

Nothing About Us Without Us!



## ECPC – Speaking with a single voice for all cancer patients

Established in 2003, **The European Cancer Patient Coalition is the voice of the European cancer patient community, uniquely** representing the interests of all cancer patient groups from the major to the rarer cancers. It has been established to represent the views of cancer patients in the European healthcare debate and to provide a forum for European cancer patients to exchange information and share best practice experiences.

We derive our mandate to speak with **"one voice"** for **all** cancer patients from our membership and our democratic structure. With its motto **"Nothing about us without us!"**, ECPC represents more than 300 patient organisations in 41 countries, including the 27 EU Member States.

### ECPC's Mission

- **Making cancer a priority for action** on the European health policy agenda
- **Effecting change** in legislative or regulatory policies to help optimise cancer prevention, detection, treatment and care throughout Europe.
- Ensuring that all cancer patients in the EU have access to timely and appropriate information about **prevention, screening, early intervention, on-going clinical trials and best quality treatment and care.**
- **Empowering cancer patients** to take an active role in shaping European and national policy that impacts on cancer prevention, treatment and care
- Ensuring that **best cancer practice is shared across the EU** and gaps within and between Member States are eradicated
- The purpose of the association is to **foster cooperation between the cancer patients' organisations** within Europe and to develop a common policy, and everything that is related to this in the broadest sense of the word, either directly or indirectly.

### ECPC's Objectives

- To ensure that **the rights of cancer patients** are upheld and enforced.
- To increase **cancer patients' representation** and influence at the highest level of decision making, nationally and Europe-wide, in all areas that affect their health.
- To **empower patients** to become true partners in the healthcare system.
- To obtain for patients certain and **timely access to appropriate and accurate prevention, medical diagnosis, treatment and care**, including psycho-social care.
- To encourage population-based **screening programmes** according to European quality guidelines.
- To promote the advance of **cancer research**, to include all applicable information on well-designed Clinical Trials and where possible the right to enrol in them.
- To call for improved **multi-disciplinary training** of health professionals.

EUROPEAN  
**CANCER**  
**PATIENT**  
COALITION

Nothing About Us  
Without Us!

## ECPC ANNUAL REPORT 2009

ECPC is speaking with a single voice for all cancer patients

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## About ECPC

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We derive our mandate to speak with "one voice" for all cancer patients from our membership and our democratic structure. With its motto "Nothing about us without us!", ECPC represents more than 300 patient organisations in 41 countries, including all 27 EU member states.

## ECPC's Six Guiding Strategic Goals

- **Making cancer a priority for action** on the European health policy agenda
- **Effecting change in legislative or regulatory policies** to help optimise cancer prevention, detection, treatment and care throughout Europe
- **Ensuring that all cancer patients in the EU have access** to timely and appropriate information about prevention, screening, early intervention, on-going clinical trials and best quality treatment and care
- **Ensuring that best cancer practice** is shared across the EU and gaps within and between Member States are eradicated
- **Empowering cancer patients** to take an active role in shaping European and national policy that impacts on cancer prevention, treatment and care
- **Fostering co-operation** between the cancer patients' organisations within Europe and to develop a common policy

## ECPC's Objectives

- To ensure that the **rights of cancer patients** are upheld and enforced
- To **increase cancer patients' representation and influence** at the highest level of decision making, nationally and Europe-wide, in all areas that affect their health
- To **empower patients to become true partners** in the healthcare system
- To obtain for patients certain and timely access to appropriate and accurate **prevention, medical diagnosis, treatment and care, including psycho-social care**
- To **encourage population-based screening programmes** according to European quality guidelines
- To **promote the advance of cancer research**, to include all applicable information on well-designed clinical trials and where possible the right to enroll in them
- To call for improved **multi-disciplinary training of health professionals**

## ECPC's Priority Areas (2009-2013)

- **Influence EU policy** that has an impact on the prevention, detection and treatment of cancer
- **Reach out to national level** to support ECPC members in their capacity building efforts on the national level
- **Build strategic partnerships** with key cancer stakeholders to create mutual benefit
- **Build ECPC's capacity** through an effective and growing organisation



## ECPC Board of Directors (2007 – 2010)

ECPC was founded by a group of cancer patients with the encouragement of healthcare professionals. It is governed by a Board of Directors, over half of whom are cancer patients or survivors from six European Union countries. These members form the board for the period 2007 – 2010:

- **Tom Hudson** (ECPC President), Europa Uomo, Ireland
- **Simona Ene** (ECPC Vice President), Sharing same Destinies, Romania
- **Heide Preuss** (ECPC Vice President), mamazone woman and research against breast cancer, Germany
- **Sandy Craine** (ECPC Secretary), CML Support Group, UK
- **Tom van der Wal** (ECPC Treasurer), Stichting Diagnose Kanker (SDK), The Netherlands
- **Lynn Faulds Wood**, Lynn's Bowel Cancer Campaign, UK
- **Luminita Andreescu**, FAVO & Anvolt, Italy
- **Evgeniya Adarska**, APOZ, Bulgaria
- **Jesme Fox**, Roy Castle Lung Cancer Foundation, UK (resigned June 2009)



Tom Hudson



Simona Ene



Heide Preuss



Sandy Craine



Tom van der Wal



Lynn Faulds Wood



Luminita Andreescu



Evgeniya Adarska



Jesme Fox

## ECPC Staff

- **Jan Geissler**, ECPC Director
- **Denis Horgan**, ECPC Political Affairs Manager
- **Hildrun Sundseth**, ECPC Director EU Policy (resigned June 2009)
- **Michaela Geissler**, ECPC Secretariat



Jan Geissler



Denis Horgan



Hildrun Sundseth



Michaela Geissler

## ECPC Patrons

ECPC is grateful for the patronage of

- **Androulla Vassiliou** (Cyprus)  
EU Health Commissioner (2008-2010)  
Former First Lady of Cyprus  
Honorary President of the Cyprus Association of Cancer Patients and Friends
- **Jolanta Kwasniewska**  
Founder and President of the "Communication Without Barriers" Foundation  
Former First Lady of Poland
- **Els Borst-Eilers** (The Netherlands)  
Former Minister of Health of the Netherlands  
Medical Doctor and Chair of the Dutch Federation of Cancer Patients



Androulla Vassiliou



Jolanta Kwasniewska



Els Borst-Eilers

## ECPC Members

ECPC welcomes all European Cancer Patient Organisations as members of ECPC. Over 300 cancer patient organisations from 41 countries have already joined ECPC as Full Members or Associate Members. The membership of the European Cancer Patient Coalition (ECPC) shall consist of cancer patient organisations. Full membership of ECPC is open to organisations meeting the following criteria:

- The organisation shall be registered as a non-profit organisation in one of the EU Member States. If the applicant organisation is not registered in an EU Member State, additional information will need to be provided demonstrating European focus and activities.
- The main objective of the organisation must be the advocacy, support and care of cancer patients and their carers, and have a clear patient focus.
- Cancer patients or their relatives shall be involved in the organisation's governing body and committees
- The organisation shall be willing to co-operate with other organisations having the same objectives.

