



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



## ECPC ANNUAL REPORT 2010



ECPC SPEAKS WITH A SINGLE VOICE FOR ALL CANCER PATIENTS

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# Letter from the President

Dear ECPC Members,

Since our establishment in 2003, the European Cancer Patient Coalition, working with you, our members, has proved to be a valuable organisation, creating actions and policies that support cancer patient organisations throughout Europe. For ECPC, as across Europe, 2010 was a year of challenge. In spite of this, we have been successful in introducing many new initiatives which have brought cancer onto the European agenda to an unprecedented degree over the last twelve months.

2010 was a year dominated by severe economic recession which raised questions on the cost-effectiveness and efficiency on every level. For us as for so many others, this financial year has proved challenging and yet we succeeded in realising an impressive work plan.

The year was shaped by five significant ECPC events. Our Annual General Meeting in March attracted a large number of delegates and observers, and was a key opportunity for the members to review and define the direction of our policy work and revisit our governance model. It also gave us an opportunity to learn from patient leaders about how the economic crisis was impacting them and how we could best contribute to their lobbying work. In May, the new ECPC board was elected, invigorating ECPC and renewing its agenda.

In June we successfully introduced our new initiative: the "Forum Against Cancer Europe" (FACE), which continues to build on the collaboration between the European cancer patient community with European Parliamentarians. It aims to learn about, debate and form policies geared towards cancer patients across cancer types, regions and political parties. We have been able to use this forum to ensure that European cancer initiatives have the widest possible outreach, and importantly, that unfinished business remains on the political agenda. Thanks in no small part to our policy work, we have attracted an informal 'core' group of nearly 100 MEPs across the political Groups who actively support our patient-centred advocacy work in the



European Parliament. We would particularly like to recognise and thank them for their invaluable ongoing interest and support.

In July 2010, we decided to bring the focus of our activities to Brussels and established a new Central Office there, recruiting new staff and increasing our contact with European institutions. This necessitated closing our office in Munich.

In October, we held the ECPC Summit: 'Making the EU Cancer Partnership Work,' which was attended by the Commissioner for Health and Consumers Affairs John Dalli, top representatives of the European Institutions, European professional organisations and of course you, our member organisations.

In November, we held a two-day conference entitled "Bridging cancer care" in Bucharest. The conference addressed patient advocates in CEE countries and aimed to build capacity, to create momentum to strengthen local groups, and to increase collaboration between patient groups and other stakeholders including nurses, pharmacists and decision-makers.

In 2010, we also addressed a number of policy dossiers which were new to us – Medical Devices, Cross-border Healthcare, the Clinical Trials Directive, Pharmacovigilance, Counterfeit Medicines, Health Inequalities, Health Technology Assessments and eHealth. We have been actively engaged in the Eu-



European Union Health Policy Forum, working closely with health NGO allies on broader health themes, always ensuring that patients are represented.

ECPC representation in major EU-level Health Forums, Consultative Committees and Working Groups has continued to grow. In addition to involvement in the European Union Health Policy Forum, the Open Health Forum, the EMA patient and consumer working party EUROCAN and the Steering Group of the European Partnership for Action Against Cancer, ECPC has participated as speaker, chair or moderator in numerous EU health meetings in 2010, presenting the work of ECPC and its membership as well as offering a patients' perspective on EU health policy.

ECPC has continued its efforts in diversifying its funding sources, with continued income from the Commission and new applications submitted in 2010 in the areas of public health, research and information society. ECPC has also continued to extend its range of industry sponsors to the broader healthcare environment, in accordance with stringent rules on transparency and independence.

Once again, on behalf of ECPC, I would like to thank and congratulate you, our members, associate members, professional partners and our friends from across the EU and around the world for your contribution to these achievements and your trust and confidence in ECPC.

As we move forward, we need your vision and unity, both to set a cancer patient-centred agenda, and also to ensure ongoing high-quality responses to all the EU institutions on behalf of cancer patients – in short, to guarantee that excellent, cancer patient-centred and equitable healthcare throughout the European Union becomes a reality.

We have had an excellent year, and I would like to thank the dedication and hard work of our staff.



Tom Hudson, ECPC President



Tom Hudson, President

Robert Hudson, known as Tom, was a co-founder of ECPC and has been ECPC President since 2009. Based in Ireland, he is also the Chairman of Europa Uomo, the European Prostate Cancer Patient Coalition, and Men Against Cancer (MAC) Ireland.

Tom is actively engaged in every stage of ECPC's development, liaising closely with both office and Board members on policy activities and strategic direction. He also has a keen interest in providing a platform to involve young people in shaping policies that will affect their health.



Sandy Craine, Secretary

Sandy Craine has served as ECPC Secretary since 2009. She set up the CML Support Group after successfully participating in a clinical trial in the USA which was not accessible to most European CML patients. She is very active in the field of rare cancers.

Sandy was co-chair of the Rare Cancer Action Group and provided policy input to a range of legislative dossiers, in addition to supporting the development of the Brussels office.



Francesco de Lorenzo

Francesco de Lorenzo is a qualified medical doctor and a professor of biochemistry at the University of Naples. A bowel cancer survivor, since 1997 he has established three cancer organisations in Italy: AIMaC; CIS; and FAVO.

Francesco has facilitated the building of relationships with other European and international organisations. He has mobilised the Italian patient organisations to provide input to ECPC's policy activities and he has represented ECPC at various European meetings.

# Board of Directors

ECPC is run by our members, over 300 cancer patient organisations, through the Board of Directors. The Board must contain a majority of cancer patients or survivors, and is directly elected by the Membership.

In May 2010, Board elections were held for the term 2010-2013. We include short biographies here to introduce you to the 2010 Board.



**Henk Van daele**

Henk Van daele was diagnosed with the very rare male breast cancer in 1999, and has since worked tirelessly to raise awareness of this poorly understood disease. He is a board or founding member of no less than three associations in Bel-

gium.

He has represented ECPC on the Patient and Consumer Working Group of EMA. He has a particular focus on rare cancers affecting men and on including the voices of older cancer patients in policy dialogue.



**Heide Preuss (resigned Sept.)**

Heide Preuss, a breast cancer survivor, joined the association Mamazone after she experienced her first recurrence. She joined the ECPC board after serving as a Mamzone Board member and has also been involved in ECCO.

Heide also represented ECPC on the EMA Patient and Consumer Working Group. She was an excellent patient advocate for ECPC and spoke at numerous conferences. We are sorry she will no longer be able to serve on the Board.



**Simona Ene, Vice-President**

Simona Ene became ECPC Vice-President in 2009. A survivor of ovarian cancer, she is involved in a number of patient organisations in Romania and the CEE area. She is involved in the Cancer Romanian Association "Sharing same Destinies" Group.

Simona has spoken at a range of European and national conferences, providing ECPC with a Central and Eastern European perspective. She organised a major conference in Romania (p16).



**Tom van der Wal, Treasurer**

Tom van der Wal has held the post of Treasurer since 2009. A melanoma survivor, he is the founder and Chair of Stichting Diagnose Kanker in the Netherlands. He is particularly involved in cancers related to rare genetic conditions.

Tom van der Wal has provided strategic input to the development of our IT and communications systems, in addition to financial guidance to the office in his role as Treasurer. He has also supported the office in the development of projects, including ICAB.



**Sarunas Narbutas**

When he was diagnosed with CML in 2006, Sarunas Narbutas set up a national campaign and petition calling for increased reimbursement of treatment. The campaign was extremely successful, signed by 5% of the Lithuanian population and doubling reimbursement rates.

He brings the voice of young cancer patients to the Board and to ECPC's activities. He has presented the young patient's perspective at European and national level, calling for more support for this group.

## Testimony to Arthur Masny

On 9th December 2010, everyone at ECPC was saddened by the news that our inspirational Board Member Arthur Masny had lost his battle with lymphoma. Even in the last days of his life, he never stopped fighting for the lives of other cancer patients.

For Arthur, helping people was an inseparable part of life, as work or home. Before the Lymphoma Patients Support Association "Owl's Eyes" ("Sowie Oczy" in Polish) was created in 2005, Arthur was active in Canadian Circle and Rotary International Warsaw – Wilanów and Rotary International Warsaw – Wilanów. In both of these associations Arthur was actively supporting cancer patients. On behalf of Canadian Circle he organized few editions of Terry Fox Run.

Later, as a member of Rotary International and founding board of "Owl's Eyes", he ran the joint project of supplying the Clinic of Lymphoid System Cancers of the Oncology Centre in Warsaw in medical equipment (30 000 EUR were dedicated to this purpose in 2008). He involved the Rotary Clubs from the United Kingdom, Germany and Italy to help the Polish Clinic. Even during the last phase of his illness, in the last days of his life, Arthur was involved in the selection of the new equipment for the Clinic for the amount of 17 500 EUR.

In 2008 Arthur Masny was elected a President of the "Owl's Eyes" Association. He organised annual social educational campaigns on Lymphoma, actively participated in the World Lymphoma Awareness Day. But above



all, he organised regular monthly patients meetings with psychologists, rehabilitants, dieticians, specialists of laughter- and music therapies, as well as Christmas Dinners. "Owl's Eyes" was also a co-publisher of a "light, easy and relaxing" book of the ex-patient on the Lymphoma treatment titled "Szeregowy Chłoniak" ("Private Lymphoma").

Arthur Masny was full of new ideas, he just had too little time to put them into practice. He knew that in Poland there are significantly less people socially involved than in other countries, that Poles are less aware of their rights, standards and quality of care they should experience during their treatment, and that is why he took his role in the Association very seriously. When he was elected a Board Member of ECPC he has great visions of the future of the organisation. Unfortunately, he didn't make it.

Arthur Masny had something that made people follow him. He encouraged them to work through his arguments, his wisdom and visionary plans. He will be sorely missed.





# ECPC Officers

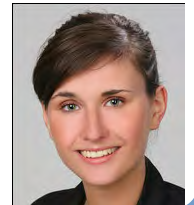
## Brussels Office

**David Ryner, Interim Director (Aug. 2010 - Jan. 2011):** David's role as Interim Director involved overseeing the closure of the Munich office, consolidation of all ECPC administrative functions in Brussels, moving to larger offices there and doubling staff numbers, introducing a more communications driven agenda and seeking to take maximum advantage of an ECPC presence at the focal point of EU decision-making with an intense round of diverse, co-ordinated activities.



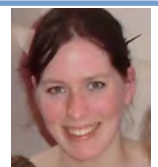
**Denis Horgan, Head of External and Political Affairs:** Denis's role as Head of External Affairs involves managing the Brussels Office, overseeing all policy responses to the European Commission and European Parliament, supporting Member organisations in their policy responses at the national level, managing the secretariat of European Parliament Interest-Group called 'Forum Against Cancer in Europe', establishing and building relationship with a range of stakeholders at the EU level and national level and managing ECPC's involvement in a range of EU projects such as EAARC, Eurocan Platform and European Partnership for Action Against Cancer.

**Danuta Rydlewska, Policy Assistant (from Sept.):** Danuta Rydlewska joined ECPC after completing a Masters degree at the College of Europe. In addition to her policy work on CEE and counterfeit medicines, she manages the websites, organises events, and liaises with members and FACE Champions. Danuta's role as Policy Assistant involves networking with a range of stakeholders including MEPs, Commission officials and member organisations. Danuta has played a key role in recruiting FACE Champions from Central and Eastern Europe and collects policy input from our member organisations in this area. A key part of Danuta's work is developing FACE workshops and other conferences, and participating in policy meetings.



**Martin Lohr, Policy Assistant (from Sept.):** Martin Lohr came to ECPC after working for the European Commission representation in Vienna. He develops ECPC policy on the Clinical Trials Directive, Cross-Border Healthcare, Personalised Medicines, Health Inequalities and Cancer Research, and also provides technological support to the office. Martin's key role is contributing to the development of ECPC's policy. He undertakes research and liaises with different organisations who provide input. He has worked on numerous policy papers on the topics listed above, in addition to technical input to the development of ECPC TV and to our online communications.

**Nicola Colson, Communications and Finance Assistant (from Jan. 2011):** Nicola Colson brings editorial experience with a UK political magazine. In addition to developing ECPC's communications, she will take over financial administration from the Munich office and contribute to the development of ECPC's youth and environmental policies. She will provide logistical support to the youth conference in autumn 2011, in addition to raising ECPC's online profile through social media and other communication tools.



