



Including rare cancers in the Europe's Beating Cancer Plan

Ariane Weinman - EURORDIS

CNA-CEF Joint Meeting

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Background overview

Main Figures: Rare Diseases & Rare Cancers

+6000

Distinct rare diseases

Prevalence RD: Not more than 5 affected persons per 10 000

Estimated **30 million people** living with a Rare Disease in Europe

+200

Distinct rare cancers

Incidence RC: less than 6 individuals per 100,000 a year

Estimated **5.1 million people** living with a Rare Cancer in Europe

Shared Challenges:

Difficult access to timely, accurate diagnosis (long delay), as well as specialised care and adequate treatment;
Less research, few registries.

Loneliness and isolation amongst patients and carers.

Sources: RARECARE & RARECARENet EU co-funded projects



Transversal activities benefiting rare cancers

The EURORDIS' advocacy work for rare conditions has benefited rare cancers across different areas:

- **Orphan Drugs:** Since 2000, contributing to the assessment of products seeking orphan designation at EMA COMP. OMPs for rare cancers account for about 1/3 of marketed OMPs
- **Clinical trials:** advocacy work for adaptive CTs for small populations + access to CTs + involving patients in the initial design of CTs
- **Innovative therapies:** contributing to fostering access to innovation
- **HTA:** strong advocacy work for enabling a fair access to marketed therapies for RDs wherever the patient lives
- **Definition of centres of expertise for RDs:** multidisciplinary care, involvement of patients
- **Access to cross-border care, support to patient-centred ERNs, establishment of ePAGs**
- **Promoting national plans for rare diseases:** accreditation of CEs, implementation of national networks **can serve as a model for fostering the inclusion of rare cancers into national cancer control plans**
- **Promoting involvement of patients in all decisions concerning his/her health = patient as expert for his/her rare disease**
- **International Rare Disease Day**

Specific activities for rare cancers

- **European Commission Expert Group on Cancer Control (2014-2017):**
Two EURORDIS representatives, **Jan Geissler, Kathy Oliver**
- **Mapping of the similarities and differences between rare cancers and rare diseases (2015-2016):** first document of this kind
- **EU Joint Action for Rare Cancers (2016-2019):** contributed to most of the work packages and fostered patient engagement; consolidated a trustful relationship with a vast majority of stakeholders in the field of rare cancers
 ➡ **Publication of the RARE CANCER AGENDA 2030**
- **Sit on different committees for or related to rare cancers:** RCE, ECO PAC, EHA WG with POs, WECAN
- **Active in the 4 ERNs relevant to rare cancers – PaedCan, EURACAN, EuroBloodNet, GENTURIS**
EURORDIS teams up with 30 leaders of International/ European/ national patient federations for specific group of rare cancers as ePAGs
 - EURORDIS is an official associate member of the **EURACAN Consortium**
 - EURORDIS is an official partner of the **EURACAN registry**
 - EURORDIS is an official partner of the **EuroBloodNet registry**

EU Joint Action on Rare Cancers (JARC)

- Coordinator: Fondazione IRCCS, Istituto Nazionale dei Tumori, Milan
- Altogether 60 partners, including the three main pan-European umbrella patient organisations: ECPC, CCI-E and EURORDIS
- Three-year project: 2016-2019
- Produced the [Rare Cancer Agenda 2030](#)

Sets out 10 main recommendations to improve rare cancer research and care through effective policies and support to ERNs



Europe's Beating Cancer Plan

Europe's Beating Cancer Plan

- **4 February 2020:** Event at the European Commission to launch the discussion on a Europe's Beating Cancer Plan
 - ➔ Cancer is one of the main public health priorities of the **European Commission 2019-2024** (latest EU action on cancer dated back to 30 years ago)
- **4 February - 21 May 2020:** Public consultation addressed to all stakeholders
 - ➔ EURORDIS, in consultation with the 30 ePAGs and its 70 members, emphasised the needs of rare cancers and advocated for the implementation of the Rare Cancer Agenda 2030
 - ➔ Each PO and other stakeholders (RCE, SIOPe, ECO etc..) actively contributed