- The organisation shall be independent of governments, political parties and commercial organisations.
- The organisation shall accept and abide by the Statutes/Constitution, Vision, Mission and Objectives, as published on the ECPC website.

Other organisations, which do not fulfil the requirements of above are welcome to join ECPC as Associate Member, as long as they are a cancer-related organization, are non-profit, have the advocacy, support and care of cancer patients and their carers as their key focus, and show involvement of cancer patients or their relatives in the organisation's governing body and committees.

If you represent an EU cancer patient organisation, we hope you will join us in the fight against cancer. To become an ECPC member please contact [info@ecpc-online.org](mailto:info@ecpc-online.org) or see the ECPC website for the application form.



## Full Members as of 31.12.2009

<http://ecpc-online.org/members>

Selbsthilfe Prostatakrebs	Austria	Associazione Italiana Malati di Cancro, parenti ed amici (AIMaC)	Italy
Myeloma and Lymphoma Aid Austria	Austria	Studio e Assistenza Neoplasie del Sangue (SANES)	Italy
Austrian Myeloma Patient Association/EMP	Austria	Associazione Italiana Stomizzati-Finco (AISTOM)	Italy
Association Cancer House/Verein Krebshaus	Austria	Association 'Pina Simone per la tutela dell' ammalato di cancro'	Italy
Us Too (Belgium)	Belgium	Associazione Vela	Italy
European Myeloma Platform (EMP)	Belgium	Italian Federation of Volunteer-based cancer organisations(FAVO)	Italy
Study Group Brain Tumours Belgium/Werkgroep		Associazione Nazionale Guariti O Lungoviventi Oncologici	Italy
Hersentumoren VZW	Belgium	Associazione Lotta Tumori Nell'eta' Giovanile (ALTEG)	Italy
Contactgroup Myeloma Patients	Belgium	Associazione Nazionale Donne Operate al Seno (ANDOS)	Italy
Ontmoeting Ontspanning Kanker	Belgium	Le Donne Scelgono	Italy
APOZ- National Association of Patients with		Assistenza Neoplastici A Domicilio Alessandra Fusci (ANDAF)	Italy
Oncological Diseases	Bulgaria	Associazione Don Franco Baroni	Italy
National Association of People suffering from CML, Bulgaria	Bulgaria	Associazione per L'Assistenza Morale e Sociale	
Bulgarian Women's Cancer Association	Bulgaria	Negli Istituti onlus (AMSO)	Italy
National Organisation For Cervical Cancer Prophylaxis	Bulgaria	Associazione Nazionale Assistenza Psicologica	
Cyprus Association of Cancer Patients and Friends	Cyprus	Ammalati di Cancro (ANAPACA)	Italy
Patients' Rights Movement of Cyprus (KIDDA)	Cyprus	Associazione Linfa Contro il Cancro	Italy
Cyprus Anti-Cancer Society	Cyprus	Moby Dick- Associazione per le Unità di Cura Continuativa Onlus	Italy
League Against Cancer Prague	Czech Republic	Associazione Italiana Oncologia Apparato Digerente (AIOAD)	Italy
ARCUS	Czech Republic	Associazione di Volontariato per Malati Oncologici (ANTHOS)	Italy
Diagnoza CML	Czech Republic	Federazione Italiana Incontinenti (FINCO)	Italy
Europa Uomo Brno (Czech Republic)	Czech Republic	Insieme per la Salute	Italy
Europa Uomo Denmark (PROPA PROstatacancer		Per Te Donna Onlus	Italy
PAtientforeningen)	Denmark	Associazione Nazionale Donne operate al Seno-Rovigo (ANDOS)	Italy
Danish Breast Cancer Organisation	Denmark	Associazione Malati Oncologici (AMO)	Italy
Patient Group for lymph and leukemia cancer patients	Denmark	Associazione Oncologica Pisana P. Trivella	Italy
Union of Estonian Leukaemia Patients	Estonia	Coordinamento La Mela Blu	Italy
Estonian Cancer Society	Estonia	Associazione CuLCaSG - ALCASE Italia ONLUS	Italy
Finnish Prostate Cancer Association (PROPO)	Finland	Progetto Vita 'Perche' Di Cancro si Puo Vivere	Italy
ANAMACAP (association Nationale de Malades		Noi e il Cancro- Volonta di Vivere	Italy
du Cancer de la Prostate)	France	Comitato Andrea Tudisco Onlus	Italy
French GIST Patient Association/Ass Francais		Gruppo Assistenza Neoplastici (GNA)	Italy
des patients du GIST	France	Fondazione Teresa e Luigi Beaumont Bonelli	
Myeloma Euronet AISBL	Germany	per le Ricerca sul cancro	Italy
Mamazone, women and research against breast cancer	Germany	Associazione 'Lotta Contro I Tumori Renzo e Pia Fiorot'	Italy
Leukaemie-Online e.V.	Germany	Associazione IO Domani	Italy
Bundesverband ProstataKrebs Selbsthilfe (BPS) e.V.	Germany	Associazione Siciliana per La Lotta Contro le Leucemie e I Tumo	Italy
PATH	Germany	Associazione Scientifica per la Terapia e la Ricerca	
German Fatigue Society / Deutsche Fatigue Gesellschaft e.V.	Germany	in oncologi (ASTRO)	Italy
German Leukaemia and Lymphoma Aid /		Associazione 'Insieme'	Italy
Deutsche Leukaemie- und Lymphom-Hilfe	Germany	Aiutiamoci a Vivere Onlus	Italy
The House of Life/Das Lebenshaus	Germany	Armonia- Associazione per la lotta contro I tumori al seno	Italy
SPAEN (Sarcoma Patients EuroNet)	Germany	Associazione Stare Bene Insieme ONLUS	Italy
Cancer Patients Society of Macedonia-Thrace	Greece	Associazione in Famiglia	Italy
Society of Cancer Patients in Katerini/Pieriz	Greece	Centro Ascolto Operate al Seno onlus (C.A.O.S)	Italy
Pan-Hellenic Association of Laryngectomees	Greece	Associazione Allegra	Italy
Cancer Patient Society of Nigrita	Greece	Associazione Guida Onlus	Italy
Society of Volunteers Against Cancer	Greece	Fondo Edo Tempia Onlus	Italy
Society Of Cancer Patients In Veria	Greece	Associazione V.I.O.L.A	Italy
Association Of Cancer KEFI Athens	Greece	Associazione Umbra per la lotta contro il cancro (AUCC)	Italy
Non-Profit Organization Friends of Cancer "BE STRONG"	Greece	Qualita Della Vita in Oncologia (Quavio)	Italy
Hungarian League Against Cancer	Hungary	Associazione per il sostegno oncologico	Italy
Childrens Cancer Foundation	Hungary	Associazione 'Mani Tese Ogliastro'	Italy
CML and GIST Patient Advocacy	Hungary	Associazione Donne Operate al Seno (BIOS)	Italy
Europa Uomo Ireland	Ireland	Associazione Nazionale Volontari Lotta contro I Tumori (ANVOLT)	Italy
Lymphoma Support Ireland	Ireland	Women Against Lung Cancer in Europe	Italy
Men Against Cancer (MAC)	Ireland	Association of Support for Leukaemia Patients	Latvia
Associazione Italiana Laringectomizzati AIL	Italy	Latvian Support Society for Oncology Patients "Dzivibas koks"	Latvia
Associazione Italiana Contro le Leucemie (AIL)	Italy	Society of Oncohematological Patients 'Kraujas' (OHLB)	Lithuania

