



European Cancer
Patient Coalition

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

Who we are?



European Cancer
Patient Coalition

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- **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



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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:

Policy



To influence the EU legal framework and the European and national political agenda

Research



To increase the role of patients in cancer research as co-researchers

Education and capacity building



To empower members to shape national cancer policy and strengthen their abilities to better serve cancer patients

Communication



To raise awareness on main challenges faced by patients to access innovations and other resources available 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



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- » A joint action between the **EU Commission and 18 Member States** → (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

RARE CANCER AGENDA 2030

*Ten Recommendations
from the EU Joint Action on Rare Cancers*



JARC Recommendations



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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



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- » 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
- » In details, the project will:



1) **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 long-term impact in cancer survivors.

Challenge Cancer Intergroup event on rare cancers



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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



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- » **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



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- » 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 → prepare easy-to-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)



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Joining forces for action



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Thank you!

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