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“Chronic Diseases’ Networks added value in policy making: Lessons from The European Cancer Patient’s Bill of Rights”

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European Cancer Concord and Queen’s University Belfast

8th European Patients’ Rights Day

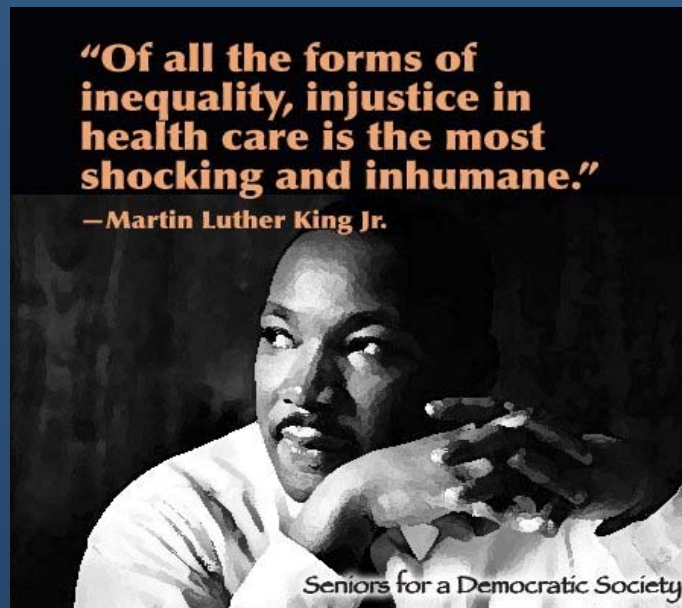
Active Citizenship Network Conference, Brussels, Belgium



*“The Greatest Wealth is
Health”*

Publius Vergilius Maro
(Better known as the
Roman poet Virgil)

Fast Forward ~2000 Years



Health care
Inequalities



Escalating Healthcare
Costs



EVERY MINUTE,
3 EUROPEAN CITIZENS
DIE FROM CANCER.

HOW CAN YOU HELP CHANGE THIS ?





Burden of cancer in Europe

-
- Cancer is the **leading cause** of **premature death** in **28 of 53** European Countries ¹
 - **Aging population** will underpin **significant increases** over the next 30 years ^{2, 3}
 - **Significant disparities** between different European countries

¹ WHO Europe Health Report (2013); ² Rechel et al, Lancet (2013) WHO IARC World Cancer Report (2014)



European Cancer Concord

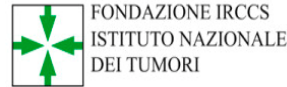
- **Equal Partnership** between **Patient Advocates** and **Healthcare Professionals**
- **Citizen focussed initiative**
- **Key goal** is to **identify inequalities** AND **do something about it!**
- **Engagement** at **European** and **National** levels



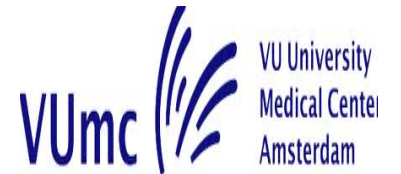
European Alliance for Personalised Medicine



50 years of Progress Against Cancer



University of Cologne



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European Cancer Concord

- Ability to
 - **Engage** at **European** level
 - **Support** particular issues **at local/in country** level
 - Consider **economic** and **societal** as well as health issues



The European Cancer Patient's Bill of Rights

- A **charter** to **challenge** the current **inequalities** that cancer patients in Europe are **experiencing** on a **daily** basis^{1, 2}
- A **catalyst for change** and an empowerment tool for cancer patients and their advocates

¹ Lawler et al *Lancet Oncology*, 4th February 2014

² Lawler et al *The Oncologist*, 4th February 2014

The European Cancer Patient's Bill of Rights

Lawler M, Le Chevalier T, Murphy MJ, Banks I, Conte PF, De Lorenzo F, Meunier F, Pinedo HM, Selby P, Armand JP, Barbacid M, Barzach M, Bergh J, Bode G, Cameron D, de Braud F, de Gramont A, Diehl V, Diler S, Erdem S, Fitzpatrick JM, Geissler J, Hollywood D, Højgaard L, Horgan D, Jassem J, Johnson PW, Kapitein P, Kelly J, Kloezen S, La Vecchia C, Löwenberg B, Oliver K, Sullivan R, Taberero J, Van de Velde CJ, Wilking N, Wilson R, Zielinski C, zur Hausen H, Johnston PG

A CATALYST FOR CHANGE: THE EUROPEAN CANCER PATIENT'S BILL OF RIGHTS

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A CATALYST FOR CHANGE: THE EUROPEAN CANCER PATIENT 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 OPT
AND TIMELY ACCESS TO APPROPRIATE SPECIALISED
UNDERPINNED BY RESEARCH AND INNOVATION

ARTICLE 3:
RIGHT OF EVERY EUROPEAN CITIZEN TO RECEIVE
HEALTH SYSTEMS THAT ENSURE IMPROVED OUTCO
PATIENT REHABILITATION, BEST QUALITY OF LIFE
AND AFFORDABLE HEALTH CARE.



