

**Fourth International DTRF  
Desmoid Tumor Research Workshop  
September 24, 2017**  
*(revised 9.6.17)*

**Participant Profiles**



**Benjamin Alman, MD, Professor & Chair, Orthopaedic Surgery, Duke University Health System**

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." Profile [here](#).



**Mushriq Al-Jazrawe, HBSc, PhD Candidate, 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.



**Steven Attia, DO, Assistant Professor of Oncology, Mayo Clinic**

Dr. Steven Attia is a medical oncologist at Mayo Clinic in Jacksonville, Florida. He is fellowship trained at the University of Wisconsin. His sole clinical and research focus is patients with desmoid tumor, sarcomas of soft tissue and bone including gastrointestinal stromal tumor (GIST), as well as chordoma, epithelioid hemangioendothelioma (EHE) and other locally aggressive or malignant tumors of soft tissue and bone. He is the research chair for the Mayo Clinic Sarcoma Disease Oriented Group. Aside from clinical trials and patient care, Dr. Attia has an interest in optimizing the way patients with rare tumors are discussed. He chairs a first-in-kind, CME accredited, weekly international sarcoma tumor board which he founded in 2010 that connects 10 sarcoma centers in the United States and Europe by videoconference to review challenging cases seen at these centers. Profile [here](#).



**Jared Barrott, PhD, Assistant Professor, Pharmacogenomics, Idaho State University DO**

Dr. Barrott's diverse training in multiple research disciplines (i.e. developmental genetics and cancer pharmacology) and top-quality pedagogical training will not only help him to accomplish his scientific aspirations but will help him to teach students and trainees so they can achieve theirs. He has a particular interest in the personalized approaches of treating cancer because it interweaves two disciplines that he is very passionate about: pharmacology and genetics. Many clinical efforts are already being made to produce genetic profiles for individual patients that expose the driving mutations of the cancer. However, the complexity of cancer in its heterogeneity and temporal regulation make it difficult to assign effective treatments to a single snapshot obtained by the current diagnostic techniques. One way to simplify our understanding of pharmacogenomics is to study disease models that are driven by very few genetic alterations. Pediatric sarcomas are examples of these minimally mutated cancers. Dr. Barrott studies chromosomal translocations and point mutations that represent the major driver mutations behind sarcomagenesis. His lab is designing disease models that will allow them to evaluate the epigenetic regulations in several sarcomas. In studying the epigenetic regulations in these genetically simple pediatric tumors, they hope to delineate druggable enzymes that should advance treatment for pediatric sarcomas that are currently lacking effective treatments.



**Robert Benjamin, MD, Clinical Professor, Sarcoma, University of Texas- MD Anderson Cancer Center**

Dr. Robert Benjamin is a Clinical Professor of Medicine in the Department of Sarcoma Medical Oncology at MD Anderson Cancer Center. He has worked in the area of Bone & Soft Tissue Sarcoma for more than 40 years and was the department's former chairman for more than 20 years. Dr. Benjamin was awarded the P.H. and Fay E. Robinson Distinguished Professorship in Cancer Research as well as the Gerald P. Bodey Professorship. In 2012 Dr. Benjamin received Herman Suit Award for his exceptional contribution to CTOS. In 2013 was the recipient of the Mendelsohn Lifetime Achievement Award.

Dr. Benjamin was a founding member of the Connective Tissue Oncology Society (CTOS), an international, multidisciplinary society devoted to the study of sarcomas, and he is past CTOS president. He is also on the Advisory Board of the Sarcoma Alliance for Research through Collaboration (SARC), a clinical trials group of CTOS members. He served on the NCI Program Review Group (PRG) for Sarcomas and was co-chairman of the PRG committee on Better Clinical Trials. Through SARC and CTOS, he has organized an international symposium on reassessing imaging techniques to determine response to treatment in sarcomas.



**Danielle Braggio, PhD, Post-Doctoral Researcher on Sarcomas, Ohio State University**

Dr. Danielle Braggio is a Post-Doctoral Researcher at The Ohio State University currently being mentored by Dr. Raphael Pollock. She started her sarcoma research as a Master's student studying gastrointestinal stromal tumors (GISTs). In February 2011, she started as a graduate student at A.C Camargo Hospital, where she was introduced to the desmoid tumors research.

During her doctoral research she had the great opportunity to work with Dr. Lev and Dr. Pollock, two experts in desmoid tumors. The main goal of her work is to extensively investigate molecular driving forces in desmoid tumors. Also, her future goals include educating people about desmoid tumors.



### **Michael Cassidy, MD, Assistant Professor of Surgery, Boston University School of Medicine**

Dr. Cassidy is a surgical oncologist and Assistant Professor of Surgery at Boston University School of Medicine as of July 15, 2017. After earning his MD degree at the Boston University School of Medicine, he completed residency in General Surgery at the Boston University Medical Center, and performed a two-year research fellowship in quality improvement and patient safety. Following residency, he completed a clinical fellowship at Memorial Sloan Kettering Cancer Center, where he was named to an endowed fellowship position as the David and Monica Gorin Fellow in Sarcoma. While at Memorial Sloan Kettering, he studied prognostic factors for predicting progression of desmoid tumors under observation, focusing on MRI characteristics.



