

## **Research Workshop Presenters**



### **Benjamin Alman, MD, Department Chair, Orthopedic Surgery, Duke University**

Dr. Alman is an orthopaedic clinician-scientist, whose research focuses on understanding role of developmentally important processes in pathologic and reparative process involving the musculoskeletal system. The long-term goal of his work is to use this knowledge to identify improved therapeutic approaches to orthopaedic disorders. He makes extensive use of genetically modified mice to model human disease, and has used this approach to identify new drug therapies for musculoskeletal tumors and to improve the repair process in cartilage, skin, and bone. He also works on cellular heterogeneity in sarcomas, and has identified a subpopulation of tumor initiating cells in musculoskeletal tumors. In this work, he also has identified specific cell populations that are responsible for joint and bone development. He has been recently recruited from the University of Toronto to Duke University to chair the department of orthopaedics, which was established in 2010, and includes a large musculoskeletal research component. He has half his time protected for his research work. Dr. Alman is the Principal Investigator in the DTRF-funded collaborative project, "Collaboration for a Cure: Identifying new therapeutic targets for desmoid tumors."



### **Justin M. Cates, MD, Vanderbilt University Medical Center**

Dr. Cates graduated from Tufts University in 1985 and subsequently obtained his M.D. and Ph.D. degrees from Tufts University Medical School and the Sackler School for Graduate Biomedical Sciences in 1997. He completed his residency training in Anatomic Pathology and fellowship in Orthopaedic Pathology at the Massachusetts General Hospital. Subsequently he spent three years as a faculty member at Dartmouth-Hitchcock Medical Center in Lebanon, New Hampshire before coming to the Department of Pathology at Vanderbilt University Medical Center in 2005. Dr. Cates' clinical interest is bone and soft tissue pathology. Dr. Cates is Principal Investigator of the DTRF-funded project, "Genetic determinants of local recurrence in desmoid-type fibromatosis."

### **Meredith Chuk, MD, Pediatric Oncologist and Medical Officer/Scientific Liaison, FDA.**

Dr. Meredith Chuk obtained her medical degree from The Pennsylvania State University College of Medicine in 2001. She subsequently completed her residency and chief residency in Pediatrics at the Children's Hospital of Pittsburgh and went on to complete a pediatric hematology/ oncology fellowship at the Johns Hopkins/National Cancer Institute (NCI) fellowship program. She served as an instructor in the Pediatric Oncology Branch of the NCI while completing a Master's Degree in Clinical Research through Duke University. Dr. Chuk was an assistant professor of Pediatrics at the Children's Hospital of Pittsburgh in the Department of Hematology/ Oncology before joining the FDA as a medical officer in the Office of Hematology and Oncology Products on the Sarcoma/Melanoma team. Dr. Chuk was recently named the Scientific Liaison for Sarcoma at the FDA, and in this role interacts with various groups with the goal of furthering drug development for new agents in sarcoma.



### **Aimee Crago, MD, PhD, Assistant Attending Surgeon, Memorial Sloan- Kettering Cancer Center**

Dr. Crago is a surgeon-scientist at Memorial Sloan-Kettering Cancer Center where she serves as an Assistant Attending. As a member of the institution's Sarcoma Disease Management Team, she is an active participant in the care of patients with desmoid fibromatosis and coordinates clinical research and basic science efforts examining the causes of desmoid formation and progression. Her research has been funded by the American Society of Clinical Oncology, the American College of Surgeons, the Kristen Ann Carr Fund, Cycle for Survival and the MSKCC SPORE in soft tissue sarcoma. Most recently she has worked to create a nomogram that uses clinical characteristics to predict outcome after surgical resection of desmoid tumors, and she is actively engaged in work characterizing genomic changes that mediate formation of desmoid tumors.



