

# ECPC Annual Report

# 2013

Last year, within a short interval of time since taking function, the new ECPC Board succeeded to have a number of concrete results in several areas:

## I. Research:

**Rare Cancers** – ECPC has established an official list of rare cancers patient organisations that will be displayed in February 2014 on the site of ECPC and Rare Care Net.

### **EurocanPlatform :**

1. Recording of a video material, at the ECCO Congress in Amsterdam, on cancer patients' educational needs in the framework of the EurocanPlatform Project.
2. ECPC started to work together with the leaders of Work Package 10 on a **FAQs document on Biobanking** to be posted in 2014 on the website as part of ECPC's dissemination role within the EurocanPlatform. ECPC has also established a good collaboration with an expert patient on Biobanking from the UK (the Independent Cancer Patients' Voice) that has played an advisory role in the revision of the FAQs document.

**EPAAC** - ECPC President, Francesco De Lorenzo and Vice-President, Kathi Apostolidis attended the EPAAC Open Forum (26-27 November) which took place in Ljubljana. During the Forum it was launched the book **Boosting Innovation and Cooperation in European Cancer Control**. The book explores some of the innovative strategies being deployed against cancer in Europe and how international collaboration has assisted in combating the cancer burden. It is a product of the European Partnership for Action Against Cancer (EPAAC) and it highlights some outstanding examples of how cooperation between national and international entities as well as policy-oriented innovation are contributing to the collective effort to control cancer. **Chapter 6 of the book, 'Building a unified European Cancer Information System to bolster cancer control' is written with the contribution of Francesco de Lorenzo, President of ECPC.**

## II. ECPC and the European institutions

1. ECPC renewed and enhanced cooperation with the European Parliament in order to give cancer patients the chance to take part in European policy shaping. Thus, an agreement was reached with the Slovenian MEP, Alojz Peterle, on a joint working plan based on re-establishing a single Parliamentary Cancer Working Group that is composed of MEPs, ECPC and ECL's representatives.
2. The President of ECPC, Prof. De Lorenzo, had several meetings with Martin Seychell, Deputy Director General, DG SANCO at the European Commission in order to ensure that ECPC will play a leading role in the new Joint Action 2014-17 and in the Expert's Commission on Cancer.

3. ECPC enhanced its **cooperation with the European Medicines Agency (EMA)**, the institution which regulates medicines policy in Europe. Our contribution and feedback as cancer patient representatives is extremely important in the present discussions regarding cancer medicine product leaflets reviewing, medicine shortages, pharmacovigilance, clinical trials regulations at European level. A special section will be developed on ECPC website, with the most useful information coming from the European Medicines Agency. **Board members Kathi Apostolidis and Rafal Swierzewski** are the ECPC representatives in EMA's Patients' and Consumers' Working Party of the Committee for Medicinal Products for Human Use (CHMP).
4. Together with the European Cancer Concord, ECPC started planning an outstanding event to be held in the European Parliament on the 4<sup>th</sup> of February 2014, namely the launch of a **Cancer Patients' Bill of Rights**. For the same day, World Cancer Day, ECPC has drafted a **manifesto for Improved Cancer Care for the European Citizen**.
5. ECPC has reached a **formal partnership agreement with the organisation of European Cancer Institutes (OEI)**.
6. ECPC developed for the following years a **project for Head and Neck cancers**. The first phase of the project started in September 2013 with the launch of a White Paper and a Call to Action in the European Parliament. For 2014 ECPC plans to set up strong Patient Advocacy Groups devoted to H&N cancer and trigger in autumn a debate in the plenary of the European Parliament. <http://makesensecampaign.eu/>
7. In 2013, ECPC focused on new innovative treatment modalities, such as **Immuno-Oncology**, by organizing a workshop in the European Parliament devoted to this topic.

### III. Participation in international events:

ECPC Board members were eager to put ECPC back on the international agenda and therefore attended a series of prestigious events:

- 3<sup>rd</sup> Annual meeting & Midterm review of Eurocan Platform in Barcelona attended by Prof. De Lorenzo;
- the European Cancer Congress in Amsterdam (attended by Francesco de Lorenzo, Kathi Apostolidis, Jana Pelouchova, Rafal and the staff of ECPC). As an ECCO PAC member, Jana Pelouchova was heavily involved both in the „Patient Track“ the session and the „Scientific Session“. She delivered a presentation in the Nurses session, outside the days of the Patient Track. She also gave a short interview with e-cancer:

<http://ecancer.org/video/2320/the-affects-of-communication-technology-on-patients.php>

- the First Melanoma MIB Conference organized by Alessandro Testori in Rome which marked a historic moment in cancer advocacy and in particular ECPC's support for melanoma patients. The meeting was attended by Francesco de Lorenzo;
- EPAAC Open Forum (26-27 November) in Ljubljana attended by Francesco de Lorenzo and Kathi Apostolidis.

