

Draft Agenda

Desmoid tumors (DTs) in patients with Familial Adenomatous Polyposis (FAP): an interdisciplinary approach

Venue: Fondazione IRCCS Istituto Nazionale dei Tumori di Milano. Via Venezian 1, Milan, Italy.

Workshop Director: Marco Vitellaro, MD

Date: 22-23 May 2023

Day 1.

10:30 Introduction

Time	Session name/Topic	Speaker and Affiliation
10:30	Introduction	
10:30	Presentation	G. Apolone , Fondazione IRCCS Istituto Nazionale dei Tumori di Milano, Milan, Italy M. Genuardi , Fondazione Policlinico Universitario A. Gemelli IRCCS, Rome, Italy
10:45	Desmoids: which epidemiological data are available?	A. Trama , Fondazione IRCCS Istituto Nazionale dei Tumori di Milano, Milan, Italy
11:00	Desmoids in FAP, genotype-phenotype correlation	M.T. Ricci , Fondazione IRCCS Istituto Nazionale dei Tumori di Milano, Milan, Italy
11:15	Sporadic Desmoids: the state of the art	E. Palassini , Fondazione IRCCS Istituto Nazionale dei Tumori di Milano, Milan, Italy
11:30	Small Intestine transplant and DT	A.J. Butler , Addenbrooke's Hospital Cambridge, England, United Kingdom
11:50	Clinical research and clinical decision-making in rare cancers	P.G. Casali , Fondazione IRCCS Istituto Nazionale dei Tumori di Milano, Milan, Italy
12:10	Radiomics and <i>Artificial Intelligence</i> as a potential tool in DT Research	E. Montin , NYU Langone Medical Center, NY, USA
12:30	Questions & Answers	
13:00	Lunch	
14:00 17:15	The Research questions	
14:00	Risk prediction and prevention: clinical assessments	M. Vitellaro , Fondazione IRCCS Istituto Nazionale dei Tumori di Milano, Milan, Italy
14:15	Panel discussion	M.T. Ricci, M. Genuardi (geneticists) A. Trama (epidemiologist) A. Gronchi, C. Colombo, M. Fiore, E. Rausa (surgeons) E. Palassini, P.G. Casali (medical oncologists) P. Verderio, C.M. Ciniselli (methodologists)]
15:00	Questions & Answers	
15:30	Coffee break	
15:45	Diagnosis: Pathognomonic imaging features	A. Casale , Fondazione IRCCS Istituto Nazionale dei Tumori di Milano, Milan, Italy
16:00	Panel discussion	M.T. Ricci, M. Genuardi (geneticists) C. Morosi, A. Casale, E. Montin (radiologists) A. Gronchi, C. Colombo, M. Fiore, E. Rausa, M. Vitellaro (surgeons) E. Palassini, P.G. Casali (medical oncologists) P. Verderio, C.M. Ciniselli (methodologists)]
16:45	Questions & Answers	
17:30	END of day	



« This project has received funding from the European Union's Horizon 2020 research and innovation programme under the EJP RD COFUND-EJP N° 825575"»

Day 2. 23 May 2023

Time	Session name/Topic	Speaker and Affiliation
08:30 - 17:00	The Research questions	
08:30	Treatment strategy: the watchful waiting strategy in extra-abdominal desmoids	C. Colombo , Fondazione IRCCS Istituto Nazionale dei Tumori di Milano, Milan, Italy
08:45	Panel discussion	M.T. Ricci , (geneticist) C. Morosi, A. Casale (radiologists) A. Gronchi, M. Fiore, E. Rausa, M. Vitellaro (surgeons) E. Palassini, P. Casali, B. Kasper (medical oncologists) P. Verderio, C.M. Ciniselli (methodologists)
09:30	Questions & Answers	
10:00	Coffee break	
10:15	Surgical option: when and how	A. Gronchi , Fondazione IRCCS Istituto Nazionale dei Tumori di Milano, Milan, Italy
10:30	Locoregional treatments	C. Morosi , Fondazione IRCCS Istituto Nazionale dei Tumori di Milano, Milan, Italy
10:45	Panel discussion	M.T. Ricci , (geneticist) A. Casale (radiologist) C. Colombo, M. Fiore, E. Rausa, M. Vitellaro (surgeons) E. Palassini, P.G. Casali, B. Kasper (medical oncologists) P. Verderio, C.M. Ciniselli (methodologists)
11:30	Questions & Answers	
12:00	Quality of Life: needs and tools	S. Alfieri , Fondazione IRCCS Istituto Nazionale dei Tumori di Milano, Milan, Italy
12:15	Panel discussion	C. Borreani (psychologist) C. Colombo, A. Gronchi, M. Fiore, E. Rausa, M. Vitellaro (surgeons) E. Palassini , (medical oncologist) P. Verderio, C.M. Ciniselli (methodologists) APTEAD, Desmoid Foundation, Patientenplattform Sarcomen; Contactgroep Desmoid (patient advocates)
13:00	Questions & Answers	
13:30	Lunch	
14:30	Parallel interactive sessions (participants will be divided into 5 groups, one for every topic, supported by each topic's chairman discussing real-world cases)	
	Action plan:	
16:00	Ideas for research: a wrap-up How to follow on within GENTURIS & EURACAN	M. Vitellaro N. Hoogerbrugge, P. Casali
16:20	Panel discussion	S. Alfieri, G. Apolone, C. Borreani, A.J. Butler, A. Casale, P.G. Casali, C. M. Ciniselli, C. Colombo, M. Fiore, M. Genuardi, A. Gronchi, N. Hoogerbrugge, B. Kasper, E. Montin, C. Morosi, E. Palassini, E. Rausa, M. T. Ricci, A. Trama, W. van der Graaf, P. Verderio, M. Vitellaro patient advocacy: APTEAD, Desmoid Foundation Patientenplattform Sarcomen ; Contactgroep Desmoid
17:00	END of WORKSHOP	



