



**ACT TOGETHER AGAINST  
LUNG CANCER**

**CENTRAL AND EASTERN EUROPE FORUM  
OF CANCER PATIENT ORGANIZATIONS**

# The power of advocacy at international level

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**EUROPEAN  
CANCER  
PATIENT  
COALITION**

# How can patients organizations influence European policy making?

## The power of credibility

# First things first: the power of credibility

- **European**
  - ECPC has a **specific geographical scope**: covers the need of the more than 10 million cancer patients across Europe
  - **Interacts directly with the European Institutions**
- **Cancer**
  - It is the **first killer in 17 out of 28 Member States**
  - The **incidence is on the rise**, due to ageing population
- **Patient**
  - **Half of the ECPC Board** must be cancer **patients** or **survivors**
  - Same rule applies for ECPC Members
- **Coalition**
  - ECPC brings together **369 cancer patient organizations**  
**Europe largest cancer patients association**

# Credibility = TRUST

## ECPC as a partner of EU institutions

### European Commission's Expert Group on Cancer Control

- Created to advise the Commission on cancer-related policies
- Kathi Apostolidis and Francesco de Lorenzo represent ECPC
- Representatives from all member states Health authorities
  - Industry
  - Other civil society organisations
  - Medical societies
- Topics of discussion:
  - Joint Action on Rare Cancers
  - Palliative Care
  - European Code Against Cancer
  - **Survivorship (thanks to ECPC input)**

# Credibility = TRUST

## ECPC as a partner of EU institutions



### Joint Action on Cancer Control – CanCon

- Follow up of EPAAC Joint Action
- Co-funded by Commission and 17 EU Member States
- Objective: create guidelines for harmonization of NCPs
- Started in February 2013 – Duration: 3 years
- 6 Operational Work Packages
  - WP4: Guide coordination
  - WP5: Member State Platform
  - WP6: Integrated Cancer Control
  - WP7: Community-Level Cancer Care
  - WP8: Survivorship and Rehabilitation
  - WP9: Screening

# Credibility = TRUST

## ECPC as a partner of EU institutions



### **ECPC is the only Collaborative Partner involved in all Work Packages**

- WP 4 -Guide coordination: De Lorenzo
- WP 5 -Member State Platform: De Lorenzo
  - ECPC promoted the creation of a position paper on inequalities in cancer care: APPROVED (to be finalized in 2016)
- WP 6 -Integrated Cancer Control: De Lorenzo - Apostolidis
- WP 7 - Community-Level Cancer Care: Apostolidis
- WP 8 – Survivorship and Rehabilitation: De Lorenzo
  - ECPC provides key contribution to recommendations
- WP9: Screening: Presti
- WP2 Dissemination (Florindi)

# **Credibility = TRUST**

## **ECPC as a partner of EU institutions**

### **European Medicines Agency Patients' and Consumers' Working Party**

- ECPC fully meets very strict criteria to be included in PCWP
- ECPC represented by Kathi Apostolidis and Rafal Swierzewski
- PCWP has important consultative role

### **European Initiative on Breast Cancer**

- Kathi Apostolidis, member in the Quality Assurance Scheme Development Group
- The working group will be directly involved in the processes required for developing and piloting the 'European Quality Assurance (QA) scheme for Breast Cancer Services'.

# Other partnerships

## Creating and nurturing a network of stakeholders

- **European Society for Medical Oncology - ESMO**
  - ECPC works within ESMO Patients Working Group
  - ECPC partners with ESMO on several policy topics
    - Data protection
    - Survivorship
- **Organisation of European Cancer Institutes - OECI**
  - Strong collaboration on various topics
    - Comprehensive Cancer Centres
    - Joint events
    - BenchCan project (Pietro Presti involved)



# Other partnerships

## Creating and nurturing a network of stakeholders

- **Cancer Drug Development Fund - CDDF**
  - Participation to CDDF events
  - CDDF will collaborate in ECPC initiatives on immuno-oncology
- **European Cancer Concord - ECC**
  - Bringing forward the mission of the European Cancer Patient Bill of Rights
  - Collaboration on « **Europe of Disparities** »
- **European CanCer Organisation**
  - Jana Pelouchova contributes to the ECCO Patient Advisory Committee
- **European Society for RadioTherapy and Oncology - ESTRO**
  - Support multidisciplinary in cancer treatment (paper)
  - ECPC represented in ESTRO Patients Group (Voiculescu)
- **European Association of Hospital Pharmacists**

# Creating new partnerships

## ECPC participating to international events

- **Previous events:**

- 30<sup>th</sup> Anniversary of Europe Against Cancer (celebration launched by the European Commission), 15<sup>th</sup> September
- OEI Oncology Days, 21-24 June
- EAHP Congress, 24<sup>th</sup> – 27<sup>th</sup> March
- World Cancer Day 2015 – Meeting with Commissioner Andriukaitis, 4<sup>th</sup> February

