

## Dear Colleague

On Tuesday 4<sup>th</sup> February, the **European Cancer Concord (ECC)** took a momentous step forward for cancer patients throughout Europe. Tuesday 4<sup>th</sup> February was World Cancer Day and appropriate to this occasion, **ECC** launched the **European Cancer Patient's Bill of Rights** in the European Parliament in Strasbourg. The launch of the Bill of Rights represented over two years of detailed work and widespread engagement. We take this opportunity to extend our thanks to all of you for your significant input and overwhelming support for this patient-centred initiative that has brought together European patient advocates, cancer healthcare and research leaders in a unique partnership that will act as a charter for change for European cancer patients

Launching the Bill of Rights at the European Parliament on World Cancer Day represented a clear indication of our 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. It also coincided with the publication of two significant papers from ECC in the prestigious international journals *Lancet Oncology*<sup>1</sup> and *The Oncologist*<sup>2</sup> which mapped out the evidence base that underpins the principles of the **European Cancer Patient's Bill of Rights**.



Ian Banks, ECC, President European Men's Health Forum and Chair Patient Advocacy Committee, European CanCer Organisation (ECCO) outlines the principles of The European Cancer Patient's Bill of Rights

<sup>1</sup>[http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045\(13\)70552-7/fulltext](http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(13)70552-7/fulltext)

<sup>2</sup><http://theoncologist.alphamedpress.org/content/early/2014/01/31/theoncologist.2013-0452.full.pdf#page=1&view=FitH>

Speaking at the Launch, **Commissioner Tonio Borg** welcomed the Bill of Rights, assuring those present that *“cancer is very high on the Commission’s agenda”*. He highlighted how the Bill of Rights’ *“emphasis on optimal and timely access to specialised care”* has particular resonance with the *“EC Directive in Cross Border Healthcare which entered into force in October of last year and sets out citizens’ rights to go to another EU country for treatment and to obtain reimbursement for such treatment.”* He also praised the *“very first right that the Bill defends, the right for the patient to receive accurate information and to be actively associated in their care,”* acknowledging that *“Information is key to enable the patient to play an active role in his or her treatment rather than just being a passive recipient.”* Overall, the principles of the Bill of Rights very much echo the commitment of the Commissioner’s action in promoting equity and combating discrimination.



EC Commissioner for Health Tonio Borg (Right), speaking at the Launch of the European Cancer Patient’s Bill of Rights. Sitting beside him on the platform is Aloiž Peterle, President of the MEPs against Cancer Group

The event in the European Parliament was hosted by **Daciana Sarbu** (MEP, Romania) member of the Environment Public Health and Food Safety Committee, European Parliament and we take this opportunity to thank her for her support for ECC and the European Cancer Patient’s Bill of Rights.

Commenting on the initiative, **Daciana Sarbu** said *“Launching the Bill of Rights in the European Parliament on World Cancer Day underlines 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.”*



Our host Darciana Sarbu (MEP Romania) speaking at the launch of The European Cancer Patient’s Bill of Rights

Crucial to the success of the initiative has been the partnership with over 20 patient advocacy groups representing approximately 1,000 national organisations and many millions of cancer patients and their families throughout Europe. The Launch of the Bill of Rights in Strasbourg was performed in partnership with the largest of these pan European organisations the European Cancer Patient Coalition (ECPC).

*“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**, member of the ECC Steering Committee and President of the European Cancer Patient Coalition (ECPC), the largest patient advocacy group in Europe.

*“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”* added **Thierry Le Chevalier**, Co-Chair of the ECC Steering Committee and Chair of the Institute of Thoracic Oncology, Institut Gustave Roussy, Paris, France.



Francesco de Lorenzo, President  
European Cancer Patient Coalition



Thierry Le Chevalier, Co-chair ECC



Jan Geissler, Leukaemia Patient  
Advocates Forum (LPAF)

*“Patients must be at the heart of all healthcare to improve outcomes,”* said **Jan Geissler**, cancer survivor for 12 years and activist for patient empowerment on the European level. *“European cancer patients, specifically those with rare cancers, have unmet needs and face inequalities. The European Cancer Patients’ Bill of Rights is an important step to further empower patients when difficult decisions have to be made. To make progress in cancers, patients must lead the way.”*



Françoise Meunier, Director General, European Organisation  
For Research and Treatment of Cancer (EORTC)



Joan Kelly, President, European Cancer Leagues (ECL)



ECC Co-Chair Patrick Johnston and ECC Member and Former French Minister for Health Michèle Barzach with the European Cancer Patient's Bill of Rights

Also speaking at the Launch was Alojz Peterle MEP, former Prime Minister of Slovenia, President of MEPs Against Cancer (M.A.C) group and a key supporter of ECPC and ECC. *"We are proud to be associated with this initiative,"* he said. *"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.



Alojz Peterle, President of the MEPs against Cancer, signing the Bill of Rights

The Launch of the European Cancer Patient's Bill of Rights represents the first step in a series of ECC engagements with policy makers at European and national levels. We very much want all our members to be part of this engagement, particularly at national level and will be in contact shortly to help in the promulgation of the Bill of Rights across Europe and in promoting political engagement



Patrick Johnston, Co-Chair ECC Steering Group, Tonio Borg, EC Commissioner for Health, Mark Lawler, ECC Project Lead and Francesco de Lorenzo, ECC Steering Committee and President ECPC

Full details of the Launch of the European Cancer Patient's Bill of Rights including press releases, press coverage, presentations etc. can be found at <http://sto-online.org/ecp-bill-of-rights>