Pink Ribbon Society	Lithuania
Lithuanian Association of Prostate Cancer Patients	Lithuania
ALMA	Lithuania
Rare Cancer Patients Association	Lithuania
A Heart for Sick Children	Luxembourg
Breast Care Support Group	Malta
Borstkanker Vereniging Nederland	
(Dutch Breast Cancer Society)	Netherlands
Longkanker Informatiecentrum/	
Lung Cancer Information Centre	Netherlands
Foundation Contact- Group Leukaemia/NFK	Netherlands
Contact Group Stem Cell Transplantation	Netherlands
CKP - MM and WM Patient Association	Netherlands
Asbestslachtoffers Vereniging Nederland (Avn)	Netherlands
Belangenvereniging Von Hippel Lindau (Vhl)	Netherlands
Belangengroep M.E.N	Netherlands
Polyposis contactgroep (PPC)	Netherlands
Vereniging HNPPC	Netherlands
Stichting OLIJF	Netherlands
Vereniging Cerebraal	Netherlands
Stichting Klankbord	Netherlands
Stichting Melanoom	Netherlands
Stichting Jongeren en Kanker (SJK)	Netherlands
Vereniging Ouders, Kinderen en Kanker' (VOKK)	Netherlands
Stichting Longkanker	Netherlands
Stichting Contactgroep Prostaatcancer (Scp)	Netherlands
Nederlandse Stomavereniging 'Harry Bacon'	Netherlands
Nederlandse Stichting Voor Gelaryngectomeerden (Nsvg)	Netherlands
Vereniging Waterloop	Netherlands
Stichting Kernzaak	Netherlands
NFK	Netherlands
Hodgkin Contactgroup	Netherlands
Stichting Diagnose Kanker/SDK	Netherlands
Support Immigrants And Cancer	Netherlands
European Waldenstrom Macroglobulinemia Network	Netherlands
Amazons (Warsaw)	Poland
Amazons (Poznan)	Poland
Association of Men with Prostate Diseases 'Gladiator'	Poland
National Association for CML Patients Aid	Poland
Polish Association of Ostomy Care, POL-ILKO	Poland
Stowarzyszenie Pomocy Chorym Na Gist	Poland
Sarcoma Patients Association	Poland
Blood Cell Foundation for children with cancer diseases	Poland
Fundacja Polska Koalicja Organizacji Pacjentow Onkologicznych	Poland
Viva Mulher Viva Association	Portugal
APLL Associacao Portuguesa de Leucemias e Linfomas	Portugal
Associacao Portuguesa dos Doentes da Prostata (APDP)	Portugal
Romanian Cancer Society	Romania
P.A.V.E.L. Association	Romania
Romanian Cancer Association - "Common Destinies" Group	Romania
Association of Cancer Patients from Romania (A.B.C)	Romania
Romanian Leukaemia Association	Romania
Myeloma Euronet, Romania	Romania
"Club of Bistrita Amazons" Association	Romania
Asociatia Oncologic Rom	Romania
Europa Uomo Slovakia	Slovakia
Cancer Patients Association of Slovenia	Slovenia
Slovenian Breast Cancer Coalition	Slovenia
FEFOC	Spain

Spanish Association of Lymphoma Sufferers	Spain
Grup Agata	Spain
FEOMA	Spain
Prostatacancerförbundet (PCF)	Sweden
Gynsam	Sweden
Swedish Lung Cancer Support	Sweden
Breakthrough Breast Cancer	United Kingdom
MacMillan/Cancerbackup	United Kingdom
Leukaemia Care Society	United Kingdom
Lymphoma Association HQ	United Kingdom
Christian Lewis Trust - Cancer Care for Children	United Kingdom
International Myeloma Foundation (UK)	United Kingdom
B.E. Bosom Friends	United Kingdom
Cancer Link Aberdeen and North (CLAN)	United Kingdom
Gist Support UK	United Kingdom
Bradford Cancer Support	United Kingdom
Samantha Dickson Research Trust	United Kingdom
Sarcoma UK	United Kingdom
National Conference of Cancer Self Help Groups	United Kingdom
Childhood Eye Cancer Trust : CHECT	United Kingdom
Riding's Asbestos Support and Awareness Group	United Kingdom
Tak Tent Cancer Support Scotland	United Kingdom
Keith Cancer Link Support Group	United Kingdom
Radiotherapy Action Group Exposure (RAGE South)	United Kingdom
Ovacome	United Kingdom
Roy Castle Lung Cancer Foundation Glasgow	United Kingdom
Mulberry Centre	United Kingdom
Manx Cancer Help Association	United Kingdom
Ulster Cancer Foundation (UCF)	United Kingdom
Let's Face It	United Kingdom
Complementary Cancer Care Trust	United Kingdom
Durham and District Womens Cancer Support Group	United Kingdom
Doncaster Cancer Support Group	United Kingdom
Cavendish Centre for Cancer Care	United Kingdom
Cancer Information and Support Services (CISS)	United Kingdom
GKT Cancercentre User Liaison Group	United Kingdom
CML Support Group UK	United Kingdom
Gynae C	United Kingdom
PCaSO (Prostate Cancer Network)	United Kingdom
Cancer Equality	United Kingdom
Lynn's Bowel Cancer Campaign (LBCC)	United Kingdom
AMEND Association for Multiple Endocrine	
Neoplasia Disorders	United Kingdom
AMEND 1 (Association for Multiple Endocrine	
Neoplasia Disorders)	United Kingdom
Brain Tumour UK	United Kingdom
East Lancs Integrated Health Care Centre	United Kingdom
Consumer Liaison Group of the National	
Cancer Research Institute	United Kingdom
Prostate Cancer Support Association (Central England)	United Kingdom
National Association of Laryngectomee Clubs	United Kingdom
Patient Cancer Support Federation/Europa Uomo	United Kingdom
Bowel Cancer Wales (BCW)	United Kingdom
Myelodysplastic Syndromes Foundation (MDSF)	United Kingdom
Rarer Cancers Forum	United Kingdom
IBTA (International Brain Tumour Alliance)	United Kingdom
Brainstrust: The Meg Jones Brain Cancer Charity	United Kingdom
Melanoma Action & Support Scotland (MASScot)	United Kingdom