## **Mrinal Gounder, MD, Assistant Professor and Medical Oncologist at Memorial Sloan-Kettering Cancer Center**

Dr. Gounder is a DTRF grant recipient and is the Foundation's Scientific Director. He is an Assistant Professor and medical oncologist at Memorial Sloan-Kettering Cancer Center specializing in the care of patients with sarcomas of soft tissue and bone and in developing new drugs in all cancers. He has a special clinical and research interest in desmoid tumors and recently showed for the first time that sorafenib is an active drug in desmoid tumors. Dr. Gounder is the Principal Investigator in a trial partially funded by DTRF studying Nexavar/ Sorafenib in desmoid tumors.



## **Shivaani Kummar, MD, Head, Early Clinical Trials Development, National Cancer Institute**

Dr. Shivaani Kummar received her medical degree from Lady Hardinge Medical College, New Delhi, India and her Internal Medicine Residency training from Emory University, Atlanta, Georgia. Upon completion of her fellowship training in Medical Oncology and Hematology from the National Institutes of Health, Bethesda, MD, she joined Yale Cancer Center, Yale University, New Haven, Connecticut as an Assistant Professor in Medical Oncology. She is currently Head of Early Clinical Trials Development in the Office of the Director, Division of Cancer Treatment and Diagnosis, National Cancer Institute. She also serves on a number of scientific committees, including the scientific planning committee of the American Society of Clinical Oncology. She has numerous publications in peer-reviewed journals and her research interests are in the translational development of novel cancer therapeutics, especially in rare diseases. Dr. Kummar is the Principal Investigator of the first desmoid tumor trial run by the Rare Tumors Initiative at the National Cancer Institute, a Phase II trial of a gamma-secretase inhibitor.



## **Paul Meltzer, MD, PhD, Chief, Genetics Branch, National Institutes of Health, Center for Cancer Research, National Cancer Institute**

Dr. Meltzer has been Chief of Genetic Branch, Center for Cancer Research, National Cancer Institute since 2006. He leads the Molecular Genetics Group. The goal of the Molecular Genetics Section is to characterize the disturbances of genome function responsible for cancer development and to utilize this information to identify genes and pathways responsible for tumor development. The central importance of somatically acquired genetic and epigenetic alterations in the tumor genome is now well established. His work uses genome technologies to attack these problems in the context of specific diseases. Dr. Meltzer received his A.B in Biology from Dartmouth College in 1967. He received his Ph.D. in Biochemistry/Developmental Biology in 1972 from California Institute of Technology, and his M.D. from the University of Tennessee in 1980. He was a Postdoctoral Fellow in the Department of Genetics at the University of Cambridge from 1972-1974. This was followed by a Residency in Pediatrics at the Arizona Health Sciences Center in Tuscon, Arizona from July 1983-1985. He was a Fellow in Pediatric Hematology-Oncology at the Arizona Health Sciences Center, in Tuscon, Arizona from 1983-1985. Before his current position, Dr. Meltzer was a Research Assistant Professor of Pediatrics at the Arizona Health Sciences Center from July 1985- June, 1987. He was Assistant Professor of Pediatrics at the University of Arizona, July 1987 –July 1990. He then became Assistant Professor of Pediatrics and Radiation Oncology at the University of Michigan from August 1990-1993. In 1993, he was Associate Professor of Pediatrics and Radiation Oncology at the University of Michigan. In 1993, he became the Chief of the Molecular Genetics Section, Cancer Genetics Branch, National Human Genome Research Institute at National Institutes of Health and he served in that capacity until 2006, when he became Chief of Genetics Branch, Center for Cancer Research, National Cancer Institute.



**Roel Nusse, PhD, Professor of Cancer Research and of Developmental Biology at Stanford University School of Medicine, Program Director of Stanford's Cancer Stem Cell Research Program, and member of Stanford's Institute for Stem Cell Biology and Regenerative Medicine**