## Munich Office



**Jan Geissler, Director (Consultant) (until Nov.):** Jan Geissler was the director of ECPC until the end of August, but continued to work for ECPC as a consultant directing ECPC and operations until November. He was responsible for overall financial and administrative work of both Brussels and Munich offices. He also represented ECPC at numerous conferences, and liaised with member organisations and other stakeholders. Jan finished his work for ECPC at the end of November to focus on his consultancy work. We thank Jan for his excellent work establishing ECPC on the European cancer stage and wish him the best of luck in the future.

**Michaela Geissler, Secretariat (until Jan. 2011):** Michaela Geissler was the head of the ECPC Administrative office in Munich until January 2011. She was responsible for ECPC finances and provided logistical and administrative support to ECPC conferences, Masterclasses, and the ECPC Board. Michaela worked closely with the ECPC Brussels office and provided daily support. She liaised with our member organisations and managed the membership lists. We wish Michaela all the best in her future endeavours.



# ECPC Activities 2010



Delegates assembled at the FACE Workshop on Palliative Care

Over the course of 2010, ECPC has been very active in a wide range of topics relevant to cancer patients. We have divided these into two sections: "Building Partnerships," and "Policy Achievements."

Throughout 2010, ECPC activities have been increasingly centralised in the Brussels office, enabling staff to interact more with partner organisations and to increase our presence in the European Parliament. This has allowed ECPC to promote cancer patients' priorities in the European policy agenda to an unprecedented degree. The Munich office has continued to undertake administrative support and representation at events, but will be closed early in 2011.

## Building Partnerships

2010 has been a very successful year in both building on existing partnerships and forming new relationships. We have in particular become more involved in European institutions and initiatives.

June 2010 saw the launch of one of our most high-profile achievements this

year: Forum Against Cancer, Europe - our initiative in the European Parliament.

Over the second half of 2010, ECPC hosted three FACE Workshops - on Cancer Research, Cross-Border Healthcare and Palliative Care. FACE also joined forces with the Health and Environment Alliance (HEAL) to bring a documentary about environmental pollution and cancer to the European Parliament.

We are also on the steering committee of the European Partnership for Action Against Cancer, and hosted our yearly summit on "Making the Partnership Work."

In November, ECPC brought stakeholders to Romania for the Central and Eastern European Learning and Sharing Conference, entitled "Bridging Cancer Care." This event included a number of workshops and capacity-building events for our members in the region, as well as bringing MEPs, ECPC members and other stakeholders together.

ECPC is also involved in other European partnerships. One of the most significant of these is the EUROCANPlatform. This is an initiative designed to take collaborative and integrated cancer research to a new level in Europe. ECPC is the only patient representation body involved,

and will be working throughout 2011 to ensure that patients are at the centre of study design and execution.

ECPC has already taken the step of combining its role in cancer research with the success of the FACE initiative in the European Parliament, by supporting the Written Declaration 2010/80 calling for greater coordination of cancer research in Europe.



Board member Sarunas Narbutas speaking at the Learning and Sharing Conference



The Learning and Sharing Conference in Romania



## Policy Achievements

2010 was a very successful year for our policy efforts in bringing European policy even closer to our member organisations and cancer patients. After nearly two years of intense input from ECPC and other stakeholders, the European Parliament and the Council of Ministers reached a political agreement paving the way for the adoption, in early 2011, of the Directive on Patients' Rights in Cross-Border Healthcare. Therefore, EU citizens will have access to clear explanations of their rights to access safe and good quality treatment in other EU Member States and to be reimbursed.

Also in the beginning of 2010, the ECPC Board decided to transfer responsibility to the Brussels office, centralising all policy activities in the heart of the European institutions. This has meant that we were better equipped to lead a consistent and coherent approach to public health policy and, more specifically, to provide input so as to ensure the protection of cancer patients and safety of medicines throughout the EU.

We also embarked upon the road of developing new models of engagement with stakeholders, such as the Forum Against Cancer in Europe initiative, designed to enhance patients' access to parliamentarians, and the Independent Community Advisory Board (ICAB) with the objective of engaging all stakeholders and partners to improve treatments for specific cancer types.

These and many other achievements are described in this annual report.

The ECPC Policy team would like to thank all our member organisations and stakeholders for their contributions to these achievements.

Denis Horgan, Head of External Affairs



EU Commissioner for Health John Dalli at the FACE Workshop on Cross-Border Healthcare

## Collaboration

ECPC actively maintains relationships with other European organisations:

- 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)



## What is FACE?

One in four Europeans will die of cancer. With better prevention, screening and treatments, more Europeans could survive – or not even get cancer at all. However, the chance of surviving cancer is often affected by where you live, where you are treated, whether you have access to information, or whether you are strong enough to defend yourself in what often seems an impersonal system. Europe has been aware of the

shops allows both patient groups and policy makers to better understand one another's needs and priorities, and enables them to work together effectively to provide timely and effective information, prevention, screening, treatment and care for patients across Europe. Each workshop is focused on a particular issue affecting cancer patients, and invites stakeholders from the pharmaceutical industry, researchers and oncologists to participate in presentations and discussions.



problems for more than a decade, but the political will to generate change has been lacking.

Following on from the success of MEPs Against Cancer (MAC), which brought together MEPs from different political groups and Member States to support EU citizens in their fight against cancer, a new ECPC initiative was launched in June 2010. The Forum Against Cancer, Europe (FACE) facilitates communication between the human face of cancer, given a voice by ECPC and other patient advocacy groups, and the faces of those who make policy and allocate funding in the European Parliament and Commission. There are currently 82 FACE Champions, MEPs who have affirmed their commitment to the goals of FACE and actively support our activities.

This face-to-face dialogue in work-

## FACE Workshop: Cancer Research

To launch FACE in June 2010, stakeholders gathered to address the need for cancer research. ECPC President Tom Hudson emphasised that cancer research is important not just for cancer patients, but for all of us. Research is currently fragmented, with duplication of studies in different countries, and many speakers called for more collaboration on research, emphasising that no one nation can achieve what is needed alone. Jan Van der Loo, from the Commission's DG Research, urged the creation of 'networks of excellence' to make more efficient use of resources, sharing infrastructures and facilities, coordinat-

## Building Pa



## Forum Against

ing clinical research and combining efforts.

This collaboration would also require greater coordination of research funding. Currently, three separate streams of research – basic, epidemiological and clinical research – are funded by government, pharmaceuticals and charities.

*"With the right u*

Rather than dividing resources between multiple agendas, funding should be allocated and research directed by a coherent policy – one which has the needs of patients at its heart. Melanoma patient Patricia Garcia-Prieto spoke of stakeholders so focused on the 'how' that they have forgotten the 'why' – the motivation must always be the cancer patients.

There is a need for policy to remove political and regulatory blocks to innovation. Currently, there is an expectation that studies should be conducted in largely uniform ways, but this has driven the most innovative research away from Europe. A crucial example is



# Partnerships



## Cancer, Europe

clinical trials – the Clinical Trials Directive, which came into force in 2004, has reduced rather than increased the number of and participation in clinical trials. Health economics are insensitive and dehumanise the patient. Policy needs to address these issues, and this outcome must be achieved through the use of

*“treatment, 80% of children with cancer could be saved” – Herbert Reul MEP*



Tom Hudson, Patricia Garcia-Prieto, Marisa Matias MEP and Herbert Reul MEP

António Fernando de Campos, MEP



political tools. Patient advocacy has an important role to play in raising public awareness, and involving MEPs and other policy-makers.

Since the workshop, ECPC has continued to promote the needs and rights of the patient in the policy agenda on this issue through its participation in the Commission's Health Policy Forum and with the European Medicines Agency, and has continued to develop relationships with other stakeholders. Five of our FACE Champions have put forward a Written Declaration on Cancer Research, which you can read more about on page 17.

## FACE Workshop: Cross-Border Healthcare

At the second FACE workshop in September 2010, patient organisations and FACE Champions were joined by representatives from the European Commission, from social security administrators and from oncological institutes. They gathered on the eve of the second reading of a directive in the European Parliament, which if passed would address obstacles to cross-border healthcare.

Cancer patients prefer to be treated near their homes, among their friends and family, but when the a patient needs specialised care or lives near a national border, the nearest appropriate facility may be in another country. While cross-border healthcare is in theory available and reimbursed in such cases, as a result of the 2005 directive, in practice there are many obstacles for patients, many of them resulting from a lack of clarity as to which patients are eligible, and how much reimbursement they are entitled to. The proposed directive, which will be voted on in January 2011, would clarify patients' rights in accessing cross-border healthcare.

The workshop was opened by Health Commissioner John Dalli, who introduced the proposed directive and





Health Commissioner John Dalli speaking at the workshop

## FACE Workshop: Palliative Care

November 2010 saw the third FACE Workshop, hosted by Gay Mitchell MEP and ECPC President Tom Hudson. Bringing together illustrious speakers from the European Parliament and Commission, the World Health Organisation and other stakeholders, the workshop examined some of the discrepancies in palliative care provision across the European Union and emphasised the importance of deepening dialogue to address these inequalities.

Our modern concept of palliative care owes a heavy debt to the work of Cicely

*“Cancer patients who are very ill should not have to engage in proceedings” – Sarunas Narbutas, ECPC Board*

explained some of its key points, alongside the existing initiative eHealth. A number of FACE Champions, including chairs Dagmar Roth-Behrendt and Nessa Childers, continued this theme, analysing the directive's strengths and weaknesses, and emphasising the importance of continued development of facilities and care on a national level, and of European collaboration in research and development. Patients need access to information about their healthcare options, including options abroad, and should be informed about their rights.

Professor Jacques Scheres explained the work of Euregio Meuse-Rhine (EMR), a well-established and successful initiative in cross-border healthcare which uses an electronic 'International Health Card' to offer needs-oriented cross-border healthcare without additional costs

to the patient or complex administrative procedures. It is a collaborative effort across Belgium, the Netherlands and Germany, involving hospitals, health insurance funds, ambulance and public health services, patient organisations and regional governments, amongst others. Expanding on the difficulties involved in crossing not just geographic but cultural borders, recognising that previous solutions had been inadequate because they were not effective (achieving healthcare policy objectives), efficient (doing so at the lowest possible cost) and equitable (sharing the burden among members in a fair manner).

Over the last year, ECPC and FACE Champions have been actively involved in amending and supporting the proposed European Parliament directive. See page 18 for more details.

Saunders and the origins of the modern hospice movement in the last century. The goal of palliative care is to ensure that each day is lived as fully as possible until the very end, and that both patients' and families' physical, emotional, social and financial needs are met. Palliative care should be included alongside treatment from the patient's diagnosis, rather than just prior to death. Studies indicate that when palliative care is offered in conjunction with treatment, patients had a better quality of life, were less depressed, and lived longer than those receiving treatment alone.

*“There is no cure for mortality”  
– Jose Martin Moreno, WHO*



Speakers called for palliative care to be included in health and social care policies at a national and European level, with the patients' needs at the centre. Guidelines and benchmarks are needed to ensure a minimum level of palliative care, and these need to take into consideration the wide variety of patients' needs, including autonomy and the right to make decisions. Provision for education and training for the health-care workforce at all levels is needed, especially during basic professional qualifications. Appropriate treatments and pain killers, particularly opioids, should be available when and where necessary. Reflecting FACE's goals, speakers joined in calling for deeper dialogue between stakeholders in promoting the inclusion of palliative care in health and social policies at a European level.

*age in lengthy legal  
d Member*

## Living Downstream: Cancer Prevention and Environmental Policies



*"This is an environmental  
holocaust"  
- Dr Sandra Steingraber*



Working in collaboration with the Health and Environment Alliance (HEAL), ECPC organised a screening of Dr Sandra Steingraber's compelling documentary "Living Downstream" in November 2010. Dr Steingraber is a biologist and cancer survivor who communicates research about environmental causes of cancers to the public and patients.

The documentary, based on her 1997 book, follows her journey "up the river of human cancer" as she travels across North America trying to break the silence about the link between cancer and environmental pollution. This screening was preceded by a science-to-policy panel discussion on how the EU could better address the latest science with policies for the 'environmental prevention' of cancer.



ECPC was represented by Viorica Cursaru from Myeloma Euronet Romania. The other panel members were Genon Jensen, Director of HEAL, and Dr Andrew Watterson, Head of the Occupational and Environmental Health Research Group at the University of Stirling in Scotland, UK.