### **Sant Chawla, MD, FRACP, Medical Director, Sarcoma Oncology Research Center**

Dr. Chawla is a leading medical oncologist in Santa Monica, California, specializing in research and treatment of sarcomas. Dr. Chawla undertook his medical training and received his degree at the All India Institute of Medical Sciences in New Delhi. He then began specializing in medical oncology at Auckland Hospital, New Zealand. He continued fellowship training in oncology at the M.D. Anderson Cancer Center, Texas. He is the director of the Sarcoma Oncology Research Center in Santa Monica, CA, a clinical research center that treats cancer patients from around the world for whom standard treatments have proven ineffective. Here he leads clinical cancer research efforts, and has conducted groundbreaking clinical research in sarcoma and solid tumors. His research has led to his recognition as one of the world's leading authorities in clinical research for bone and soft-tissue sarcomas and sarcoma therapy. He has published or contributed to more than 100 research publications on cancer treatment in leading national and international peer-reviewed journals. He is frequent presenter at international conferences such as ASCO and CTOS. He is an associate professor at the University of Texas, M.D. Anderson Cancer Center. He is a clinical faculty of Medical Center of UCLA, USC and John Wayne Cancer Institute and is a medical oncologist at Cedars Sinai Comprehensive Cancer center.



### **Rashmi Chugh, MD, Assistant Professor, Medical Oncology, Department of Internal Medicine, University of Michigan Health System**

Dr. Chugh's research focus is on the development of new therapies in the management of sarcoma and desmoid tumors. Sarcomas are cancers derived from connective tissue and span a wide range of histologic subtypes, clinical behaviors, and afflicted populations. They comprise less than 1% of all cancers and given their rarity and complexity of multi-disciplinary management, are best handled by a tertiary care sarcoma center. Our sarcoma multi-disciplinary treatment team is actively involved in research in all aspects of sarcoma care including systemic therapy, radiation therapy, and surgery. Unfortunately, systemic therapy for sarcomas is limited and only a minority of patients benefit from treatment. Dr. Chugh's research involves conducting phase I clinical trials of novel therapies alone or in combination with standard cytotoxic therapy or targeted agents in this disease. The combinations are chosen based on rational laboratory or clinical evidence of potential benefit, and are taken to the bedside for further evaluation. Promising combinations will continue to be tested in her program in phase II trials.



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

Chiara Colombo, MD is in charge at Sarcoma Service, Fondazione IRCCS Istituto Nazionale dei Tumori (INT), Milan- Italy as Surgical Oncologist. Dr. Colombo graduated in Medicine in 2003 with distinction at University of Milan and obtained the General Surgery Board Certification in Milan in 2009. Since 2009 she started her full-time collaboration at the Sarcoma Service at INT under the supervision of Dr. Alessandro Gronchi.

In 2010, Dr. Colombo won an AIRC grant for abroad fellowship and she joined the Sarcoma Research Laboratory at The University of Texas MD Anderson Cancer Center where she focused her studies on sarcomas and mainly on desmoid tumors under the supervision of Dr. Dina Lev. Presently she is in charge as Surgical Oncologist and gained surgical experience on soft tissue sarcoma surgery of the limbs, trunk and retroperitoneum. She also continues her translational research mainly on desmoid tumors. She won in 2011 a 3-years Young Research Grant (MFGA) and in 2013 DTRF grant for clinical and translational study on desmoid tumors. Since 2009, Dr. Colombo co-authored more than 30 original papers in high-ranking international journals and participated to several international meetings as presenter.



### **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. Profile [here](#).



### **Casey Cunningham, MD, Chief Scientific Officer, Sante Ventures**

Casey Cunningham, MD is the Chief Scientific Officer of Santé Ventures. Dr. Cunningham received his fellowship training in oncology and hematology at Harvard Medical School, where he subsequently served on the faculty. He was also one of the founding members of the Division of Experimental Medicine at the Brigham & Women's Hospital in Boston, where he established a basic research laboratory in Cell and Molecular Biology. He has over 70 publications in peer-reviewed journals and many abstracts and meeting presentations. Casey received his medical degree from the University of Texas

Southwestern Medical School with a residency in Internal Medicine at the Medical College of Wisconsin. Casey returned to Texas in 1999 as the Associate Director of the Mary Crowley Cancer Research Center in Dallas, a position he held until 2007. He joined Santé Ventures shortly after its founding. He has served in operating roles in Terapio, Molecular Templates and Beta Cat Pharmaceuticals and has been, or is currently on, the Boards of Terapio Corp., Molecular Templates, Lyric Pharmaceuticals, AbVitro and Mirna Therapeutics.



### **Palma Dileo, MD, Consultant Medical Oncologist, London Sarcoma Service, University College London Hospitals**

Dr. Palma Dileo is Consultant Medical Oncologist on the Sarcoma Unit at University College Hospital, UCLH NHS Trust, specialising exclusively in the management of soft tissue and bone sarcomas. The Sarcoma Unit at UCLH, together with the Sarcoma Unit at the Royal National Orthopaedic Hospital, is the London Sarcoma Service ([www.londonsarcoma.org](http://www.londonsarcoma.org)) which offers a comprehensive clinical service to patients of all ages with sarcoma at all sites of the body. She continued to provide patient care since 1996 (general oncology), with more emphasis on sarcoma and rare tumours starting from 1998. She completed her training at the Istituto Nazionale Tumori of Milan, Italy and at Dana-Farber Cancer Institute, Boston, USA. From 2006 to 2010 she has been Associate Physician, Medical Oncology, Istituto Nazionale Tumori, Milan working in the Sarcoma Team. She has a strong interest in early phase clinical trials and is a co-investigator for a number of clinical trials in sarcoma. She is a member of the EORTC Soft Tissue and Bone Sarcoma Group and ASCO. Profile [here](#).

