly the regulation of notochord formation in the past. My current research is focused primarily on limb development as a model system for understanding how signaling molecules and regulatory networks drive morphogenesis.

Chordoma Projects

Currently, my lab, which is small, has mainly focused efforts on using limb development as a model system.

Chordoma Interests

My lab has studied the regulation of normal notochord formation in the past, using the chick embryo as a model system. We focused on the roles of a homeobox gene (Not1) and T-box genes (T, TbxT, Tbx6L) in regulating mesoderm formation and notochord fate in the early embryo. In the course of our work, we also began to examine expression of T (Brachyury) in chordomas.

Resources

background in the embryology and molecular genetics of notochord formation during normal development

Robert Maki, MD PhD

Primary Specialty: Medical Oncology

Bio

Robert Maki, MD PhD, is co-director of the Adult Sarcoma Program and Associate Member, Department of Medicine at Memorial Sloan-Kettering Cancer Center, New York, NY. His research focuses on novel drug development and clinical trial design for patients with sarcomas of soft tissue and bone. He is a graduate of Northwestern University in the Integrated Science Program and has an MD and PhD in Immunology from Cornell University Medical College.

Chordoma Projects

Identify key pathways in chordoma and target them in clinical studies

Chordoma Interests

Clinical trials for patients with recurrent or metastatic disease

Resources

Clinical Drug Development, Clinical Trial Design

Cheryl Marks, PhD

Primary Specialty: mouse models

Mary McMaster, M.D.

Primary Specialty: Medical Oncology

Secondary Specialty: Medical Genetics

Chordoma Projects

To continue to work to identify families with chordoma or other avenues that will facilitate the identification of a gene or genes that contribute to chordoma susceptibility.

Chordoma Interests

I am interested in the epidemiology and genetics of chordoma. I have worked with Drs. Dilys Parry and Rose Yang in studies of familial chordoma at the National Cancer Institute.

Paul Meltzer, MD,PhD

Primary Specialty: Pediatric Oncology/Tumor Genetics

Arnulfo Mendoza, DVM

Primary Specialty: Cancer Research

Chordoma Interests

Help develop a mouse model to study the chordoma biology.

Isis Mikhail, MD, MPH, DrPH

Primary Specialty: Epidemiology

Secondary Specialty: Cancer

Bio

Isis Mikhail, MD, MPH, DrPH is a Medical Epidemiologist and Program Director at the Clinical and Translational Epidemiology Branch (CTEB), Epidemiology and Genetics Research Program (EGRP) at the National Cancer Institute (NCI).

Srinivasan Mukundan, PhD, MD

Primary Specialty: Neuroradiology

John Nelson

Primary Specialty: Software Development

David Ng, MD

Primary Specialty: Medical Genetics

Secondary Specialty: Internal Medicine

Anna Nikoghosyan, Dr. med.

Primary Specialty: radiation oncology

Claudia Palena, Ph.D.

Primary Specialty: Tumor Immunology

Deric Park, M.D.

Primary Specialty: Neuro-Oncology



Dilys Parry, Ph.D.

Primary Specialty: cancer genetics

Bio

Ph.D. in Genetics, 1970; Post doctoral fellow 1970-73; Post doctoral fellows and then tenured staff (mostly recently staff clinician) at the National Cancer Institute from 1976 until my recent retirement. Co-founder/Associate Director/Director of the Interinstitute Medical Genetics Program at NIH from 1979-1995. I was board certified at a PH.D Medical Geneticist in 1984.

Chordoma Interest

Clinical evaluation of members of multiplex chordoma families and carrying out gene mapping studies with them. My future research goals are to identify genes that confer susceptibility to chordoma and to identify tumors that are associated with familial chordoma.

Chordoma Projects

We have clinically evaluated multiplex chordoma families and mapped a putative susceptibility gene for familial chordoma to chromosome 7q33 in 3 of them. The clinical and gene mapping studies are currently on-going.

Resources

Clinical evaluation of affected and at-risk members of chordoma families including neuroaxis MRI; clinical and genetic counseling as appropriate. All of the clinical studies are done at no cost to the family members. We can also pay for travel to and from NIH for members of these families. At the end of the visit we review individual clinical findings with each family member. We follow-up the visits by providing family members (and their physicians if requested by participants) with written results of all studies and copies of the MRIs. My colleagues will carry out genotyping of DNA from family members and conduct linkage analysis of the STR and SNP marker information in these families.