Patients Rights Protection Center	Armenia	The Fulfilled Dreams Fund/Fundacja Spełnionych Marzeń	Poland
Breast Cancer Network Australia	Australia	Triedinstvo	Russian Federation
Cancer Voices NSW Australia	Australia	Association ILCO Serbia	Serbia and Montenegro
Humanitarian Association Of Prijateljice		ISKRA	Serbia and Montenegro
'Girlfriends'	Bosnia and Herzegovina	Association of Myeloma Patients in Serbia	Serbia and Montenegro
LIFE/Zenica	Bosnia and Herzegovina	Slovak League against Cancer/Venus Club	Slovakia
Association Of Stoma Patients ILCO		Myeloma Euronet, Slovakia	Slovakia
Of Republic Of Srpska	Bosnia and Herzegovina	Slovenian Union for Health promotion and health education	Slovenia
Association for those affected by acromegaly and pituitary disease	Bosnia and Herzegovina	Mieloma.Com	Spain
ABRALE	Brazil	Blodcancerfoerbundet (Blood Cancer Foundation)	Sweden
Bulgarian Association for Patient's Defence	Bulgaria	Foundation for the Promotion of Bone Marrow	
Willow Breast Cancer Support and Resource Services	Canada	Transplantation Switzerland	Switzerland
HULL Croatian Leukemia and Lymphoma Society	Croatia	Taichung Kai-Huai	Taiwan
Invalid Society ILCO Karlovac	Croatia	Turkey Oncology Patients Friendly Society	Turkey
Invalid Society ILCO/Stoma Klub Nova Gradiska	Croatia	Trabzon Hope and Welfare Organisation	Turkey
Croatian Disabled Societies ILCO Association	Croatia	Youth Accumulation Association	Turkey
"FOR A NEW DAY"	Croatia	Pioneering Association of Stem Cell Transplantations	Turkey
Help those with Cancer/KHYD	Cyprus	Sakarya Leukemia and cancer patients health and education association	Turkey
Friends For Life	Cyprus	FANCONI ANEMIA ASSOCIATION	Turkey
Faculty Of Medicine	Czech Republic	Skinship	United Kingdom
Independent Patient Group	Denmark	African Caribbean Leukaemia Trust (ACLT)	United Kingdom
ESCSG Basel	France	Mustard Tree MacMillan Centre	United Kingdom
Myelom - Plasmazytom Hilfe Muenchen	Germany	MacMillan Butterfly Centre	United Kingdom
Laugh and Walk (LAW)	Germany	Ardgowan Hospice	United Kingdom
Selbsthilfegruppe für Patientinnen mit Tumoren der Genitalien	Germany	Solihull Cancer Support Group	United Kingdom
Selbsthilfegruppe Plasmazytom/Multiple Myeloma - Berlin	Germany	Wirral Holistic Care Services	United Kingdom
Plasmazytom/Multiple Myelom Selbsthilfegruppe In Der Pfalz	Germany	UK Children's Cancer Study Group Hearts of Oak	United Kingdom
The Omylia Foundation, Center for Disease Prevention, "Panagia Philanthropini"	Greece	Abacus Cancer Self Help and Support Group	United Kingdom
Irish Cancer Society	Ireland	Hospice of St Mary of Furness	United Kingdom
Israeli CML Patients Support	Israel	Castleside Group	United Kingdom
Israel Cancer Association	Israel	Cornwall Cancer Help Groups (Truro)	United Kingdom
PROST	Italy	British Thyroid Foundation	United Kingdom
Associazione House Hospital Onlus	Italy	British Lung Foundation	United Kingdom
Associazione Maria Bianchi	Italy	CancerCare	United Kingdom
ANTEA Associazione - Onlus	Italy	Patients Association	United Kingdom
Cancer Patient Advocacy Bureau	Latvia	Vulva Awareness Campaign Organisation	United Kingdom
Myeloma Patients Organisation	Latvia	Myeloma UK - Yorkshire Support Group	United Kingdom
CancerVoices New Zealand	New Zealand	Myeloma People Network (Scotland)	United Kingdom
Esperantra	Peru	Cancer Partnership Research Group	
Foundation for Support of People with Urology Cancer	Poland	(SWSH Cancer Network)	United Kingdom
Stowarzyszenie Pomocy Chorym na Szpiczaka	Poland	Life Raft Group	United States
		Kidney Cancer Association	United States

## ECPC's EU Health Policy Work

One of ECPC's key priorities is to make cancer a priority for action on the European health policy agenda. With its policy activities, ECPC aims to effect change in legislative or regulatory policies to help optimise cancer prevention, detection, treatment and care throughout Europe. The policies also need to ensure that gaps within and between Member States are identified and eradicated, and that best practice is shared.

By speaking with a united voice for all cancer patients, with cancer affecting one third of the EU population, ECPC managed to give a new impetus to tackling cancer more forcefully and collaboratively by the EU and its 27 Member States. Combined efforts between patient groups, members of the European Parliament, the Commission, the European Medical Agency, EU Member States, industry and the oncology community made the fight against cancer once again a political priority for action.

### European Partnership for Action Against Cancer

The "European Partnership for Action Against Cancer" was initiated by the EU Commission in September 2009 with the support of a number of stakeholders like ECPC, bringing together the Commission, Member States and their Ministries of Health, patient organisations, health professionals, researchers, industry and civil society. The Partnership aims to engage relevant stakeholders across the EU in a collective effort to tackle cancer by providing a framework for identifying and sharing information, capacity and expertise in cancer prevention and control. The long-term aim set out by the Commission is to reduce new cancer cases by 15% by 2020.

ECPC played a very active role in the Cancer Partnership when it was initiated in 2009. At the launch event, Lynn Faulds Wood facilitated the panel discussion titled 'The Way Forward', constituted by experts and politicians. Mr. Alojz Peterle, co-chair of MEPs Against Cancer (MAC), gave the example of ECPC efforts and the MAC initiative as evidence

Through our Brussels office, ECPC will continue influencing the European health policy agenda by working closely with e.g. the Members of the European Parliament, the EU Commission (DG Sanco, DG Research, DG Internal Market, DG Enterprise), the Health Policy Forum (HPF), the European Medicines Agency and the EU Committee of Experts on Rare Diseases.

In 2009, ECPC has worked with all stakeholders to make cancer a political priority: for example, in the "European Partnership on Action against Cancer", with the "MEPs Against Cancer", in the European Parliament Elections, the European Medical Agency "Patient & Consumer Working Party", the European Health Policy Forum, the Rare Disease Task Force, or EU research projects like "European Guidelines for Colorectal Cancer Screening" or "RARECARE".

of a partnership in action at the EU level. ECPC presented stories of cancer survivors from the ECPC Membership from all 27 EU Member States, also including ECPC's Board Members Heide Preuß and Tom van der Wal. The patient was at the centre of the Partnership's launch.