Dr. Roeland Nusse is a professor in the Department of Developmental Biology at Stanford University School of Medicine, the Virginia and Daniel K. Ludwig Professor of Cancer Research and a Howard Hughes Medical Institute Investigator. He is a member of the Institute for Stem Cell Biology and Regenerative Medicine at Stanford and the Stanford Ludwig Center for Cancer Stem Cell Research and Medicine. Dr. Nusse received his PhD from the Netherlands Cancer Institute at the University of Amsterdam in 1980. He completed postdoctoral studies at the University of California, San Francisco in 1982 working with Dr. Harold Varmus. After several years as head of the molecular biology department at the Netherlands Cancer Institute, he returned to the Bay Area and joined the Stanford medical faculty in 1990 as an associate professor of developmental biology. In 1994 he was promoted to professor. In 1997 he became associate chair of the Department of Developmental Biology, and in 1999 he was appointed as chair of the department. In 2010, he was elected as a member of the National Academy of Sciences. Dr. Nusse is also a fellow of the American Academy of Arts and Sciences and a member of the Royal Dutch Academy of Sciences.



**Matthew van de Rijn, MD, PhD, Professor, Department of Pathology, Stanford University Medical Center**

Matt van de Rijn received his MD and PhD degrees from the University of Amsterdam, the latter based on his research at the Netherlands Cancer Institute and the Dana Farber Cancer Institute. After a postdoctoral fellowship at Stanford University he completed his residency training in surgical pathology and joined the faculty at the University of Pennsylvania. In 1998 he returned to Stanford where he is now a Professor in Pathology. His research has focused on sarcoma and he reported the first major gene expression profiling study on sarcomas in 2002. The identification of a novel translocation involving CSF1 in PVNS resulted in several ongoing clinical trials. In addition his group discovered a novel diagnostic marker for GIST (DOG1). Gene expression profiling studies also led to the investigation of the role of macrophages in leiomyosarcoma (LMS) and GIST with an opportunity to develop therapeutic targets for these tumors. In addition to his work on LMS and GIST he has performed gene expression profiling studies on Desmoid Tumors to study the biology that underlies the aggressive behavior of these tumors, to develop novel diagnostic markers and discover novel therapeutic targets. Dr. van de Rijn is Principal Investigator of the DTRF-funded study, "Next generation sequencing approach to desmoid tumors."



**Aaron Weiss, DO, Maine Medical Center, Maine Children's Cancer Program, Pediatric Hematology and Oncology**

Dr. Weiss graduated from the University of Rochester in 1994 and subsequently earned his medical degree from the Philadelphia College of Osteopathic Medicine in 1999. He completed a pediatric emphasis internship at the Philadelphia College of Osteopathic Medicine/Albert Einstein Medical Center in 2000 followed by a pediatric residency at the AI duPont Hospital for Children in Wilmington, DE in 2003. He then went on to complete a pediatric hematology-oncology fellowship at St. Jude Children's Research Hospital in Memphis, TN in 2006. He subsequently spent six years as an attending pediatric hematologist-oncologist at the Cancer Institute of New Jersey/University of Medicine and Dentistry of New Jersey and Jersey Shore University Medical Center. In 2012, Dr. Weiss joined the Maine Children's Cancer Program at Maine Medical Center in Portland, ME. Dr. Weiss has particular interest in pediatric sarcomas. He has co-authored a number of publications on this subject and is currently involved in conducting pediatric clinical trials both locally and nationally in the fields of desmoid tumor and non-rhabdomyosarcoma soft tissue sarcoma. He is the Principal Investigator of the DTRF-funded project, "Deregulated mTOR in Desmoid-type Fibromatosis: Identification and Validation of a New Therapeutic Target."

## Additional Research Workshop Participants



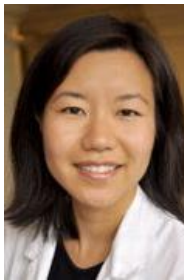
### **Mushriq Al-Jazrawe, University of Toronto, Laboratory Medicine & Pathobiology**

Mushriq received his bachelor of science at the University of Toronto in Genes, Genetics, and Biotechnology. He is currently a PhD candidate in the Department of Laboratory Medicine & Pathobiology, University of Toronto in Dr. Benjamin Alman lab, studying the role of platelet-derived growth factor signaling and microRNAs in desmoid tumors.