Svetlana Pravdenkova, MD

Primary Specialty: Reseach, brain tumors

Nadege Presneau, PhD

Primary Specialty: Molecular Biologist

Bio

I did my PhD training in France at University Blaise Pascal on predisposition to breast and ovarian cancer in French Families. I did a post-doc training in MONTreal at McGill University working on identifying new tumour suppressor gene in sporadic ovarian cancer with Patricia Tonin. Then i moved to London to be a research fellow working on molecular signature of sarcoma with Chris Boshoff and Adrienne Flanagan. Now I am a senior research Fellow working on bone tumours with Adrienne Flanagan.

Chordoma Projects

Our future research goals are to develop a model in order to be able to do functional analysis.

Chordoma Interests

I took part in the identification of Brachyury as a novel biomarker for Chordoma. We are interested in pursuing the involvement of Brachyury in Chordoma pathogenesis. Also I am interested in translational research and I am developing with Adrienne Flanagan some projects related to identifying new drug targets in bone cancer and particularly Chordoma.

Ravi Raghavan, MBBS, MD, MRCPath

Primary Specialty: Neuropathology

Chordoma Projects

Proteomic profiles of chordoma

Resources

Loma Linda is a major referral center for chordomas and chondrosarcomas for Proton radiation treatment

Vijaya Ramesh, Ph.D.

Primary Specialty: Tumor suppressors

Secondary Specialty: cell signaling

Bio

Dr. Ramesh is an Associate Professor of Neurology (Genetics) at Harvard Medical School and an Associate Neurologist at MGH. She obtained her Ph.D. from University of Madras, India and completed postdoctoral training in the laboratories of James Gusella (MGH) and Dr. Vivian Shih (MGH). She is a member of the Molecular Neurogenetics Unit and the Center for Human Genetic Research at MGH. Dr. Ramesh's laboratory investigates tumor suppressor genes and their functions, particularly tumor suppressors related to Neurofibromatosis 2 (NF2) and Tuberous Sclerosis 1 and 2 (TSC).

Chordoma Interest

The rare occurrence of chordomas in TSC patients has been reported. In our earlier work we shown somatic inactivation of the TSC proteins in 2 chordomas associated with TSC. Our future research plans are to investigate the involvement of TSC genes in sporadic chordomas seen in adults as well as children.

Andrew Rosenberg, MD



Primary Specialty: musculoskeletal pathology

Bio

diagnostic surgical pathologist with expertise in bone and soft tissue neoplasia

Joseph Schwab, MD, MS

Primary Specialty: orthopedic surgery

Chandranath Sen, MD

Primary Specialty: neurosurgery

Bio

I am a neurosurgeon specializing in surgery for skull base tumors

Chordoma Projects

continue the present work

Chordoma Interests

I have treated a large number of clival chordomas and have also done work with my colleagues in studying the expression of cadherins and catenins in these tumors and evaluating the relation with the clinical course of patients.

Josh Sommer,

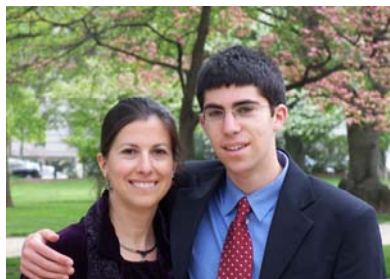


Primary Specialty: Curing Chordoma

Josh Sommer is vice president of the Chordoma Foundation, which he co-founded along with his mother, Dr. Simone Sommer, after he was diagnosed with a clival chordoma in 2006. He believes that patients should play an active role in bringing about treatments for their own conditions, and that patients represent a largely untapped source of funding, energy, and know-how in the treatment development process.

Josh is a Junior at Duke University, where he is a Trinity Scholar. He is currently conducting research in the lab of Dr. Michael Kelley at Duke to understand the unique biology of chordoma, and search for therapeutic targets. His investigations include gene-expression microarray analysis, candidate gene knockdown using RNAi, in vitro drug screening, and analysis of known oncogenic pathways in chordoma. In high school Josh received numerous honors and awards including the USA Today All-USA Academic First Team Award, Prudential Spirit of Community Award, Coca-Cola Scholarship, and AXA Achievement National Award.