ECPC's aim in the Partnership is to contribute the patients' voice and to include ECPC's member organisations in the work. ECPC proposed two key activities which were welcomed: The **"Virtual Partnership"** as an internet collaboration platform that will enable all partners to collaborate via the Internet, and encourage the public to contribute ideas. In addition, ECPC with the European Cancer League has suggested an initiative **"Young Europeans in the Partnership"** to acknowledge the important role of young people and engage with youth-driven energy and unfettered inspiration using "Social Media". First projects within the Partnership are expected to start their work in 2010.

<http://ecpc-online.org/partnership>



### Clinical Trials

After consulting its membership, having meetings with the Commission and clinicians, and an alignment with other patient groups, ECPC submitted a response to the EU Commission's "Impact Assessment of the Clinical Trials Directive". ECPC highlighted that clinical trials have been a key factor in improving cancer survival and advancement in treatment. However, the Directive and their national implementations have slowed the opening of trials, without a large improvement in patient safety, which already had a good track record in trials in oncology, or a desired acceleration or harmonization of pan-European cancer research. ECPC's detailed response is available on ECPC's website.

ECPC has also presented the patient perspective on clinical trials at various conferences, e.g.

- "Access to follow-on treatment" (EPPOSI Workshop on Clinical Trials, April 2009)
- "Cancer patient perspective on patient protection in centralized clinical trials applications and ethics reviews" (EFGCP, July 2009)
- "Access to Clinical Trials (ECCO, Sept 2009)
- "Therapy compliance, and patient perspective on collaborative, translational cancer research" (DG Sanco, Sept 2009)
- "Clinical research, therapy development and regulatory considerations" (EPPOSI, Oct 2009)
- "Understandability of informed consent and information in clinical trials" (AIO, Nov 2009)

<http://ecpc-online.org/trials>

### Health Policy Forum (DG Sanco)

ECPC is a member of the Commission's Health Policy Forum that brings together about 40 key stakeholders with an interest in health policy. The HPF provides a platform for policy formulation and consensus building around the EU health strategy. It also aims to ensure that the Commis-

sion's health strategy is made clear to the public. It offers ECPC the opportunity to influence and contribute at an early stage to health policy development, setting of priorities and actions. In 2009, ECPC has supported the Health Policy Forum e.g. with input on a common response of the Health Policy Forum on the Commission's consultation on the future EU 2020 strategy.

### Rare Diseases Task Force (DG Sanco)

The aims of the Rare Diseases Task Force are to advise and assist DG Sanco in promoting optimal prevention, diagnosis and treatment of rare diseases in Europe, in recognition of

the unique added value to be gained through European coordination. Being an observer of the Task Force, ECPC provided input into the discussions on behalf of rare cancer patients.

### Pharmacy Services (DG Internal Market)

In 2009, ECPC has developed new contacts with EU Directorate General "Internal Market" which is responsible e.g. for pharmacy services in the EU. Discussions were based around the risks of online sales in terms of counterfeit medicine, the need of self-payers for competitive

pricing of over-the-counter medicines, home delivery, and the potential role of pharmacies tackling adherence issues in oral cancer therapies. In 2009, ECPC presented at the Commission's "Workshop on Access to High Quality Pharmacy Services" which was attended by both the Commission and Member State representatives, outlining the patients' interests in pharmaceutical care.

### European Medicines Agency - Patient and Consumer Working Party

ECPC sits on the official Patient and Consumer Working Party (PCWP) of the European Medicines Agency. The PCWP provides a permanent forum for interaction with patients and consumer organizations to ensure that there is on ongoing dialogue between the Agency and the end users of medicines. Specifically, ECPC ensures that the cancer the patient's voice regarded by the regulator. In its

PCWP work, ECPC is consulted about the user-friendliness of product information for the public (EPARS) and package leaflets (SPCs), and is involved in the preparation of guidelines and consulted by Agency's scientific committees, working parties, and scientific advisory groups.

ECPC participates in two PCWP working groups: "Patient Information" and "Pharmco-vigilance and Risk Management".

More information at <http://ecpc-online.org/ema>

### EU Project: European Guidelines for Quality Assurance of Colorectal Cancer Screening

ECPC is an associate partner in the Commission-funded consortium set up to produce quality cancer screening guidelines for colorectal cancer. ECPC's role is to make sure that the Guidelines will be patient-friendly and to create

public awareness of the need for screening. ECPC, represented by Lynn Faulds Wood, has strongly supported the dissemination of the project's activities, and has assisted in the launch of colon cancer screening programmes e.g. in Cyprus and Slovenia. ECPC also sits on the steering committee of the project.

### EU Project: RARECARE

The burden of rare cancers in Europe is unknown, and no generally accepted definition exists. There are large variations in clinical outcome for rare cancers, with poorer survival among older patients and in eastern European countries. By aligning the epidemiological data of more than 80 cancer registries across Europe, the EU-funded project "RARECARE - Surveillance of Rare Cancers in Europe" aims to provide an operational definition of "rare cancers", and a list of cancers that meet this definition, and to estimate the burden of rare cancers in Europe. It has published a list of rare cancers with data on incidence,

survival, prevalence and mortality. It will develop strategies and mechanisms for the exchange of information among all the key players involved in Europe-wide surveillance for rare cancers.

ECPC, as a project partner and member of the Steering Committee, provides the patient perspective and supports the communication to a wider public. There have been several meetings in 2009 where ECPC has presented the patients' perspective, and has provided feedback on the projects' deliverables.

<http://www.rarecare.eu>

### MEPs Against Cancer (MAC)

After the Europe against Cancer programme closed in 2002, cancer had not been high on the political agenda of the European Union. This is why as a first step, ECPC encouraged Members of the European Parliament to set up an informal all-party forum called **MAC - MEPs Against Cancer**. ECPC provided the MAC Secretariat since MAC's initial start in 2006. Until the 2009 elections of the European Parliament, the group had grown to 70 MEPs from across the major political groups and Member States. MAC members were committed to make the fight against cancer once again an EU priority. As a work basis, MAC had adopted a "MAC Statement" with 7 policy recommendations which had been sent to Ministers of Health.

Since its initiation in 2006, MAC held 7 meetings to discuss important cancer issues that need urgent attention, e.g. on cancer screening, cancer control strategies, national cancer plans or young people and cancer prevention. ECPC as the MAC Secretariat facilitated these meetings.

In summer 2009, with the end of the 5 year legislature of the European Parliament, ECPC encouraged its membership to send letters to their MEPs requesting them to support the battle against cancer in their election campaigns, and to join MAC after elections. ECPC then also campaigned to transform MAC into a more formal group of the European Parliament. Even though the transformation did not happen, the campaign was very successful with over 120 MEPs supporting this issue. ECPC continues to support MAC and their co-chairs.

The MAC Statement, meeting reports and press releases can be found on the website [www.mepsagainstcancer.org](http://www.mepsagainstcancer.org). The website was developed and maintained by ECPC to keep MEPs in touch with the concerns of cancer patients and citizens.