### **Tom Ellingson, MBA, Managing Director, Community Dynamics, Inc.**

Mr. Ellingson's family has been affected by Desmoid Tumors. Having lost a brother to complications associated with Desmoid Tumors and with a father and niece fighting complications resulting from Desmoids, Tom is passionate about applying information systems to help more efficiently leverage research dollars and help medical experts learn from others' discoveries and contributions related to Desmoid Tumors.

Tom is applying his over 27 years of experience in the technology sector to help evolve the use of information systems to allow for more efficient sharing of knowledge. Applying discoveries in the newly developing fields within information technology he and his business partner are creating systems and tools to help experts from around the world collaborate and form a topic based collective conscious of knowledge. Some compare this to Big Data, but instead harvesting results from data they are working to harvest insight from many, many words - Big Knowledge. Some have also compared the effort to artificial intelligence or an advanced, topic based research assistant.

Tom is established as a leader in sales, marketing, business development, product management, and executive management while at IBM, PricewaterhouseCoopers, and 11 technology and marketing companies. The companies focused on cloud based SaaS, online marketing, and leveraging the internet to collect data and improve business performance. Some of Tom's professional accomplishments include introducing the world's largest consulting company to a large US intelligence agency, an over 500% increase in annual sales at a SaaS software firm and leading an IBM sales team to consecutive years of 110%, 58%, and 35% revenue growth for a \$28 million 12,000-client territory. The positions Tom has held include the of VP of Sales, VP of Business Development, Interim CFO, Interim Division President, Division General Manager (including product development and product management), Managing Director, Managing Member, Advisory Board Member, Board Member, and CEO.

Tom lives in Minneapolis with his wife and two daughters where has spent time on the board of a large youth based non-profit.



### **Yoni Falkson, Strategy & Operations, Commercial Development, Pfizer, Inc.**

Yoni recently joined the newly created Pfizer CURES platform which aims to bring together patient foundations, impact investors and venture philanthropy with Pfizer assets that serve specific patient populations. These novel partnerships and alliances with financial, philanthropic and public sector partners will extend the scientific and development innovation opportunities for a select number of quality assets in Pfizer's portfolio that have the potential to offer significant benefits to patients. Yoni has been with Pfizer since 2012 focused on early commercial strategy in metabolic diseases and global pricing and market access. Previously, Yoni led US payer marketing for Purdue Pharma and was a consultant to various leading pharmaceutical companies to inform global pricing & market access in multiple therapeutic areas. Yoni holds an MBA from NYU Stern and bachelor's degrees in psychology and economics from Cornell University.



### **Jesica Garcia, Board Member, SPAEN**

Jesica was diagnosed with a desmoid tumor in 2014 and she is still fighting the disease. She's had surgery, radiotherapy and a relapse happened several months ago and she has been involved in SPAEN since mid- 2016 as a pretty active member. She became an appointed board member at the last SPAEN AGM in September 2016. Jesica is also working with AEAS (Spanish Sarcoma Affected Patients). Desmoid tumor patient advocacy work holds most of her spare time when she is not working or swimming.



### **Mrinal Gounder, MD, Assistant Professor and Medical Oncologist, 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. Profile [here](#).



### **Shunsuke Hamada, MD, PhD, Department of Orthopaedic Surgery, Nagoya University**

Shunsuke Hamada MD, PhD specializes in orthopedic surgery and musculoskeletal oncology. His present research theme is clinical and molecular analysis of desmoid fibromatosis. He graduated from Mie University of Medical Science, Japan, and passed National Board of Medicine in 2004. He became Japan Orthopedic Association Board certified orthopedic surgeon in 2011. Currently, he practices with an orthopedic oncology group and performs clinical treatment and research at Nagoya University Hospital.



### **Stephen Horrigan, PhD, Chief Scientific Officer, Beta Cat Pharmaceuticals**

Dr. Horrigan is the Chief Scientific Officer of BetaCat Pharmaceuticals, a biotechnology company developing inhibitors of the beta catenin signalling pathway. Prior to joining BetaCat Pharmaceuticals, Dr. Horrigan was the Vice President of Research at Avalon Pharmaceuticals, where he directed both internal and collaborative research programs for the discovery and development of cancer therapeutics. Prior to joining Avalon, Dr. Horrigan was Associate Professor in the Department of Pediatrics and Lombardi Cancer Center at Georgetown University Medical Center where he led a research group focused on cancer genomics and the application of biomarkers in cancer diagnostics. He has also held positions at the University of Illinois, College of Medicine and the University of Chicago School of Medicine.