## What is EPAAC?

The European Partnership for Action Against Cancer, a European Commission initiative to coordinate a collaborative European approach to cancer, was launched on September 2009. The Partnership's target is to reduce cancer in Europe by 15% before 2020, by maximising resources for research, treatment and prevention; sharing expertise, data and best practice; and helping all EU member states to tackle cancer evenly and effectively. Health Commissioner John Dalli has been involved in the Partnership, and in March EPAAC and ECPC submitted a joint funding proposal to the European Commission Agency EAHC for Work Package Five, which was granted.

Believing strongly that patients should be at the heart of this endeavour, ECPC has been heavily involved in the Partnership from its conception, and has been invited to sit on the Steering Committee. Our priority is ensuring that the patient's voice should be heard on all aspects of EPAAC's work.



*“Partnerships can be the catalyst for new initiatives” - Sandy Craine, ECPC Rare Cancer Action Group*

European Partnership for Action Against Cancer

Second Partnership Meeting



Following on from the previous meeting in December 2009, EPAAC stakeholders convened to agree on the activities within the core work packages of the joint action on cancer that would be proposed for the period of the following three years (2010-2013), to identify leaders for each work package, and to agree on the way forward.

Two of ECPC's proposals were particularly well received. We are excited about the Virtual Partnership, which will enable organisations and individuals not



## ECPC Cancer Summit: Making the Partnership Work

In Brussels in October 2010, ECPC brought around 150 stakeholders together, including patient representatives, policy makers, politicians and oncologists, to communicate the work of the Cancer Partnership to a wide audience and generate the grass-roots momentum to drive it forward. Centred on the themes of cancer prevention, cross-border collaboration, sharing best-practice, cancer research and inequalities in healthcare provision, the ECPC Summit explored the role the patient can play within EPAAC.

In his keynote address, Health Commissioner John Dalli emphasised the



Sarah Faithful, EONS, at the Summit

*“Treat the patient, not the cancer”  
- Louis Denis, Europa Uomo*



European Commission's commitment to cancer prevention, screening and sharing of information between member states. The European Parliament was represented by FACE Champions Marisa Matias MEP, Nessa Childers MEP and Linda McAvan MEP, who gave passionate speeches confirming their commitment to take action against cancer in Europe

and involve patients in every aspect.

Recognising the great discrepancies in provision for cancer patients across Europe, patient organisations called for the standardisation and harmonisation of member state National Cancer Plans. Access to cross-border healthcare must be increased, as patients cannot wait 20 year for policies and research to deliver the treatment they need in their own countries. ECPC's strong connections with NGOs, politicians and the medical industry will ensure that the European Partnership for Action Against Cancer will adopt patient-centred approaches.

This conference was held with the kind support of the European Commission through its Health Programme.



already directly involved in EPAAC to participate and submit ideas via the internet. This will be an ideal tool for ECPC's member organisations, as well as individual patients. Board members Tom Hudson, Tom Van Der Wal and Simona Ene have started up focus and discussion groups in their own countries to support the Young Europeans in the Partnership (YEP) initiative, which will use social media to engage young people and acknowledge the role they play.



Delegates at a parallel workshop at the Conference

campaigning on a variety of patient issues for many years, were the local partners who hosted the conference.

A series of parallel workshops at the Conference provided the opportunity to share experiences of specific projects being run in Central and Eastern European countries by a variety of not-for-profit organisations and societies. Many of them were projects funded by BMS foundation Bridging Cancer Care grants, and were focused particularly on strengthening community-based healthcare worker capacity, integrating medical care and community-based services, and mobilising communities to fight cancer.

## ECPC CEE Learning & Sharing Conference: "Bridging the Gap"

At its conference in Bucharest on 27th – 28th November 2010, ECPC brought together patient groups, advocates, professionals, policy makers and politicians from Central and Eastern European countries, with the aim to build capacity and create momentum to strengthen local groups and increase collaboration between patient groups and other

in the region through its Bridging Cancer Care initiative, which focuses on closing the gap between East and West particularly in psychosocial support for cancer patients and their families, education and screening, and expanding training and awareness for professional and lay health care workers. The Romanian Cancer Society, which has been



Simona Ene, ECPC Vice President

*"Educating patients helps them overcome the fear of the unknown" - Jana Pelouchova, Diagnoza CML*

stakeholders. In addition to a strong presence from Romania, patients and advocates also attended from Bulgaria, the Czech Republic, Hungary, Latvia, Lithuania, Poland, Russia, and Serbia.

The region is seen as a priority for the ECPC because it still lags significantly behind the rest of Europe in terms of access to quality cancer care, with the result that the risk of dying of cancer before the age of 75 is 25% higher for people of this region than the average risk for Europe as a whole.

The conference was co-funded by a grant from the Bristol-Myers Squibb Foundation, and provided an opportunity to share information and lessons from many of the projects it has funded



Delegates from across Central and Eastern Europe at the Conference



# Cancer Research



## EUROCANPlatform

As was clearly expressed at the FACE Workshop on cancer research in June 2010, European cancer research urgently needs greater collaboration and innovation. To this end, a number of research institutes are joining together in a Europe-wide initiative called EUROCANPlatform, which will link cancer centres, enabling the sharing of infrastructure and development of collaborative projects. ECPC has been active in the development of this project, which was awarded funding and support by the European Commission under its Seventh Framework Programme.

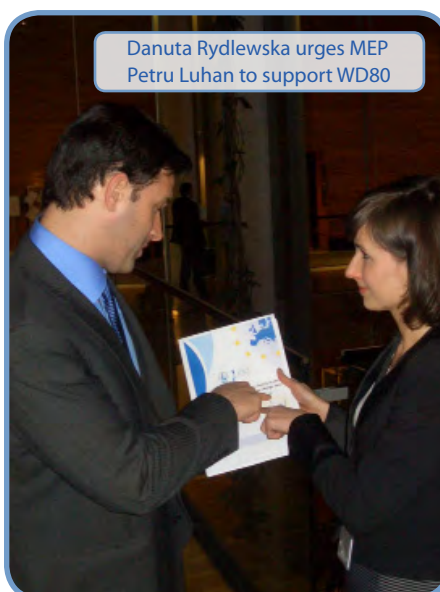
ECPC is the only patient organisation of the 28 participants in EUROCANPlatform. In addition to representing cancer patients when establishing priority areas for cancer research, we will be heavily involved in improving communication between researchers and patients. Focusing on decreasing cancer mortality through strategic research in prevention, early detection and improved treatments, the platform will build the resources and expertise for a variety of research types and methods, though with a strong focus on translational research.

Part of the EUROCANPlatform project will involve developing websites and other tools, and ECPC Board Members have been particularly active in two projects. The first, called the Virtual Partnership, will enable organisations not directly involved in the project to participate, enabling other patient organisations to offer their input. The second will make use of social media and other online tools to engage young people in

EUROCANPlatform and its goals. ECPC will also be facilitating communication between stakeholders through future FACE Workshops.

EUROCANPlatform will be launched in Stockholm, Sweden in January 2011, and we are very excited about the opportunities for improvement it offers cancer patients now and in the future. We will be informing our members of progress in this area through our website and newsletters.

## Written Declaration 2010/80



Danuta Rydlewska urges MEP Petru Luhan to support WD80



Five FACE Champions, MEPs Marisa Matias (Portugal), Jo Leinen (Germany), Michele Rivasi (France), Herbert Reul (Germany) and Antonia Parvanova (Bulgaria) submitted a Written Declaration in October 2010. A Written Declaration used to launch a debate on a particular subject. If this short text is signed by a majority of MEPs, it will be announced in the European Parliament plenary and discussed.

Inspired by the June 2010 FACE Workshop, the Written Declaration no. 80/2010 aims to improve the coordination, cooperation and coherence of pan-European, national, regional and local cancer research activities, avoiding duplication and focusing on unmet needs in cancer treatment.

Since the launch of the Written Declaration, ECPC staff members have promoted it during plenary parliamentary sessions. In addition, ECPC member organisations have been active in lobbying their own representatives. We will continue to promote this important topic in 2011.





In the summer of 2008, the European Commission released proposals for a Cross-Border Healthcare Directive. This would clarify and define patient entitlements and provider responsibilities. This was developed and consulted on over the course of 2010, and will be voted on in January 2011.

ECPC has been very active in shaping and supporting this directive, which is particularly relevant to rare cancer patients. Our contribution includes proposing numerous amendments and participating in debates at the European and national level.

# Policy Achievements

## Cross-Border Healthcare Directive

### ECPC Priorities:

- Putting cancer patients first, and guaranteeing that the principles of universality, access to good quality care, equity and solidarity apply for all.
- Ensuring an adequate codification of the existing European Court of Justice case law and making sure that the future directive will not create any new legal uncertainty or loopholes for patients and healthcare providers.
- Maintaining the financial and organisational sustainability of national healthcare systems and fostering opportunities for cooperation, notably in the field of eHealth and Health Technology Assessment (HTA).

### Key points of ECPC's advocacy:

- The costs of cross-border healthcare should be covered by the Member State of affiliation up to the level of costs that the treatment would cost by the MS.
- The MS can establish a system of prior authorisation for reimbursement of costs of cross-border healthcare, but can only require authorisation in limited cases.
- The MS cannot refuse authorisation if the patient cannot be treated within a medically-justified time limit in the MS.
- Member States will establish national contact points. Their role will be to provide information on patient's rights, healthcare providers and other relevant topics.
- The Commission must support Member States in developing reference networks between healthcare providers and centres of excellence, with requirements on quality and safety for patients as key responsibilities for Member States.
- The EU must support and facilitate cooperation and exchange of information on health technology assessments.
- EHealth will be developed through a network connecting national authorities.



### ECPC achievements:

The ECPC position has been crucial for in supporting specific provisions, to which the Council was initially completely opposed:

- A new article, specifically on rare disease (which includes rare cancers) has been added to the Directive, asking the Commission to support Member States in cooperating in the development of diagnosis and treatment for rare disease
- The newly established European Reference Network will have a specific focus on rare diseases, most particularly in order to foster the development of diagnosis and treatment of rare diseases and to share expertise among Member States in domain the expertise is rare
- When a patient affected or suspected of being affected by a rare disease applies for prior authorisation, a clinical evaluation may be carried out by experts in that field. If no experts can be found within the Member State of affiliation or if the expert's opinion is inconclusive, the Member State of affiliation may request scientific advice. This would facilitate the possibility for patient to seek a proper diagnosis (which is the first problem for patients affected by a rare disease)

# EU 2020 Strategy

The EU 2020 Strategy is the EU's growth strategy for the decade 2010-2020. It strives towards the goal of smart, sustainable and inclusive growth through seven flagship initiatives. Targets for the strategy have been set in five areas, all of which have an implication for current and future cancer patients. These are:

- Employment
- Innovation
- Education
- Social inclusion
- Climate and energy

ECPC strongly advocates that the strategy must be built on the correct identification of the challenges to be tackled. This is an opportunity to mobilise different sectors of European society and levels of government to address the health challenges we face.

We proposed that the EU 2020 Strategy should play a vital role by promoting the coordination of Member States activities and ensuring the full implementation of existing tools which can play a key role in implementing and integrating national cancer plans.

## ECPC called for:

- Participation of civil society, NGOs and patient advocacy groups: citizens and patients must be key partners in constructing the strategy.
- Funding for the Health Actions: Achieve measurable progress in bridging the health gap between the Member States in the enlarged EU by (1) allocating a larger share of financing for projects under the annual work plans of the public health programme, and (2) helping to mobilise a larger share of the structural funds for health-related investment in the new Member States
- Cancer Registers: Increase establishment and collaboration between national cancer registers in Member States where they do not exist or have fallen in disrepair, and encourage the maintenance of existing registers.
- Centres of Excellence: Develop centres of reference/excellence where expertise is pooled and quality standards and guidelines are developed.
- Education: By 2020, Community programmes should have systems established to support citizens and patients in making healthy choices. Education systems should teach children enough about healthy living.
- Transparency: EU should adopt a policy on full transparency of health information. The existing Health Portal should be expanded to include such vital information for patients as clinical evidence. Currently such information is often only available to the medical community.
- Counterfeit medicines: By 2020, agreements should be reached regionally and internationally to tackle counterfeiting of medicines
- End of tobacco subsidies: EU should not subsidise activities that promote a disease. Everyone knows that smoking kills, yet year in, year out, tobacco growing has been subsidised in Europe. A strategy should be put in place to ensure that farmers are provided with an alternative to develop a new livelihood.