### **Dina Chelouche Lev, MD**

Dr. Lev's training includes medical school and general surgery residency at Tel Aviv University, where she began her career as a general surgical oncologist with special interests in soft tissue tumors. A molecular oncology research sabbatical at the University of Texas MD Anderson Cancer Center from 2002-2004 led to her relocating to Houston on a more permanent basis in 2006 to serve as the Principal Investigator of the Sarcoma Research Laboratory, a key component of the Sarcoma Research Center that was established at MD Anderson in 2006. She also became Assistant Professor of Cancer Biology at the University of Texas MD Anderson Cancer Center. Dr. Lev's laboratory focused exclusively on the study of soft tissue tumors and included faculty from different departments at MD Anderson as well as pre- and post-doctoral MD, MD-PhD, and PhD trainees from throughout the world. A major focus of Dr. Lev's DTRF-funded research, now being continued by Dr. Raphael Pollock at Ohio State Comprehensive Cancer Center, is to improve our understanding of the molecular factors underlying desmoid tumor inception, progression, and recurrence with the hope and conviction that these investigations will ultimately translate into better therapeutics for desmoid patients everywhere.



### **Nancy Cho, MD, Assistant Professor of Surgery, Harvard Medical School**

Dr. Nancy Cho received her A.B. from Harvard College, magna cum laude in Biochemical Sciences, and M.D. from Columbia University, College of Physicians and Surgeons. She completed her General Surgery training at Brigham and Women's Hospital (BWH) where she spent two years as a Clinical Research Fellow in Surgical Oncology studying the molecular biology of carcinogenesis. Following residency, she was recruited to join the faculty at BWH where she is currently an Associate Surgeon and Assistant Professor of Surgery at Harvard Medical School. Her primary research focus involves studying tumor-stroma interactions with the goal of developing more effective, patient-specific treatment strategies. Dr. Cho is the recipient of a number of career development awards including the Eleanor and Miles Shore Fellowship, Harvard Catalyst KL2 MeRIT Award, Associate of Women Surgeons Faculty Award, Karin Grunebaum Cancer Research Foundation, and Franklin H. Martin Faculty Research Fellowship from the American College of Surgeons. She is currently the recipient of a DTRF grant for her project, "Targeting Hyaluronic Acid in Desmoid Tumors."



### **Chiara Colombo, MD, Surgical Oncologist, Fondazione IRCCS Istituto Nazionale dei Tumori**

Dr. Colombo is devoted to sarcoma and in particular to desmoid tumor (including translational research). She is the Principal Investigator in the DTRF-funded project, "High throughput genome study to identify predictors of aggressiveness in patients with sporadic desmoid tumor who undergo a wait and see approach."



**Meera Hameed, MD, Attending Pathologist, Memorial Sloan- Kettering**

Dr. Hameed is an experienced sarcoma pathologist, who is also board certified in molecular genetic pathology and cytogenetics. Her research is focused on the characterization of new molecular markers that can improve pathologic diagnosis and classification of bone and soft tissue tumors. She is an active member of the sarcoma DMT service at MSKCC and collaborate with other members providing pathologic expertise to their research projects.



**Alexander Lazar, MD, PhD, Director, Department of Pathology, The University of Texas MD Anderson Cancer Center Selective (Soft Tissue) Pathology Fellowship Training Program**

Alexander Lazar MD/PhD is a practicing academic pathologist at The University of Texas MD Anderson Cancer Center where his clinical, academic and research interests are focused on sarcoma and the genomics of solid tumors. Working within a multidisciplinary team at a high volume treatment center for desmoid tumors, over the last decade he has participated with colleagues on multiple projects involving these tumors. Dr. Lazar is a collaborator in the DTRF-funded project, "Collaboration for a Cure: Identifying new therapeutic targets for desmoid tumors."



**Rodrigo Munhoz, MD, Fellow, Memorial Sloan- Kettering**

Dr. Munhoz is a sarcoma/ melanoma advanced fellow at Memorial Sloan Kettering Cancer Center.



