

**EUROPEAN PATIENTS' FORUM SPRING CONFERENCE**  
**Empowerment, Information, Sustainability**

**Renaissance Hotel, Brussels: 20/21 March, 2007.**

*Tuesday, 20<sup>th</sup> March, 2007.*

**12.30 to 14.00** Registration and Buffet Lunch

**14.00 to 14.10** Welcome and outline of the Meeting Programme by Mr Anders Olauson, President, European Patients' Forum

**14.10 to 14.30** Keynote Address by Mr Bernard Merkel, Health and Consumer Protection Directorate

**The Empowered Patient: A benefit or a liability?**

**14.30 to 14.50** The Regulatory Perspective – Mr. Noel Wathion, The European Medicines Agency  
What role should the EMEA perform with regard to the provision of information on medicines?

**14.50 to 15.10** The Physician's Perspective – Dr. Daniel Mart, President of CPME  
Should the healthcare profession be the gatekeeper of all information?

**15.10 to 15.30** The Economic Perspective – Mr. David Mc Daid, London School of Economics  
Is there a financial case to be made for an informed patient?

**15.30 to 15.50** Tea Break

European Patients' Forum, "Park Leopold" Rue Wiertz 50/28, B1050 Brussels  
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**15.50 to 16.10** The Politician's Perspective - Ms Dagmar Roth-Behrendt, MEP

Can information be controlled by legislation nationally or internationally?

**16.10 to 16.30** The Commission's Perspective – Mr Rui Santos,

Consumer Goods, Enterprise and Industry Directorate-General

By whom and to whom should information be provided?

**16.30 to 16.50** How can we ensure the sustainability of patient organizations and who will be funding them in 2017? What part will corporate social

responsibility play? Mr Richard Bergstrom, Director of Swedish Association of the Pharmaceutical Industry. Followed by Patient Perspective, Mr Anders Olauson

**16.50 to 17.30** General Discussion with Speakers comprising the panel

**19.30 to 22.00** Conference Dinner, Renaissance Hotel

*Wednesday, 21<sup>st</sup> March, 2007.*

**Break out into 3 Breakout Groups 09.15 to 12.45**

**GROUP A**

**Who really represents patients?**

Patient organisations may be experts in their condition but rarely represent more than 2% of those affected by the condition. How can they speak for all patients? What is the role of consumer bodies? Are they legitimate representatives? How can increased solidarity be achieved across the European Patients' Movement? Should healthcare professionals be involved? Who validates the information provided by patient organisations?

*Facilitator:* Ms Mel Read  
Member of European Parliament 1989-2004  
President of European Cervical Cancer Assoc  
Honorary Chair of Health First Europe  
Member of GlaxoSmithKline Health Advisory Board

*Rapporteur:* Mr Mike O'Donovan  
Treasurer  
European Patients' Forum

**GROUP B**

**Is ignorance bliss or is an informed patient a sound economic investment?**

What is the evidence that an informed and educated patient uses healthcare services more effectively and more efficiently? Or does the more informed and empowered patient cost more by demanding the latest and most costly drugs and treatments? Should health be viewed as an investment or a cost?

*Facilitator:* Mr Jorgo Chatzimarkakis,  
Member of the European Parliament

*Rapporteur:* Mr Jean Georges  
European Patients' Forum

**GROUP C**

**Are patient organisations viable and sustainable? If so, by whom?**

Many national and supranational patient organisations have become highly effective in their respective disease areas. But many are extremely fragile financially. How sustainable are they in the medium to long term? Competition is fierce for the finite funding available. How

realistic is it for patient groups to devote such many resources to fundraising to ensure their continued existence? Is this a good and legitimate use of such resources? Is there too much duplication within a disease area resulting in wastage? What may be classified as legitimate funding sources? What role should the pharmaceutical industry continue to play? Who else would provide funding? What should be the Commission's position?

*Facilitator:* Ms Celine van Doosselaere  
European Health Management Assoc

*Rapporteur:* Mr Rodney Elgie  
GAMIAN Europe

It is suggested that each breakout group should last for 90 minutes with a coffee break at 10.45 until 11.15. Delegates may then attend another breakout group from 11.15 until 12.45.

**12.45 to 14.00** Lunch

Plenary Session : How do we manage the future?

**14.00 to 14.30** Feedback from each Rapporteur

**14.30 to 14.55** The prevailing environment in 2017. How well informed will patients be ten years from now and from what sources will information be available? Dr. Ilona Kickbusch, Senior Health Policy Advisor and WHO Consultant.

**14.55 to 15.20** The Patients' Perspective – Ms Susanna Palkonen, European Federation of Allergy and Airways Disease Patients' Associations

**15.20 to 16.00** General facilitated discussion

**16.00 to 16.15** Conclusions and close of the meeting- Mr Anders Olauson, President EPF

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