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 1: Overarching Principles

- **Patient-centered** cancer services
- Most **up-to-date** information
- **Good communication and collaboration**
- **Shared transparent decision making** between healthcare provider and European citizen



The European Cancer Patient's Bill of Rights

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



Article 2: Overarching Principles

- **Equitable and transparent access** to optimal cancer care is the **right of the European Citizen**
- Clear **pathways to clinical innovation**, (diagnostics, surgery, radiotherapy, medicines) informed by research and innovation



The European Cancer Patient's Bill of Rights

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 health care



Article 3: Overarching Principles

- **National Cancer Control Plan**
- **Cost effective** cancer care
- Cancer **survivorship: active re-integration** and **participation** in society
- **Patient** Advocates as **equal partners**

Ageism in Cancer Care

- **Decisions** are being **made** on **date of birth** rather than the **fitness** of the patient
- **Mounting evidence** base
 - **Prostate** cancer
 - **Colorectal** cancer
 - **Breast** cancer



Remember

- **Age** is just a number
- **We NEED to CHANGE the MINDSET!** ¹
- **Need for a “Geriatric” approach**
 - Promote **early diagnosis** in the elderly
 - Make existing **treatments more available**
 - Develop **new approaches** for older patients
 - **Remove** upper **age limit** for **clinical trials**

¹ Lawler et al, British Medical Journal 2014



The Economic Burden of Cancer

- **Global economic burden** of cancer, due to premature death and disability, was **\$1.16 Trillion (2010)**¹ (>2% of worldwide GDP)
- **Europe: €124 billion (2009)**²
 - Direct Healthcare Costs (39%)
 - Loss of Productive Life Years (61%)

¹ American Cancer Society (2010)

² Luengo Fernandez R et al Lancet Oncology (2013)



Wealth is Health 2008

- **Tallinn** Charter
- Pledge to **invest** in improvement of **European Health Care Systems**
- Now a distant memory
- **BUT!**



Justification should not be forgotten

- **Appropriate investment** brings not only **better health** but
 - Drives **economic growth**
 - Increases **innovation**
 - Improves **productivity**
 - **Reduces pressure** on future **health** and **social welfare** systems



Rekindling “Greatest Wealth is Health” Agenda

- **Earlier access** to high quality diagnosis **underpins** more **successful therapeutic intervention**
- **Optimal cancer care** contributes to the **health and socio-economic benefit** of **European citizens**



A CALL TO ACTION

- **A MANDATE to MEPs FOR IMPROVED CANCER CARE FOR THE EUROPEAN CITIZEN**
 - Make **Cancer** part of their **Election Mandate**
 - Establish an **EU Cancer Plan**
 - **Strengthen** a cross party **MEPs against Cancer (M.A.C) Alliance**
 - Create a **European Cancer Survivorship Plan**



Acting at local level

- Northern Ireland
- **Partnership** with Cancer Focus Northern Ireland
- Addressing an **inequality** in cancer care **in the UK**



Cancer Drugs Fund

- Initiated in England in 2010
- **Access to innovative cancer drugs**
- **Scotland** and **Wales** moving towards variation of the English model
- **Whither Northern Ireland?**



Cancer Drugs – addressing the inequality issue

- Act as **catalyst**
- Effective **partnerships**
- **Influence** political thinking
- **Engage the Public**



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search for missing Flight MH370

mirror.co.uk

'Postcode lottery keeps cancer drugs from Ulster patients'

SDLP man says life-extending medicines only offered in Britain

BY VICTORIA McMAHON



Influencing the political agenda

- Forum to **inform** health care **spokespeople** from **each political party**
- **Debate** in the NI **Parliament**
- **Get the message out there!**

A newspaper clipping with a dark background and white text. The main headline reads "Drug access for cancer patients to be reviewed" in a large, bold, sans-serif font. Below it, a sub-headline says "Postcode lottery could be at an end". To the right of the text is a photograph of a man's face. At the bottom left, there is a smaller inset photo of two people and a caption that reads "Postcode lottery keeps cancer drugs from Usher patients". The main text discusses the issue of drug access, mentioning a "postcode lottery" and the need for a review. It also mentions a "Health Secretary" and "NHS".

Drug access for cancer patients to be reviewed

Postcode lottery could be at an end

Postcode lottery keeps cancer drugs from Usher patients

Health Secretary... NHS...

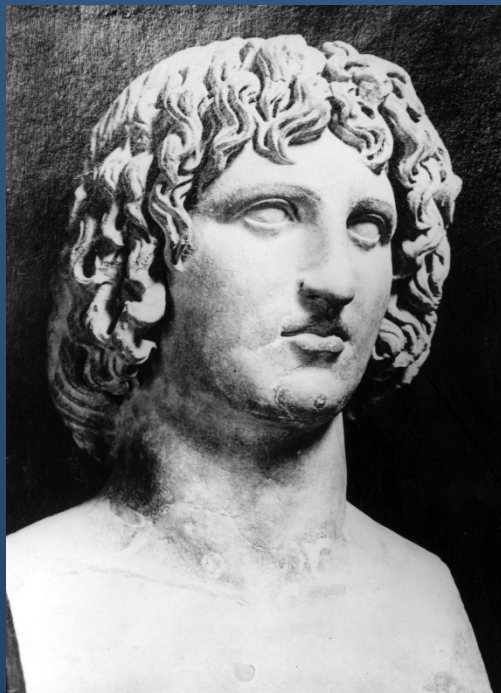
Sometimes it does work!



- Review announced
- Keep the pressure on!
Public campaign



Back to Virgil





“The noblest motive is the public good.”



Remember

- In 2012, **three European citizens** died **every minute** from this deadly disease
- By 2035, there will be a **cancer death** in Europe **every 10 seconds**
- Cancer respects no borders
- **We need to act NOW!**



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ECC Partners ¹

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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)

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International Brain Tumour Alliance (IBTA)

International Confederation of Childhood Cancer Parent Organisations (ICCCPO)

¹ ECC is actively engaging with potential partners



ECC Partners (continued)¹

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Italian Association of Cancer Patients (AIMaC)

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VU University Medical Center , Amsterdam, The Netherlands (VUmc)

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- Society for Translational Oncology

¹ ECC is approaching other organisations/foundations to provide funding for this initiative