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

**4<sup>th</sup> 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.

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.**

*"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. *"Launching the Bill of Rights at the European Parliament on World Cancer Day represents 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"* he added.

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.

*“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. *“Both national and regional inequalities in disease prevalence and impact are holding the development of Europe back in every country in the Union”* stated Joan Kelly, President of the Association of European Cancer Leagues (ECL) and added that *“This Bill of Rights is a bold step forward to empowering cancer patients and citizens everywhere.”*

*“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*<sup>i</sup> and *The Oncologist*<sup>ii</sup>.

*“Patients must be at the heart of all healthcare to improve outcomes”,* says 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.”*

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**.

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<sup>i</sup> Lawler et al Lancet Oncology ([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))

<sup>ii</sup> Lawler et al The Oncologist (<http://theoncologist.alphamedpress.org/content/early/2014/01/31/theoncologist.2013-0452.full.pdf>)

The European Cancer Concorde currently involves 17 European countries and represents over 1,000 national organisations and many millions of cancer patients and survivors. For further information on the European Cancer Concord visit: <https://sto-online.org/european-cancer-concord>

The Bill of Rights can also be read at <http://sto-online.org/european-cancer-concord>

## ***Current List of ECC Partners<sup>1</sup>***

Cancer Research UK (CRUK)

Centro Nacional de Investigaciones Oncológicas (CNIO), Madrid, Spain.

Chronic Myeloid Leukaemia Advocates Network  
Dutch Breast Cancer Organisation (BVN)  
Erasmus University Medical Center, Rotterdam, The Netherlands  
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)  
Hôpital Saint-Antoine, Paris, France.  
Inspire 2 Live (I2L)  
Istituto Oncologico Veneto, Padova, Italy  
Istituto di Ricerche Farmacologiche "Mario Negri" Milan, Italy  
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.)  
Kings Health Partners Integrated Cancer Centre, London UK  
Leiden University Medical Center, Leiden, The Netherlands.(LUMC)  
Leukaemia Patient Advocates Foundation (LPAF)  
Medical University of Gdansk, Gdansk, Poland.  
Medical University Vienna Austria  
Myeloma Patients Europe (MPE)  
National Cancer Institute, Milan, Italy  
Northern Ireland Cancer Research Consumers Forum (NICRCF)  
Queens University Belfast, UK (QUB)  
Sarcoma UK  
Sarcoma Patients EuroNet  
Society for Translational Oncology, North Carolina, USA (STO)  
University of Cologne, Germany  
University of Edinburgh, Scotland  
University of Southampton, UK  
Vall D'Hebron Institute of Oncology, Barcelona, Spain  
VU University Medical Center , Amsterdam, The Netherlands (VUmc)

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