#### **IV. Two scholarships for the SABCS-San Antonio Breast Cancer Symposium**

ECPC offered in 2013, for the first time in Europe, two full scholarships to breast cancer patient advocates to attend **SABCS-San Antonio Breast Cancer Symposium**, the annual global breast cancer congress (San Antonio, Texas, USA, from December 9 to 14, 2013).

#### **V. Launch of a new website**

We are proud to have succeeded in purchasing the domain name 'ecpc.org'. Thus, the website address changed from [www.ecpc-online.org](http://www.ecpc-online.org) to [www.ecpc.org](http://www.ecpc.org).

#### **VI. Setting up the Office in Brussels with new staff**

For 2014 we plan to build on ECPC's achievements of the last years and to continue to be a strong voice for all cancer patients in Europe.

## ECPC ACTIVITY IN 2013

Following the elections that took place in April 2013, ECPC has a new Board.

Its members are:



**President:**  
**Francesco de Lorenzo,**  
**Italy**



**Vice-President:**  
**Kathi Apostolidis,**  
**Greece**



**Board Member:**  
**Elena Caruso,**  
**Italy**



**Vice-President and Treasurer:**  
**Vlad Vasile Voiculescu,**  
**Romania**



**Board Member:**  
**Sarah Lindsell,**  
**UK**



**Secretary:**  
**Jana Pelouchova,**  
**Czech Republic**



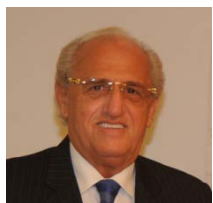
**Board Member:**  
**Rafal Swierzewski,**  
**Poland**

### A New Audit Committee:



#### 1. Pietro Presti : Italy

He holds several functions in National and International associations, such as Managing Director and founder at "Edo ed Elvo Tempia", CEO and Member of Board of Directors at im3D Clinic Scarl (Turin, Italy). He is also President of the College of the Auditors of Account of Italian Federation "FAVO" (Rome, Italy).



#### 2. Balogh Istvan : Hungary

He has been the President of the Children Cancer Foundation for over ten years, has provided success for the organization for over a decade. He is a board member of several organizations in Hungary and in the USA.



#### 3. Hannu Tavio: Finland

By education as a Lawyer he has been dealing with many kind of financial procedures and worked as auditor for a number of private companies and associations. He wrote several articles and books on cancer topics (e.g. in 2005 he published the informative Prostate Cancer Patient book: "Uninvited Companion" and in 2010 together with oncologist Timo Joensuu published a science book: "Life carries".)

## **ECPC also has a new Office Secretariat**



### **Office Director: Mihaela Militaru**

Mihaela joined ECPC in August 2013.

She has worked in EU affairs for 12 years, first as a liaison officer of the Senate of Romania with the European Parliament and subsequently as a policy adviser within the European Parliament (8 years).

Her activity in the European Parliament focused in the last years on healthcare policy and the measures needed at EU-level for fighting diseases such as cancer, multiple sclerosis, autism and fibromyalgia.



### **Projects and Policy Officer:**

#### **Kalliopi Anna Christoforidi**

Kalliopi joined ECPC in September 2013. She has a Bsc in Biomedical Sciences from the University of Warwick and a Master of Neuroscience from the University College London. In 2012 she worked in Paris at the "Institut du cerveau et de la moelle épinière" on experimental psychology and behaviour.

### **Office Assistant:**

#### **Anh Tran**



Anh joined ECPC in February 2013. She holds a Master of Development Studies from the University of Melbourne, Australia and a B.A. in International Relations from Vietnam. She worked a couple of years in the Department of Foreign Affairs in Vietnam and after moving to Belgium, she was an Administrative and Finance Officer for the International Disability and Development Consortium.

## **ECPC Annual General Meeting - 8 June 2013**

**ECPC members and supporters had the opportunity to meet and discuss about cancer care in their countries and meet the departing and new Boards of Directors.**

Following the General Meeting, the following issues were put on the agenda of the ECPC for the coming period:

1. Improve access to frontline cancer care;
2. Ensure a minimum standard of cancer care;
3. Create working groups consisting of ECPC members<sup>1</sup>;
4. Focus on rare cancer;
5. Advocate for the establishment of an EU Action Plan on cancer;
6. Diversify fundraising possibilities;
7. Share ECPC office premises with another umbrella European organization;
8. Increase collaboration with research organizations;
9. Review ECPC status and transfer the seat of the organization to Belgium.

## **ECPC offered two scholarships for SABCS to celebrate October Breast Cancer Month**

ECPC offered in 2013, for the first time in Europe, two full scholarships to breast cancer patient advocates to attend **SABCS-San Antonio Breast Cancer Symposium**.

