

**Fifth International DTRF  
Desmoid Tumor Research Workshop  
September 23, 2018**  
*(revised 7.5.18)*

**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, HBS, PhD Candidate, Laboratory Medicine & Pathobiology, University of Toronto**

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.



**Rahul Aras, PhD, CEO of Beta Cat Pharmaceuticals, Inc.**

Dr. Aras has been the President & CEO for Beta Cat Pharmaceuticals since 2018. He is an experienced biotechnology executive with an established track record of raising capital for early and mid-stage companies and advancing product through key development milestones. Dr. Aras brings deep international business development experience in all aspects of deal sourcing, negotiation, and strategic alliance management. Prior to Beta Cat, he was the founding CEO for Juventas Therapeutics, a gene therapy company developing novel regenerative therapies for treatment of cardiovascular disease. He led Juventas since its inception in 2007, successfully advancing their lead program from the concept through Phase 2b clinical studies. Prior to leading Juventas, Dr. Aras was the Director of Life Science Commercialization at Cleveland Clinic Innovations where he managed commercialization of all biotechnology and pharmaceutical related technologies developed at Cleveland Clinic. Dr. Aras has held research positions at Vanderbilt University Medical Center and Massachusetts General Hospital and has published articles in several leading scientific journals. He received a B.S. from Tufts University and a Ph.D. in biomedical research from New York University.



### **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](#).



### **Christina Baumgarten, Sarcoma Patients Euro Net (SPAEN) Co-founder and Board member, President sos-desmoid e.V. Germany**

Christina Baumgarten started her work for desmoid patients 2005. In 2009 she founded sos-desmoid e.V the german association for desmoid patients and co founded SPAEN the european association for GIST, desmoid and sarcoma patients. The aim of the european organisation is to extend information services, patient support advocacy so that patients across the whole Europe benefit. SPAEN is acting in partnership with experts, the healthcare industry and other stakeholders. SPAEN will work to improve treatment and care

of GIST, desmoid and sarcoma patients in Europe through improving information and support and by increasing the visibility of sarcoma, desmoid and GIST patients supported by leading european sarcoma, desmoid and GIST experts.

Together with her colleagues from the board of SPAEN and Prof. Kasper and Prof Hohenberger from Germany he initiated a "round table" meeting to create a consensus paper for the management of desmoid tumors based on patients and professionals expertise. The paper was published by Prof Kasper in the EJC January 2015.



### **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 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.



### **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](#).



### **Eldad Elnkave, MD, Director of Interventional Oncology Clinic, Rabin Medical Center**

Dr. Eldad Elnkave, MD serves as the director of the Clinic for Interventional Oncology at the Davidoff Cancer Institute, Rabin Medical Center, Israel. He obtained his medical degree from Tufts University in Boston, Massachusetts and spent two years as a Howard Hughes Medical Institute Research Scholar at the National Institutes of Health in 2003-2005. Dr. Elnkave completed radiology training at Albert Einstein Medical Center and trained in Vascular and Interventional Radiology at Memorial Sloan-Kettering Cancer Center. His clinical and research focus is on the combination of anatomical and molecular targeting to treat disease in the most precise and minimally invasive method possible. His primary clinical focus is treatment of mesenchymal tumors and sarcoma. Dr. Elnkave also serves as the founding Chief Medical Officer of Zebra Medical Vision, LTD.



### **Jessica Foley, PhD, Chief Scientific Officer, Focused Ultrasound Foundation**

Jessica Foley, PhD is the Chief Scientific Officer for the Focused Ultrasound Foundation, whose mission is to accelerate the development and adoption of focused ultrasound, a breakthrough non-invasive medical technology. As Chief Scientific Officer, Foley oversees the Foundation's scientific and research programs and activities, and aligns these with communications and development efforts. She also leads alliance-building efforts with external stakeholders including (but not limited to) governmental policymakers, regulatory agencies, and disease-specific foundations whose interests are complementary to those of the Foundation. She is a representative and advocate for the Foundation and the focused ultrasound community among a wide variety of stakeholders. Dr. Foley joined the Foundation in 2012 after completing a one-year AAAS Science and Technology Policy Fellowship at the National Science Foundation. Prior to that, she was Neuro Projects Manager and Clinical Marketing Manager at InSightec, one of the leading focused ultrasound medical device manufacturers. Other previous experience included Senior Scientist at Medtronic. She holds a BSE in Biomedical Engineering from Duke University and a PhD in Bioengineering from the University of Washington.