### EU Parliament Elections 2009

Elections for Members of the European Parliament (MEPs) took place across Europe from 4-7 June 2009. ECPC provided a toolbox to its ECPC member organisations to prepare their campaign. The toolbox contained the "ECPC Guide to the 2009 European Parliament elections",

template letters and the "ECPC Manifesto against Cancer", a draft press release and a newsflash to translate and personalize in national campaigns. In addition, ECPC sent letters to all MEPs, highlighting the concerns of cancer patients, and asking them to support the fight against cancer in their future work.

### European Forum for Good Clinical Practice (EFGCP)

The European Forum for Good Clinical Practice (EFGCP) is a leading European non-profit think tank for discussion, research, and critical evaluation in the development of European health re-search. Its purpose is to promote Good Clinical Practice (GCP) and encourage the practice of common, high-quality standards in all stages of clinical

research throughout Europe. EFGCP organises international conferences on these topics.

In July 2009, ECPC presented the cancer patient perspective at the "Multidisciplinary Workshop on A Single CTA in Multinational Clinical Trials - Dream or Option?". Looking at the complicated field of ethics reviews, ECPC supported the idea of centralized trial applications and ethical reviews of clinical trials across Europe and called for less diversity in ethical reviews.

### European Platform for Patients' Organisations, Sciency and Industry (EPPOSI)

EPPOSI is an EU patient-led partnership between patients' organisations, science and industry, founded in 1994 for the exchange of information and discussion of policies in EU human healthcare. It aims to establish a strong European alliance of these stakeholders, jointly working on healthcare policies towards treatment and prevention of serious diseases.

In 2009, ECPC has been on the Steering Committee and Organizing committee of the "EPPOSI 10th Workshop on Partnering for Rare Diseases Therapy Development", and has been presenting a cancer patient's voice at the conference. In addition, ECPC has co-chaired a session at the "Workshop on Clinical Trials - Shaping the Future of European Clinical Research Legislation".



## EFPIA Think Tank

In 1998, patients' organisations and the pharmaceutical industry decided to set up a joint Think Tank in order to have a dialogue on EU policy issues in the area of health and research. Patients' organisations and industry recognised that on many EU policies, patients and industry may work together towards achieving the same policy goals, without compromising the others autonomy.

## ECCO Patient Advisory Committee

ECPC is a member of the ECCO Patient Advisory Committee, an independent initiative of ECCO (European CanCer Organisation). The committee's main function is to

Patients' organisations bring their own unique knowledge on the challenges of living with their particular illnesses, their attitudes, perceptions and expectations.

ECPC is a member of this Think Tank which includes 28 patient groups and 14 companies across all disease areas, and has participated in their meetings in 2009, contributing the perspective and special needs of the cancer patient community.

provide the patients' perspective and advice to ECCO's activities. With that activity, ECPC has provided input to the organisers of the patient track of ECCO's annual congress which was held in September 2009 in Berlin, Germany.

## European Patients Right Day 2009

ECPC, together with other national and European patient organisations, has always advocated for improvement of the rights of cancer patients. For example, the Warsaw Declaration, which was co-signed in 2005 by more than 140 cancer advocates, called on policy makers, politicians and key stakeholders urgently to "encourage and adopt national Charters of Patients' Rights according to European guidelines". ECPC has played a major role in organizing the Warsaw Summit.

On 18 April 2009, ECPC participated in the second "European Patients Rights Day" and encouraged its member organisations to communicate the "European Charter of Patients Rights", established by Active Citizenship Network. On that day, ECPC also published its position on Cancer Patients Rights, highlighting a number of amendments that outline the specific needs of cancer patients.

<http://ecpc-online.org/rights>

## "European Action Against Rare Cancers" Campaign

In June 2009 a new campaign "European Action Against Rare Cancers" has been launched. The new campaign urges European policy-makers to prioritize better treatment and care for patients with rare cancers within the framework of the new Commission Communication on cancer and other recent policy initiatives such as the Council Recommendation on Rare Diseases. The initiative has established a **Call to Action** – an international petition to be endorsed by organisations and private individuals. The Call to Action appeals to policy-makers and all other relevant stakeholders to initiate targeted actions and policies that will address the challenges that rare cancers entail for the patients who are living with the

disease, for the physicians who are treating the patients, and for the researchers who are working to acquire more knowledge in this field.

European Action Against Rare Cancers is a joint initiative led by the European Society for Medical Oncology (ESMO), based on a partnership between ESMO, the European Organisation for Rare Diseases (Eurordis), **European Cancer Patient Coalition (ECPC)**, Conticanet, the Association of European Cancer Leagues (ECL), the Chronic Myeloid Leukaemia Support Group UK, the International Brain Tumour Alliance (IBTA), Orphanet, Chronic Myeloid Leukaemia Advocates Network and the European Institute of Oncology (EIO) and Novartis Oncology. The organisations collaborate as equal partners and all decisions are made on the basis of consensus. See also <http://www.rarecancers.eu>

## Other ECPC Policy Activities in 2009

- Animal Welfare Directive – ECPC Response
- Patients' rights in cross-border healthcare – ECPC Member Brief
- Information to Patients – ECPC Position Paper
- Rare Cancers – ECPC Position Paper
- Rare Diseases – Member Update on Commission Communication and Rare Disease Day
- DG Sanco Roundtable
- DG Sanco Europe for Patients Portal
- Counterfeit Medicines – ECPC Position Paper / Member Brief
- Pharmacovigilance / Patient Safety – ECPC Member Briefs

## ECPC's Capacity Building work for ECPC Members

### ECPC Advocacy Toolbox

ECPC provides a forum for European cancer patient groups to share best practice and skills. Its "Advocacy Toolbox" was set up to provide helpful resources for cancer patient advocates and organisations. In 2009, ECPC has put a lot of effort in extending the toolbox to support its membership.

In 2009, the following tools were developed or updated:

- **ECPC Conference Toolbox** – the ECPC step by step guide for organizing patient conferences, with ready to use templates.

- **ECPC EU Elections 2009 Toolbox**, with a guide, template letters, the "ECPC Manifesto against Cancer", a draft press release and a draft newsflash.
- **ECPC Patients Rights Charter** – which was translated into other languages by ECPC's members
- **Building Good Patient Group Websites** – a guide on how to design and set up a websites for patient organization
- **EU Policy Handbook** - 30-page handbook with a broad introduction of EU cancer policy, legislative procedures and measures.

<http://ecpc-online.org/toolbox>

### ECPC Masterclass: Members in Action 2009

The ECPC Members in Action 2009" conference (held 24-25 Oct 2009 in Munich) which brought together more than 100 representatives of patient organisations from 30 European countries as well as other stakeholders to discuss the pressing concerns for European citizens diagnosed with Cancer.

"ECPC Members in Action 2009" particular aimed to

1. identify how ECPC, in close cooperation with its members, can play a meaningful role in developing Europe-wide initiatives to tackle the significant and growing burden of cancer,
2. to identify ways how ECPC can encourage partnerships and interactions between different stakeholders on the pan-European and national level,

3. to ensure that representatives of cancer patient organisations have the information, tools, knowledge and support they need to advocate on behalf of patients in their countries.

