RARE CANCERS EUROPE

Joining forces for action

RCE-ESMO-ESO Training Course for Rare Cancer Patient Advocates 2022

Europe's Beating Cancer Plan and its implementation roadmap: what will this change for rare cancers?

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European Patient Organisation for Rare Diseases

Rare Cancers Policy
Who are the actors involved?

- Member States / National Health Authorities / National medical societies
- The European Commission
- The European Parliament
- The healthcare professionals; the European Reference Networks (PaedCan, EURACAN, EuroBloodNet and GENTURIS)
- The researchers ; European/ Int'l medical and research societies
- Industry
- **Rare Cancers Europe**
- The patient organisations/ patient advocates/ **ePAG advocates**

Who are the ePAGs & ePAG Advocates?

- 2016: in parallel to the establishment of 24 ERNs, EURORDIS has established 24 European Patient Advocacy Groups (ePAGs) corresponding each to one specific ERN
- European Patient Advocacy Groups are represented by ePAG Advocates (who are all affiliated with a patient organisation)
- ePAG Advocates are nominated by their peers based on their advocacy track records to represent their patient community in a ERN
- ePAG Advocates are the voice of patients in the ERNs and are involved in the Board, clinical domains and transversal task forces
- ePAG Advocates are coordinated by EURORDIS

Who are the Rare Cancer ePAG Advocates?

Very active within ERNs, and amongst themselves across ERNs, they represent International, European and national patient organisations

ERN EURACAN (Rare solid tumours in adults): **15 ePAGs**

ERN PaedCan (Paediatric cancers): **5 ePAGs** (Childhood Cancer International – Europe)

ERN EuroBloodNet (rare haematological diseases & cancers): **9 ePAGs including 5 in oncology**

ER GENTURIS (Genetic Tumour Risk Syndromes): **7 ePAGs**

ERN ENDO (Rare endocrine diseases): **2 ePAGs in the clinical domain rare endocrine tumours**

What's in for rare cancers in the Europe's Beating Cancer Plan?

- Dedicated flagship initiative for paediatric cancer:
  - "Helping children with cancer initiative" *(improve access to early detection, diagnosis, treatments and care, follow up care)*
  - Establish a youth cancer survivors EU network
  - Increase understanding of paediatric cancers

- Rare cancers (in adults) are hardly mentioned in the Plan:
  - No figures about rare cancers *(despite publications from EU projects RARECARE, RARECARENet, EU Joint Action on Rare Cancers).*
  - Rare Cancers could benefit from envisaged actions in the field of research, early detection (e.g. hereditary cancers), access to care and innovative products, follow up treatments, **however the particular attention they deserve due to their rarity and specificity is not emphasised**

Milestones

Sept. 2019
Rare Cancer Agenda 2030

4 Feb. 2020
Public Consult. EBCP

18 June 2020
EP BECA set up (till Dec 21)

3 Feb. 2021
EBCP: No mention of RAC but Paed. cancers included

Feb-Dec 2021
Advocacy RCE /ERNs/ ePAGs

28 Sept 2021
RCE's Call to Action

Sept 2021
Cancer Mission Implementation Plan

9 Dec. 2021
Adoption BECA Report
Specific section on RAC

- **Letters to S. Kyriakides, V. Trillet-Lenoir co-signed RCE/ ERN Coordinators**
- **Preparation of the RCE Call to Action**
- **All ePAGs (including EURORDIS, ECPC, CCI-E): Suggested amendments to RCE Call to Action and to the draft BECA report**

- **Recommendations from the EU Joint Action on Rare Cancers (JARC, 2016-2019) to decision-makers on improving Rare Cancer's research and care/support to ERNs**
- **Build on previous EU projects (RARECARE, RARECARENet)**
- **Altogether 60 partners including ECPC, CCI-E, EURORDIS and thus ePAGs (see chapter 10)**

Successful recent achievement

The European Parliament’s Special Committee on Beating Cancer (BECA) has integrated a specific section on rare adult cancers – which is lacking in the Europe’s Beating Cancer Plan – in their final report adopted on 9 December 2021 “Strengthening Europe in the fight against cancer – towards a comprehensive and coordinated strategy.”

Moreover, the BECA report includes additional recommendations for paediatric cancers, complementing those in the Europe’s Beating Cancer Plan.