**Michael A. Freitas, PhD, Associate Professor, Director of CCC Proteomics Shared Resource, Department of Cancer Biology and Genetics, The Ohio State University**

Dr Michael A. Freitas, PhD, is the Director of the OSU Comprehensive Cancer Center Proteomics Shared Resource. He is an Associate Professor in the Department of Cancer Biology and Genetics, and the Department of Biomedical Informatics in the College of Medicine at the OSU Wexner Medical Center. Dr. Freitas has been working

in the field of mass spectrometry for >30 years and has spent the last 20 years developing and improving mass spectrometry and bioinformatic methods in the fields of cancer proteomics and chromatin biology. He is a recipient of the Camille and Henry Dreyfus New Faculty Award and the American Society for Mass Spectrometry Research Award. Dr. Freitas serves as a scientific advisor to the OSU Campus Chemical Instrument Center's Mass Spectrometry and Proteomics Facility. Current research is focused on development and application of multiomic methods to understand chromatin regulatory networks in cancer. The lab has extensive expertise in characterizing protein modifications and identifying protein:protein interactions by mass spectrometry. Dr. Freitas also has a passion for training scientists to utilize modern data analytics. He formed the OSU Data Science Club, which meets weekly with biologists to discuss topics in quantitative data analysis.



**Rebecca Gladdy, MD, PhD, Staff Surgeon/Clinician Scientist, Mt. Sinai Hospital, Sinai Health System/Lunenfeld-Tanenbaum Res. Inst/Sinai Health System**

Dr. Rebecca Gladdy is a Surgeon Scientist and Assistant Professor at the University of Toronto, who joined the faculty in 2008 after completing a Surgical Oncology Fellowship at Memorial Sloan-Kettering Cancer Center in New York. Dr. Gladdy trained in the General Surgery residency program at the University of Toronto and attained a PhD in cancer genetics in 2003 as member of the Surgical Scientist Training Program. Her independent research program at the Lunenfeld-Tanenbaum Research Institute is focused on

developing functional genomics platforms to inform the development of much-needed effective therapies for sarcoma patients. Her clinical expertise is in the surgical management of soft tissue sarcoma. Dr. Gladdy is a member of the Sarcoma Program, which is the Centre of Excellence for Sarcoma Care in Canada and is affiliated with Princess Margaret Cancer Centre, Mount Sinai Hospital (MSH) and the Hospital for Sick Children. In addition to heading a translational research lab, she is the Director of the GI Sarcoma Clinical Research Group at MSH, which is dedicated to advancing clinical care through engaging in clinical trials and improving quality of life for sarcoma patients.



**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](#).



**Peter Hohenberger, MD, PhD, Professor of Surgical Oncology, Mannheim University Medical Center, University of Heidelberg**

Peter Hohenberger, MD, is Head of the Division of Surgical Oncology and Thoracic Surgery at the Medical Faculty Mannheim, University of Heidelberg. He is a boarded surgeon in visceral and vascular surgery as well as in thoracic surgery and surgical intensive care. He got his professional education at the University of Erlangen and, was trained in psychology and pathology. His surgical qualifications were received at the University of Heidelberg. He held senior positions at the Department of Surgery, University of Heidelberg as well as at Charité, Berlin. He is a surgical oncologist now specialized in the treatment of GIST and soft tissue tumors and is the Past-Chairman of the EORTC Soft Tissue and Bone Sarcoma

Group. He is a collaborator to EORTC organisation (GI, melanoma and STBSG) since the 1980s and has been member of the Protocol Review Committee as well as to the Board of EORTC for nine years each. His center has participated in major multinational randomized studies on the treatment of GIST and sarcoma. Trial activities also include the EU-funded EUROSARC and CONTICANET consortia. MITIGATE is a most recently started research network pursuing the treatment of imatinib-resistant GIST. He served on the faculty of the AACR/ASCO/FECS course on Methods of Clinical Cancer Research for seven years and is also member to the advisory board of SPAEN (Sarcoma Patients Euronet), Das LEBENSHAUS and was one of the initiators of SOS-DESMOID. In addition, the Mannheim center hosts the German Interdisciplinary Sarcoma Group (GISG). Profile [here](#).