This 4th "Masterclass in cancer patient advocacy" represented the continued commitment to a process which has the aim that all cancer patients are able to work within a partnership, no matter where they live and which cancer they are affected by. This was reflected by the diverse range of participants at "ECPC Members in Action 2009" which included patients, but also clinicians, academics, politicians and industry, all striving to encourage innovative, creative thinking in order to stimulate a change to the wider public perceptions on cancer.

A detailed report of the "ECPC Members in Action 2009" is available on the ECPC website.

<http://ecpc-online.org/mc09>





## ECPC Member Updates and Press Releases

All ECPC's members regularly receive newsletters with news about ECPC's activities on behalf of their membership.

### Member Updates 2009

- ECPC Member Background Briefing on the European Parliament hearings of the EU Commissioners-designate (Jan 2010)
- EU 2020 Strategy (Jan 2010)
- Falsified/Counterfeit Medicinal Products (Dec 2009)
- Cross-Border Healthcare: Failure to reach political agreement on a draft directive (Dec 2009)
- Review of Animal Welfare Directive (Dec 2009)
- European Parliament adopts resolution on smoke-free environments (Nov 2009)
- Impact Assessment of Clinical Trials Directive: Meeting of patients' organisations with EU Commission (Nov 2009)
- European Commission on Health Inequalities (Oct 2009)

- Launch European Partnership for Action Against Cancer (Sept 2009)
- Launch Campaign European Action Against Rare Cancers (June 2009)
- EU draft legislation - patient access to information on prescription medicines in peril (June 2009)
- European Parliament votes for balance between medical research and animal welfare (May 2009)
- Patient's Rights Day (April 2009)
- More cancer screening needed in EU, concludes EC report (Jan 2009)

### Press Releases 2009

- World Cancer Day (Feb 2009)
- European Partnership for Action against Cancer (June 2009)
- ECPC Members in Action Conference and ECPC Awards (Oct 2009)

<http://ecpc-online.org/updates>

## ECPC Presentations at Conferences in 2009

ECPC represented the cancers patients' perspectives when speaking at international meetings, including, among others:

- Biovision, The World Life Sciences Forum, France, 03/2009
- European Parliament Magazine Conference "Action on Cancer" Brussels, 03/2009
- EPPOSI Clinical Trials Workshop, Belgium, 04/2009
- New York, USA, Putting Knowledge into Practice: First transatlantic symposium on practical strategies to increase colon cancer screening and save more lives (Felix Burda Foundation) 04/2009
- EPPOSI Workshop on Partnering for Rare Disease Therapy Development, Belgium, 04/2009
- 4th European Liver Patients Association "Viral Hepatitis - a Continue Challenge", Brasov, Romania, 05/2009
- 7th International Conference of Organizations of Peoples with CML and GIST "New Horizons in Treating Cancer", Lisbon, Portugal, 06/2009
- EFGCP Workshop on centralized CTA and Ethics Reviews, Belgium, 07/2009
- Lance Armstrong Cancer Summit, Ireland, 08/2009
- World Conference on Lung Cancer, 08/2009
- "Proactive Prostates" Initiative, Belgium, 09/2009
- ECCO/ESMO Annual Congress, Berlin, Germany, 09/2009
- London, UK. London School of Economics HTA Summer School, 09/2009
- DG Research Workshop "Trends in translational research", Norway, 09/2009
- Launch Event of the DG SANCO European Partnership on Action against Cancer, Belgium, 09/2009
- ECPC Members in Action Conference/4th ECPC Masterclass, Germany, 10/2009
- EPPOSI workshop on Rare Disease Therapy Development (Specific challenges of rare Cancers), Belgium 10/2009
- Jolanta Kwasniewska's Foundation Childrens Cancer Event, Poland, 10/2009
- Chronic Disease & Health Management International Conference (Under the High Patronage of the President of Romania), Bucharest, Romania, 10/2009
- 3rd International Cancer Control Congress (ICCC), Italy 11/2009
- AIO Annual Meeting, Berlin, Germany, 11/2009
- EONS Advisory Council Meeting, 11/2009
- GASTRO 2009, UEGW / WCOG, UK, 11/2009
- "Daily challenges of Patient's Lives" Exhibition at the European Parliament, Belgium 12/2009
- BBMRI Stakeholders Forum on Biobanking, Paris, France, 12/2009
- Training Course on "Increasing the awareness of young people about cancer, Ankara, Turkey 12/2009
- 3rd International "Blooming Plant" Oncology Days, Ankara, Turkey 12/2009
- over 15 workshops in the European Parliament on Health-related issues including - Information to Patients, Counterfeits medicines and Cross Border Health Care

## Collaboration

ECPC actively maintains relationships with other European organisations, for example:

- European Cancer Organisation (ECCO)
- European Society for Medical Oncology (ESMO)
- European School of Oncology (ESO)
- European Cancer Leagues (ECL)
- European Oncology Nursing Society (EONS)
- European Platform for Patient Organisations, Science and Industry (EPPOSI)
- European Organisation for Rare Diseases (EURORDIS)
- European Organisation for research and Treatment of Cancer (EORTC)
- European Federation of Pharmaceutical Industries (EFPIA)
- European Patients' Forum (EPF)
- Europa Uomo
- Europa Donna
- European Forum for Good Clinical Practice (EFGCP)
- European Haematological Association (EHA)
- Drug Information Association (DIA)
- International Agency for Research on Cancer (IARC)
- International Union Against Cancer (UICC)
- International Alliance of Patient Organisations (IAPO)
- European Genetic Alliances' Network (EGAN)

## Outlook on ECPC's Activities in 2010

ECPC's four key priority areas for 2010 are:

### 1. EU Policy:

ECPC will continue to make sure cancer is a priority for action on the European health policy agenda by working closely with the new EU Commission's DG Sanco, DG Research, DG Internal Market, DG Enterprise, DG Youth, the Health Policy Forum (HPF), EU Committee of Experts on Rare Diseases, MEPs and the European Medicines Agency. Through our new Brussels office, we will continue with our EU Policy work, and look forward to collaborating with and supporting future EU presidencies (Spain, Belgium) as well as MEPs Against Cancer.

### 2. Outreach to the national level supporting members:

We are preparing two conferences for 2010. One focuses on the political process and will be held in Brussels, with another focused on capacity building in CEE countries. We would like to invite members to become National Advisers to ECPC, and will support initiatives wherever local (national) 'MACs groups' can be initiated. We also plan to extend our very popular 'Advocacy Toolbox', for example in the areas of social media and influencing policy. By setting up a 'Rare Cancers Action Group', we will be supporting ECPC member organisations that represent rarer and less common cancers to work together towards common goals.

### 3. Building strategic partnerships:

We want to expand our partnerships with other cancer groups & stakeholders in order to widen our cooperative work with other key patient advocacy groups, as well as further develop our relationships with professional organisations.

### 4. ECPC capacity building:

We will expand its infrastructure, resources and, as much as possible in such challenging economic times, try to enlarge the funding base. We will further extend communications with regular website updates, newswatches, member updates, press communications etc.



