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

Ariane Weinman
EURORDIS
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**
- 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)

- 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

**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** Advocacy RCE/ERNs/ePAGs
- **Feb-Dec 2021** RCE’s Call to Action
- **28 Sept 2021** Cancer Mission Implementation Plan
- **Sept 2021** BECA Report
- **28 Sept 2021** Specific section on RAC
- **9 Dec. 2021** Adoption BECA Report

**Stages:**

- **4 Feb. 2020**
  - Public Consultation EBCP

- **18 June 2020**
  - EBCP: No mention of RAC but Paed. cancers included

- **3 Feb. 2021**
  - Advocacy RCE/ERNs/ePAGs

- **Feb-Dec 2021**
  - RCE’s Call to Action

- **28 Sept 2021**
  - Cancer Mission Implementation Plan

- **9 Dec. 2021**
  - Adoption BECA Report
  - Specific section on RAC

**Recommendations:**

- 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.
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
- 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**

- **2015**
  - Rare Cancer Agenda 2030
  - Report EU Court of Auditors on CBHC Dir.: renew RD policy framework

- **2019**
  - EBCP Published

- **2020**
  - Cancer Mission Recos.

- **2021**
  - Adoption BECA Report
  - Cancer Mission Implementation Plan
  - Feb: RARE 2030 Foresight Study Recos published
  - Launch RARE 2030 Campaign: Europe RD Action Plan

- **2022 >>>>**
  - 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...

**Continuous advocacy EURORDIS / Rare Diseases International (RDI)**

**Adoption UN Resolution on RDs**

**Launch RARE DISEASES 2030 Foresight Study**
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

<table>
<thead>
<tr>
<th>ERN EURACAN – rare solid tumours in adults</th>
<th>Sarcoma</th>
<th>Markus Wartenberg and Estelle Lecointe, Sarcoma Patients EuroNet (SPAEN)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female genital organs</td>
<td>Eva-Maria Strömsholm, European Network of Gynaecological Cancer Advocacy Groups (ENGAGe) &amp; Gynecological cancer patients association in Finland</td>
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<tr>
<td>male genital organs</td>
<td>Pending confirmation</td>
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<tr>
<td>NET-Neuroendocrine tumours</td>
<td>Teodora Kolarova, International Neuroendocrine Cancer Alliance (INCA) Catherine Bouvier, NET patient Foundation UK &amp; INCA</td>
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<tr>
<td>Digestive tract</td>
<td>Marianna Vitaloni and Giulia Barenghi, Digestive Cancers Europe</td>
<td></td>
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<tr>
<td>Endocrine tumours</td>
<td>Judith Taylor, Thyroid Cancer Alliance</td>
<td></td>
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<tr>
<td>Rare Head &amp; Neck cancers</td>
<td>Emma Kinloch, UK Salivary Gland Cancer Roberto Persio, Associazione Italiana Laryngectomizzati (AILAR)</td>
<td></td>
</tr>
<tr>
<td>Rare thoracic tumours</td>
<td>Laura Abate Daga, Associazione Tumori Toracici Rari Onlus (Tu.To.R.)</td>
<td></td>
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<tr>
<td>Rare Skin/Eye melanoma</td>
<td>Iain Galloway, MPNE Ocular/Rare Petya Zyumbileva, Melanom Info Deutschland</td>
<td></td>
</tr>
<tr>
<td>Rare Brain and Spine Tumours</td>
<td>Kathy Oliver, International Brain Tumour Alliance (IBTA)</td>
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<tr>
<td>Transversal</td>
<td>Adela Maghear, European Cancer Patient Coalition (ECPC)</td>
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<th>ERN PaedCan – Paediatric cancers</th>
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<tbody>
<tr>
<td><strong>Childhood Cancer International – Europe</strong></td>
<td>Anita Kienesberger; Luisa Basset; Anne Goeres; Lejla Kamerić</td>
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</tbody>
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<tr>
<th>ERN EuroBloodNet – Rare haematological diseases including haematological malignancies</th>
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<tbody>
<tr>
<td><strong>Myeloid malignancies</strong></td>
<td>Jan Geissler, Leukemia Patient Advocates Foundation Sophie Wintrich, MDS UK Patient Support Group and MDS Alliance</td>
</tr>
<tr>
<td><strong>Lymphoid malignancies</strong></td>
<td>Ananda Plate, Myeloma Patients Europe Pierre Aumont, Ensemble Leucémie, Lymphomes Espoir (ELLyE) &amp; Chronic Lymphocytic Leukaemia Advocates Network (CLLAN) Natacha Bolanos, Lymphoma Coalition</td>
</tr>
<tr>
<td><strong>RBC (Red blood cells)</strong></td>
<td>Loris Brunetta, Thalassaemia International Federation</td>
</tr>
<tr>
<td><strong>Bleeding</strong></td>
<td>Baiba Ziemele, European Haemophilia Consortium</td>
</tr>
<tr>
<td><strong>BMF (bone marrow failure syndromes)</strong></td>
<td>Maria Piggin, PNH Support UK</td>
</tr>
<tr>
<td><strong>HHIron</strong></td>
<td>Dag Erling Stakvik, European Federation of Associations of Patients with Haemochromatosis (EFAPH)</td>
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### ERN GENTURIS – Genetic Tumour Risk Syndromes

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<tr>
<th>Condition</th>
<th>Advocate/Association</th>
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| **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

<table>
<thead>
<tr>
<th>Condition</th>
<th>Advocate/Association</th>
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</thead>
</table>
| **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) |