### **George Jour, MD, Assistant Professor of Pathology and Dermatology, MD Anderson Cooper**

George Jour MD, earned his medical degree in 2007 from Université Saint Joseph, Beirut, followed by a Surgery internship at Hotel Dieu Beirut Lebanon and an Internal medicine internship at Montefiore Medical Center, Albert Einstein college of Medicine. Afterwards, he pursued an anatomic and clinical Pathology residency at St Luke's Roosevelt -Columbia College

for Physicians and Surgeons, New York. That was followed by a Bone and soft tissue Pathology fellowship at University of Washington, Seattle, a Molecular diagnostics fellowship at Memorial Sloan Kettering, and a Dermatopathology fellowship at MD Anderson Cancer center, Houston.

In 2016, he joined MD Anderson at Cooper, Camden, New Jersey as Assistant Professor of Pathology and Dermatology and as associate Director of Molecular diagnostics. He worked since then on establishing a next generation sequencing Laboratory with a service scope covering different specialties including sarcoma service and dermatopathology/melanoma consult service. As a soft tissue and molecular pathologist, he always aims to help sarcoma/melanoma oncologists and surgeons better stratify and triage our patients for potential additional adjuvant therapies and targeted therapies.



**Bernd Kasper, MD, PhD, Professor, Mannheim University Medical Center, Interdisciplinary Tumor Center, Sarcoma Unit**

Prof. Bernd Kasper studied Medicine at the University of Heidelberg. In 2001, he finalised his thesis at the German Cancer Research Centre (DKFZ) dealing with new treatment strategies for chronic myelogenous leukaemia patients using the tyrosine kinase inhibitor imatinib. To deepen his training, he stayed in London (Imperial College School of Medicine, Hammersmith Hospital, Department of Haematology) and Brussels (Jules Bordet Institute, Medical Oncology Clinic). In 2007 and 2008, he specialized in Internal Medicine and Medical Haematology/Oncology at the Department of Internal Medicine V at the University of Heidelberg. Currently, he works together with Prof. Peter Hohenberger at the Sarcoma Unit at the Interdisciplinary Tumor Center Mannheim (ITM) at the Mannheim University Medical Center, University of Heidelberg. Since 2011, he is leading the ITM. His special interest lies in the treatment of patients with bone and soft tissue sarcomas including GIST and desmoids. He is head of the study center of the German Interdisciplinary Sarcoma Group (GISG) and Secretary of the Soft Tissue and Bone Sarcoma Group (STBSG) of the European Organisation for Research and Treatment of Cancer (EORTC). Bernd Kasper is actively involved in patient advocacy work on the national as well as international level as a board member of Sarcoma Patients EuroNet (SPAEN).

**Giorgos Karakousis, MD, Associate Professor of Surgery, Hospital of the University of Pennsylvania**



**David Kirsch, MD, PhD, Barbara Levine University Professor Professor and Vice Chair for Basic & Translational Research, Department of Radiation Oncology Professor, Department of Pharmacology & Cancer Biology, Duke University**

David Kirsch, MD, PhD, is the Barbara Levine University Professor at Duke in the Departments of Radiation Oncology and Pharmacology & Cancer Biology. After graduating from Duke with a BS in Biology, he completed the MD/PhD program at Johns Hopkins School of Medicine, where he performed his thesis research with Dr. Michael Kastan. After an internship in Internal Medicine, Dr. Kirsch trained in radiation oncology at Massachusetts General Hospital. He worked as a post-doc in the laboratory of Dr. Tyler Jacks at M.I.T., where he developed a genetically engineered mouse model of soft tissue sarcoma. In 2007 Dr. Kirsch moved to Duke, where he uses radiation therapy to care for patients with sarcomas at the Duke Cancer Center. Dr. Kirsch is the leader of the Radiation Oncology & Imaging Program in the Duke Cancer Institute and serves as Vice Chair for Basic and Translational Research in the Department of Radiation Oncology. Dr. Kirsch's laboratory utilizes sophisticated genetically engineered mouse models to study mechanisms of sarcoma and normal tissue response to radiation.



**Robert Lefkowitz, MD, Associate Professor, Radiology, Weill Cornell Medical College/Memorial Sloan-Kettering Cancer Center**

Dr. Lefkowitz is a radiologist specializing in abdominal and musculoskeletal imaging and he has a particular interest in imaging of soft tissue tumors. Currently, he is involved in several prospective and retrospective research projects evaluating the treatment response of desmoid tumors to medical therapy and the associated changes seen on MRI. Profile [here](#).



**Robert G. Maki, MD, PhD, FACP, Professor of Medicine, Hofstra Northwell School of Medicine & Cold Spring Harbor Laboratories / Director, Center for New Cancer Therapies, Northwell Health Cancer Institute**

Dr. Robert Maki is Professor of Medicine, Pediatrics, and Orthopaedics, and the Steven Ravitch Chair in Pediatric Hematology-Oncology. He has published more than 100 articles on sarcoma treatment and basic science research, having worked on studies related to sarcoma since 1985. He treats adults and children with sarcomas (connective tissue cancers of bone, cartilage, muscle, fat and other soft tissue) and has an interest in translational research and the biology that leads to different types of sarcomas. After his MD/PhD at Cornell Medical College in New York City, he was a resident at Brigham and Women's Hospital in Boston before a medical oncology fellowship at Dana-Farber, and was on staff at Dana-Farber before starting at Memorial Sloan-Kettering in 1999. In March, 2011 he moved to the Mount Sinai Medical Center to develop the effort in adult sarcoma therapy and research. Dr. Maki's efforts at Mount Sinai will be directed towards an increasingly integrative effort sarcoma biology and treatment of sarcomas. His group will conduct clinical trials in adults with sarcomas, and they will also conduct translational studies in sarcoma biology to identify the next possible targets for new drugs to treat sarcomas. Dr. Maki is also the Director of Translational Oncology at the Sarcoma Alliance for Research through Collaboration (SARC).