Summary

The International Workshop “Desmoid tumors in patients with FAP: an interdisciplinary approach” aims to promote networking in the context of two ERNs, EURACAN and GENTURIS, thanks to their mutual focus on DT in FAP, a solid tumor which is both rare and associated to a genetic condition.

This workshop is addressed to physicians, researchers from ERN Full Members or Affiliated Partners from the junior to senior level. Particularly, this workshop is directed to participants who want to ameliorate their knowledge in FAP patient management and DTs treatment.

This networking activity will foster the exchange of experiences and allow participants to appreciate the effectiveness of different approaches, as a basis for future collaborations and joint research projects involving ERN full and affiliated members.

The aforementioned research questions will be shared and discussed among all participants. There will be interactive plenary presentations and question & answer sessions between speakers and participants.

Participants registration

A selection process coordinated with WP17 will be performed based on the applicant's background and motivation letters. Attendance from representatives of different ERN-Full Members or Affiliated Partner Institutions will be privileged.

23/1/2023 Opening registration; 31/3/2023 Closure registration

Speakers:

Sara **Alfieri** Clinical Psychology Unit, Fondazione IRCCS Istituto Nazionale dei Tumori di Milano, Milan, Italy
Giovanni **Apolone** Scientific Directorate, Fondazione IRCCS Istituto Nazionale dei Tumori di Milano, Milan, Italy
Claudia **Borreani** Clinical Psychology Unit, Fondazione IRCCS Istituto Nazionale dei Tumori di Milano, Milan, Italy
Andrew J. **Butler** Department of Surgery, Addenbrooke's Hospital Cambridge, England, United Kingdom
Alessandra **Casale** Department of Radiology, Fondazione IRCCS Istituto Nazionale dei Tumori di Milano, Milan, Italy
Paolo G. **Casali** Department of Medical Oncology Fondazione IRCCS Istituto Nazionale dei Tumori di Milano ; University of Milan, Milan, Italy
Chiara M. **Ciniselli** Bioinformatics and Biostatistics Unit, Fondazione IRCCS Istituto Nazionale dei Tumori di Milano, Milan, Italy
Chiara **Colombo** Department of Surgery, Fondazione IRCCS Istituto Nazionale dei Tumori di Milano, Milan, Italy
Marco **Fiore** Department of Surgery, Fondazione IRCCS Istituto Nazionale dei Tumori di Milano, Milan, Italy
Maurizio **Genuardi**, Fondazione Policlinico Universitario A. Gemelli IRCCS, Rome, Italy
Alessandro **Gronchi** Department of Surgery, Fondazione IRCCS Istituto Nazionale dei Tumori di Milano, Milan, Italy
Nicoline **Hoogerbrugge** Department of Human Genetics, Radboud Medical Center, Netherlands. ERN GENTURIS coordinator
Bernd **Kasper** Sarcoma Unit, Mannheim University Medical Center, Germany
Eros **Montin** Department of Radiology, NYU Langone Medical Center, NY, USA
Carlo **Morosi** Department of Radiology, Fondazione IRCCS Istituto Nazionale dei Tumori di Milano, Milan, Italy
Elena **Palassini** Department of Medical Oncology, Fondazione IRCCS Istituto Nazionale dei Tumori di Milano, Milan, Italy
Giulia **Personeni** Desmoid Foundation Italia
Emanuele **Rausa** Department of Surgery, Fondazione IRCCS Istituto Nazionale dei Tumori di Milano, Milan, Italy
Maria Teresa **Ricci** Unit of Hereditary Digestive Tract Tumors, Fondazione IRCCS Istituto Nazionale dei Tumori di Milano, Milan, Italy
Evelyne **Roets** Contactgroep Desmoid – Belgium
Silvio Leonardo **Rostagno** APTEAD
Annalisa **Trama** Evaluative Epidemiology Unit, Fondazione IRCCS Istituto Nazionale dei Tumori di Milano, Milan, Italy
Kim **Van der Zande** Patiëntenplatform Sarcomen - Netherlands
Paolo **Verderio** Bioinformatics and Biostatistics Unit, Fondazione IRCCS Istituto Nazionale dei Tumori di Milano, Milan, Italy
Marco **Vitellaro** Department of Surgery, Fondazione IRCCS Istituto Nazionale dei Tumori di Milano, Milan, Italy

Patient Advocacy

Associazione Pazienti Tumori Ereditari Apparato Digerente – APTEAD, Italy
Associazione Italiana Tumore Desmoide ONLUS - Desmoid Foundation, Italy
Contactgroep Desmoid - Belgium
Patiëntenplatform Sarcomen - Netherlands



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