The winners of the two scholarships offered by ECPC were **Ragna van Hummel** and **Maria Skotida**.

### **Ragna van Hummel (Netherlands)**

Breast cancer survivor and BRCA2 carrier Ragna made a career change and became the founder of Re-turn, a national organization that supports workers with (breast) cancer and their employers. She is also a volunteer for the BVN, the largest cancer patients organization in the Netherlands. Ragna is both an expert on workplace issues and an advisor on how to organize patient involvement better. She is also an editor at B magazine, the official BVN publication.

### **Maria Skotida (Greece)**

Maria is an active member of the Association of Cancer Patients of Athens (KEFI) and member of the Board of Directors, having designed and implemented a Pan-Hellenic campaign on the rights of cancer patients, not only on a theoretical part (EU framework), but also the practical side of what is applied in Greece, a country in which the health system has deteriorated immensely due to the financial crisis.

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<sup>1</sup> *The following working groups were set up:*

- § **Paediatric oncology: led by Rafal Swierzewski**
- § **Rare cancers: led by Sarah Lindsell**
- § **Melanoma: led by Francesco de Lorenzo and Jana Pelouchova**
- § **Bio-banking: led by Kathi Apostolidis & Francesco de Lorenzo**
- § **Access to medicines: led by Vlad Voiculescu**
- § **Access to radiotherapy: led by Vlad Voiculescu**
- § **Access to employment and social benefits: led by Kathi Apostolidis**
- § **Head and Neck Cancers: led by Francesco de Lorenzo**

## **Head and Neck Cancers: Launch of a WHITE PAPER and A CALL TO ACTION in the European Parliament on the 24<sup>th</sup> of September 2013**

The European Cancer Patient Coalition (ECPC) and the European Head and Neck Society (EHNS) joined forces with 12 Members of the European Parliament to highlight the challenges in treating head and neck cancer. **On the 24<sup>th</sup> of September 2013** ECPC initiated a round table debate for political and patient advocacy representatives to launch a head and neck cancer white paper and call-to-action – both demonstrating their commitment to improve standards of care and to deliver best outcomes for patients with head and neck cancer across Europe.



The EHNS/ECPC White Paper and Call-to-Action outline proposals on how members of European Parliament can take action to support the management of head and neck cancer. Key action areas include:

- Screening and treatment options are available to all patients;
- Introduction of European guidelines and support of best clinical practice across EU member states to ensure that all citizens have access to the best available treatment;
- Prioritisation of a multidisciplinary team approach for head and neck cancer treatment;
- Provision of appropriate emotive support and rehabilitation programmes for head and neck cancer patients/survivors.

### **ECPC is committed to:**

- Ensure that the rights of cancer patients are upheld and enforced;
- Increase cancer patients' representation and influence at the highest level of decision making, nationally and Europe-wide, in all areas that affect their health;
- Empower patients to become true partners in the healthcare system;
- Obtain for patients timely access to appropriate prevention, medical diagnosis, treatment and care, including psycho-social care;
- Encourage population-based screening programmes according to European quality guidelines;
- Promote the advance of cancer research, to include all applicable information on well-designed Clinical Trials and where possible, the right to enrol in them;
- Call for improved multi-disciplinary training of health professionals.

**In 2014, ECPC and EHNS will have a meeting with representatives of the European Commission as a follow up to the event organised in 2013 in the European Parliament.**



### **ECPC at ECCO Congress 2013 Amsterdam**

During the Congress in Amsterdam ECPC Board Members (Francesco de Lorenzo and Kathi Apostolidis) were involved in a video debate, speaking about cancer patients' educational needs in the framework of the EurocanPlatform Project.



**The video material made in Amsterdam can be viewed at the following link:**

**[http://www.ecpc.org/?page\\_id=90](http://www.ecpc.org/?page_id=90)**

### **ECPC ran for IBC Cancer – 6<sup>th</sup> of October**

The European Cancer Patient Coalition team ran the half-marathon in Brussels, on the 6th of October.

ECPC has a long standing history in raising awareness and advocating for adequate access to health care and social services at the EU level by cancer patients. As cancer is the 2<sup>nd</sup> cause of death in Europe, ECPC has allocated much of its resources also in research on biobanking, biomarkers, clinical trials and use of electronic resources by cancer patients and clinicians, being an active partner in 3 EU funded multinational projects.

In 2013 ECPC focused on a rare type of breast cancer, namely, inflammatory breast cancer (IBC). IBC is the most aggressive form of breast cancer which usually cannot be detected during a mammogram. Women diagnosed with IBC (less than 30% survive in 5 years time) are also known to have poorer survival outcomes compared with those with non-IBC tumours (more than 80% survive in five years time). The non-specificity of the current diagnostic criteria coupled with the recognition that many women with IBC are misdiagnosed with mastitis are the primary causes of delayed diagnosis and management of this aggressive disease. The late diagnosis and the aggressiveness of the cancer not only lead to poorer survival but also to poor quality of life.