**Antoine Italiano, MD, PhD, Medical Oncologist, Institut Bergonie**

Dr. Italiano is a professor of medicine at the University of Bordeaux, France, and the coordinating investigator of the DESMOPAZ study.



**O. Hans Iwenofu, MD, FCAP, Associate Professor, Divisions of Head & Neck Pathology and Soft Tissue & Bone Pathology, Department of Pathology, The Ohio State University**

Dr. Hans Iwenofu is an Associate Professor of Pathology and the Chief of Division of Soft Tissue and Bone Pathology, Department of Pathology, The Ohio State University Wexner Medical Center. He earned his MBBS at the University of Nigeria and did his residency in Anatomic and Clinical Pathology at the University of Oklahoma Health Sciences Center, OK. He subsequently completed oncologic surgical pathology and soft tissue and bone

pathology fellowships at Roswell Park Cancer Institute, Buffalo, NY and the University of Pennsylvania respectively. Dr. Iwenofu's research interest is focused on understanding the underpinnings of sarcomagenesis, biomarker discovery and personalized medicine as it applies to soft issue and bone tumors. In a collaborative seminal study titled: "miR-29 acts as a decoy in sarcomas to protect the tumor suppressor A20 mRNA from degradation by HuR" they discovered a unique regulatory circuitry of the decoy function of miR-29 on HuR in the regulation of A20 tumor suppressor activity. This finding uncovers a completely new role of the microRNA-29 besides its tumor suppressor function and provides insightful clues as to why NF-kB is constitutively elevated in different sarcoma subtypes thus maintaining cells in a perpetual primitive state. He has published many papers focused on clinical and translational aspects of soft tissue and bone bones and serves on the editorial boards of Human Pathology, Journal of Surgical Oncology and BMC Cancer. He is a recent recipient of the DTRF grant titled: "Quantitative Proteomic Analysis of Desmoid-Type Fibromatosis".



**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).

**Prakesh Katariya, PhD, Laser Medicine & Ayurveda, Laser Cure**



**Shivaani Kummar, MD, FACP, Professor of Medicine, Director of Phase I Clinical Research Program, Stanford University School of Medicine**

Upon completing her MBBS in New Delhi, India, Dr. Kummar moved to the United States to train in Internal Medicine at Emory University in Atlanta Georgia in 1992. She was selected to pursue her fellowship training at the National Institutes of Health in Medical Oncology and Hematology from 1995 to 1999. After spending four years as Attending Staff Physician at the VA Connecticut Healthcare System and Assistant Professor of Medicine at Yale Cancer Center, Yale University School of Medicine, New Haven CT, Dr. Kummar was offered a position at NIH in 2004 in the Developmental Therapeutics Section, National Cancer Institute. She developed a clinical research program in novel cancer therapeutics and in 2011 became the Head of the Early Clinical Trials Development program in the Office of the Director, Division of Cancer Treatment and Diagnosis at the NCI. Currently, She is at Stanford University and serves as the Director of the Translational Oncology and the Phase 1 programs. My research interests focus on developing novel therapies for cancer. I specialize in conducting pharmacokinetic and pharmacodynamic driven trials in molecularly characterized patient populations to evaluate novel molecular agents for further clinical investigation. One of her principal areas of interest is to develop new therapies for rare forms of cancer, an unmet medical need. Molecularly characterizing rare tumors, identifying potential therapeutic targets and novel agents in development, working with various laboratories to evaluate these agents in preclinical models of rare tumors and then designing and conducting proof of concept clinical trials are my areas of interest and expertise. Dr. Kummar was the founding member of NCI's Rare Tumor Initiative. She spear-headed the evaluation of a novel gamma-secretase inhibitor in the treatment of recurrent, progressive, symptomatic desmoids. Promising data from this trial was recently published in Journal of Clinical Oncology she was also the Principal Investigator of the largest, prospective trial of cediranib, an oral VEGFR inhibitor, in advanced alveolar soft part sarcoma, a rare cancer. High response rates and clinical benefit were demonstrated and follow up randomized trial is ongoing within my group.



