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)
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!