Simone Sommer, MD, MPH



Primary Specialty: Family Medicine

Secondary Specialty: Preventive Medicine

Simone Sommer is president of the Chordoma Foundation, which she formed after her son and best friend, Josh, was diagnosed with a chordoma in 2006. Dr. Sommer is dedicated to improving the quality of life for people affected by chordomas, and has devoted herself to bringing about effective treatments, and ultimately a cure for this disease. Under her direction, the Chordoma Foundation has initiated numerous collaborative research projects with scientists and physicians at institutions across the world. Dr. Sommer's goal is to serve as the focal point for a coordinated international chordoma research effort.

Dr. Sommer, is a graduate of George Washington University School of Medicine. She completed her internship at Duke University Medical Center and completed a Residency and Faculty Development Fellowship in Family Medicine at the University of North Carolina in Chapel Hill. Dr. Sommer also holds a Masters Degree in Public Health in Epidemiology from the University of North Carolina School of Public Health. She was formerly Associate Clinical Professor at the University of North Carolina, Department of Family-Medicine and previously served as Medical Director of the Guilford County Health Department Infectious and Chronic Disease Prevention Program. She is past president of Sommer Health Services of Greensboro, North Carolina, which delivered comprehensive on-site corporate health promotion, disease prevention and targeted interventions for self-insured companies.

Neil Spector, MD

Primary Specialty: Medical Oncology

Bio

Board Certified in Hematology, Medical Oncology; Fellowship at Harvard Medical School (1986-1989); Faculty: Dana-Farber Cancer (1989-1993), U. Miami School of Medicine (1993-1998); UNC-Chapel Hill (Adjunct Appt. 2000-2006); Duke University (2006-Present). Director of Translational Oncology Research and program leader for lapatinib (Tykerb) and Nelarabine (1998-2006).

Chordoma Interest

Understanding the signaling pathways regulating chordoma cell growth and survival. Developing targeted therapies for chordoma.

Chordoma Projects

We are currently addressing the growth and survival pathways regulating chordoma and how targeted therapies might affect those targets.

Expertise & Resources

We have a variety of targeted agents that we routinely use in our laboratory. In addition, we have a DNA for several ErbB receptor family members and site specific mutations of the tyrosine residues in the cytoplasmic kinase domain for transfection.

Derek Stemple, PhD

Primary Specialty: Genetics

Secondary Specialty: Developmental Biology

Chordoma Projects

Expression / Genotype analysis of chordomas

Chordoma Interests

Identification of genes important for notochord development using zebrafish as a model organism
Characterisation of notochord extracellular matrix proteins

Elena Tamborini, PhD

Primary Specialty: RTKs in sarcomas

Chordoma Interests

RTK expression in chordomas, surgical specimens analysis

Jie Tang, MD

Primary Specialty: neurosurgeon

Chordoma Projects

risk factors of recurrence

Chordoma Interests

surgical resection of clivus chordoma,

Resources

large clinic resource

Aymara Triana, MD

Primary Specialty: Neurosurgery

Madhura Vipra, M.Sc., Ph.D.

Primary Specialty: Cell Biology

Secondary Specialty: Image analysis and Intellectual Property Rights

Bio

Dr. Madhura Vipra, holds an expertise in multiple disciplines of Biotechnology, Bioinformatics, and Intellectual Property Rights. Having earned her Ph.D. in Biotechnology (cancer biology) from University of Pune, India, she further advanced her knowledgebase by acquiring a Diploma in Biotech patents from WIPO, Switzerland. Originally a cell biologist, she has gained research experience at the bench in a variety of experimental systems bacteria and mammalian cell cultures. Dr. Vipra has used molecular biology and cell culture to investigate signal transduction and metastatic events in uterine cervical cancer cells. Having a broad base of knowledge in Microscopy and Digital Imaging, she was positioned better as a Domain Scientist with a USA Image analysis software firm for the development of software for medical and life-sciences imaging. She is active in the field, as advisor to Biotechnology and BioPharmaceutical firms. Dr.Vipra's extensive laboratory research experience contributes a valuable perspective to her consultancy services. She also provides career guidance in Biotechnology and Bioinformatics and conducts workshops for the same. She is an invited speaker for many workshops/colleges. She has been recipient of scholarships to attend conferences in USA and Australia.

