



ECPC Sustaining Partner Meeting

1. Nov. 2005, ECCO 13, Paris

CHAMPIONING THE INTERESTS OF EUROPEAN CANCER PATIENTS

What is ECPC?

The **European Cancer Patient Coalition** has been established to represent the views of cancer patients in the European healthcare debate and to provide a forum for European cancer patient organisations to exchange information and share best practice

ECPC Goals

- Nothing About Us, Without Us!
- Promoting the fundamental rights of European cancer patients
- Increasing cancer patients' influence over European health policy
- Ensuring timely access to appropriate prevention advice, treatment and care
- Promoting the advancement of cancer research



ECPC Facts & Figures

- ECPC was launched in Sept 2003
- More than 160 full EU members
- Representing more than 19 EU countries
- Many representing rare cancers but also breast, prostate, lung and colorectal cancer
- Virtual 'trade union' of European cancer patients
- Speaking with "one voice" for all cancer patients

ECPC Board Members

Lynn Faulds Wood, President (UK)

Member organisation: Lynn's Bowel Cancer Campaign



Jesme Baird (UK)

Member organisation: The Roy Castle Lung Cancer Foundation



Jan Geißler (Germany)

Member organisation: Leukaemie-Online.de,



Tom Hudson (Ireland)

Member organisation: Europa Uomo, Men Against Cancer (MAC)



Heide Preuß (Germany)

Member organisation: Mamazone women and genomics against breast cancer



Panayiotis E Mallis (Cyprus)

Member organisation: The Cyprus Association of Cancer Patients and Friends



Harm Jan Roelants (The Netherlands)

Member organisation: Dutch Federation of Cancer Patients' Organizations (NFK)



Kees van Bezooijen (The Netherlands)

Member organisation: Contact group Leukaemia



Elisabetta Iannelli (Italy)

Member organisation: Italian Association for Cancer Patients, relatives and friends (AIMaC)

ECPC GOALS AND ACHIEVEMENTS



What we've achieved so far ...

- Secured 3 years core funding from ESO and built relationship with 9 sustaining partners
- Held two ECPC Masterclasses in Patient Advocacy
- Established ECPC office and set up ECPC intranet
- Appointed Head of EU Policy based in Brussels
- Appointed Secretariat for MEPs Against Cancer
- Built up ECPC website ecpc-online.org under the Cancerworld.org umbrella/set up electronic newsletter
- Represented ECPC at major medical conferences – ESMO, ECCO, ESO Cancer on Internet, etc. etc.

Relationship with Sustaining Partners

- 9 Sustaining Partners:
 - AstraZeneca
 - Bristol-Myers Squibb
 - Eli Lilly
 - GlaxoSmithKline
 - Merck KGaA
 - Novartis
 - Ortho Biotech
 - Roche
 - Amgen
- Policy on Funding Arrangements with Commercial Companies

Opportunities for Sustaining Partners

- project sponsorship

- ECPC Masterclass
 - Travel sponsorships
 - Faculty dinner
 - Simultaneous translation
- Translation into major EU languages (e.g. ECPC website, documents, briefs)
- Pan-European Clinical Trials Registry project
- Media training
- Health expertise (resources and know how)
- Patient advocacy activities

Benefits for Sustaining Partners

- Annual sustaining partner meeting and quarterly report about ECPC activities
- Access to uniquely informed patients
 - Represented at ECPC Masterclass
- Link to corporate site from ECPC site
- Patients perspective on key health policy issues
- Networking with patients and other key stakeholders (Commission officials, MEPs...)
- Demonstrate social corporate responsibility
- Support patient advocacy
- Named as ECPC sponsor

ECPC Priority Activities 2005/2006

- Build and sustain the Coalition (funding, network and communication)
- Establish strategic alliances with EU stakeholders
 - MAC (MEPs against Cancer)
 - EMEA
 - SANCO Patient Working Groups etc.
- Influence the EU Health Care Debate
 - Cancer Screening
 - Paediatrics etc.
- Masterclass on Patient Advocacy
- Strengthen ECPC communication network
 - ECPC News and Newsletter
 - Web-site www.ecpc-online.org
 - Online forum



2nd ECPC Masterclass on Cancer Patient Advocacy (May 2005):

- More than 150 cancer patient organisations
- Representing more than 30 countries
- Speakers like John O'Toole (Health attachee), Horst Kloppenburg (Commission Official DG SANCO)
- Key pad voting with questions concerning important cancer issues
- Attendance was fuelled by
 - Europa Uomo meeting immediately prior to Masterclass
 - Clinical trials registry brainstorming meeting with key different stakeholders



3rd ECPC Masterclass 2006

- Milan, May 13-14 2006
- Honorary chair: Alojz Peterle (MEP)
- Coordinators: Jesme Baird (ECPC Board member, Royal CastleLung Cancer Foundation) & Hildrun Sundseth (Head of EU policy)
- Basic and advanced trainings and workshops for Patient Advocates
 - Funding
 - Working with the media
 - Patient Empowerment
 - Access to patient information
 - Clinical trials
 - Screening programme

'Nothing About Us, Without Us'

- Invited to help organise and chair patient seminars:
 - ESMO (Vienna Oct. 2004)
 - ECCO 13 (Paris Nov. 2005)
 - Patient Summit in Central/Eastern Europe (Nov. 2005)
- Invited to speak at medical meetings
 - BDA (Oct 2005)
 - ESO Cancer on Internet Conference (Sept 2005)
 - ESO Conference Oncological Cancer Care (Sept 2005)
 - ... and many more

Influencing European Policies and Legislation

- Appointed a Head of EU Policy based in Brussels
- Hildrun Sundseth –
A former policy advisor for a major pharmaceutical company (and cancer survivor)
- Aims to influence policies that impact on cancer prevention, treatment and care



Main focus ECPC EU lobbying



- MAC initiative (MEPs against cancer)
- EU Public Health Strategy
- EU Framework Research Programme
- Access to information about about best quality prevention, treatment and care
 - Pan-European clinical trials registry
- Cancer screening
- Paediatrics
- Patient mobility
- Equity of cancer care across Europe

NOW IT IS YOUR TURN!

Thank you for your support!