**Michelle Manalang, MD, Pediatric oncologist, Marshfield Clinic**

Dr. Manalang earned her medical degree from University of Illinois. She completed her pediatric residency at University of Iowa in Iowa City IA. Upon completion of her pediatric hematology-oncology fellowship at Children's Mercy Hospital in Kansas City MO, she was invited to join the faculty, where she was the Clinical Director of the Liver Tumor Program and involved in research in both hepatoblastoma and desmoid tumors. She recently joined the Marshfield Clinic in Marshfield WI, as one of their pediatric hematologist-oncologists. She has a special interest in solid tumors, particularly hepatoblastoma and desmoid tumors in pediatrics.



**Javier Martin-Broto, MD, PhD, Consultant in Medical Oncology, Hospital Universitario Virgen del Rocio, Sevilla**

Dr. Javier Martin-Broto studied Medicine between 1982 and 1988 at the School of Medicine of Zaragoza. He obtained the official title of Specialist in Medical Oncology at Son Dureta Hospital, Palma de Mallorca in 1994, after successfully passing the national exam. From 1994 to 2014, he treated sarcomas in this hospital, which ultimately became a Center of Reference for Sarcoma. In September 2014, Dr. Martin moved to the University Hospital of Virgen del Rocio in Sevilla to coordinate the multidisciplinary sarcoma team and to apply to a selective number of centers of reference in sarcoma care in Spain. The hospital was accredited as a National Health System Reference Center for Sarcoma Care (along with other 4 hospitals). It was also accredited within ERN (European Network for Rare Diseases) as a European Center of Reference in Sarcoma in 2017.

Dr. Martin was a founding member of The Spanish Group for Research on Sarcomas (GEIS) in 1994 and has served as the chairman of this group since 2010. Since September 2014, he has coordinated the Sarcoma Multidisciplinary Team of Virgen del Rocio Hospital in Sevilla. Dr. Martin obtained his PhD in Molecular Biology in 2010 focusing on molecular prognostic biomarkers in GIST. He is a member of The American Society of Clinical Oncology (ASCO), The European Society of Medical Oncology (ESMO), The Connective Tissue Oncology Society (CTOS), and Sociedad Española de Oncología Médica (SEOM). He has been an ESMO faculty member in Sarcomas since 2010 and member of board directors of CTOS since 2014. Currently Dr. Martin combines clinical sarcoma assistance with translational research, leading a basic research team in the lab. Additionally, he is running several trials on sarcoma patients, some of them as coordinator at the national and international level.



**Kelly Mercier, PhD, Research Scientist in Metabolomics, RTI International**

Dr. Kelly Mercier is a research scientist in the Systems and Translational Sciences Center at the non-profit institute, RTI International, and conducts research in the NIH Eastern Regional Metabolomics Research Center (RCMRC). Since joining RTI, Dr. Mercier has used metabolomics in several collaborations with basic researchers and clinicians aimed at determining biomarkers and gaining insights into mechanisms of disease. Dr. Mercier has on-going collaborations in neonatal kidney injury, immune system development and allergies, and Barth Syndrome, a rare disease characterized by genetic condition as mutation of the tafazzin gene. Dr. Mercier received a Ph.D. in Chemistry from the University of Nebraska Lincoln in the area of analytical biochemistry and completed a post-doctoral fellowship at the National Institutes of Environmental Health Sciences. Her son has suffered from desmoid tumors and she is personally invested in finding a cure.

**Christian Meyer, MD, PhD, Instructor & Medical Oncologist, Johns Hopkins Hospital**

Dr. Meyer serves as the lead medical oncologist for adult sarcoma patients at Johns Hopkins. Dr. Meyer received his bachelors and masters degrees in cell and molecular biology from Stanford University. From there, he joined the Medical Scientist Training Program at Baylor College of Medicine and earned his medical degree followed by a doctorate in immunology. Meyer completed his residency at the University of Maryland and served as chief resident in medicine from 2004-2005. He joined the Hopkins Fellowship program in medical oncology and has been worked in the laboratory of Jonathan Powell, M.D., Ph.D., on projects relating to the characterization of molecular regulatory pathways involved in T-cell activation and energy. As a third-year fellow, Meyer served as the chief fellow for our Training Programs in Hematology and Medical Oncology and he received a Young Investigator Award from the American Society of Clinical Oncology in 2010. His current work focuses on building the Adult Sarcoma and Connective Tissue Oncology Program through the Hopkins sarcoma multidisciplinary clinic. In collaboration with pediatric oncologist Christine Pratalis, M.D., Ph.D., orthopaedic surgeon Carol Morris, MD, and general surgeon Nita Ahuja, MD, Dr. Meyer works to bring novel therapies to the clinic for sarcoma patients.