- **Next events:**

- « The Economist » War on Cancer, 20th October

# Monitoring relevant EU policies

- **General Data Protection Regulation**
  - In partnership with ESMO
  - Results achieved:
    - ECPC facilitated meeting between the Italian Ministry of Justice and ESMO to present amendments to the current draft
- **Cross Border Healthcare Directive**
  - Meeting with DG SANTE Healthcare systems Unit
    - Discussion on the implementation of the Directive, following meeting with the Commissioner
- **Clinical Trials Regulation**
  - Follow up: monitoring the creation of the EU CTR Directory

# Awareness campaigns: Working with Members ECPC lead on Immuno-Oncology



# Two key outputs

A policy action framework for policymakers

A guide to immuno-oncology for patients  
translated in 20 European languages



## Immuno-Oncology Policy Action Framework, 19<sup>th</sup> Nov. 2014

- Launch at the European Parliament;
- First EU cancer patients initiative on immuno-oncology;
- Our Members proof-read and distributed the Guide!  
**20 translations** already available thanks to:

NFK	Estonian cancer society	Magyar Rakellenes Liga
AIMaC	BAPD	Dzivibas koks
POLA	Let's Win Health	Pulmonale
FABC	DOBS	GEPAC
Pembe Hanim	SVE za NJU	Greek patients' org.
Czech Rep. Patients' org.	France Lymphome Espoir	Swedish patient orgs
Dansk Myelomatase Forening	Icelandic Cancer Society	

# Action framework and patient leaflet translation impact

**7 European countries** ( France, Germany, Sweden, Italy, Turkey, Portugal and Spain ) and **Latin-America**

- Sweden - A bill in the Parliament for **introducing urgently needed medicines e.g. I-O**
- Italy - Minister of Health publicly **supportive of immuno-oncology**
- Turkey - **Ministry of Health in Turkey endorsed the Immuno-Oncology Patient Guide - on their website**



**200** hard copies of Action Framework and Patient Guide distributed **ESMO I-O Symposium, November 2014**

**500** hard copies at multiple events in the **European Parliament**

peer reviewed articles



Newsletter



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# Awareness campaigns: Working with Members

- **1<sup>st</sup> World Pancreatic Cancer Day – 13<sup>th</sup> Nov. 2014**
  - Event and stand in the European Parliament
  - Launch of multi-stakeholder Pancreatic platform and ECPC Working Group, with the participation of two ECPC Members:
    - Pancreatic Action UK
    - EuropaColon





# Awareness campaigns: Making the Institutions understand our position

- **Get Tested Campaign, 24<sup>th</sup> March 2015**
  - Raising awareness on RAS biomarkers for patients with metastatic colorectal cancer
  - 2016 the campaign will be carried out mainly at national level



# Awareness campaigns

## Creating resources for our Members

- **Nutrition**

- Fundamental need of cancer patients and survivors
- In practice, it is neglected by physicians and patients!
- **What to do?**  
**Understand first what patients & advocates know about nutrition!**

- **Survey on medical nutrition in cancer**

- Created in partnership with academia, communication company
- Translated into 11 languages
- **Result: 658 single replies!!!**

# Awareness campaigns

## Working in partnership with our Members

**ECPC policy and advocacy work becomes even more precious, if translated in initiatives**  
**WITH our members at national level!**

- **Immuno-Oncology**
  - Members translated and disseminated the leaflet
  - I-O event planned in Greece in October 2015
- **LuCE**
  - Event at the European Parliament on innovative treatments for lung cancer on 10 November 2015
- **Fight Bladder Cancer UK & Action Bladder Cancer UK**
  - Launch of the White Paper « Bladder: the forgotten cancer »
- **KEFI/Greece**
  - Awareness activities on pancreatic cancer

# Awareness campaigns

## Working in partnership with our Members

### Head and neck cancers: the model to follow

- **Make Sense Campaign**
  - Launched at EU level, in partnership with several ECPC Members
  - Implemented for 3 years in a row, involving 15 countries in 2015

### Next step: ACT LOCAL

- **Italy** – AILAR & ECPC H&N Awareness Campaign
  - Bus touring several member states offering free consultations
- **Spain** – GEPAC & ECPC Testimonial
  - A Spanish mezzosoprano with tongue cancer – testimonial clip launched this week
  - Funding raised through **sports events**

# Europe of Disparities

## ECPC attempt to solve inequalities in cancer care

- **3 objectives:**
  - Identify nature of inequalities in cancer care in Europe
  - Identify the causes of inequalities
  - Suggest policy recommendations to solve inequalities
- **Multidisciplinary and participative**
  - Based on **our members** input
  - Contribution from various experts (health economists, oncologists, epidemiologists, geneticists, patients & carers, industry, pharmacists, radiologists, etc...)
- **Press Conference in Vienna, Sunday from 10.00 to 11.00, Press Conference Center**
- **Next step: use EoD at national level**

***Thank for your attention***

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**European Cancer Patient Coalition**



**ECPCtv**

***Nothing About Us Without Us***

