

Members of the Rare Cancer Advocates Network

ERN PaedCan (paediatric cancers) - ePAG Advocates			
All paediatric cancers	Anita Kienesberger	Chair of CCI Europe Committee	Childhood Cancer International – Europe (CCI-E)
	Luisa Basset	Vice-Chair of CCI Europe Committee & representative at the international level of the Federación Española de Padres de Niños con Cáncer	Childhood Cancer International – Europe (CCI-E) & Federación Española de Padres de Niños con Cáncer, Spain
	Anne Goeres	CCI Europe Committee member	Childhood Cancer International – Europe (CCI-E)
	Delphine Heenen	CCI Europe Committee member & Co-founder and CEO of KickCancer	Childhood Cancer International – Europe (CCI-E) & KickCancer, Belgium
	Lejla Kamerić	CCI Europe Committee member & Advisor to the Association heart for kids with cancer in FBiH	Childhood Cancer International – Europe (CCI-E) & Heart for kids with cancer in Federation of Bosnia and Herzegovina (FBiH)
	Lidiya Vitanova	Founder and Chair	Together Fighting Sarcoma, Bulgaria
ERN EURACAN (rare adult solid cancers) - ePAG Advocates			
G1 Connective tissue (sarcoma)	Markus Wartenberg	Chair	Sarcoma Patient Advocacy Global Network (SPAGN)
	Arthur Koroglu	President	Association TGCT Support France
G2 Female genital organs and placenta	Eva-Maria Strömsholm	ENGAGe's nominated representative & founder/Chair of Gynecological cancer patients association, Finland	European Network of Gynaecological Cancer Advocacy Groups (ENGAGe) & Gynecological cancer patients association in Finland
G3 Male genital organs and urinary tract	Pending Confirmation		
G4 NET – Neuroendocrine tumours	Teodora Kolarova	Executive Director	International Neuroendocrine Cancer Alliance (INCA)
	Mark McDonnell	INCA former President & Chair of NET Patient Network Ireland	INCA & NET Patient Network – Ireland
G5 Digestive tract	Laura Urena	Medical and Scientific Project Manager	Digestive Cancers Europe (DiCE)
G6 Endocrine tumours	Judith Taylor	Board member / Secretary	Thyroid Cancer Alliance (TCA)

G7 Head & Neck	Roberto Persio	Member of the National Council	Associazione Italiana Laryngectomizzati (AILAR)
	Emma Kinloch	Founder and Trustee	Salivary Gland Cancer UK
G8 Thoracic Tumours	Laura Abate Daga	Founder and Chair	Associazione Tumori Toracici Rari Onlus (TUTOR)
G9 Skin and eye melanomas	Petya Zyumbileva	Member	Melanom Info Deutschland
	Jo Gumbs	Founder and CEO	OcuMel UK
G10 Brain and spinal cord	Kathy Oliver	Chair and co-Director	International Brain Tumour Alliance (IBTA)
Transversal	Birgitta Huibregtsen	Volunteer	Dutch Rare Cancer Patients Platform
ERN EuroBloodNet (rare haematological diseases) - ePAG Advocates for rare adult haematological malignancies			
Myeloid	Jan Geissler	Co-founder, Member of the Steering Committee	CML Advocates Network & Leukemia Patient Advocates Foundation (LePAF)
	Jacqueline Dubow	Chair of MDS Alliance	MDS Alliance (international)
Lymphoid	Ananda Plate	Former Vice-President and former CEO	Myeloma Patients Europe (MPE)
	Natacha Bolanos	Head, Membership & Alliances	Lymphoma Coalition
	Pierre Aumont	ELLyE Board member /international affairs & Vice-Chair of CLLAN	Ensemble Leucémie, Lymphomes Espoir (ELLyE) & Chronic Lymphocytic Leukemia Advocates Network (CLLAN)
ERN GENTURIS (Genetic Tumour Risk Syndromes) - ePAG Advocates			
Neurofibromatosis	Claas Röhl	Chair NF Kinder and NF Patients United	NF Kinder – Verein zur Förderung der Neurofibromatoseforschung Österreich & NF Patients United (Europe)
	João de Sousa e Silva	Member	NF Patients United (Europe)
Lynch syndrome and polyposis	Nicola Reents	Board member/ Secretary	Familienhilfe Darmkrebs e.V. / Semi-Colon (German patient association for Lynch and Polyposis)
Hereditary breast and ovarian cancers	Tamara Hussong Milagre	President	Evita (Portuguese Association for hereditary cancers)
	Darja Molan	Projects manager	Europa Donna Slovenia
	Salvo Testa	President	MUTAGENS

Other rare – predominantly malignant- genitouris	Claudio Ales	President	Associazione Italiana per la lotta alle PHTS
ENDO-ERN (rare endocrine conditions) - ePAG Advocates for rare endocrine tumours			
Genetic endocrine tumour syndromes	Petra Brüggmann	President of the European MEN Alliance & co-leader and Board member of Netzwerk Hypophysen - und Nebennierenerkrankungen e.V	European MEN (Multiple Endocrine Neoplasia) Alliance (EMENA) & Netzwerk Hypophysen - und Nebennierenerkrankungen e.V (Network Pituitary and Adrenal Diseases e.V)
Thyroid	Beate Bartés	President	Vivre sans Thyroïde
EURORDIS Board member			
Rare Cancers	Dorica Dan	EURORDIS Vice-President & President of Romanian association for rare cancers & Romanian National Alliance for Rare Diseases	EURORDIS & Romanian Association for Rare Cancers & National Alliance for Rare Diseases