## EUROPE 2020

A European strategy for smart, sustainable and inclusive growth

## Health Inequalities

### ECPC demanded action on:

- Raising awareness, promoting information, best-practice exchange and policy coordination and advocating the tackling of health inequalities as a policy priority
- Improving data availability and the mechanisms to measure, monitor and report on health inequalities and improving the knowledge base on the causes of health inequalities and the effective policies to address them.
- Developing the contribution of relevant EU policies towards reducing inequalities in health.

Health inequalities embraces a wide variety of topics and issues, ranging from gender stereotypes to geographical variations to cultural differences. Essentially, through this topic, ECPC seeks to address and minimise those factors which lead to inequalities in the incidence of cancer, and inequalities affecting cancer outcomes.

Within the European context, there is a heavy focus on closing the health gaps between Western European states, and Central and Eastern European states. This is very noticeable in cancer. Currently, two of the risk factors for cancer have been targeted: tobacco consumption and obesity.



### ECPC supported actions to:

- Produce headline indicators to monitor health inequalities, support further development and collection of data by age, sex, socio-economic status and geographic dimension and stimulate a reflection on target development in the Social Protection Committee.
- Provide funding under PROGRESS including for peer reviews and a call for proposals in 2010 to assist Member States in developing relevant strategies.
- Develop health inequality audit approaches through the Health Programme in joint action with Member States willing to participate.
- Develop ways to engage relevant stakeholders at European level to promote the uptake and dissemination of good practice.
- Include health in the priority areas within the ongoing cooperation arrangements on health between the European regions and the Commission.
- Review the possibilities to assist Member States to make better use of EU structural funds to support activities to address factors contributing to health inequalities
- Develop actions and tools on professional training to address health inequalities using the health programme, ESF and other mechanisms.
- Launch initiatives in collaboration with Member States to raise awareness and promote actions to improve access and appropriateness of health services, health promotion and preventive care for migrants and ethnic minorities and other vulnerable groups.
- Encourage Member States to further use the existing options under the EU rural development policy and CAP (school milk, food for most deprived persons, school fruit scheme) to support vulnerable groups and rural areas with high needs.

ECPC participated in the public consultation on the revision of the Tobacco Products Directive (2001/37/EC). The revision of the directive seeks to regulate tobacco products on a uniform basis in all Member States, to improve awareness of dangers of tobacco use, to increase motivation to quit and to discourage initiation of smoking.

During the consultation on the Tobacco Products Directive, the line that ECPC has taken was that all tobacco products are hazardous to health and cause cancer – there is no safe level of usage. Therefore we recommended that the scope of the Directive include the regulation of any new smoked tobacco products (such as low emission or nicotine-free cigarettes), while the prohibition of any novel forms of oral tobacco, including snuff, should be maintained.

### ECPC promoted:

- Large mandatory picture warnings at the front and back of all tobacco products (not only cigarette packs) in combination with standardised/plain packaging,
- Adding quit lines on the pack of all tobacco products.
- The removal of misleading tar/nicotine/CO figures on all tobacco products.
- Graphic warnings

## Tobacco Products





# Active and Healthy Ageing

ECPC contributed to the consultation on the Innovation Partnership on Active and Healthy Ageing. The partnership is part of the Innovation Union strategy that sets out to boost Europe's competitiveness while tackling major social issues. The issue that we focused on was active and healthy ageing – which is relevant to all European countries, and Europe has the potential to lead the world in providing innovative responses. The main target is to add 2 years to the average healthy lifespan in the EU by 2020.

ECPC called for European funding to be spent on research and innovation more efficiently as highlighted in the FACE Workshop on Cancer Research, June 22nd, 2010. The output of this research should directly benefit patients and citizens. We asked that the partnership should identify and remove barriers to the use of life improving and life saving technologies. It should connect research and innovation, from the lab to the citizen.

## Guiding Principles:

- prevention and health promotion - medical technology, medicines and treatment for age-related chronic diseases and others.
- integrated health and social care for the elderly, improving home-based care and self-care; and new large-scale, innovative solutions for long-term care of the elderly.
- independent, active living for elderly people, supported by innovative products, devices and services.

## Information to Patients

With the proposed Directive and Regulation, ECPC advocated for a clear framework for provision of information of the prescription-only medicines to the general public. There is a great deal of reluctance about providing patients with information about prescription medicines. Many Member States are critical of the confusion that could arise between information and advertising.

Nevertheless, access to this information adds value to informed decision making if it accurately reflects current understanding, is scientifically sound, complete, unbiased, evidence-based, reliable, verifiable and enables patients to assess the value of one proposed intervention relative to another diagnostic or therapeutic choice.

Optimum treatment is only possible if patients have access to information about the medicinal products that they are taking so that informed choices can be made and the rational use of these medicines is enhanced. Suboptimal information results in patient dissatisfaction, reduced compliance, poorer health outcomes, increased demand on health resources, and stressed patients.

The current proposals supplement Directive 2001/83/EC and the Regulation n° 726/2004. Neither the Directive nor the Regulation includes detailed provisions on information on medical prod-

ucts to be provided to the general public. Therefore, the Community legislation does not currently prevent Member States from interpreting the boundaries between information and advertisements differently.

The proposal for the regulation COM (2008) 662 increases the power of the European Medicines Agency (EMA) by making it responsible for vetting the information provided by the marketing authorisation holder prior to the distribution to the general public. The EMA has 60 days to object to the information provided. The information for approval

which is submitted to EMA is subject to a payable fee by the marketing authorisation holder.

Various amendments that we proposed called for the strengthen the independence and reliability of information (AM 5, AM 6, AM 7, AM 10, AM 11, and AM 12).

We supported the Commission's proposal that the dissemination of information should not be allowed on radio and TV. The information permitted includes: summary of products characteristics, environmental impact of medicinal product, non-interventional scientific studies medical product related information. The key indicators on the information to patients are objectivity, reliability, matching patients needs, understandable and up-to-date.

## Proposed Amendments included:

- The approval of vaccination campaigns by the Competent Authorities.
- Health care professional to be asked to publicly disclose their relations with marketing authorisation holders.
- Materials provided to health care professionals for their use to be excluded for prior authorisation system.
- Peer reviewed medical journals - patient groups should get access to health-related publications such as peer-reviewed medical journals.
- Requesting for an ongoing update of information made available to the public.
- The information not to be allowed in newspapers, magazines and similar publications in addition to Radio and TV,.
- Information to be readable by elderly people.
- Comparisons between medicines are allowed provide that the conditions of objectivity are met.
- Inclusion of Patients organisations and healthcare professionals in consultation performed by the Commission.
- Introducing of a complain-handling system.
- The directive should apply to herbal medicinal products subject to prescription.

# Falsified Medicinal Products

Following a rapid increase of falsified medicinal products in the EU, the Commission proposed the current legislation in order to amend the Directive 2001/83/EC on the Community code relating to medicinal products for human use. The ECPC line, which is reflected in the final agreement, was to impose effective measures to fight against counterfeited medicinal products based on their risk of falsification and at the same time to avoid creating an unjustified high burden on companies. Principles of data protection principle were followed in order to avoid misuse of the safety features system.

ECPC proposed various amendments to this proposal and also supported other proposals including obligatory specific safety features (such as a serialisation number or a seal) on the packaging of prescription medicines; obligatory audits of supplying wholesale distributors of medicinal products in order to ensure reliability of business partners; strengthened requirements for imports of API from third countries; strengthened rules for inspections including increased transparency of inspection.

## Amendments include:

- Safety features are included for “on prescription medicinal products” except for radiopharmaceuticals with the possibility for extending it to OTCs. (non prescription) following a Commission assessment.
- The rules for imports from third countries of active substances are strengthened compared with the Commission text by requiring regular and unannounced inspections to manufacturing plants performed by third countries.
- Liability of manufacturing authorisation holders is increase in relation to marketing authorisation holder and consumers irrespective of whether the product is falsified or genuine. ENVI committee introduced several amendments related to the internet pharmacies.
- The main requirements were to provide an authorisation of internet pharmacies at the Member State level, create an EU logo to be published on their websites and list the internet pharmacies on the web.
- The inspections are required to be performed by the Member States Competent authorities. The penalties should be equivalent to those typically applied for illegal acts related to narcotics and should be equivalent in all Member States.

## Falsified Medicines vs Counterfeit Medicines:

### What is the difference?

**Counterfeit Medicines:** Counterfeit medicines are medicines that do not comply with EU law on intellectual and industrial property rights, such as registered trademarks and patent rights.

**Falsified Medicines:** Falsified medicines are fake medicines, containing ingredients of low quality, in the wrong dosage or even toxic effects. These can jeopardise patients' lives either by failing to deliver the beneficial effect of the drug or by having an actively harmful impact.



## Online Pharmacy Counterfeit Products

ECPC welcomed the efforts made at EU level to improve patient safety by tackling counterfeit medicines.

ECPC advocated that patients need to be absolutely sure that the medicines they consume are really the medicines they expect to be. Nevertheless, ECPC recognized that pharmaceutical legislation is one element in a broader effort to tackle this effort. Any effort requires awareness raising (patients can play an important role), strengthening weak control mechanisms of infringements of intellectual property (in the EU and abroad) and insufficient deterrents in criminal law (in particular in view of organized crime).

ECPC sent a detailed letter to the MEPs in the ENVI Committee about this before their vote in this Committee on 24 April and 26 April, 2010. The European Parliament's committee voted overwhelmingly on 27 April 2010 that a draft EU Commission Directive should be extended to cover the Internet and should also



# Pharmacovigilance



ECPC worked closely with the rapporteur Linda McAvan MEP, who is a FACE Champion, and various MEPs on the EU Directive amending the Pharmacovigilance Directive 2001/83/EC on the Community code relating to medicinal products for human use and a proposal for a Regulation on the same subject. ECPC supported the cancer patient during the negotiations and managed to maintain its line towards a more efficient pharmacovigilance system in Europe, based on three key principles:

- Safety
- Transparency
- Patients' confidence



## Pharmacies and Medicinal Products

obliged Member States to set tougher sanctions against counterfeiters.

ECPC felt that the first priority is to increase public awareness of the risks of buying medicinal products through the internet. ECPC advocated at the European Parliament level that educational programmes to increase patient awareness about the existence of falsified products and the risk of buying medicines from unauthorised channels should be put in place. The second priority is to ensure that patients can recognise those sites which are in compliance with the relevant legislation. Addressing these two key areas is one of the key issues to prevent counterfeit medicines being accessible to patients.

To garner increased support for the EU to tackle to this issue, we have attached a short questionnaire to get your views on these issues. This questionnaire will allow us to provide your feedback at the European Parliament, European Council and at the European Commission level.

### ECPC advocated for:

#### A strengthened pharmacovigilance system at European level

- A central database collecting adverse drug reactions at EU level should be established and should be at the corner stone of the European pharmacovigilance systems.
- A Pharmacovigilance Risk Assessment Committee (PRAC) should be set up and be the only body in charge of pharmacovigilance and risk assessment, in order to avoid undue duplication of roles. Specific provision on experts independence are included.

#### Marketing authorisations and post-authorisation safety and efficacy studies

- Marketing authorisation may be subject to the requirement to conduct post-authorisation safety studies or post-authorisation safety and efficacy studies where important questions relating to the efficacy of a product remain, or when scientific advances in the understanding of the disease or in the clinical methodology would significantly change previous efficacy evaluations. For this purpose, the Commission shall provide guidelines.

#### Transparency and communication

- The Pharmacovigilance Risk Assessment Committee should hold public hearings when it considers it appropriate on justified grounds, particularly with regard to the extent and seriousness of the issue.
- Creation of a European medicines safety web-portal for a better EU coordination of communication about safety issues.
- Patients should have the possibility to directly report adverse drug reactions (ADRs), or via health professionals, through a large number of formats to facilitate the reporting.

#### Measures affecting the patient information leaflet (PIL)

- To maintain coherence and confidence, improvements should be made towards the readability of the summaries of product characteristics and the packaging leaflets and their value to the healthcare professionals and the general public.
- Products referred as "under intensive monitoring" will be notified as product "subject to additional monitoring" and should identified with a symbol.
- To encouraging patients to report, contact details for the reporting are included in the patient information leaflet.