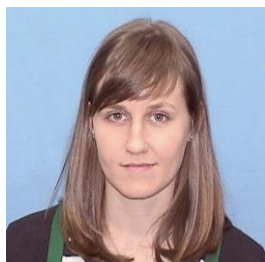
**Raphael E. Pollock, MD, PhD, Professor of Surgery; Director, Division of Surgical Oncology, Ohio State University Comprehensive Cancer Center**

Dr. Raphael Pollock is a professor and the Director of the Division of Surgical Oncology at The Ohio State University Wexner Medical Center College of Medicine's Department of Surgery. He also serves as the chief of surgical services of the Ohio State University Comprehensive Cancer Center – Arthur G. James Cancer Hospital and Richard J. Solove Research Institute. Previously, Dr. Pollock served as the senior sarcoma surgeon at UTMDACC where he has been a member of the faculty since 1982; he is also the Director of the UTMDACC Sarcoma Research Center, an entity that includes the Sarcoma Research Laboratory, the Sarcoma Tissue Repository, and the UTMDACC Sarcoma database. The Sarcoma Research Laboratory includes faculty from six different clinical and basic science departments (described below); the Sarcoma Tissue Repository was initiated by Dr. Pollock in the early 1990s and currently consists of > 2500 clinically annotated sarcoma tissue specimens, many with autologous normal tissues. Dr. Pollock serves as Chair of the AJCC Sarcoma Committee, is a member of the Advisory Boards of the Sarcoma Foundation of America (SFA), the Sarcoma Alliance, the Liddy Shriver Sarcoma Initiative, the Desmoid Tumor Research Foundation, the UICC TNM Expert Advisory Panel on Sarcoma, the NCCN Sarcoma Committee, the Desmoid Tumor Research Foundation, the Sarcoma Alliance for Research through Collaboration (SARC) Executive Committee, and also serves as Co-Chair of the NCI Genomic Atlas Sarcoma Steering Committee. Dr. Pollock is also a member of the NIH/NCI Board of Scientific Counselors. He is the Principal Investigator of the DTRF-funded project, "A rational search for novel anti-drug therapies."



### **Marlene Portnoy, Co-Founder & Executive Director, Desmond Tumor Research Foundation**

Marlene Portnoy, co-founded The Desmond Tumor Research Foundation with Jeanne Whiting because of the frustration she felt with the lack of information and lack of research on this rare sarcoma. Her husband, Steve, was diagnosed in August 2004 with a retroperitoneal desmoid and has since been treated with surgery and radiation. After graduating magna cum laude from Albany State University in 1981, Ms. Portnoy pursued a career in sales, which she started at Corning Glass Works from 1982-1985 in Chicago, Illinois. She then moved to New York and worked for Playskool Toys, a division of Hasbro Toys, first as a sales representative and then as a District Sales Manager for the Middle Atlantic territory from 1986-1993. She then took time out to raise her two young children and became active in community service. She resides in Suffern, New York with her husband, Steve, and two daughters Brittany and Danielle.



### **Joanna Przybyl, PhD, Department of Pathology, Stanford University**

Dr. Przybyl obtained joint PhD degree from the Catholic University of Leuven, Belgium and Maria Skłodowska-Curie Memorial Cancer Center – Institute of Oncology in Warsaw, Poland. Her doctoral research was focused on new prognostic and predictive markers for selected malignant soft tissue tumors including synovial sarcoma, Ewing sarcoma and endometrial stromal tumors. She currently is a postdoctoral research fellow in Dr. Matt van de Rijn lab in the Department of Pathology, Stanford University, where she is involved in the DTRF-funded study “Next generation sequencing approach to desmoid tumors”.