Final BECA Report: VI. Challenges of rare adult cancers & additional recommendations throughout the report

- Rare adult cancers acknowledged as a **public health challenge**
- Supports the introduction of a **dedicated flagship initiative on rare adult cancers** within the Plan […], make the **best use of the recommendations set out in the Rare Cancer Agenda 2030, ensure rare adult cancers are included in all initiatives across the four pillars of the Plan**
- Calls for **dedicated research funding** in the Cancer Mission/ Horizon Europe
- Improves access to **timely diagnosis**, including easier access to molecular testing
- Increases awareness of rare adult cancers amongst **primary and secondary healthcare professionals** for timely referral to multidisciplinary expert centres
- Provides long term and reinforced **support to ERNs** dedicated to rare cancers
- Calls for **improving access to clinical trials and compassionate use programmes within one country as well as abroad**

Final BECA Report: VI. Challenges of rare adult cancers & additional recommendations throughout the report

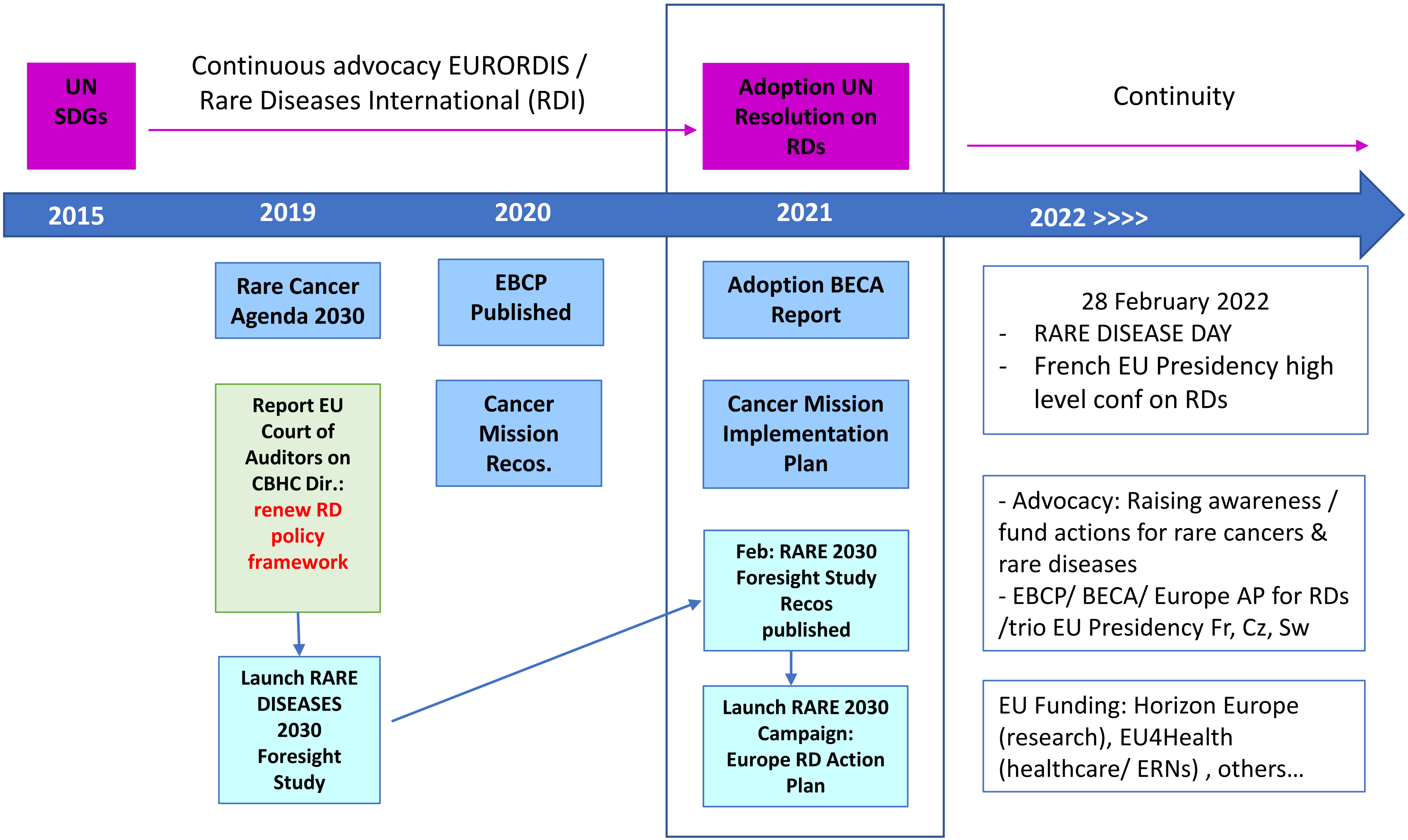
- Calls on the European Commission to **support a regulatory framework which strengthens incentives for rare cancer treatment** to effectively address existing shortcomings
- Encourages **novel regulatory approaches to access new innovative therapies** under safe monitoring, while facilitating collection of real world data
- Supports dedicated **training programmes** for healthcare professionals and for patients, carers, patient organisations
- Acknowledges the specificities of rare adult cancers **in programmes dedicated to improving the quality of life of cancer patients, survivors and carers**; recommends that rare adult cancer patients also be provided with a **survivorship care plan**
- Encourages Member States to integrate **dedicated measures for rare adult cancers (as well as for paediatric cancers) in their national cancer plan and establish national networks for groups of rare adult cancers (mirroring ERNs' clinical domains)**