# Clinical Trials Directive

ECPC welcomes that the Clinical Trials Directive introduced Good Clinical Practice (GCP) principles to ensure that trials are conducted in accordance with high standards of ethics and science. Although the practice of GCP were standard in all Member States, only a minority of Member States had previously codified the obligations of the different parties and the involvement of the competent authorities as now imposed by the Directive. However, ECPC believes that even if the CTD provided some benefits like central trial registration, CTA principles, and some reduction in complexity in Ethics reviews and standards in informed consent, it has severely hampered cancer research in Europe, and threatens to further destruct existing multi-national research networks which have been established prior to the CTD.

The Directive and implementing guidelines imposed many administrative requirements that did not exist, or were not similarly developed in the Member States. Especially exhaustive reporting on adverse reactions and on the qualification of doctors seem to have led to problems causing a reduction of participating centres and hence local availability of cancer trials to patients. The CTD has created many additional burdens for the conduction of trials, while it did not meet the primary objective of harmonizing and simplifying the legislation in the Member States. Whilst the CTD was based on the requirements for

studies aiming to approve distinct drugs or modalities (commercial studies), it did not take into account studies to improve treatment or diagnostic procedures on the basis of already approved drugs or modalities (investigator-driven trials, therapy optimization trials) irrespective of potential commercial consequences.

## Key points for consideration:

- Risk-adapted approaches
- Applicability to non-drug trials
- Assessment of cost/benefit of new insurance requirements
- Patient involvement in Ethics Committees
- Increased transparency of public information about trials
- Therapy continuation after trials end



# EHealth

## ECPC's concerns:

- Lack of users' (i.e. patients' and healthcare professionals') awareness.
- Limited users' (i.e. especially patients' and to certain degree healthcare professionals') skills in using ICT.
- Inappropriate legal frameworks and lack of reimbursement schemes.
- Lack of interoperability.
- Lack of cross-sectoral coordination/integrated healthcare schemas.

eHealth is the use of electronic processes and practices to support healthcare delivery and learning. The European Commission has developed an eHealth Action Plan (EHAP) to run from 2012 to 2020. It has four objectives:

1. Increase awareness of the benefits and opportunities of eHealth, and empower citizens, patients and healthcare professionals
2. Address issues currently impeding eHealth interoperability
3. Improve legal certainty for eHealth
4. Support innovation and research in

eHealth and development of a competitive European and global market.

ECPC participated in these consultations, expressing a number of concerns. ECPC particularly called for the establishment of a European Interoperability Framework to harmonise standards, profiles and technical specifications across the EU, as well as medical terminologies, ontology, classification and codification systems.

We also encouraged the development of a legal framework to cover the rights of eHealth users in a cross-border context, and the involvement of professional associations, scientific societies and civil society organisations in the development of guidelines.



Rare cancers include all cancers affecting children and teenagers and many of those affecting young adults. Rare cancers thus constitute a significant healthcare burden and an important subset of the population diagnosed with cancer. There is considerable public awareness of common cancers such as breast and lung, but very little understanding that not all cancers are common. The presentation of rare cancers is often less straightforward than common cancers as there may not be an obvious physical sign such as a lump or cough, for example. General physicians are unlikely during their professional career to see a patient with many of the rare cancers. The low incidence of rare cancers means that they have not, individually, been a priority either for healthcare professionals nor governments.

### Key problems for rare cancer patients:

1. Prevention/screening usually not relevant
2. Late or incorrect diagnosis
3. Finding the right doctor
4. Lack of access to appropriate therapies and clinical expertise
5. Slowness of research (due to lack of clinical trials and commercial interest)
6. Lack of support groups / availability of support
7. Lack of interest in funding rare cancer patient groups
8. Facing stigma and inequity - lack of public understanding

### What is the RCAG?

ECPC Rare Cancers Action Group on demand of its member was set up. It is a small group of advocates within the umbrella of ECPC, to:

1. Raise awareness about rare cancers and the ESMO/campaign recommendations ("European Action Against Rare Cancers") at the European Parliament/European Commission
2. Understand existing EU policy (e.g. on rare disease, on health) in the context of rare cancers
3. Support capacity building of rare cancer patient groups
4. Partnerships with international cancer control organisations (e.g. UICC)

It is not a new patient (umbrella) group, and it is built on what ECPC and all other groups do for all cancers, and what the rare disease community has already achieved in terms of orphan drug legislation. In its first meeting, it brought together key advocates within the ECPC membership to think about specific action, and drive its implementation.

## Rare Cancers Action Group

### Issues RCAG has highlighted:

- Rare cancers are often diagnosed late due to lack of knowledge about these diseases, no (or few) diagnostic pathways and few centres of excellence.
- rare cancers can affect people of all ages adding to the diagnostic challenges.
- Treatment for rare cancers often is not based on trial evidence since the number of patients with a particular cancer is too small for trials to be easily completed.
- treatment is often off-label, which brings additional challenges, including for reimbursement of treatment.
- Despite the significant number of patients who are diagnosed with rare cancers in Europe, this population is often grouped together with other rare diseases when policy is formulated simply because their population size falls within a rare disease population threshold.
- Policy is directed towards the commonalities of these groups and does not, therefore, reflect the needs of people living with a rare cancer. This approach does not, in the view of ECPC, deliver policy which meets the needs of the rare cancers community.
- ECPC believes that an EU recommendation on rare cancers as part of the European Partnership for Action Against Cancer is urgently needed and calls on members of the European Partnership to support this call for action.

## Health Technology Assessments

A Health Technology Assessment, or HTA, involves assessing the use of medical technology from the medical, economic, ethical and social perspectives. This multi-disciplinary approach provides a bridge between academic research and policy-making.

Cancer Patients have something to say about all aspects of an HTA, but the most important thing they can contribute is a description of the benefits or unwanted effects of a healthcare technology. The recent past has shown a number of controversial discussions around the costs and value of new and expensive

treatments. The most important thing patients can contribute is a fair assessment of the benefits, value or unwanted effects of a healthcare technology. ECPC has advocated that no one can judge the impact of a healthcare technology on the patient better than patients.

With HTA becoming an integral part of the process whether a technology be-comes available to patients or not, ECPC stated that it is important that patient groups are listened to regarding the methodologies used in HTAs. Unfortunately, ECPC noted that there is no standard methodology to process

of HTAs in the various EU Member States today.

ECPC has urged that a review of scientific evidence that is solely based on clinical studies and economic value must be complemented by the patient's perspective. Without this, there may only be limited insight about the real impact and value of a technology on the daily lives of patients, their caregivers and society.

In the EUnetHTA, ECPC will bring in expert patients from countries where HTA has been established and convey this issue to the different participants

This is a collection of Written Questions proposed by ECPC that were posed by Members of the European Parliament (MEPs) and answers provided by Commissioner Dalli and the European Commission. Tom Hudson speaking at the official reception for the European Partnership on Action Against Cancer hosted by the Belgian Presidency stated that “by asking the correct questions from the cancer patients community, we can influence and shape European and national policy for the different un-met needs of cancer patients all over Europe”.

The authors of these questions have cooperated with the European Cancer Patient Coalition on a regular basis with-

in the framework of the Forum Against Cancer Europe (FACE) initiative. As FACE Champions, backed by ECPC, MEPs foster patients interest and concerns at the European level. The questions below were posed and responses provided during the 7th term of the European Parliament, which started in July 2009. Our aim is to get answers to the questions that matter to cancer patients all around the European Union. These questions cover topics such as clinical trials, drug pricing, screening, health technology assessment, and cross-border health care etc.

We include summaries of some of the questions and answers here.

### How can the Commission ensure that drug pricing is transparent and comparable across countries?

National authorities are free to set the prices of medicinal products, to influence these prices through specific national policies or to leave them to the market forces. Similarly, each Member State may determine the conditions of reimbursement of medicinal products under its national social security system. National pricing and reimbursement decisions are based on a variety of factors specific to each country, such as historical and social traditions, public health priorities or budgetary considerations. This inevitably results in price discrepancies and differences in reimbursement status across the European Union.

However, there is no established mechanism or observatory for monitoring the prices of medicinal products across the EU. A project managed by the Hungarian National Health Insurance Fund Administration (OEP), with the financial support of the European Commission, has just been launched to examine the possibility of establishing a European-wide price database for medicines included in the national health insurance systems. This project relies on the voluntary participation of the competent national authorities and is still in a preliminary phase of contacts with potentially interested Member States.

### What concrete measures is the Commission undertaking to encourage the use of multimodality approaches to treating cancer?

On 24 June 2009 the Commission adopted a Communication on Action Against Cancer: European Partnership. This partnership approach is essential given the many different fields of expertise which need to come together to combat cancer. Notably, the Commission hopes that the partnership will help Member States to exchange best practices and experiences in cancer care and treatment.

Best practice in the field of cancer diagnosis, treatment and care emerged as the concept of the comprehensive cancer centre, which is commonly regarded as the most appropriate way of organising cancer services, and may lead to multimodal treatment and care. This concept also has bearings on the concept of centres of reference, and European networks of centres of reference to deal with the majority of types of cancer which occur rarely.

At the same time, the Commission underlines that the responsibility for the organisation and delivery of health services and medical care is under the competence of Member States. Therefore, the Commission does not intend to take any measures to encourage the use of multimodal approaches to treating cancer.

## Wiki Patient



### What measures is the Commission undertaking to increase the amount of cancer screening?

The diagnosis and treatment of cancer as such is not the focus of this document. However, in 2003, EU Health Ministers unanimously adopted a recommendation on screening, setting out best practice principles for Member States to implement national population-based screening programmes for breast, colorectal and cervical cancer. The recommendation further states that the implementation should be completed not later than the end of the fourth year of the programme.

In addition, to complement Member States' actions, the Commission has developed evidence-based best practice guidelines for the prevention and early detection of cancer within the framework of the 'Europe against Cancer' initiative.

The fourth edition of the European guidelines for the prevention and early detection of cancer was published in 2006, providing guidance on screening and diagnosis. The second edition of the guidelines for breast screening was published in 2008 and European Commission's communication on cancer screening will be put forward for the first time. This further highlights the importance of cancer screening in the ageing European population.

Finally, the recently adopted Commission Communication on Action Against Cancer puts the goal of achieving 100% coverage of cervical and colorectal cancer among its objectives.

### How will the Commission encourage Member States to place a greater focus on cancer prevention and less on curative treatment?

The Commission is aware of the situation with regard to cancer prevention by citizens suffering from such diseases. This is the reason why the Commission adopted a communication on European action against cancer in 2003.

The Council recommendation calls for European Union common policy guidelines to be developed and shared among Member States. Action is planned in areas such as research, centres of reference, the development of orphan medicines and screening.



# ent Leaks



## Commission currently taking to in- cancer screening in the EU?

is the responsibility of the Member States. How-  
adopted a Council Recommendation on cancer  
early detection of cancer, and inviting all Mem-  
based screening programmes for breast, cervical  
er invites the Commission to report on its imple-  
ear after the date of its adoption.

tion, the Commission has been supporting the  
in cancer screening over the last two decades,  
'cancer' Programmes, and the Health Programme.

for quality assurance in breast cancer screening  
g a benchmark for European practice in screen-  
guidelines for quality assurance in cervical cancer  
Guidelines for quality assurance in colorectal can-  
e in the coming months. The EU Health Strategy  
creening as a means to foster good health in an

munication on the European Partnership for Ac-  
0 % population coverage of screening for breast,  
ves for action by 2013.

## courage cancer control organ- on patients suffering from rare mon cancers?

egard to rare cancers and of the difficulties faced  
the reason why in November 2008 the Commis-  
sion in the field of rare diseases which covers rare

on support and cooperation to ensure that com-  
d throughout Europe. This would require coordi-  
f expertise, access to information, incentives for  
ening.

## How will the European Commission ensure that cancer organisations are included as a key stakehold- er in serving patients crossing borders, rather than lip service being paid to patient inclusion?

The proposed Directive on the application of patients' rights in cross-border healthcare foresees that national contact points in the Member State of affiliation provide and disseminate information to patients on their entitlements, quality and safety of healthcare, data protection, and procedures of appeal and redress.

Patient organisations play an important role in providing further information to patients seeking cross-border healthcare to help them to make informed choices.

Once this directive is adopted, implementation of its specific provisions will require further consultation of stakeholders, including patient organisations.

## How can the proposed Directive on the appli- cation of patients' rights in cross-border healthcare avoid the need for the patient to engage in lengthy legal and bureaucratic proceedings?

The Commission's proposal for a directive on the application of patients' rights in cross-border healthcare foresees procedural guarantees for the processing of requests for prior authorisation and reimbursement.

