

"The role of citizens' organisations in the empowerment of patients with chronic diseases".

8th European Patients' Rights Day

May 12-13 2014

VM3 (2nd floor) Van Maerlant Building, 2, rue Van Maerlant, 1040
Brussels

DRAFT PROGRAMME

9:30-10:00 Arrival, Registration and Welcome Coffee

Please allow time (up to ½ hour) for security check and registration before the meeting starts

First Day (12 May)

10:00 – 10:30 “Empowerment: a more clear definition”

Opening Remarks:

Tonio Borg, Health Commissioner (Video Message)

Ingrid Kössler, European Economic and Social Committee

Mariano Votta, Director of Active Citizenship Network

10:30 – 11:10 Keynote Presentations about the empowerment concept in its complementary dimensions:

1. individual empowerment: improvement of a person's capabilities to effectively self-manage his/her chronic disease;

2. organizations empowerment: enhancement of patient groups' capacities to participate efficiently in health policies.

- Institutional Point of view

Katja Neubauer, Deputy Head of Unit, Healthcare Systems Unit, DG SANCO

Rosa Suñol, EMPATHiE: the Study on "Empowering patients in the management of chronic diseases"

- Professional point of view:

Paul De Raeve, Secretary General, European Federation of Nurses Associations EFN,

Birgit Beger, Secretary General, The Standing Committee of European Doctors (CPME)

11.10 – 12.10 “Chronic diseases’ networks added value in policy making “

Keynote **Presentations** about different successful models to networking:

1) Vertical networks (*focused on one single chronic disease*):

Joao Nabais, President, [International Diabetes Federation IDF Europe](#)

2) Horizontal networks (*focused on similar diseases*):)

Mark Lawler, European Cancer Concord and Queens University Belfast

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- 3) Crosscutting networks (*who bring together different chronic diseases*):
Tonino Aceti, National Coordinator, Italian Coalition of Associations for Patients suffering Chronic Diseases, [CNAMC](#)
Catherine Hartmann, [European Chronic Disease Alliance \(ECDA\)](#)
- 4) Multistakeholders crosscutting networks:
Jaqueline Bowman Busato, [EPPOSI](#), EU and
James Ruvolo, “[Partnership to Fight Chronic Disease](#)”, USA

12.10-12.30 Question & answers from the public about the benefits and the weaknesses of the different models to networking

12.45 – 14.00 Lunch

14.00 – 14.40 “Empowerment in chronic diseases: best practices“

- Examples of National Best Practices from different EU Countries

Federico Cantelli, LUSS , Belgium

Manuel Serrano, EUGENIE, Spain

Janet Mifsud, Caritas Epilepsy Association, Malta

Ugo Viora, National Association Rheumatic Patients, Italy

14.40-15.10 Question & answers from the public

15:10 – 15:30 Coffe break

15:30 –16:00 “MANIFESTO FOR THE EMPOWERMENT “Produce a Joint declaration on the empowerment of chronic patients and their associations addressed to the new MEPs”

16:00 -17:00 Open debate at the presence of the representatives of the different health-care stakeholders (EU, national institutions, healthcare professionals, patients’ organizations, European Networks, etc...).

17:00 -17:15 Conclusions

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Second Day (13 May, only Morning Session)

VM3 (2nd floor) Van Maerlant Bulding, 2, rue Van Maerlant, 1040

9:30-10:00 Arrival

FOCUS

10:00 – 12:30

The role of patient organizations in promoting and supporting life changing and life- saving research into treatments or cures for chronic diseases

The panel and discussion will consider the importance of engaging the patient voice in the formulation and support of national and international policies that promote pharmaceutical and other medical research that leads to new preventions, treatments and cures for chronic diseases for which there are few, if any adequate treatments and cures.

10:00 -10:10 Introduction

Antonio Gaudio, Secretary General, Cittadinanzattiva

10:10 – 10:50 Panel 1: Responding to growing societal challenges

How can the effectiveness of medical research and innovation be incentivized to ensure that there are adequate treatment options for patients?

David Taylor, UCL School of Pharmacy, USA (Moderator)

Brendan Barnes, Director, Multilateral Organizations and Health Policy, European Federation of Pharmaceutical Industries and Associations (EFPIA)

Audrey Craven, Secretary General, European Federation of Neurological Association

Emma Woodford, Interim Secretary General, European Public Health Alliance, EPHA

Question & answers from the public

11:15 – 11: 55 Panel 2: Sustaining innovation and access

How can we better incentivize innovations while improving timely access to new and better medicines to those in need across the world?

Dr Ruxandra Draghia-Akli*, Director of the Health Directorate at the Research DG of the European Commission

Nathalie Moll, Secretary General of EuropaBio

Gianluigi Di Bello, Horizon 2020

Ratna Devi, Patient Advocate, Former Director, Chronic Care Foundation, India

Question & answers from the public

12: 30 Conclusion: Antonio Gaudio, Secretary General, Cittadinanzattiva

12:30 -13:30 Lunch

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