## Finances

### Funding Policy

ECPC welcomes EU grants, private donations, corporate donations, grants and sponsorship to fund certain projects and to enable the Coalition to grow and develop independently from commercial and governmental influences.

We owe it to our membership and patients across Europe, who have placed their trust in us, to act in a fully democratic, independent and transparent manner, according to the highest standards of good governance. We derive our legitimacy from our membership, ECPC's constitution and democratically elected board of whom more than half are cancer survivors. We are most anxious to work on a constructive approach together with all stakeholders to ensure the credibility of patient groups is safeguarded.

ECPC will foster dialogue, and establish collaborative partnerships, with all stakeholders whose decisions will affect the chance of survival and quality of life of millions of European cancer patients, including the industry. ECPC's relationship with funders is guided by its "Policy on Funding Arrangements with Commercial Partners" and ECPC's "Transparency Statement". These principles are used to guide ECPC's decisions, applying to all potential relations with any company from any industry as well as with governmental agencies. The purpose is to ensure that ECPC has a consistent and transparent approach to working with any funder, and to clarify ECPC's position on funding to its member organizations, commercial companies and the wider public.

<http://ecpc-online.org/finances>

### Funding 2009

ECPC gratefully acknowledges the financial support of the European Commission for work in the ongoing EU projects "Colorectal Cancer Screening Guidelines" and "RARECARE".

ECPC invites companies and individuals to become Sustaining Partners with an annual unrestricted grant. ECPC's relationship with its Sustaining Partners is guided by aforementioned policies. For 2009, ECPC would like to thank the following Sustaining Partners for their unrestricted educational grants:

- AMGEN
- AstraZeneca
- Ortho Biotech

- GSK
- Eli Lilly
- Merck
- Novartis
- Pfizer
- Sanofi Aventis
- Sanofi Pasteur MSD

In addition, the following companies have provided unrestricted educational grants for the "ECPC Members in Action Conference": Bristol-Myers Squibb, Eli Lilly, Glaxo Smith Kline, Novartis and Pfizer.

ECPC also gratefully acknowledges the continued support of the European School of Oncology (ESO), e.g. for supporting the maintenance of the ECPC website.

### ECPC Accounts 2009

#### Internal Balance Sheet as per 31 December 2009

ASSETS SIDE			LIABILITIES SIDE	
	EUR	EUR		EUR
<b>A. Current Assets</b>			<b>A. Equity</b>	
Trade accounts receivables		40.000,00	Status as per 1.1.2009	420.964,20
Cash Assets, Bank Deposits			Receipts	411.889,51
Cash Assets	1.007,71		Expenses	- 321.064,82
Kreissparkasse München	36.255,47		Status as per 31.12.2009	511.788,98
Lloyds TSB	17.451,43		<b>B. Deferred income and accrued expenses</b>	60.000,00
Lloyds TSB fixed term deposit	282.030,00			
Rabobank	15.044,37			
Rabobank savings account	180.000,00	531.788,98		
		571.788,98		571.788,98

### Profit and Loss Account for the period of January 1 until December 31, 2009

Income	2009 EUR
Unrestricted grants ECPC Sustaining Partners	330.000,00
Project sponsoring (in 2009: ECPC Masterclass Conference)	45.000,00
Cancerworld.org/ESO Sponsoring	5.000,00
EU Funding for EU Research Projects	
in 2009 Project "Colorectal Cancer Screening Guidelines"	23.685,60
Other Income	1.165,00
Interests	2.027,02
Refund of expenses	5.011,89
	411.889,51
<b>Expenses/Expenditures</b>	
200 ECPC projects	
201 MAC project	380,00
202 ECPC Masterclass Conference 2009	49.809,49
205 EU Research project expenditures	7.088,76
	57.278,25
300 ECPC Office Brussels	
301 Office rent and administrative support (until 31.12.2008)	0,00
301a Office rent (from 1.9.2009)	3.044,36
301b Political Affairs Manager (from 1.9.2009)	20.333,96
302 Director EU Policy (until 30.4.2009)	24.485,30
303 Assistant Head of EU Policy	6.000,00
	53.863,62
400 Operating and administrative costs	
401 Staff costs Head Office (Director and Administrator/Secretariat)	151.860,61
402 Office equipment, porti	1.832,60
403 IT/e Room	3.443,26
404 Telephone	1.349,46
405 Marketing/communication/PR	3.669,39
406 Legal and Tax Consulting Services	14.227,42
407 Miscellaneous	3.316,84
	179.699,58
500 Costs of the Board of Directors	19.750,13
600 Losses from exchange differences	10.473,24
<b>Expenses/expenditures in total</b>	321.064,82
<b>Excess of earnings over expenses</b>	90.824,69

### Legal Registration

ECPC is legally registered in Utrecht, The Netherlands, Register-Nr. 30211815. Registered address is ECPC, Oosterhaven 29, 1671 AM Medemblik, The Netherlands.

ECPC has non-profit status (ANBI = Algemeen Nut Beogende Instelling, Public Welfare Institution) with fiscal number 816853575, re-confirmed on 23 October 2009 by the Dutch tax authorities in Hertogenbosch, The Netherlands.

## ECPC Cancer Manifesto

The European Cancer Patient Coalition (ECPC) and its member organizations call on all candidates for the European Parliament elections to help us fight cancer in their country and across the European Union. One third of EU citizens are diagnosed with cancer and cancer kills about 1.7 million each year. We are aware that there are considerable inequalities in health status and cancer survival rates within and between Member States of the European Union. These inequalities will only increase under the current economic crisis as our health and social systems come under financial pressure.

We call on you to work towards implementing the European Parliament Cancer Resolution by supporting us in our campaign to:

- Encourage and adopt national Charters for patients' rights according to European guidelines to ensure that the rights of cancer patients are upheld and enforced.
- Urgently develop and, where existing, improve national cancer plans, setting priorities and effectively allocating resources for improving cancer control and research across the European Union, paying attention to rare or difficult to treat cancers.

- Ensure cancer patients are included in formulating and monitoring all research, legislation and policies that affect their health.
- Invest in cancer prevention in Member States and implement the Council Recommendation on Cancer Screening of 2003 by setting up or improving national high quality population-based screening programmes.
- Vigorously promote cancer awareness in the general public through the existing Europe against Cancer Code.
- Make timely, high quality and up to date information, diagnosis, treatment and care available for all cancer patients in each European Member State.
- Firmly tackle the socio-economic and geographic divide, which leads to inequalities in cancer control
- Oppose discrimination in the latest cancer treatment because of age, race, gender and domicile.

## How to contact ECPC

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### ECPC Website

<http://www.ecpc-online.org>

## Join ECPC

We welcome all European Cancer Patient Organisations as members of ECPC. Membership is free, please contact us at [info@ecpc-online.org](mailto:info@ecpc-online.org) or visit the ECPC website at <http://ecpc-online.org/members> to download the application form. Join us in the fight against cancer!

## Impressions