The proposal foresees that Member States of affiliation ensure that national administrative procedures regarding cross-border healthcare are based on objective, non-discriminatory and transparent criteria, so that national decisions are made in a timely manner and with due care. This applies also to the actual reimbursement of the costs of healthcare incurred in another Member State as well as to procedures such as referral or seeking second opinions.

## How can it be made sure that the system of prior approval will not result in increasing inequalities?

The Commission believes that the best guarantee to ensure that the system of prior approval will not result in increasing inequalities between patients is to provide clarity on the type of healthcare which may be subject to prior authorisation as well as the criteria that may justify refusing prior authorisation. These elements are currently under debate between the Council and the Parliament.

The patients who have received prior authorisation on the basis of the regulation receive care in the Member State of treatment as if they were insured there. This implies that no payment is required from the person authorised to receive treatment in that Member State if in the Member State of treatment the healthcare is provided for free to the persons insured there.

## How can the directive enable patients in life- threatening conditions to access cross-border cancer care without the need to obtain prior approval?

In setting time limits within which request for cross-border healthcare should be dealt with, Member States should take into account the specific medical condition of a patient, his/her degree of pain, the nature of his/her disability, and his/her ability to carry out a professional activity. In due account of these criteria, Member States should shorten the time limits for a decision on the approval of a prior authorisation to the necessary minimum.

The directive in principle further extends the rights already granted in Regulation 883/2004. Whenever a person suffering from a life threatening disease cannot receive a treatment in their Member State of affiliation within a time limit that is justified by her/his state of health, the regulation obliges a competent institution of that Member State to issue that person an authorisation for a treatment abroad. In these circumstances, when the regulation applies, the institutions are bound by provisions of Article 76 of Regulation 883/2004 and Article 26 of Regulation 987/2009, which assures that the decision is taken without delay.

## Overview

Looking forward to 2011, ECPC aims to improve and extend our work representing patient organisations at the heart of the European Parliament.

We have isolated three key areas to focus on – communication, developing ECPC's relationships with our member organisations and encouraging partnerships between members; developing partnerships to expand the range and number of stakeholders ECPC interacts with and building further support for ECPC's work within the European Parliament and Commission, among others; and involvement in European projects, allowing patients to have their voices heard through ECPC in pan-European collaborative efforts to tackle cancer in various ways.

## ECPC Activities 2011

### Involvement in European Projects

We will also be involved in a number of European projects in 2011. In January, the EUROCANPlatform will be launched in Stockholm. This brings together a number of prestigious cancer research institutes, and ECPC is the only patient organisation involved. We will be actively promoting the needs and interests of cancer patients in all aspects and stages of this collaborative research project.

March will see the launch of the European Partnership for Action Against Cancer in Dublin, which brings a number of stakeholders together to devise actions to reduce incidence of cancer by 15% by 2020.

As always, we will continue to develop our presence in European institutions, raising awareness of how policies at national and European level can help or hinder cancer prevention, diagnosis and treatment.

One of our first projects for 2011 will be to support Written Declaration 80 on cancer research. We will be promoting the importance of collaboration and coherence in cancer research at European Parliament plenary sessions in Strasbourg and Brussels as we strive to attain the signatures needed for the parliament to formally adopt the declaration.

### Communication

ECPC intends to make further use of the internet and social media sites to connect better with member organisations. We want to facilitate the sharing of experiences, information and inspiration between members, and to communicate your passion and your ideas to decision-makers on a European level. By sharing our own experiences with you, we hope we can encourage you to be politically active at a national level, involving national MPs as we do MEPs.

We anticipate launching the ECPCtv channel in March in Dublin, when the European Partnership for Action Against Cancer will be formally launched. A number of videos filmed at FACE Workshops are currently available at [www.youtube.com/ecpcv](http://www.youtube.com/ecpcv), enabling member and partner organisations to pass beyond the doors of the European Parliament and see an example of an ECPC/FACE event. We will be expanding the repertoire of the ECPCtv channel, both by recording events and interviews with key figures in Brussels, and by raising the profile of the work done by some of our member organisations.

Over 2011, the ECPC camera crew will journey across Europe to film our member organisations in action, allowing us to bring your activities closer to MEPs and other stakeholders in Brussels.



### Developing relationships with stakeholders and partners

Through 2011, we will be developing new and existing relationships in all aspects of our work. Our Forum Against Cancer, Europe initiative, launched in June, has the support of more than 80 MEPs at the end of 2010. We will be celebrating the work of FACE and thanking our Champions at its one year anniversary in June 2011.

We will also be developing relationships with further Directorate Generals in the European Commission, and with additional stakeholders in academic research, clinical oncology and the pharmaceutical industry, as well as with other NGOs such as the Health and Environment Alliance (HEAL).

We will be holding at least six FACE Workshops in 2011. On January 12th, we will be addressing the difficulties faced by rare cancer patients in particular, and how action at the European level can address these.

On January 24th, the ENVI Committee at the European Parliament (which considers Environment, Public Health and Food Safety issues) will be addressing health inequalities across Europe, and a FACE event on this day will highlight the inequalities affecting cancer patients. Workshops later in the year will include one addressing prevention and screening issues, and another focusing on the Clinical Trials Directive.



# Member Activities 2010

ECPC's membership is large and varied, with over 300 organisations in 42 countries across Europe and beyond. These organisations, many of them non-profit and staffed by volunteers, work to address the full range and scope of the needs of all cancer patients. Some of the activities they have engaged in over the course of 2010 can be found in the following pages.

Many of our members serve patients directly, offering much needed and often scarce psycho-social support and friendship to those undergoing treatment, providing financial support where possible and organising social events which bring patients together, proving that cancer patients can still have fun. This can include providing access to services such as play therapy for children, subsidised massage and rehabilitation workshops, and teaches patients that they can lead full and rich lives.

In addition to cultural trips, our members provide workshops on how to look stylish without your own hair. Most importantly, they create a safe space where patients can share their experiences and make friends.

Through advocacy and lobbying at national and European levels, our members secure more rights and better provision and ensure existing legislation is properly implemented. Representing patients' views, organisations have secured greater drug availability and more thorough reimbursement for patients. Raising awareness of national screening programmes and the importance of par-

ticipation is an essential complement to formal measures. In some cases, our members bring screening and tests to those in isolated communities who do not have access to nationally organised programmes.

Working with other stakeholders such as employers, oncologists and researchers, our member organisations help shape programmes such as employment and rehabilitation schemes; research tailored to the needs of patients; and a better understanding of their condition.

Building a new kind of relationship between patient and clinician depends on access to comprehensible and up-to-date information, and through websites, published leaflets and booklets and open lectures our members spread this essential information online and in



seen creative and effective campaigns making use of a wide range of media channels, including national television and the internet.

All these activities take place across 42 countries, and one of ECPC's roles is to bring these member organisations together and promote the sharing of experience and best practice. The partnerships that grow out of this sharing offer mutual strength and growth. A number of our members also facilitate this process and help organisations to build capacity through workshops and trainings.

Unfortunately, we have not been able to include details of all the members who sent us reports. We have endeavoured to present members from both different parts of Europe and to show a wide variety of activity types and scales.



public places including metro stations, schools and beaches.

National awareness campaigns endeavour to break taboos, change embedded stereotypes and stop discrimination based on ignorance among the general public, which leaves cancer patients isolated, and can lead to late diagnosis. Over the last year, we have





Educational training



Seniors



Young Breast Cancer Survivors

Bringing together 196 clubs across Poland, the Federation of Breast Cancer Survivor Associations has been very active in education and awareness raising.

In 2010, Amazonki organised workshops and training events for club leaders, for those setting up new clubs, for volunteers and for rehabilitators.

There are now around 980 'Amazonki' who support cancer patients in hospital oncology departments by distributing leaflets, DVDs and support.

Their website, <http://www.amazonki.net>, which offers patients a safe meeting space to share experiences, read up on the latest science and have an expert answer their questions, was re-launched with more material and facilities in June.

Amazonki is currently pressuring the Ministry of Health about the classification of lymphedema. As it is not classified as a disease, patients are unable to obtain reimbursement for treatment.

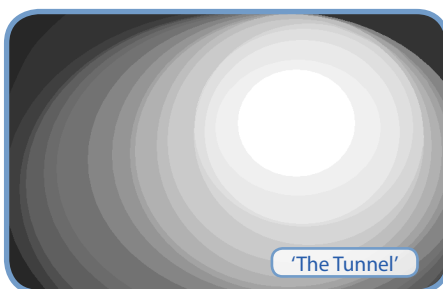
## Amazonki

'Study Group Brain Tumours' have had a number of significant achievements in the work for better care for brain tumour patients in Belgium in 2010. In addition to pushing for the National Cancer Registry to be made available for scientific use, they have obtained an agreement between Belgian authorities and Roche to make the drug bevacizumab more widely available.

In September, they organized a round table involving every Belgian stakeholder and welcoming Kathy Oliver from the International Brain Tumour Alliance (IBTA). Entitled "Treatment and Support of Brain Tumour Patients and their Families in Belgium", the consensus reached will form the basis for negotiations in the development of a National Cancer Plan over the next two years.

Belgium ratified the UN Convention on the Rights of People with Disabilities in 2010, but the terms detailed are continually violated in a number of capacities and Wekgroep Hersentumoren is actively engaging to prevent this.

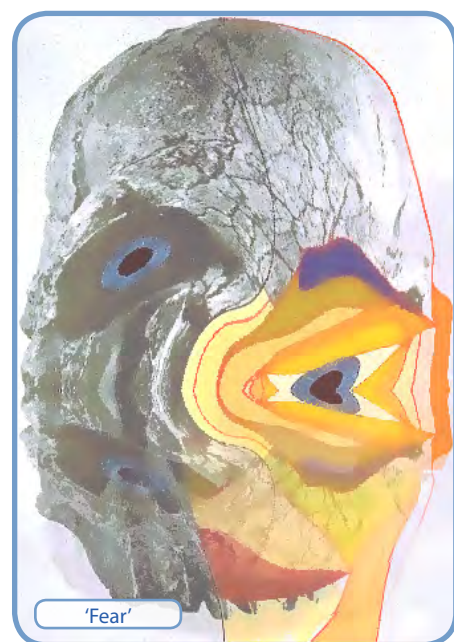
They have also provided patients with information and contacts with the support of the Oncology Centre Antwerp



'The Tunnel'

and the Flemish League Against Cancer.

In addition to being very active at a national level in Belgium, Wekgroep Hersentumoren has been heavily involved in a number of initiatives at a European level, including participation in ECPC events such as FACE Workshops, the development of a potential European Glioblastoma Network, and representing the needs of rare cancer patients to DG Sanco in Luxembourg.



'Fear'

## Wekgroep Hersentumoren

## Study Group Brain Tumours



# Dzivibas Koks

## The Latvian Cancer Society



Pink Ribbon Solidarity Day

The Latvian Cancer Society have worked to change the perspectives of Latvian society and government about cancer patients and their needs. In February, for World Cancer Day, they released and distributed a video in Latvian with English subtitles to change the attitude to the public to cancer. (This video is available through Dzīvības Koks's youtube channel.) In October, the Society organised a number of activities for Breast Cancer Awareness Month, culminating in Pink Ribbon Solidarity Day.



Pink Ribbon Solidarity Day



A summer rehabilitation camp

Over the summer, the Latvian Cancer Society offered psychosocial rehabilitation camps to patients, hosting 40 patients across two 5-day camps at which they could participate in sporting activities and workshops, and attend lectures. The Society is currently lobbying the government to offer more psychosocial and rehabilitation support to patients.

## AIMaC

**KEEPING A JOB WITH / AFTER CANCER**  
HOW TO FACILITATE ACCESS TO EMPLOYMENT BENEFITS

E. Iannelli\*, M. Colarusso\*\*, A. Lesma\*\*, L. Del Campo\*, M.C. Petroni\*\* and F. De Lorenzo\*

**Article 35 of the European Parliament resolution of 10 April 2008 on combating cancer in the enlarged European Union calls on the Commission to draw up a charter for the protection of cancer patients and chronically sick people in the workplace with a view to requiring companies to enable patients to continue in employment during their treatment and to return to their normal professional activities.**

**SOCIAL REHABILITATION**

Since the early XXI century AIMaC's successful lobbying activity has primed the Government for responding to the emerging needs of cancer patients, a considerable rate of whom tend to become chronic as a result of new treatments. Welfare and job protection benefits have to play a major role within cancer rehabilitation programs since they are important to improve QoL for cancer survivors, and to help them return to a 'normal' life after cancer treatment ends. Italy's most influential governmental authorities have paid heed to the requests coming from cancer organizations. As a result, changes have been introduced in the present regulations, for instance in the fields of welfare and healthcare, public and private employment, equal treatment of all cancer patients, communications and awareness campaigns, including specific programs to be performed at a European, national and local level.