EUROPE'S BEATING CANCER PLAN
LET'S STRIVE FOR MORE

#EUCancerPlan

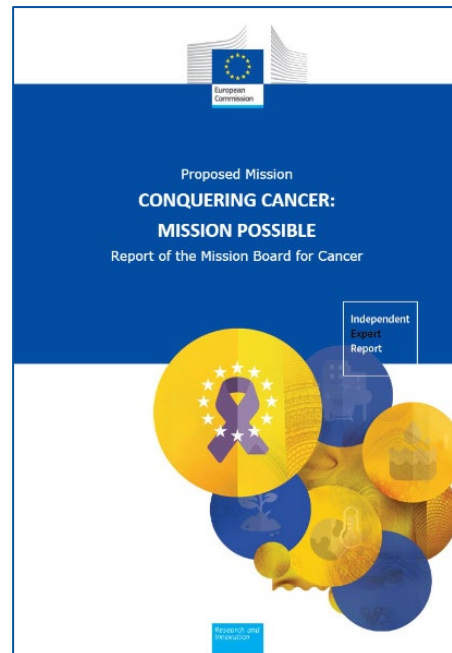


Mission on Cancer

- **Mission:** Within Horizon Europe 2021-2027, novel initiative aimed at maximizing the EU support to research and innovation.
- **Five specific missions including one on Cancer**
 - **Cancer Mission Board:** 15 independent top-level experts
1st Meeting: Sept 2019
Patient rep: Bettina Ryll
 - **Cancer Mission Assembly:** 26 independent top-level experts
Support citizens engagement
Patient reps: Jan Geissler, Patricia Blanc

Advise the EC on which areas to focus on and develop

Dialogue as well with the EU Member States and the European Parliament (BECA)



Proposed Recommendations
September 2020



Establishment of the Special Committee on Beating Cancer - BECA

- **June 2020: BECA: Special Committee on Beating Cancer at the European Parliament** (end of mandate December 2021)
- **Objective:** Establish a set of concrete recommendations for the member states and the EU institutions in order to strengthen resilience against cancer
- **Members:** 33 MEP members + substitutes
- **13 Hearings:** Covered key issues from research to access to care, and to cancer survivorship. MEPs listened to a wide range of stakeholders

BECA Website: click [here](#)



BECA Members

First	Last Name	Status	Party	Additional information
Bartosz	ARŁUKOWICZ	Chair	EPP	
Joanna	KOPCIŃSKA	Vice-Chair and BECA Coordinator	ECR	Shadow Rapporteur EU4Health
Sara	CERDAS	Vice-Chair	S&D	Shadow Rapporteur EU4Health
Nathalie	COLIN-OESTERLÉ	Vice-Chair	EPP	Rapporteur "Shortage of medicines" (contacted by EURORDIS)
Ivars	IJABS	Vice-Chair	Renew Europe	
Véronique	TRILLET-LENOIR	Rapporteur	Renew Europe	Shadow Rapporteur EU4Health_Received statement on ERN plus contacted by French ERN Coordinators
Cyndy	FRANSSEN	BECA Coordinator	EPP	
Alessandra	MORETTI	BECA Coordinator	S&D	
Nicolae	STEFANUTA	BECA Coordinator	Renew Europe	
Michèle	RIVASI	BECA Coordinator	Greens/EFA	Shadow Rapporteur EU4Health_Contacted by French ERN Coordinators
Kateřina	KONEČNÁ	Member	The Left	Shadow Rapporteur EU4Health_Received statement on ERN
Peter	LIESE	Shadow Rapporteur	EPP	EU4Health_Received statement on ERN
Tomislav	SOKOL	Substitute	EPP	Supportive of ERNs/ Cross-border healthcare
Tiemo	Wölken	Substitute	S&D	EU4Health_Received statement on ERN

Europe's Beating Cancer Plan

- **3 February 2021: Communication from the European Commission to the European Parliament and the Council on a Europe's Beating Cancer Plan:**
 - ➔ **Ambitious plan: 4 pillars** (Prevention; Early detection; Diagnosis & Treatment; Quality of Life); **10 flagship initiatives, 32 actions, 4 Billion €**
 - ➔ **BUT rare adult cancers are not mentioned as such (except with regard to ERNs).** This group of diseases could benefit from envisaged actions in the field of research, prevention (hereditary cancers), access to care and innovative products, however the particular attention they deserve due to their rarity and specificity is not emphasised
 - ➔ On the other hand, **paediatric cancers benefit from some specific, targeted actions (also in the Cancer Mission).** The messages from the paediatric cancer community are clear, thanks to a longstanding cooperation and coordinated actions amongst the various members of this community

Action towards the BECA Committee – European Parliament

- **21 June 2021:** Publication of the draft BECA opinion report on the **Europe's Beating Cancer Plan** (motion for a resolution) – Rapporteur Dr Véronique Trillet-Lenoir
- **Summer 2021:** the 30 ePAG advocates and EURORDIS worked together to submit proposed amendments:

Need two flagship initiatives to address the challenges faced by the rare cancer community:

- **A flagship initiative for paediatric cancers (including adolescents and young adults)**
- **A flagship initiative for rare adult cancers**