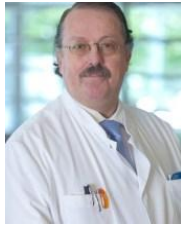


### **Sean Ryan, Desmoid tumor patient and current medical student and desmoid tumor researcher at Ohio State. Member of the Board of the Ryan Foundation**



### **Abby Sandler, PhD, Special Assistant to the Director, Rare Tumors Initiative, National Cancer Institute**

Dr. Abby Sandler works part-time in the National Cancer Institute (NCI) Center for Cancer Research Office of the Director as Special Assistant for the Rare Tumors Initiative (RTI). The RTI was launched in early 2013 to increase and facilitate collaborations between basic and clinical investigators studying rare tumors within the NCI’s Intramural Research Program, with a goal of speeding development of potential therapies for rare tumors. Since 2004, Dr. Sandler has also worked part-time in the NCI Office of the Director as the Executive Secretary for the President’s Cancer Panel, a Federally-chartered advisory committee that reports annually to the President on impediments to the execution of the National Cancer Program. Dr. Sandler earned her B.S. in biology from Rensselaer Polytechnic Institute (Troy, NY) and her Ph.D. in biology from The Johns Hopkins University (Baltimore, MD). She carried out her postdoctoral research in the NCI’s Intramural Research Program.



### **Frits van Coevorden, MD, PhD, Netherlands Cancer Institute**

Surgical oncologist, interested in Sarcoma treatment since 1979. Chair NKI-AVL Sarcoma Unit. Member of CTOS, EORTC STBSG, Dutch Sarcoma Research Group.



### **William Ward, MD, Orthopaedic oncologist, Emeritus Professor, Wake Forest University**

Dr. Ward has performed over 5,000 musculoskeletal oncologic related surgeries, including nearly 700 bone and soft tissue sarcoma resections, and has participated in over 100 published scientific articles, the majority in the field of musculoskeletal oncology. He is a Past President of the North American Musculoskeletal Tumor Society, and has treated numerous patients with desmoid tumors. His interests include epidemiologic and demographic data, as well as treatment and outcome data.



### **Jeanne Whiting, Co-Founder & President, Desmoid Tumor Research Foundation**

In 2005, Jeanne Whiting The Desmoid Tumor Research Foundation with Marlene Portnoy to facilitate and fund desmoid tumor research and support patients with access to information. Jeanne's personal journey with a retroperitoneal desmoid tumor involved resection, recurrence, 2 1/2 years of two different chemotherapies and eventual loss of her right kidney. She is keenly aware of the needs of the desmoid community, and is dedicated to accelerating the search for a cure. Prior to co-founding DTRF, Jeanne spent most of her career as an attorney. After attending University of Michigan Law School and J. Reuben Clark Law School, she received a Juris Doctor degree, magna cum laude, in 1980. She then clerked for the *Michigan Court of Appeals* in Detroit, Michigan, and in succeeding years practiced with *Sidley & Austin* in Cairo, Egypt and *in Washington, D.C.*; with *Shearman & Sterling* in New York, New York; with *Stern, Dubrow & Marcus* in Maplewood, NJ; and, as a sole practitioner. After retiring from the practice of law to raise her family, Jeanne became involved in various nonprofit organizations, including serving as *Northeast Director for Choice Humanitarian* (1997-1998) and *Executive Director of FamilyCares* (2000). She feels that getting a desmoid tumor was both a wake-up call and a calling to a new endeavor as it became clear to her as a patient that this was a field that needed jumpstarting into a new level of accelerated research to develop new treatments. Jeanne resides in New Canaan, Connecticut with her husband Steve. They are the parents of four sons and a daughter.



### **Breelyn A. Wilky, MD, Assistant Professor, Hematology/Oncology, University of Miami's Sylvester Comprehensive Cancer Center**

Dr. Wilky is board certified in medical oncology and internal medicine. She completed her undergraduate studies at Bates College and graduated from the University of Medicine and Dentistry of New Jersey-Robert Wood Johnson Medical School, receiving her MD degree with Distinction in Research. Dr. Wilky completed her internship and residency program in Internal Medicine, and her Medical Oncology fellowship at The Johns Hopkins Hospital in Baltimore, Maryland. She is a translational researcher in sarcomas, facilitating bench to bedside development of novel therapies. She works with basic researchers to promote and expand laboratory discoveries into early phase clinical trials. In her dedicated sarcoma clinic, she sees GIST and sarcoma patients, as well as other bone/soft tissue tumors including desmoid fibromatosis, and strives to enroll patients on clinical trials whenever possible.