**CURRENT SITUATION IN ITALY**

~2 000 000 cancer survivors  
~650 000 of working age (1/3 of the total)

**ITALIAN SOCIAL CAMPAIGNS**

**AIMaC - PIEPOLI INSTITUTE SURVEY**  
"THE 'UNNAMABLE DISEASE'"

**"A SUPPORT NETWORK TO IMPLEMENT REGULATIONS IN DEFENCE OF CANCER PATIENTS IN THE WORKPLACE"**

AIMaC and Eni have obtained a grant from the Ministry of Labour and Social Policies for this project. AIMS:

- to promote knowledge within the company of the support measures provided for under current legislation and in company agreements for workers affected either directly or indirectly by cancer and of the forms of protection presently available;
- to raise awareness among management and employees of the need to adopt ethical conduct targeted at protecting the working conditions of cancer patients in terms of their psycho-physical integrity and their dignity

The pilot project is unfolding in two phases and has been initially applied to a significant number of employees in a Division/Company of Eni Group (3,000 people), so as to make the results of the initiative that much more meaningful.

**1<sup>st</sup> phase:** anonymous questionnaire survey. The results are currently being processed and statistically evaluated.

**2<sup>nd</sup> phase:** production, in cooperation with AIMaC, of an information booklet to provide all the elements needed to cultivate updated knowledge of cancer and of the legal and contractual support of which a worker with cancer or his/her carer can avail. This will be supplemented by information, news and articles published on the company intranet.

Recognising the importance of employment in quality of life and rehabilitation, the Associazione Italiana Malati di Cancro Parenti e Amici have been involved in a project to improve the working lives of cancer patients and survivors.

Working with the employer eni, they have developed a prototype model suitable for adoption by other businesses, identifying and facilitating support measures for staff with cancer.

The project informed employees affected by cancer of their rights under current legislation and company agreements, and the legal, professional and contractual protection they can benefit from, through a booklet.

AIMaC and eni encouraged other managers and employees to adopt an ethical attitude to those affected by cancer, respecting their dignity, and facilitated access to the opportunities provided for by law and by specific work agreements, which allow for ongoing therapy for cancer patients or care for employee family members combating the illness.

AIMaC have also run public awareness campaigns and lobbied for changes to legislation to promote equal rights for cancer survivors in welfare and in working life, and are developing training programmes with eni.



## European Waldenströms Macroglobulinemia Network

The European Waldenströms Macroglobulinemia Network brings together patient organisations from Belgium, Denmark, Finland, France, Germany, Greece, Ireland, the Netherlands and the UK and aims to represent WM patients at a European level.

It is able to do this with the support of Multiple Myeloma Waldenström (CMWP). Looking ahead to 2011, the EWMnetwork Board adopted a new Strategy Plan in October, which aims to enlarge the number of WM patient support groups in Europe, in addition to consolidating information activities.

The Polish Cancer Patient Coalition builds links between its member organisations to share experiences and best practice, and represents those organisations to public institutions.

In 2010, they have developed strong partnerships with important bodies in the field of health policy. A meeting with the Ministry of Health early in the year

In addition to reaching a wider audience through their website, in 2010 EWMnetwork have gained three new affiliates in Switzerland, Ireland and the UK.

They have also welcomed nine specialists to their Medical Advisory Board: Dr. Jan Van Droogenbroeck (Belgium), Dr. Lars Munksgaard (Denmark), Dr. Petri Oivanen (Finland), Dr. Pierre Morel (France), Dr. Veronique Leblond (France), Prof. Dr. med. Christian Buske (Germany), Prof. Dr. Henk Lokhorst (Netherlands), Ass. Prof. Dr. Eva Kimby (Sweden) and Dr. Roger Owen (UK).

EWMnetwork have been very active at an international level. They have been heavily involved in a number of ECPC and EURORDIS initiatives, such as those by ECPC's Action Group Against Rare Cancers, or the 5th European Conference on Rare Diseases.

They were invited to attend part of the 6th International Workshop on WM for European Physicians, and have also become a member of the Lymphoma Coalition.

At the Second European WM Forum, they worked with a number of affiliates to improve organization of patient support groups, and worked with the International WM Foundation to increase the number of WM support groups in Europe.



representatives of the Agency for Health Technology Assessments and the National Health Fund.

In 2010, they launched an ambitious project entitled "Professional Management of Cancer Patient Organisations". This was a series of workshops and lectures aimed at leaders and volunteers in cancer associations, designed to develop the tools and networks needed to progress the goals of associations.

The programme also offered an opportunity to participate in sport competitions organised with the National Athletics Meeting of Breast Cancer Patient "Amazons". PKPO has also been involved in a number of other initiatives as a partner or honorary patron, including the "Healthy Municipality" campaign which raised awareness of screening programmes in local communities.

## Polish Cancer Patient Coalition



has led to an arrangement for quarterly meetings between the Ministry and the Board of the PKPO to discuss topics relevant to health policy in the context of oncological treatment.

PKPO also regularly meets with the Parliamentary Health Committee, rep-





LIPA is a Serbian organisation supporting lymphoma patients. Enjoying the support of the Serbian Ministry of Health, media and numerous local communities, this association has organised a number of events in addition to creating a 2011 calendar and launching a partnership with the Rotary Club of Constantin the Great.

Believing that a good relationship between doctor and patient, full of mutual trust, is very important to the outcome of medical treatment, LIPA organised a

gathering of association members with doctors of different specialties early in 2010.

In September they also held a workshop for doctors at the Congress of Medicine on World Lymphoma Awareness Day.

In May, they participated as an instructor in the second National Seminar for Representatives of Patients' Rights, and

## LIPA



"Step to Health"



"Power to Patients"

in July highlighted the importance of teamwork and solidarity through an open-air tango class called "Step to Health".

They ended the year by visiting patients in hospital over Christmas and distributing gifts.

Ontmoeting & Ontspanning Kanker (Meeting and Recreation Cancer) is a Belgian organisation entirely staffed by volunteers. It aims to improve the well-being of cancer patients and their families, through organised activities including swimming and Nordic walking, film showings, and day-trips to events in Belgium like the flower festival Floralien in Ghent.



LiveStrong weekend



Members of OK at Floralien, Ghent

As a member of the Lance Armstrong Foundation, they organise a yearly sporting LiveStrong weekend, often featuring mountain biking and walk-

ing. They also offer well-being therapies such as massages at affordable prices thanks to sponsorship.

## Ontmoeting & Onstpanning Kanker Meeting and Recreation Cancer

The Romanian Cancer Society provide information for patients, promote prevention and detection measures, and support patients practically and through their advocacy work. They also provide financial support for around twenty patients with low income, helping them with medicines transport to oncology units and other associated costs of cancer therapies.

In 2010, the Romanian Cancer Society reached over 1,000 girls in high schools in Cluj Napoca to raise awareness about breast cancer, teaching them to perform breast self-examinations and encouraging them to share this and screening programmes with their mothers. This was supplemented by a number of leaflets and booklets on prevention and early detection of a range of cancers, published and distributed by the Romanian Cancer Society.

The “smile for little cancer patients” programme, supported by Sanofi Aventis, offered social counselling and psychological support for parents of children with cancer, as well as providing fresh fruit and organising creative activities for the children, improving their well-being. Special events and parties are arranged with entertainment such as clowns or fairy tale characters, and this programme will continue in 2011.

2010 has seen remarkable success in the Romanian Cancer Society’s advocacy work. Their campaign “Dignity and Respect – Rights for breast cancer survivors”, started in 2009 with the support of



## Romanian Cancer Society



“The Society of Volunteers-Agaliazo is a not-for-profit NGO in Greece. They have branches in Achaia and Greece in addition to their headquarters in Piraeus.. With 5,000 readers of their free magazine, they work to raise awareness about early cancer detection and population screening.

Agaliazo provided screening opportunities in remote areas, arranging for doctors to visit remote islands and cities along the Greek-Turkish border to perform tests and conduct open lectures to inform the population about cancer prevention methods.

In 2010, Agaliazo also developed their

## AgaliaZO

advocacy activities, campaigning for equal rights for cancer patients when the Ministry of Health decided that Social Security Organisations would cover the cost of medication to help patients to stop smoking – with the exception of patients with cancer. They also offer advice and assistance to cancer patients individually through their Advocacy Committee. Agaliazo anticipate expanding their advocacy work in 2011 when Greece will formulate a National Cancer Strategy.

Agaliazo are very creative in their awareness activities. In addition to public awareness campaigns patronised by the Greek Ministry of Health, this year they have used information stands staffed by volunteers and doctors in

the Susan G Komen for the Cure Foundation. It has involved obtaining qualitative research based on focus groups of survivors, a legal report comparing Romania with other EU countries, and a petition of 45,000 signatures. This has been building towards a legislative proposal heavily amended in parliament, which will provide for the rights of breast cancer survivors. In 2010, the campaign coordinator and a number of survivors met with the Committee for Family and Health from the Chamber of Deputies, who agreed to support the proposed legislation, and the Romanian Cancer Society is now waiting for the law to be finally approved in 2011.

public places to raise the profile of cancer screening and prevention: distributing leaflets and answering questions about cervical cancer in Athens Mall; offering dermatological examinations on beaches in the summer; training women to perform self-examinations for breast cancer using DVDs; and using an Inflatable Colon in metro stations and city halls to inform the public about colon cancer. Open lectures, sometimes held in high schools, raise awareness of the importance of prevention and screening measures. At the Christmas bazaar, Agaliazo set up a stand in the metro station Syntagma in Athens and, supported by the gynaecological clinic Gaea, handed out vouchers for free PAP tests and half-price mammographies.



The "Pioneering Cancer and Stemcell Transplantation Coordination Association" has provided assistance and support to cancer patients in Turkey since 2006. Coordinating and organising medical, psychological, social and legal support for patients and relatives for free, in 2010 Kökder launched two imaginative initiatives in addition to collaborative projects with Istanbul Municipality.

60 volunteers have been recruited and trained, and the Blue Angels are now regularly visiting two state hospitals in Istanbul, offering support and a friendly smile to cancer patients. A parallel initiative called Young Blue Angels has seen 100 university students working towards qualifications to join this activity.

Six 'cancer patient schools' have been established to educate patients and relatives, and to gather medical, social and economic feedback.

PAVEL stands for "Primind Ajutor, Viata Este Luminoasa", which means "Getting Help, Life Is Bright". This non-profit, non-governmental organisation was created in 1996 by a group of parents of children with cancer and is active in a range of ways.

From lobbying Romanian authorities to improve access to and quality of services to distributing free wigs, wheel chairs and prosthetic breasts, they endeavour to help each family with a child experiencing cancer with as many needs as possible.

Their Parents House offers free accommodation to families in financial difficulties who come to Bucharest for treatment, while their playrooms and relaxation rooms offer valuable psycho-social care in two of the main hospitals.

PAVEL organises many events for children who are cancer patients or survivors, ranging from play therapy staffed by social workers to festivals at Christmas and Easter. Parties for birthdays,

## PAVEL



## KÖKDER

camp and trips out, displays of artwork and other projects have been supplemented in recent years by trips outside Romania.

