

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 & Director of Fondatioun Kriibskrank Kanner	Childhood Cancer International – Europe (CCI-E) & Fondatioun Kriibskrank Kanner, Luxemburg
	Delphine Heenen	CCI Europe Committee member & Co-founder / Board member 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)
ERN EURACAN (rare adult solid cancers) - ePAG Advocates			
G1 Sarcoma	Markus Wartenberg	Chair	Sarcoma Patient Advocacy Global Network (SPAGN)
G2 Rare female genital organs	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 Rare male genital organs	Pending confirmation		
G4 NET - Neuroendocrine Tumours	Teodora Kolarova	Executive Director	International Neuroendocrine Cancer Alliance (INCA)
	Mark McDonnell	INCA President & Chair of NET Patient Network – Ireland	INCA & NET Patient Network – Ireland
G5 Rare cancers of the digestive tract	Haidar Akl	Medical and Scientific Project Manager	Digestive Cancers Europe (DiCE)
G6 Rare endocrine tumours	Judith Taylor	Board member / Secretary	Thyroid Cancer Alliance (TCA)
G7 Rare Head & Neck cancers	Roberto Persio	Member of the National Council	Associazione Italiana Laryngectomizzati (AILAR)
	Emma Kinloch	Founder and Trustee	Salivary Gland Cancer UK
G8 Rare thoracic tumours	Laura Abate Daga	Founder and Chair	Associazione Tumori Toracici Rari Onlus (TUTOR)

G9 Rare skin/eye melanomas	Petya Zyumbileva	Member	Melanom Info Deutschland
G10 Rare brain tumours	Kathy Oliver	Chair and Co-Director	International Brain Tumour Alliance (IBTA)
Transversal/ EURACAN registry	Adela Maghear	Senior EU Affairs Officer	European Cancer Patient Coalition (ECPC)
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)
	Sophie Wintrich	Chief Executive Officer MDS UK & Steering Committee member of MDS Alliance	MDS UK Patient Support Group & MDS Alliance (international)
	Jacqueline Dubow	Steering Committee member of MDS Alliance	MDS Alliance (international)
Lymphoid	Ananda Plate	Board member (former CEO)	Myeloma Patients Europe (MPE)
	Natacha Bolanos	Head, Membership & Alliances	Lymphoma Coalition
	Pierre Aumont	ELLYE Board member/international affairs & CLLAN Vice-Chair	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 & 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 of carriers of genetic mutations related to Hereditary Cancer)
	Darja Molan	Team member	Europa Donna Slovenia
	Salvo Testa	President	MUTAGENS
Other rare – predominantly malignant- genturis	Claudio Ales	President	Associazione Italiana per la lotta alle PHTS

Endo-ERN / endocrine tumours - ePAG Advocates

Genetic Endocrine Tumour Syndromes	Petra Bruegmann	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 - President of both the Romanian Association for Rare Cancers and the Romanian National Alliance for Rare Diseases			
Rare Cancers	Dorica Dan	EURORDIS Board member & President of Romanian association for rare cancers and Romanian National Alliance for Rare Diseases	EURORDIS & Romanian Association for Rare Cancers & Romanian National Alliance for Rare Diseases