Chordoma Projects

1. Create a tissue bank for chordoma in India.
2. Find out as much statistical data on occurrence, symptoms and survival of chordoma patients in India.
3. Extend my expertise in in-vitro cancer cell biology especially with reference to cell biology to the researchers working in the field.
4. Wish to contribute my best in finding a cure/ a drug for chordoma for future generations.

Chordoma Interests

I am chordoma survivor. I underwent a surgery for removal of lesion at C2 in June 2007 which was compressing my spinal chord. Histopathological exam later confirmed it to be chordoma. Infact, since chordoma is very rare, first it was mistaken for something else. I underwent radiation after the surgery for one and half months. With chordoma being rare, I also happen to be still rare species being a cancer biology scientist to have chordoma. I have strong desire to make use of my expertise and knowledge to learn more about this condition and do my best to find out cure for it. The disease has completely changed course of my life.

Kathy Warren, M.D.

Primary Specialty: Pediatric Neuro-Oncology

Secondary Specialty: Pediatric Oncology

Jean-Paul Wolinsky, MD

Primary Specialty: Neurosurgery

Don Wright, MD

Primary Specialty: Neurosurgery

Bio

Cranial Base Neurosurgical specialty, with fellowship training and >20 years experience in tumor surgery. Former fellow at NINCDS/NIH. Publications in the clinical management of chordoma.

Chordoma Projects

Clinical practice with patient population harboring chordoma/chondrosarcoma

Resources

Access to pathological (tumor) specimens

Zhen Wu, MD

Primary Specialty: neurosurgery

Chordoma Projects

comprehensive treatment for skullbase chordoma

Chordoma Interests

the clinic treatment and basic research of skullbase chordoma

Resources

our institute have large clinic resource of skullbase chordoma

Ramnik Xavier, MD

Primary Specialty: Molecular Biology

Secondary Specialty: Computational Biology

Bio

Principal Investigator, Center for Computational and Integrative Biology

Chordoma Interests

understanding signaling pathways in chordoma with a goal towards better diagnosis and treatment

Takehiko Yamaguchi, MD, PhD

Primary Specialty: Bone and joint pathology

Rose Yang, PhD, MPH

Primary Specialty: Genetic Epidemiology

Michael Yaszemski, M.D., Ph.D.



Primary Specialty: Spine Surgery
Secondary Specialty: Chemical Engineering

Bio

Dr. Yaszemski is a Professor of Orthopaedics and Bioengineering at the Mayo Clinic, and the Director of the Tissue Engineering and Biomaterials Laboratory. He received bachelors and masters degrees in chemical engineering from Lehigh University. He received his doctorate of medicine degree from Georgetown University and a Ph.D. in chemical engineering from MIT. His clinical practice encompasses spinal surgery and sacropelvic tumor surgery. His research interests are in the synthesis and characterization of novel degradable polymers for use in bone regeneration, spinal cord regeneration via tissue engineering strategies, and controlled local drug delivery to musculoskeletal tumors.

Chordoma Projects

We seek to refine both the resection techniques as well as the reconstruction techniques to enhance both survival and post-resection function. We are interested in exploring local chemotherapy strategies for those patients in whom a wide or marginal resection is either not possible or has not been accomplished.

Chordoma Interests

Our medical-surgical team treats patients with chordoma. We have reported on the clinical results of en bloc resection, and on the reconstruction techniques to address spino-pelvic discontinuity.

Resources

We have a surgical team that includes spine surgeons, orthopedic oncologists, colon rectal surgeons, urologists, plastic surgeons, vascular surgeons, and anesthesia critical care physicians. We have done these surgeries together for over a decade, and continue to refine our technique for these challenging resection-reconstruction operations. Our laboratory has expertise in cell and molecular biology and polymer synthesis/characterization for tissue engineering and controlled drug delivery.

Jinghui Zhan, Master

Primary Specialty: Cell and molecular biology

Chordoma Projects

Identify potential targets

Resources

May help with BioBank, develop cell lines