**Robert Lefkowitz, MD, Attending Physician, 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](#).

**Herbert Loong, MBBS, PDipMDPath, MRCP, FHKCP, FHKAM (Medicine), Clinical Assistant Professor & Deputy Medical Director, Phase I Clinical Trials Centre, The Chinese University of Hong Kong**

Dr. Herbert Loong obtained his medical degree with a Distinction in Surgery from The University of Hong Kong in 2003. He subsequently completed his postgraduate internal medicine and medical oncology training in Queen Elizabeth Hospital and Prince of Wales Hospital in Hong Kong. He was admitted as a Member of the Royal College of Physicians (United Kingdom) in 2006 and a Fellow of the Hong Kong College of Physicians and Hong Kong Academy of Medicine in 2010. He has completed a Fellowship in Drug Development at Princess Margaret Cancer Centre in Toronto, Canada with special focuses on Experimental Therapeutics, Sarcoma Medical Oncology and Neuro-oncology. Dr. Loong joined The Chinese University of Hong Kong (CUHK) in March 2014 and is currently an Assistant Professor in the Department of Clinical Oncology, CUHK and the Deputy Medical Director of the Phase 1 Clinical Trials Centre, CUHK. He is also the Convenor of the Adult Sarcoma Multi-Disciplinary Tumour Board at Prince of Wales Hospital. His academic accolades include being the recipient of the Hong Kong Society for Neuro-oncology Traveling Scholarship in 2015 & 2016, an American Society of Clinical Oncology (ASCO) Merit Award in 2014, European Cancer Congress Fellowship Grant in 2013, European Society for Medical Oncology (ESMO) Preceptorship Award in 2012 & 2013, as well as an ESMO Translational Research Unit Visit Scholarship in 2012.



**Kelly Mercier, PhD, Adjunct associate, Duke University and Sr. Clinical Scientist at bioMerieux**

Dr. Kelly Mercier is a DTRF grant recipient, the DTRF Natural History Study and Patient Registry Principal Investigator, a lead clinical trial scientist at bioMerieux, and an adjunct associate professor at Duke University. She specializes in designing and implementing novel diagnostic tools for clinical care. She has received grants to understand the metabolic differences between desmoid tumors and normal adjacent tissue in the same patient with Dr. Ben Alman. Dr. Mercier is passionate about desmoid tumor research and is thrilled to be able to contribute her scientific knowledge to better understand and treat desmoid tumors.



**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.



**Scott Okuno, MD, Professor of Oncology, Mayo Clinic**

Dr. Okuno is a Professor of Oncology at Mayo Clinic in Rochester Minnesota where he is also the Sarcoma Tumor Chair in the Division of Medical Oncology. In addition, Dr. Okuno is the Medical Director of the Oncology Department for Mayo Clinic Health System for Northwest Wisconsin, and Chair of the Cancer Coordinating Committee for the entire Mayo Clinic Health System. Dr. Okuno’s work focuses on clinical trials for bone and soft tissue sarcoma. He is the Medical Officer for SARC and collaborates with sarcoma researchers in the Midwest Sarcoma Trials Partnership as well as the Sarcoma Working Group of the NRG. Dr. Okuno earned his MD degree at the University of Illinois at Chicago and completed his residency in internal medicine and hematology and oncology fellowship at Mayo Clinic Graduate School of Medicine in Rochester, Minnesota.



**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 as 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](#).



**Joanna Przybyl, PhD, Postdoctoral Research Fellow, Molecular Biology/Computational Biology, Stanford University**

Dr. Przybyl obtained a 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 soft tissue tumors including synovial sarcoma, Ewing sarcoma and endometrial stromal tumors. She also worked in Dr. James E. Darnell Jr. lab at the Rockefeller University (New York, USA) and Dr. Montse Sanchez-Cespedes lab at the Spanish National Cancer Research Center (CNIO) (Madrid, Spain). She is a member of AACR and ASCO.

Dr. Przybyl’s research interest involves the development of a comprehensive understanding of molecular mechanisms contributing to soft tissue sarcomas and improvement of the treatment outcomes for patients diagnosed with these tumors. Her academic training and research experience have provided me with expertise in multiple disciplines including molecular biology, biotechnology, and computational biology. Currently she works as a postdoctoral research fellow in Dr. Matt van de Rijn laboratory at Stanford University. My research is focused on the development of novel prognostic/predictive markers and discovery of novel therapeutic targets for selected histological types of sarcomas, including desmoid tumors, using next generation sequencing.