Need for a specific support to existing ERNs relevant to rare cancers and ensure their long-term sustainability

- **14 September – 6 December 2021:** Discussions on amendments until final vote (06/12/21)

Inputs from EURORDIS & 30 ePAGs RC

- **National Cancer Control Plans (NCCPs):** each EU MS should include a section on rare cancers in adults and on paediatric cancers with a view to implement an effective referral system and optimal care pathways for patients, and to foster research and improve patients' outcomes. **NCCPs & NRDPs should be linked.**
- **Need for:**
 - raising awareness of rare cancers
 - prevention programmes where applicable, for instance for hereditary cancers and rare diseases giving rise to (rare) tumours
 - mapping out the expertise on rare cancers and implementing appropriate referrals from the general practitioner up to highly specialised care units
 - access to cross-border healthcare and sharing of expertise **through European Reference Networks for rare cancers**
 - fostering patient and clinical registries and research on rare cancers
 - fostering clinical guidelines on rare cancers
 - guaranteeing a fair access to treatments to all EU citizens
 - fostering medical education on rare cancers
 - Rehabilitation and psychological programmes adapted to the needs of rare cancer patients and survivors, support to integration at school, university, at work...
 - a true recognition of the key role played by patient organisations

List of ePAG Advocates in ERNs for Rare Cancers

ePAG ADVOCATES in ERNs RARE CANCERS

EURACAN – rare solid tumours in adults

Across clinical domains - Adela Maghear– European Cancer Patient Coalition (ECPC)

Sarcoma	Estelle Lecointe & Markus Wartenberg; Sarcoma Patients EuroNet (SPAEN)
Female genital organs	Eva-Maria Strömsholm, European Network of Gynaecological Cancer Advocacy Groups (ENGAGe)
male genital organs	Pending confirmation
NET-Neuroendocrine tumours	Teodora Kolarova, International Neuroendocrine Cancer Alliance (INCA) Catherine Bouvier, NET patient Foundation UK & INCA
Digestive tract	Vassiliki Fotaki, Digestive Cancers Europe
Endocrine tumours	Judith Taylor, Thyroid Cancer Alliance
Rare Head & Neck cancers	Emma Kinloch, UK Salivary Gland Cancer Roberto Persio, Associazione Italiana Laryngectomizzati (AILAR)
Rare thoracic tumours	Laura Abate Daga, T.U.T.O.R
Rare Skin/Eye melanoma	Iain Galloway, MPNE Ocular/Rare Petya Zyumbileva, Melanom Info Deutschland
Rare Brain and Spine Tumours	Kathy Oliver, International Brain Tumour Alliance (IBTA)

ePAG ADVOCATES in ERNs RARE CANCERS

PaedCan – Paediatric cancers

Childhood Cancer International – Europe	Anita Kienesberger; Luisa Basset; Anne Goeres; Lejla Kamerić
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EuroBloodNet – Rare haematological diseases including haematological malignancies

Myeloid malignancies	Jan Geissler, Leukemia Patient Advocates Foundation Sophie Wintrich, MDS UK Patient Support Group and MDS Alliance
Lymphoid malignancies	Ananda Plate, Myeloma Patients Europe Pierre Aumont, Chronic Lymphocytic Leukaemia Advocates Network (CLLAN) & Ensemble Leucémie Lymphomes Espoir (ELLyE)
RBC (Red blood cells)	Loris Brunetta, Thalassaemia International Federation
Bleeding	European Haemophilia Consortium
BMF (bone marrow failure syndromes)	Maria Piggin, PNH Support UK
HHIron	Dag Erling Stakvik, European Federation of Associations of Patients with Haemochromatosis (EFAPH)

ePAG ADVOCATES in ERNs RARE CANCERS

GENTURIS – Genetic Tumour Risk Syndromes

Neurofibromatosis	Claas Röhl, NF Kinder – Verein zur Förderung der Neurofibromatoseforschung Österreich & NF Patients United João de Sousa e Silva, NF Patients United
Lynch syndrome and polyposis	Nicola Reents, Familienhilfe Darmkrebs e.V. / Semi-Colon (German patient association for Lynch and Polyposis)
Hereditary breast and ovarian cancer	Tamara Hussong Milagre, Evita (Portuguese Association of carriers of genetic mutations related to Hereditary Cancer) Tanja Spanic, Europa Donna Slovenia & Europa Donna European Coalition Salvo Testa, Mutagens
Other rare – predominantly malignant- genturis	Claudio Ales, Associazione Italiana per la lotta alle PHTS Rita Magenheim, German Li Fraumeni Association



**THANK YOU FOR
YOUR ATTENTION**

**Please send your questions to
ariane.weinman@eurordis.org**

