

PRESSMEDDELANDE

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Initiativ på EU-nivå i samband med Världscancerdagen den 4 februari:

Rättvisare vård till Europas cancerpatienter

Under 2012 hade Europa 3,45 miljoner människor en cancerdiagnos. Samma år dog 1,75 miljoner personer i cancer. Det motsvarar 3 dödsfall per minut. I hälften av EU-länderna har cancer ersatt hjärt-och kärlsjukdomar som den ledande orsaken till en för tidig död. Dessutom kommer en åldrande befolkning innebära att en person dör i cancer var 10:e sekund, om inte effektiva förebyggande och behandlingsstrategier införs.

Därför har en grupp bestående av patientorganisationer, sjukvårdsledare, före detta hälsoministrar, en Nobelpristagare och ledamöter vid EU-parlamentet gått samman för att lansera The European Cancer Patient's Bill of Rights. Ett initiativ som leds av The European Cancer Concord (ECC) * och är en uppmaning till handling för att ta itu med de stora skillnader som finns för cancerpatienter i Europa idag.

ECC uppmanar EU-parlamentet att arbeta för "Cancerpatienternas Bill of Rights" och då speciellt tre grundläggande principer. Rätten för alla EU-medborgare att:

- få den mest korrekta informationen och vara aktivt involverad i sin vård
- få optimal och snabb tillgång till lämplig specialiserad vård, stödd av forskning och innovation
- få vård i hälso-och sjukvårdssystem som säkerställer förbättrade resultat, patientens rehabilitering, bästa livskvalitet och hälsovård till ett rimligt pris.

I samband med lanseringen har två artiklar publicerats i de internationella concertidskrifterna *Lancet Oncology* och *The Oncologist*.

Lancet artikel, endast förhandsinfo för journalister: <http://press.thelancet.com/billofrights.pdf>

Lancet artikel som finns tillgänglig efter klockan 12:00, 4/2:

[http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045\(13\)70552-7/abstract](http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(13)70552-7/abstract)

The Oncologist

<http://theoncologist.alphamedpress.org/content/early/2014/02/03/theoncologist.2013-0452.abstract>

* The European Cancer Concord (ECC) is a partnership which will enable improved access to cancer care, research and innovation for the European citizen.

För mer information kontakta:

Mark Lawler
Queen's University Belfast
Tel: +44 (0)28-9097-2931
Mob: +353 (0) 87 2263949
Email: mark.lawler@qub.ac.uk

Mihaela Militaru
European Cancer Patient Coalition
Tel: +32 234 201 04
Mob: +32 473 49 18 43
Email: mihaela.militaru@ecpc.org

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The European Cancer Patient's Bill of Rights: A Catalyst for Change addressing inequalities in cancer in Europe

4th February, 2014, Strasbourg, France A unique group of patient advocacy organisations, healthcare leaders (including two former health ministers and a Nobel Laureate) and Members of the European Parliament against Cancer (MAC) have come together to launch the **European Cancer Patient's Bill of Rights** to coincide with World Cancer Day, in the European Parliament in Strasbourg. The result of over two years of work and widespread engagement, the initiative is led by the **European Cancer Concord (ECC)** and is a call to action to address the significant disparities that exist for European cancer patients today. Among the speakers at the launch was Tonio Borg, European Commissioner for Health and Consumer Policy.

"This increasing cancer burden will impact not only on patients and their families, but will also be a significant issue for healthcare systems and for the future economic competitiveness of Europe," said Prof Patrick Johnston, Co-Chair of ECC and Dean of Medicine, Dentistry and Biomedical Sciences at Queen's University Belfast, UK. *"We are proud that this Bill of Rights represents the input of oncology and patient advocacy leaders from 17 European countries representing over 1,000 national organisations and many millions of cancer patients and survivors in Europe"*, added Prof Mark Lawler, ECC Project Lead, based at Queen's University Belfast.

In Europe, in 2012, 3.45 million people were diagnosed with cancer with 1.75 million cancer deaths, representing 3 deaths every minute from this killer disease. In 28 of the 53 European countries, cancer has replaced cardiovascular disease as the leading cause of premature death. In addition, the exponential aging of the population means that unless effective preventive and treatment strategies are put in place, 1 person will die from cancer every 10 seconds.

Significant differences in cancer incidences and mortalities are evident within Europe, reflecting inequalities in access to optimal cancer care between different national cancer healthcare systems. Cancer is cited as a prime example of increasing disparities between and within countries in Europe in the recent "Health in Europe" series in The Lancet.

Three patient-centered principles (termed Articles) underpin the ***European Cancer Patient's Bill of Rights***:

Article 1: The right of every European citizen to receive the most accurate information and to be proactively involved in his/her care.

Article 2: The right of every European citizen to optimal and timely access to appropriate specialised care, underpinned by research and innovation.

Article 3: The right of every European citizen to receive care in health systems that ensure improved outcomes, patient rehabilitation, best quality of life and affordable healthcare.

Launching the Bill of Rights at the European Parliament on World Cancer Day represents a clear indication of the Group's will to focus attention on the unequal nature of cancer care in Europe, to engage and influence political representatives and most crucially to empower every European citizen to use the Bill of Rights as a catalyst to achieve effective change in cancer care delivery in their own country/region.

"The European Cancer Patient's Bill of Rights is a Patient Charter that aims to address the inequalities that cancer patients in Europe face every day linked to socioeconomic status, patient age, access to quality care and lack of a comprehensive National Cancer Control Plan," said Francesco de Lorenzo, ECC member and President of the European Cancer Patient Coalition (ECPC), the largest patient advocacy group in Europe. *"The economic burden of cancer is now approaching €1000 billion worldwide, making it the Number 1 disease in terms of financial drain on our global economy. This unique partnership will, we hope, deliver real benefit for the cancer patient,"* he added.