### **Denise Reinke, MS, NP, MBA, President & CEO, SARC**

Denise has been the President and CEO of SARC since 2002. Denise was a Nurse Practitioner for over 30 years, mostly caring for people with cancer in a variety of settings. She received her diploma in nursing from Milwaukee County School of Nursing and a Bachelor of Science in Nursing from Alverno College in Milwaukee, Wisconsin. She went on to get her Master of Science from University of Michigan where she graduated with honors. Denise also earned her Master of Business Administration from University of Michigan, Ross School of Business. She has also served as the administrative director of Southwest Oncology Group (SWOG) and is a member of ASCO (American Society of Clinical Oncology), the American Academy of Nurse Practitioners, and CTOS (Connective Tissue Oncology Society). Denise has coauthored numerous publications and been a frequent guest lecturer at major conferences across the country providing information and updates on sarcoma diagnosis and treatment.



### **Daniel Rushing, MD, Medical Oncology, Indiana University**

### **Wiesje Simons, Co-Founder, Contactgroup Desmoid**

Wiesje has been a desmoid patient since end 2016. She is from the Dutch patient platform Contactgroup desmoid, that was founded in January 2018.



### **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 (American 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.



**Katherine Thornton, MD, Clinical Director, Sarcoma and Bone Oncology, Dana-Farber Cancer Institute**

Dr. Thornton is a medical oncologist specializing in the care of patients with sarcoma and connective tissue cancers. She is currently the Clinical Director for the Center for Sarcoma and Bone Oncology at the Dana-Farber Cancer Institute, and Assistant Professor of Medicine at Harvard Medical School. Previously, she was the medical director for the Kimmel Cancer Center in Washington, D.C. and Assistant Professor of Medical Oncology at The Johns Hopkins Sidney Kimmel Comprehensive Cancer Center. Additionally, she worked for the U.S. Food and Drug Administration in the Office of Hematology and Oncology Products specializing in sarcoma drug approval. Dr. Thornton's research and clinical practice focuses on the development of new therapies for the treatment and prevention of sarcoma and other musculoskeletal tumors.



**Milea J.M. Timbergen, MD, PhD candidate, Surgical Oncology, Erasmus Medical Center Cancer Institute**

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.



**Keila Torres, MD, PhD, FACS, Assistant Professor, Department of Surgical Oncology, Division of Surgery, The University of Texas MD Anderson Cancer Center, Houston, TX**

Dr. Keila Torres (a graduate from Albert Einstein College of Medicine, of Yeshiva University in New York) decided to make a difference in the lives of those affected by cancer after losing a loved one to cancer. As a surgeon at MD Anderson Cancer Center, Dr. Torres specializes in providing surgical care to patients with sarcoma. As a scientist, she also leads a laboratory whose primary goal is to understand how sarcomas grow & how they can be treated more effectively. Her efforts have culminated in several scientific publications, as well as clinical articles & book chapters that have advanced the standard of care for sarcoma patients. Dr. Torres has received numerous awards including the 2011 SARC Career Development Award, the National Cancer Institute Mentored Clinical Scientist Research Career Development Award (2012-2016), & the 2015 American Society of Clinical Investigation Young Physician-Scientist Award. Dr. Torres' commitment to sarcoma patients does not stop at her professional calling. She serves on the Board of Directors of the Amschwand Sarcoma Cancer Foundation & actively supports the Sally M. Kingsbury Sarcoma Cancer Research Foundation. In fact, much of Keila's passion & charity work revolves around increasing sarcoma education & awareness. One of her most recent projects was a sarcoma awareness campaign using canine companions as advocates. She is the founder and CEO of Sniffing for the Cure, LLC, an independent publishing company founded with the primary intent to empower people with knowledge, hope and inspiration

by incorporating their pets into everyday activity. With sarcoma being the most common form of cancer in dogs, Sniffing for the Cure is committed to increase sarcoma awareness in both canines and humans and advance canine cancer research & related clinical trials that may also offer insight into treatment for human sarcoma patients.

## **Kim van der Zande, Co-Founder, Contactgroup Desmoid**

Kim is a patient advocate for Dutch desmoid patients and representative of Contactgroup Desmoid.



## **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, Medical 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.