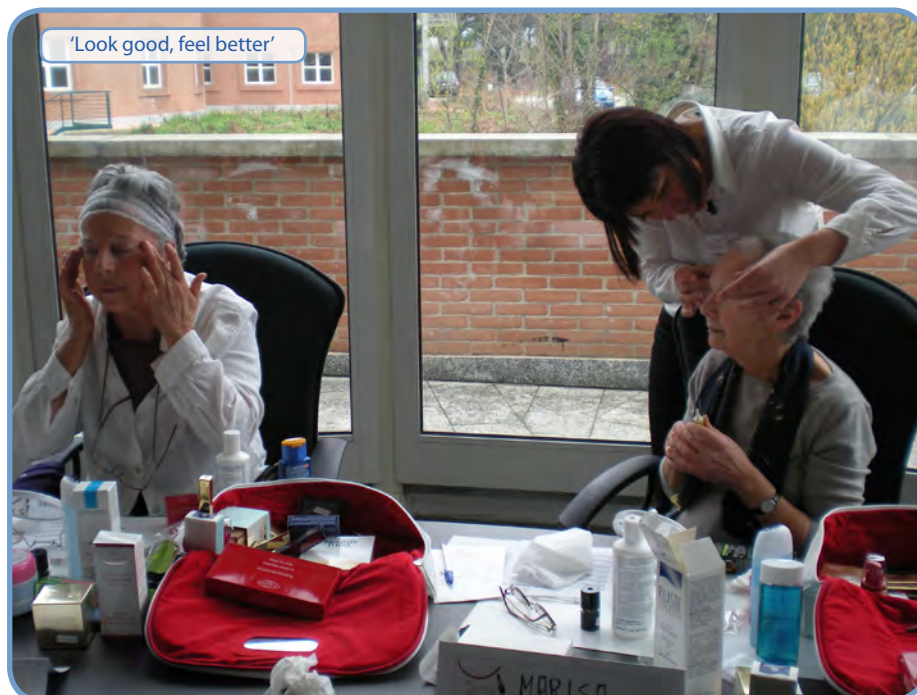
In 2010, 7 children accompanied by parents and PAVEL team members travelled to Russia to take part in the World Children Winner's Games, sponsored by Novartis Romania. Participating in a number of sporting competitions, two children won second prize – Chisa Ionela Claudia at chess and Campean Alexandra Maria at table tennis.

As part of their ongoing work to inform patients of their options, in 2010 PAVEL

have launched a website informing patients about drugs unavailable in Romania. They also ran a national awareness campaign which used the media as well as major towns to spread awareness of "Childhood Cancer Signs and Symptoms" among the public and community health workers, with the support of the International Union Against Cancer.

PAVEL have recently joined a new initiative the Alliance for Health, which brings together representatives from different disease communities, and in 2010 represented patient concerns at the National Conference for Onco-Paediatrics.





Women Against Lung Cancer Europe has centres across Italy, as well as a number in Spain and one each in Serbian and Germany. These centres offer psychosocial support in creative ways to women experiencing lung cancer, focusing on self-esteem and a positive self-image. These include wig reimbursement and relaxation technique classes, and programmes such as “An idea of your head”, at which hairdressers and beauty consultants offered practical advice to pa-

tients experiencing hair-loss. The “Look good, feel better” programme invited make-up artists into cancer centres.

WALCE has also organised a number of events to raise awareness on communities as well as raise funds for their activities. In 2010, these included a Gospel concert, the national Ecomaretona, the Virgin London Marathon and a Fundraising Dinner. They have also published a new educational booklet “The Mesothelioma”, available in English or Italian,

## WALCE Women Against Lung Cancer Europe

covering a collection of topics relevant to lung cancer. WALCE represent the voice of lung cancer patients in a number of arenas, including ESMO and AIOM cancers, and participated in the Global Lung Cancer Coalition Annual Meeting in Hong Kong.

In November, for Lung Cancer Awareness Month, WALCE ran a free telephone hotline for people to call and ask any questions. They ran a make-up service in cancer centres and disseminated lung cancer information among the general public.



## Za Novi Dan



This Croatian association supporting cancer patients and their families, whose name means ‘for a new day’, have been particularly active in raising awareness of cancer prevention and screening, and fighting for justice for cancer patients. Za novi dan have also co-organised a workshop on curing and treating rare diseases, and participated in the first national rare diseases conference.

In February 2010, the University Hospital Centre in Rijeka refused to continue the treatment of cancer patients to cut costs, putting these patients on the hospital waiting list. Not only is this appalling and unjust, it was also illegal in the light of a recent Parliamentary Resolution. Za novi dan organised a press conference on World Patient Day to raise awareness of this, entitled “Health rationalization harms cancer patients”.

Hospitals across Croatia have been allocated shamefully low budgets, denying patients a chance of a cure or even adequate end-of-life care. Doctors want to speak out but fear sanctions, and success in healthcare management is measured by successfully cutting costs rather than providing treatment or improving care.

Awareness-raising programmes have included CroMSIC’s “Buggy campaign”, a joint initiative with the Croatian Obesity Prevention Association, Health Associations Coalition and Europacolon,

which sends medical students into high schools to educate pupils about cancer prevention and early diagnosis.

A video featuring Croatian actor Filip Šovagović has been successful in promoting screening for colonic cancer, and a three-year national education campaign has been launched. This will focus on colorectal cancers but will also address breast, lung, testicular, prostate and uterus cancers. It is officially sponsored by the Croatian Ministry of Health (HZZO), the city of Zagreb and the Ministry of Science, Education and Sport.

In December, a charity fashion show raised funds and awareness as part of this campaign.





## FAVO

## Italian Federation of Volunteers in Oncology



'Look good, feel better'

FAVO, the Italian Federation of Associations of Volunteers in Oncology, has been particularly active behind the scenes improving cancer care on a national scale, particularly rehabilitation support for cancer survivors. FAVO have been involved in developing Italy's National Cancer Plan this year.

Thanks to FAVO's demonstration that rehabilitating cancer patients brings economic benefits rather than costs, Italy is one of the few European countries to have taken a comprehensive approach to cancer rehabilitation.

Following on from reports published by the National Observatory of Disparities in Cancer Treatment, FAVO have achieved two significant changes. One report found that access to benefits varied across the country as local governments used different processing procedures. FAVO has supported the introduction of a uniform process in which applications are submitted by the doctor directly to the INPS, allowing patients access to the relevant benefits within four months.

Another report also indicated that cancer patients do not have the same right to immediate access to treatment with life-saving new biological drugs across the country. The State-Regions Conference and the Italian government have approved a route suggested by FAVO to ensure that in all Italian regions innovative life-saving drugs become available to all (once approved by EMA and AIFA) without additional bureaucratic steps.

In addition to this, on National Cancer Survivor Day in May, the news and debate programme 'Matrix', presented by Alessio Vinci, dedicated a show to FAVO and AIMaC. They participated in the 8th ESMO Patient Seminar, alongside other ECPC members, focusing on rehabilitation activities, and in collaboration with the Committee Fondazione IRCCS "Istituto Nazionale Tumori - Milano", FAVO have published a booklet entitled "From the biobank to the research biorepository: ethical and legal recommendations", which was edited by OECD and is available to download from their website ([www.favo.it](http://www.favo.it)).

**FAVO**  
Federazione italiana delle Associazioni di Volontariato in Oncologia

**V Giornata nazionale del malato oncologico**  
vinciamo insieme la vita

**Roma, 13-16 maggio 2010**

**Pictures from FAVO's activities on National Cancer Survivor Day**

**Matrix per la giornata 11 maggio 2010**  
Il conduttore di Matrix, Alessio Vinci, con Elisabetta Iannelli (Segretario Generale FAVO) e Francesco De Lorenzo

**Conferenza stampa di presentazione del rapporto 13 maggio 2010**  
Il Ministro Fazio, Antonio Mastrapasqua e Francesco De Lorenzo alla conferenza stampa di presentazione del 2° rapporto sulla condizione assistenziale dei malati oncologici

**Auditorium della Conciliazione 15 e 16 maggio 2010**  
La sessione sul tumore nei pazienti anziani. Da sinistra: Stefania Gori (aiom), Alessandro Meluzzi (AIMaC), Umberto Tirelli (cro Aviano), Rosa Oricchio (AIMaC)

**Istituto Regina Elena 14 maggio 2010**  
sessione dedicata ai diritti dei malati di cancro alla prostata presso l'Istituto Regina Elena di Roma.

**Conferenza stampa di presentazione del rapporto 13 maggio 2010**  
Lo staff di FAVO insieme a Cristina Parodi, testimonial della FAVO e moderatrice della conferenza stampa.

**Conferenza stampa di presentazione del rapporto 13 maggio 2010**  
Biblioteca del Senato, Sala degli Atti Parlamentari, 13 maggio 2010

**Matrix per la giornata 11 maggio 2010**  
Francesco De Lorenzo con gli altri ospiti di Matrix dell'11 maggio: Matteo Mastromauro, giornalista Mediaset e Fabio Salvatore, scrittore.

# Financial Report 2010

## Directors' Report

### Introduction

Established in 2003, the European Cancer Patient Coalition (ECPC) 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 was established to represent the views of cancer patients in the European healthcare debate and to provide a forum for European cancer patients to share best practice on patient advocacy. 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.

### Results

In 2010, net income increased by EUR 25.987 compared to 2009. Expenditure increased by EUR 124.537.

This was mostly due to significant increases in costs in 2010 compared to 2009, which were primarily due to high internal consultancy costs which were considered unacceptable. This led to a complete revision and re organisation of the management of ECPC during the second half of 2010, including the closure of the Munich Office.

The formation of the provisional Finance Committee during the first half of 2011 has enabled an in depth examination of the 2010 accounts to be carried out.

Office financial policies, based on the Treasurer's Recommendations approved by the Board in 2009, are continuously reviewed and updated to ensure that we maintain cost effectiveness. Minutes of the findings of the acting Finance Committee have been disseminated to all Board members.

### Future outlook

ECPC has created a very ambitious programme for 2011 which has been thoroughly evaluated for cost effectiveness. Our programmes are continuously monitored and evaluated for cost effectiveness on a quarterly basis.

The Board of Directors are not aware of any events subsequent to the date of closure of the accounts which could affect the validity of the financial statements.



## Results 2010

	2010 EUR	2010 %	2009 EUR	2009 %
<b>Net turnover</b>	<u>437.446</u>	<u>100,0</u>	<u>409.863</u>	<u>100,0</u>
Wages and salaries	145.270	33,2	166.088	40,5
Depreciations	211	-	-	-
Other operating costs	<u>464.754</u>	<u>106,2</u>	<u>144.502</u>	<u>35,3</u>
<b>Total operating costs (B)</b>	<u><u>610.235</u></u>	<u><u>139,4</u></u>	<u><u>310.590</u></u>	<u><u>75,8</u></u>
<b>Operating result (A-B)</b>	-172.789	-39,4	99.273	24,2
Financial result	<u>430</u>	<u>0,1</u>	<u>-8.446</u>	<u>-2,1</u>
<b>Result from ordinary activities before taxation</b>	-172.359	-39,3	90.827	22,1
Taxation	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>
<b>Net result</b>	<u><u>-172.359</u></u>	<u><u>-39,3</u></u>	<u><u>90.827</u></u>	<u><u>22,1</u></u>

Source: 2010

## Statement of Financial Position

	2010 EUR	%	2009 EUR	%
<b>Assets</b>				
Tangible fixed assets	3.345	0,7	-	-
Accounts receivable	40.526	8,7	40.003	7,0
Cash at bank and in hand	<u>421.775</u>	<u>90,6</u>	<u>531.788</u>	<u>93,0</u>
	<u><u>465.646</u></u>	<u><u>100,0</u></u>	<u><u>571.791</u></u>	<u><u>100,0</u></u>
<b>Liabilities</b>				
Shareholders' equity	339.432	72,9	511.791	89,5
Current liabilities	<u>126.214</u>	<u>27,1</u>	<u>60.000</u>	<u>10,5</u>
	<u><u>465.646</u></u>	<u><u>100,0</u></u>	<u><u>571.791</u></u>	<u><u>100,0</u></u>

Source: 2010 financial statements

A full copy of our Annual Financial Report 2010, produced by our bookkeepers Accounting Square and reviewed by our auditors KPMG Netherlands, is available to download from our website.



### How to contact ECPC

ECPC Brussels Office  
Rue de la Loi, 26  
1040 Brussels  
Belgium  
E-Mail: [info@ecpc-online.org](mailto:info@ecpc-online.org)

### ECPC Website

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

ECPC is registered as a non-profit association in  
The Netherlands, Reg.-Nr. 30211815

### Join ECPC

Please join us in the fight against cancer.  
Contact ECPC via [info@ecpc-online.org](mailto:info@ecpc-online.org) if  
you are interested in learning more about  
ECPC or FACE.

### FACE Website

<http://www.forumagainstcancer.eu>



### About ECPC

Established in 2003, The European Cancer Patient Coalition (ECPC) 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 was created

to represent the views of cancer patients in the European health-care debate and to provide a forum for European cancer patients to exchange information and share best practice experiences. ECPC represents over 300 patient organisations across Europe. ECPC is run by and for patients. During the last legislative period, ECPC provided the MEPs with a platform to discuss issues of relevance and to communicate to their constituents.