**David da Silva Moura, PhD, Molecular and Cellular Biologist, Institute of Biomedicine of Sevilla**

David da Silva Moura, Ph.D. in Biosciences: Biology and Cancer Clinic and Translational Medicine, at the University of Salamanca; is a postdoctoral researcher in the group of advanced therapies and biomarkers in biology (TERABIO), at the Institute of Biomedicine of Sevilla. During his years of research, David S. Moura has accumulated extensive knowledge in molecular and cellular biology techniques and molecular mechanisms of cancer, which he currently applies to sarcoma-focused research, including to Desmoid Tumor. David S. Moura has published several scientific papers in first quartile journals and regularly participates in national and international congresses with oral and / or poster presentations. He is member of the European Association for Cancer Research (EACR) and the Spanish Association for Cancer Research (ASEICA).



**Yoshihiro Nishida, MD, PhD, Chairman, Department of Orthopaedic Surgery, Nagoya University Graduate School of Medicine**

Dr. Yoshihiro Nishida is Associate Professor, Chairman, Department of Orthopaedic Surgery, Nagoya University Graduate School and School of Medicine. He has published more than 100 articles on Orthopaedic Oncology and basic research area. His present specialty is surgical and conservative treatment for patients with bone and soft tissue tumors, and doing translational and clinical research. He graduated from Nagoya University School of Medicine, Japan, in 1988. He was selected as a traveling fellow of Japanese Orthopaedic Association—American Orthopaedic association in 2005. He has been a PI of “Study for understanding of current status and established of treatment guideline for patients with extra-peritoneal desmoid tumors” which is selected by Health, Labour, and Welfare Ministry of Japan. Profile [here](#).



**Jonathan Northrup, CEO, Beta Cat Pharmaceuticals Inc.**

Jon is CEO of Beta Cat Pharmaceuticals, a Houston based biotech developing a small molecule inhibitor of beta catenin. The program should begin clinical studies this year. Unlike other programs, Beta Cat's is unique in drugging the pathway right before transcription at the very bottom of the pathway. We believe this holds promise for an inhibitor that is more specific and potent than any other program currently in development.

Jon has been CEO of Beta Cat since its founding and he is also a co-founder of the company. Prior to that, Jon was COO of Jubilant Innovation, the venturing arm of a large Indian CRO, founding partner of Horizon Biotechnologies, and a VP in Business Development, and many roles in Sales and Marketing for Eli Lilly and Company.



**Jean Paty, PhD, Patient-Centered Endpoints, QuintilesIMS**

Jean is an acknowledged leader in the effective strategies and practices of capturing patient perspective data for use in the clinical development and commercial success of new medical products. He has not only published extensively in the areas of Patient Reported Outcomes (PRO) and electronic PRO (ePRO), but also on the regulatory guidance for development and implementation of ePRO. He has worked closely with the international industry and regulatory agencies on ePRO best practices. Dr. Paty's work is well-referenced in a wide variety of peer-reviewed journals and in numerous conferences and events, where he has presented his findings on the scientific, clinical, and regulatory implications of Clinical Outcome Assessment (COA) data collection in clinical trials. Profile [here](#).



**Raphael Pollock, MD, PhD, FACS, Professor and Director, Division of Surgical Oncology, Surgeon in Chief, James Comprehensive Cancer Center, The Ohio State University Wexner Medical Center**

Dr. Raphael Pollock is Professor and Director of the Division of Surgical Oncology at the Ohio State University Wexner Medical Center, and holds the Kathleen Wellenreiter Klotz Chair in Cancer Research. He also serves at Surgeon in Chief for the James Comprehensive Cancer Center and the Ohio State University Health System. Dr. Pollock's work focuses on soft tissue sarcoma. His laboratory research activities are examining multiple facets of the molecular drivers underlying soft tissue sarcoma inception focus on soft tissue sarcoma, a rare cancer in adults but rather prevalent in children. He has published widely on sarcoma surgery and treatment, and his funded research includes sarcoma molecular biology and the development of novel therapeutics for this group of diseases. His laboratory work involves the

discovery of oncogenes and tumor suppressor genes in soft tissue sarcoma. He is principal investigator of an \$11.5 million National Cancer Institute (NCI) grant to support collaborative sarcoma translational research. The NCI Specialized Programs of Research Excellence (SPORE) grant, awarded to the Sarcoma Alliance for Research for Collaboration, represents the largest award ever to study sarcoma. Profile [here](#).



**R. Lor Randall, MD, FACS, Director of Sarcoma Services, Huntsman Cancer Institute, University of Utah**

R. Lor Randall, MD, FACS, is the Director of Sarcoma Services at the University of Utah's Huntsman Cancer Institute and Primary Children's Hospital. Dr. Randall is a Professor of Orthopaedics and The L.B. & Olive S. Young Endowed Chair for Cancer Research. He has a busy quaternary referral clinical practice specializing in musculoskeletal surgical oncology. Dr. Randall is also Co-Directs the Huntsman-Intermountain Adolescent & Young Adult Oncology Program. As an active researcher, he Co-Leads the Sarcoma Disease Oriented Research Team overseeing collaborative, across-department research budgets. The Sarcoma Services at HCI, because of its comprehensive experience in sarcomas, is continually developing and refining institutional based research and treatment protocols to improve the outcome in these rare but highly malignant conditions. HCI is a SARC participant and is also very active in the Children's Oncology Group.