In the future ECPC intends to:

- **Raise awareness about IBC (e.g. risk factors, symptoms) and promote education of patient and physician;**
- **Advocate for IBC research in Europe for defining a clear diagnosis and management protocol of IBC;**
- **Advocate for psycho-social support to IBC patients and carers by IBC trained oncology nurses, social workers and psychologists.**



**ECPC staff will continue to run marathons in 2014, fund raising for different types of cancer.**

**ECPC was involved in the InSup-C Project on integrated palliative care**

On the 7th and 8th of November, ECPC joined the InSup-C team on integrated palliative care. More information about this project can be found at <http://www.insup-c.eu/>.



## Conference on Immuno-Oncology – 5 December 2013



On 5<sup>th</sup> of December Dr Philippe de Backer, Member of the European Parliament, and the European Cancer Patient Coalition (ECPC), co-hosted a policy workshop entitled ***“Immuno-Oncology: adapting policies to a new modality in cancer treatment”*** at the premises of the European Parliament. The key objective was to start identifying the challenges faced by healthcare systems and the policy adaptations needed to ensure better access to innovative cancer treatments that bring

better clinical and societal outcomes for cancer patients.

### Main Conclusions

#### Assessing the value of cancer medicines

- More and more policymakers, budget-holders, patients and medical experts alike recognise that the key target for new cancer treatments should be long-term survival, coupled with improved quality of life.
- However, the traditional criteria assessing value of a medicine in oncology are still focused on short-term, incremental benefit. Therefore, new metrics, focused on long-term survival and quality of life, need to be used when assessing the value of innovative treatments in oncology.

#### Facilitating processes

- A progressive, Europe-wide standardisation of Health Technology Assessment methods is needed in order to close the gap in access to new treatments and diagnostics.
- To achieve affordability and more equal access to healthcare in Europe, Member States should encourage innovative pricing arrangements, reflecting the different economic situations between countries and prevalence of cancer in their country.
- A multidisciplinary approach needs to be established in order to look for consensus on challenges posed by the cost of treatments and the cost of the disease overall. The impact of innovative medicines on healthcare budgets needs to be looked at and solutions need to be co-created to ensure patients have access to appropriate innovative treatments.

#### Equity in cancer care

- Access inequalities between and within EU countries should be addressed. This requires a holistic approach encompassing priority setting in healthcare, comprehensive cancer plans, availability and affordability of treatments as well as enabling policies.

## A policy approach to clinical research

- For cancer patients where the only option is to enroll in a clinical trial, the “zero-risk” approach often taken by policy makers and regulators is not the one preferred by patients. With this “zero risk approach” it could be more difficult for patients but also for the industry to take the full benefit of clinical trials.
- For highly innovative treatments approved on the basis of phase II data, methodology of HTA/payer bodies need to be adapted to recognize the added value of these treatments based on lesser data, where appropriate, and provided the safety of patients is guarded.
- Innovation, research and clinical trials play an important role in the development of new medicines. There is a need for new, meaningful endpoints in clinical trials that measure true benefit e.g. long-term survival.

## Patient-centered care

- Increased collaboration and exchange of data between European Cancer Institutes can facilitate a holistic approach to comprehensive cancer care.

### Strategic Partnerships in 2013



ECPC will organize in February 2014 together with OECEI a conference at the European Parliament on “**How uniform is cancer care in Europe?**” The Conference will be the first step for the **development of a common Action Plan towards the reduction of inequalities in cancer care in Europe and the beginning of the strategic partnership with OECEI concluded in 2013.**

## ECPC Honorary Patronages

### The Polish “Citizen Partnership on Cancer”

Polish cancer patient organizations are currently working on developing a “**Citizens’ Partnership on Cancer**”. The main goal of this project is to solve the urgent problems of Polish oncology, which patients cannot longer accept. The Polish Partnership is a strong opposition to the proposed amendment of the Reimbursement Act proposed by the Polish Ministry of Health. The Partnership is going to develop a civic formulation of the National Programme for Fighting Cancer.

ECPC believes that front line cancer care for patients and moreover for cancer survivors is steadily deteriorating in the member states most hit by the financial crisis while in other member states the spending cuts in health care substantially affect the cancer and social care services. ECPC has been advocating for years to safeguard access of socially vulnerable populations groups to cancer care. ECPC was therefore honoured to take the high patronage of the Polish Citizen Partnership on Cancer.

### The Conference on Survivors and Chronic Patients - Syracuse (Sicily), 7th of June 2014.

ECPC was honoured to take the patronage of this Conference as in the past ECPC has acted at national and international level in order to **develop a comprehensive cancer survivors care plan.**