



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

How to develop a successful advocacy campaign

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- » ECPC has no financial disclosure or conflict of interests with the topic presented.
- » ECPC receives funds from several pharmaceutical industry but no funds are related to the work presented today









- Largest European cancer patients' umbrella organisation established in 2003
- **447 member organizations** in 47 countries globally
- advocate for patients to be acknowledged as equal partners & co-creators of their own health
- we work for a Europe of equality, where all Europeans with cancer have timely & affordable access to the best treatment and care available, throughout their life

ECPC leads capacity building in cancer research





ECPC increases the capacity of its members to understand and partake in innovative research by leading communication and dissemination activities in a number of EU-funded research projects.

ECPC is integrating patient views and build the capacity of patients across Europe in the following projects:

- T2Evolve
- INTERVENE
- LEGACy
- DIAdIC
- LifeChamps
- PREFER
- PIONEER
- Immune Image
- ImmunoSABR
- Palliative Sedation
- Transcan-2
- ELBA
- PREDICT





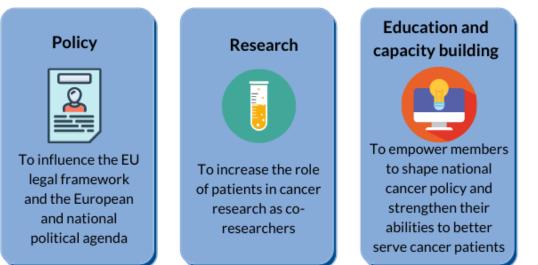
Funded by the Horizon 2020 Framework Programme of the European Union







The European Cancer Patient Coalition Board's 2019-2022 strategy is based upon five pillars:





for cancer patients

Governance



To build a sustainable model for governance and cooperation with its Members

What does cancer patient advocacy look like?





Liaise between patients and their medical professionals

Defend patients' rights

Lobby government for policy change

Raise funds for research and support

Build knowledge and capacity in patient communities

Address the challenges of patient-centred care

Provide educational materials

Support and empower patients, their families and caregivers

Raise awareness



Help reduce anxiety, uncertainty and fear

Sustain hope

Joint Action on Rare Cancers



European Cancer Patient Coalition



- A joint action between the EU **》** Commission and 18 Member States \rightarrow (2016 - 2019)
- JARC aimed at optimizing the process **>>** of creation of the ERNs, by providing them with operational solutions and professional guidance in the areas of quality of care, research and innovation, education, clinical practice guidelines development and epidemiology
- **ECPC contributed to the Chapter 10 >>** on patient engagement: RARE CANCER AGENDA 2030 Ten Recommendations from the EU Joint Action on Rare Cancers



Ten Recommendations from the EU Joint Action on Rare Cancers





JARC Recommendations

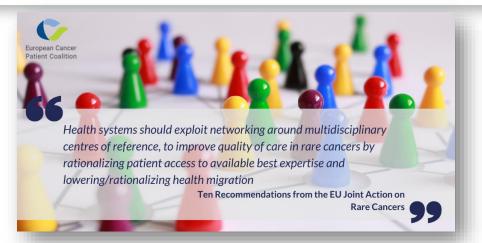


European Cancer Patient Coalition



- 1. Rare cancers are the **rare diseases of oncology**
- 2. Rare cancers should **be monitored**
- 3. Health systems should exploit networking

4. Medical education should **exploit and** serve healthcare networking



5. **Research should be fostered** by networking and should take into account an expected higher degree of uncertainty

- 6. Patient-physician shared clinical decision-making should be especially valued
- 7. Appropriate state-of-the-art instruments should be developed in rare cancer
- 8. Regulation on rare cancers should tolerate a higher degree of uncertainty
- 9. **Policy strategies** on rare cancers and sustainability of interventions should be based on networking
- 10. Rare cancer patients should be engaged

Campaign hosted to commemorate the #RareDiseaseDay

Starting an Adult Rare Tumour **European Registry project**



European Cancer Patient Coalition



- This project (2020 2023) aims to set-up **》** the rare cancer registry for the ERN **EURACAN** and it will be a hospital-based, disease registry, i.e., defined by patients having the same diagnosis
- RT STarting an Adult Rare Tumour European Registry

In details, the project will: **>>**



build the IT infrastructure of the EURACAN registry;



2) promote EURACAN-registry-based research;



3) **assess** the feasibility of integrating additional data sources (administrative, population-based cancer registries) to the EURACAN registry in order to study longterm impact in cancer survivors.

Challenge Cancer Intergroup event on rare cancers



European Cancer CANCE Patient Coalition EUROPE



Policy relevance and activities of the event:

- » Disseminate the EU Joint Action on Rare Cancers (JARC) recommendations for the Rare Cancer Agenda 2030 in Member States
- Call on the EC to support the implementation of the Cross-Border Healthcare Directive



- Work with patient organisations at a national level to ensure the timely and appropriate implementation of the EU Joint Action on Rare Cancers (JARC) recommendations for the Rare Cancer Agenda 2030 and that the Cross-Border Healthcare Directive is functional and its provisions accessible in the interest of rare cancer patients
- » The event will take place during the week of **25th January**.

The Rare Cancers WG





- » 98 members from 25 countries representing rare cancers such as Thyroid cancer, acute leukaemia, paediatric cancers, peritoneal cancer, laryngeal cancer, brain tumour, sarcoma cancer, etc.
- » ECPC involves the national members (cancer patient organisations) in its policy and advocacy activities on rare cancers
- » ECPC seeks support for implementing EU cancer policies at the national level



Advocacy campaigns



European Cancer **Patient Coalition**



- Develop communication materials and **>>** templates → toolkit
- Ensure **translation** of the toolkit to **>>** support national advocating activities
- Contact stakeholders and ask them to **>>** support the campaign \rightarrow prepare easyto-use steps to follow
- **Disseminate** the campaign among **>>** relevant stakeholders, policy makers and media



Ensure follow-up **>>**

ECPC campaigns





- » Nutrition and Physical Activity (March 2021)
- » Merkel Cell Carcinoma (May 2021)
- » Bladder Cancer Awareness Month (May 2021)
- » Non-Melanoma Skin Cancer (13th June 2021)
- » Head and Neck Cancer (September 2021)
- » Personalised Medicine
 Awareness (November 2021)
- » Survivorship day (June 2021)

CALL TO ACTION

ECPC calls for MEPs to prioritise Merkel Cell Carcinoma (MCC) and other rare cancers in the

Europe's Beating Cancer Plan. Primary measure. Therefore policy makers shou underlining the importance of early dia support a multidisciplinary treatment access to the best treatment and suppor act not only at EU level, but also as amba origin supporting synergies among patie



We're



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Thank you!

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