**Gary K. Schwartz, MD, Chief, Division of Hematology Oncology, Columbia University**

Gary K. Schwartz, MD is Professor of Medicine and current Chief of the Division of Hematology and Oncology and Associate Director of the Herbert Irving Comprehensive Cancer Center at Columbia University School of Medicine. He is a recognized leader in the field of translational research and has been able to bridge the clinical and basic science elements of drug development. Previously he was an Attending Physician and Member at Memorial Sloan-Kettering Cancer Center and Chief of the Melanoma Sarcoma Oncology Service. His clinical focus is in melanoma and sarcoma. He is the Principal Investigator of a series of phase I and II trials that are based on his laboratory studies. His work has extensively been supported by his own peer-reviewed grants. This has included an R01 to develop cyclin dependent kinase inhibitors with chemotherapy, an R01 and a SPORE grant to evaluate combinations of receptor tyrosine kinase inhibitors of IGF-1R and PDGFR with inhibitors of mTOR in sarcomas, a RAID and an R21 grant to develop the sphingosine kinase inhibitor safingol with cisplatin, a DOD grant to develop the botanical herb huanglian, and an FDA-R01 to develop imatinib for the treatment of patients with c-kit mutant melanomas. He is PI of the Columbia University Minority/Underserved Site NCI Community Oncology Research Program. In addition, he was recently awarded the Team Science Award by the Melanoma Research Alliance to lead a national effort in developing new therapies for patients with ocular melanoma. His contributions to teaching and mentoring have been recognized by his former fellows, who have awarded him the annual Teaching Award on multiple occasions and by the junior faculty for the Excellence in Mentoring Award. In 2000 and 2006 respectively, he received NCI K24 and K12 Clinical Oncology Research Career Development Awards aimed at the mentoring of medical trainees in translational research. He has mentored several of our leading junior faculty on NCI Career Development Awards. In addition, he has served on numerous committees for the American Society of Clinical Oncology, the American Association of Cancer Research and for the NCI including the NExT committee which has been established to assist the NCI in identifying new agents for drug development. He is co-Chair of the Experimental Therapeutic Committee of the Alliance which has provided a platform for junior faculty to take leadership positions on national clinical trials. He also serves as Vice Chair of ASCO's Targeted Agent and Profiling Utilization Registry (TAPUR) Study Molecular Tumor Board. In addition, he has authored or co-authored over 200 manuscripts in the field of both basic and clinical cancer research.

**Keith Skubitz, MD, Professor of Oncology-Hematology, University of Minnesota**

Dr. Skubitz has led the medical oncology arm of the Bone and Soft Tissue Tumor program at the University of Minnesota since 1988. He received an AB in physics and chemistry from Cornell University and an MD from the Johns Hopkins University School of Medicine, and then did internal medicine training at the University of Minnesota. He completed two fellowships, one in Clinical Pharmacology at Johns Hopkins and one in Medical Oncology at the University of Minnesota. Dr. Skubitz cares for patients with a variety of malignancies and related diseases. His research primarily involves drug development and clinical trials, the use of genomics to identify new drug targets and predict disease outcome, as well as neutrophil biology and structure.



**Silvia Stacchiotti, Medical Oncologist, Fondazione IRCCS Istituto Nazionale Dei Tumori**

A medical oncologist, Dr. S. Stacchiotti, works in the Adult mesenchymal and rare tumor medical treatment unit, Cancer Medicine Department, Fondazione IRCCS Istituto Nazionale Tumori (INT), Milano, Italy.

Dr Stacchiotti clinical and research activities focus on adult soft tissue and bone sarcomas, including gastrointestinal stromal tumors (GIST). She is involved in all institutional

research activities on sarcoma, with a special focus on very uncommon subtypes such as chordoma, chondrosarcoma, giant cell tumor of the bone, alveolar soft part sarcoma, clear cell sarcoma, DFSP, desmoid, solitary fibrous tumor, vascular tumor, PVNS, PEComa. She is the Principal Investigator and Coinvestigator of several trials on Sarcoma and GIST. She is a member of the Italian Sarcoma Group, a national cooperative group for clinical and translational research on soft tissue and bone sarcomas, and is a member of the EORTC Soft Tissue & Bone Sarcoma Group. She collaborates to the Italian Network on Rare Tumors, a collaborative effort among Italian cancer centers, which tries to exploit distant patient sharing in order to improve quality of care and diminish health migration for rare solid cancers. She is a member of ESMO (European Society for Medical Oncology), Connective Tissue Oncology Society (CTOS) and of ASCO (America Society of Medical Oncology). She is a member of the advisory board of the Chordoma Foundation and of Desmoid Tumor Research Foundation. She is included in the list of European Medical Agency (EMA) external expert. She serves as associate Editor of the European Journal of Cancer and of Sarcoma Journal.

She has authored more than 100 scientific publications on sarcoma.

Born in 1968, dr Silvia Stacchiotti received his medical degree in 1993 in Milan, and trained at the INT. She is certified in Clinical Oncology.



**Arthur Staddon, Medical Director, Sarcoma Program, University of Pennsylvania**



**Lara Sullivan, MD, MBA**



**Milea J.M. Timbergen, MD, PhD candidate, Erasmus Medical Center**

Dr. Timbergen started medical school in Maastricht, the Netherlands in 2009. After graduation in 2015 she started working as a medical doctor in the surgical ward of the Erasmus MC, Rotterdam. In 2017 she started her PhD with desmoid tumors as a specific interest. Today her research involves a broad spectrum of topics regarding desmoid tumors including pre-clinical experimental work and both retro- and prospective clinical studies.