"We are proud to be associated with this initiative" said Alojz Peterle MEP (Slovenia), President of MEPs Against Cancer group (MAC) and a key supporter of ECC and ECPC. *"It represents a clear mandate to our colleagues that we need to achieve an effective change for the benefit of the European cancer patient,"* he added.

"This equal partnership between patients and health care professionals which ECC has created and is nurturing, provides a springboard for the change required to deliver improved outcomes for European citizens and societies" said Prof Thierry Le Chevalier, Co-Chair of ECC and Chair of the Institute of Thoracic Oncology, Institut Gustave Roussy, Paris, France.

"Launching the Bill of Rights in the European Parliament on World Cancer Day underlines our will and the commitment of the European Parliament to abolish disparities in cancer care across for the European citizen. In the current socio-economic circumstances in Southern, Eastern and Central Europe, where the public health systems are under constant pressure from austerity measures, cancer patients and their families are the first to feel the impact on their health, finances and quality of life," said Daciana Sarbu (S&D MEP, Romania) member of the Environment Public Health and Food Safety Committee, European Parliament.

To coincide with the launch and to provide the evidence base for the initiative, two papers have been published in the international cancer journals *Lancet Oncology*ⁱ and *The Oncologist*ⁱⁱ.

One in three people die of this deadly disease. Cancer knows no boundaries, affecting all sectors of society. Thus, despite individual constituencies, the launch of the European Cancer Patient's Bill of Rights demonstrates that one must compete, not with each other, but against the common enemy: **Cancer**.

-Ends-

Contacts

Mark Lawler
Queen's University Belfast
Tel: +44 (0)28-9097-2931
Mob: +353 (0) 87 2263949
Email: mark.lawler@qub.ac.uk

Mihaela Militaru
European Cancer Patient Coalition
Tel: +32 234 201 04
Mob: +32 473 49 18 43
Email: mihaela.militaru@ecpc.org

Background Briefing Note

The **European Cancer Concord (ECC)** is a patient-centred initiative, born out of the need to deliver an optimal standard of cancer care and research for Europe's citizens. Strengthening and upholding the rights of the individual cancer patient/cancer survivor are its guiding principles. **ECC** was formed 2 years ago under the stewardship of the Society for Translational Oncology (STO).

ECC involves oncology and patient advocacy leaders from 17 European countries, who have come together in a unique partnership to address the inequalities in cancer care and research and to help develop effective solutions for European citizens and societies. To date, over 20 European and pan-European cancer Patient Advocacy Organisations (PAO), representing over 1,000 national organisations and many millions of cancer patients and survivors in Europe have become active partners.

Engagement and promulgation is a crucial part of the **ECC** strategy, both at pan European level and through national dialogue. This has involved interaction with the *European Cancer Organisation (ECCO)*, through its Patient Advocacy Committee and with the *European Cancer Patient Coalition (ECPC)* and the *European Cancer Leagues (ECL)*, two of the largest pan European patient advocacy organisations. Engagement with national cancer societies and national Departments of Health or their equivalents are helping to embed the initiative at local Member State level.

This partnership will encourage and attract multi-stakeholder engagement. Patients, patient advocacy organisations and healthcare professionals are the joint foundation stone of this initiative, but we are also reaching out to families of those with cancer, patient carers, cancer registries, cancer charities, learned societies, industry, governmental agencies, politicians and policy makers, the European Commission, health care payers, health technology assessment agencies and other key stakeholders.

About ECPC

Established in 2003, the **European Cancer Patient Coalition** is the pan European voice of the European cancer patient community, representing the interests of all cancer patient groups from the most common to the rare forms of cancer. With its motto "**Nothing about us without us!**" ECPC represents [341 Member Organisations in 46 countries](http://www.ecpc.org). (<http://www.ecpc.org>)

About STO

The Society for Translational Oncology is a professional association committed to speeding the discovery and translation of important new treatments in the field of cancer medicine to the practice of global oncology. It bridges the "translational gap" between discovery and delivery of care to the cancer patient. STO provides educational activities in many areas including screening, prevention, diagnosis, treatment and management of patients with cancer (<http://sto-online.org>)

Appendix 1: Current List of ECC Patient Advocacy/NGO Partners

ECC Partners ¹

Cancer Research UK
Central European Cooperative Oncology Group (CECOG)
Chronic Myeloid Leukaemia Advocates Network
Dutch Breast Cancer Organisation (BVN)
Europa Donna
EuropaColon
European Alliance for Personalised Medicine (EAPM)
European Cancer Leagues (ECL)
European Cancer Patient Coalition (ECPC)
European Men's Health Forum (EMHF)
European Organisation for the Research and Treatment of Cancer (EORTC)
European Patient's Academy of Therapeutic Innovation (EUPATI)
Inspire 2 Live (I2L)
International Brain Tumour Alliance (IBTA)
International Confederation of Childhood Cancer Parent Organisations (ICCCPO)
Irish Cancer Society (ICS)
Italian Association of Cancer Patients (AIMaC)
Italian Federation of Volunteer-based Cancer Organizations (F.A.V.O.)
Leukaemia Patient Advocates Foundation (LPAF)
Myeloma Patients Europe (MPE)
Northern Ireland Cancer Research Consumers Forum (NICRCF)
Sarcoma UK
Sarcoma Patients EuroNet

¹ ECC is actively engaging with other professional organizations/patient advocacy organizations/non governmental organizations to join the partnership

ⁱ The Lancet [http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045\(13\)70552-7/abstract](http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(13)70552-7/abstract)

ⁱⁱ The Oncologist (<http://theoncologist.alphamedpress.org/content/early/2014/02/03/theoncologist.2013-0452.abstract>)