Next steps

Translate the recommendations for rare adult cancers and paediatric cancers into concrete actions, including the development and reinforcement of European Reference Networks

The Rare Cancers community is mobilised at both national and European levels to work towards the implementation of the adopted recommendations

Actions at European and International level



UN SDGs

Continuous advocacy EURORDIS / Rare Diseases International (RDI)

Adoption UN Resolution on RDs

Continuity

2015

2019

2020

2021

2022 >>>>

Rare Cancer Agenda 2030

Report EU Court of Auditors on CBHC Dir.: renew RD policy framework

Launch RARE DISEASES 2030 Foresight Study

EBCP Published

Cancer Mission Recos.

Adoption BECA Report

Cancer Mission Implementation Plan

Feb: RARE 2030 Foresight Study Recos published

Launch RARE 2030 Campaign: Europe RD Action Plan

28 February 2022

- RARE DISEASE DAY
- French EU Presidency high level conf on RDs

- Advocacy: Raising awareness / fund actions for rare cancers & rare diseases
- EBCP/ BECA/ Europe AP for RDs /trio EU Presidency Fr, Cz, Sw

EU Funding: Horizon Europe (research), EU4Health (healthcare/ ERNs) , others…

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Thank you!

Annexe 1: Links to reference texts

- UN Resolution on Addressing the Challenges of Persons Living with a Rare Disease and their Families, 16 December 2021
- UN 17 Sustainable Development Goals, 2015
- Final opinion report of the European Parliament’s Special Committee on Beating Cancer (BECA), 9 December 2021
- Cancer Mission – Implementation Plan, September 2021
- Europe’s Beating Cancer Plan, 3 February 2021
- Europe’s Beating Cancer Plan – List of Actions, 3 February 2021
- RARE CANCER AGENDA 2030 - Ten Recommendations from the EU Joint Action on Rare Cancers, September 2019
- Recommendations from the Rare 2030 Foresight Study: The Future of Rare Diseases Starts Today, February 2021

Annexe 2: List of ePAG Advocates

ERN EURACAN – rare solid tumours in adults	
Sarcoma	Markus Wartenberg and Estelle Lecointe, Sarcoma Patients EuroNet (SPAEN)
Female genital organs	Eva-Maria Strömsholm, European Network of Gynaecological Cancer Advocacy Groups (ENGAGe) & Gynecological cancer patients association in Finland
male genital organs	Pending confirmation
NET-Neuroendocrine tumours	Teodora Kolarova, International Neuroendocrine Cancer Alliance (INCA) Catherine Bouvier, NET patient Foundation UK & INCA
Digestive tract	Marianna Vitaloni and Giulia Barenghi, 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, Associazione Tumori Toracici Rari Onlus (Tu.To.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)
Transversal	Adela Maghear, European Cancer Patient Coalition (ECPC)

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ERN PaedCan – Paediatric cancers	
Childhood Cancer International – Europe	Anita Kienesberger; Luisa Basset; Anne Goeres; Lejla Kamerić

ERN 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, Ensemble Leucémie, Lymphomes Espoir (ELLyE) & Chronic Lymphocytic Leukaemia Advocates Network (CLLAN) Natacha Bolanos, Lymphoma Coalition
RBC (Red blood cells)	Loris Brunetta, Thalassaemia International Federation
Bleeding	Baiba Ziemele, 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)

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ERN 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 European Coalition, and Europa Donna Slovenia Salvo Testa, MUTAGENS
Other rare – predominantly malignant- genturis	Claudio Ales, Associazione Italiana per la lotta alle PHTS

ERN ENDO –Sub clinical rare endocrine tumours Genetic Tumour Risk Syndromes	
Rare endocrine tumours	Beate Bartes, Vivre sans thyroide Petra Brügmann, European MEN (Multiple Endocrine Neoplasia) Alliance (EMENA) & Netzwerk Hypophysen - und Nebennierenerkrankungen e.V (Network Pituitary and Adrenal Diseases e.V)