**Tom Van Cann, MD, Medical Oncologist, KU Leuven**

Dr. van Cann studied medicine at the KU Leuven until he obtained his degree of Master in Medicine in 2011. He then started his internships in General Internal Medicine and in 2014 in General Medical Oncology in the UZ Leuven and affiliated hospitals. From 2015 onwards he is working as a PhD student in the field of soft tissue sarcoma. Together with his promoter, Prof. Dr. Patrick Schöffski, he is working on his PhD, entitled: "Clinical outcome, pathological results and immunohistochemical findings in selected subtypes of soft tissue sarcoma."



**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." His lab uses next generation sequencing approaches to study gene expression profiles of desmoid tumors, scars and other fibroblastic lesions with the goal of identifying diagnostic and prognostic markers. Profile [here](#).



**Victor Villalobos, MD, PhD, Assistant Professor, Director of Sarcoma and T3 (Target-based Therapeutics Team), University of Colorado- Denver**

Dr. Villalobos is a Medical Oncologist that specializing in sarcoma and early phase drug development. His primary interests in sarcoma are in the development of novel immunotherapeutic combinations and targeted therapies for the treatment of both soft tissue and bone sarcomas. At this institution we see over 250 new sarcoma cases each year and serve as a regional center of expertise within the Inner-Mountain West.



## **Kris Vleminckx, PhD, Professor of Developmental Biology, Ghent University**

Dr. Kris Vleminckx is a cell and developmental biologist at Ghent University in Belgium. He was trained as a cancer cell biologist documenting for the first time the invasion suppressor activities of the cell adhesion molecule E-cadherin. He went for a first post-doc to the Memorial Sloan-Kettering Cancer Center in New York where he initially studied the developmental role of cadherin complexes during early vertebrate development (using the model organism *Xenopus*) in the laboratory of Dr. Barry Gumbiner, who around that time was one of the first groups to show that beta-catenin, a protein associated with cadherins, had a parallel function in the Wnt signaling

pathway. Kris Vleminckx studied the role of the tumor suppressor gene APC in *Xenopus* development and has ever since focused on investigating the Wnt pathway, primarily in early development. After a second post-doc at the Max-Planck Institute in Freiburg, Germany, he returned to Ghent in 2000 to start up his research group. He is also associated with the Center of Medical Genetics at the Ghent University Hospital. When the novel revolutionary techniques for genome editing using TALEN and CRISPR/Cas9 emerged, he realized that this created unique opportunities for modeling human disease in the model organism *Xenopus tropicalis* and he generated the first genetic cancer model in this organism by mutating the APC tumor suppressor gene, hence mimicking the Familial Adenomatous Polyposis cancer syndrome. Since then, modeling human cancer, including desmoid tumors, is the major focus of his research group.



## **Aaron Weiss, DO, Assistant Clinical Professor of Pediatrics, Maine Medical Center**

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 DTFR-funded project: Deregulated mTOR in Desmoid-type Fibromatosis: Identification and Validation of a New Therapeutic Target.



## **Gerlinde Wernig, MD, Assistant Professor, Department of Pathology, Stanford University School of Medicine**

Dr. Gerlinde Wernig is an Assistant Professor of Pathology at Stanford University Medical Center. After receiving her residency training in internal medicine (Germany) and pathology (US) specializing in hematology/oncology and hematopathology, she sought postdoctoral training in leukemia research and joined Gary Gilliland's lab where she was involved in the discovery of the now famous JAKV617F mutation. She then joined Irv Weissman's laboratory for her second postdoc and also started her

pathology residency training at Stanford University. Now, Dr. Wernig has her own lab which focuses on understanding the pathomechanisms of end stage organ fibrosis with the ultimate goal to help identify new targets for effective therapies. They have found that the transcription factor c-JUN is specifically activated in human idiopathic pulmonary fibrosis and many other human fibrotic diseases and that induction of c-Jun in mice mimics the pathological hallmarks of these diseases.



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

Dr. Wilky is medical oncologist specializing in benign and malignant disorders of bone and soft tissue, including sarcomas. In addition to clinical care of patients suffering from these rare cancers, she is a clinical and translational researcher, working to develop new therapies apart from traditional chemotherapy approaches. Dr. Wilky is particularly interested in the role of immunotherapy for sarcomas, and is currently leading three clinical trials at Sylvester Comprehensive Cancer Center investigating immune checkpoint inhibitors and patient-derived vaccines. In addition to studying whether these treatment approaches can help patients with sarcoma, she also works with laboratory investigators to study the immune cells from patients treated on these trials, to understand how to help the immune system fight cancer more effectively. In addition to her research for sarcoma patients, I am an active member of Sylvester's Phase I Site Disease Group and also participate in Sylvester's Personalized Medicine Initiatives, which aim to match patients to the best molecularly targeted treatments available based on the patient's own genetic sequencing results from tumor tissue. Dr. Wilky's work with the Desmoid Tumor Research Foundation aims to utilize the specific genetic mutations identified in a patient's desmoid to help predict the most effective and least toxic systemic treatments, including the identification of patients likely to benefit from observation only.