



EUROPEAN
CANCER
PATIENT
COALITION

ECPC ANNUAL REPORT 2011



ECPC SPEAKS WITH A SINGLE VOICE FOR ALL CANCER PATIENTS

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FACE Workshop on Health Inequalities, European Parliament, January 2011

Dear ECPC Members,

2011 has been busy for ECPC. Despite turbulent political times, we have had a very successful year.

Since moving all our staff and operations to Brussels at the beginning of 2011, we have seen our presence in the European Parliament grow and our policy activities flourish. We have organised and co-organised six workshops in the European Parliament, consolidating our relationships with the parliamentary Members and other key stakeholders. This progress is shown in the success of the Written Declaration on cancer research supported by ECPC, which was signed by a majority of all MEPs in January 2011.

We have also launched an innovative new model of engaging stakeholders on specific issues. The Melanoma Independent Community Advisory Board was established at a conference held in April, identifying and addressing key obstacles to access for new treatments for malignant melanoma patients. This initiative owes much to Patricia Garcia Prieto, a stage IV melanoma patient who brought these issues to the attention of ECPC and who has worked tirelessly on this project.

We did not organise a patient masterclass this year, as we usually do. Instead, we organised a conference for patient advocacy groups in EU-candidate and -neighbouring countries, as part of the European Week Against Cancer. ECPC managed two days of the four day event, at which a number of ECPC members shared best practice experiences with other groups.

There have been a number of changes to the Board over 2011. The Board decided to co-opt two new members, Jana Pelouchová and Ingrid Kössler, to make up numbers following the resignation of our Secretary, Sandy Craine. Sandy has been a Board member and Secretary since 2009 and we are sorry that she no longer feels able to remain on the Board. We were also sorry when, in February 2012, our Treasurer Tom van der Wal also resigned. I wish to personally thank both of them for the time and energy they have given to ECPC, and wish them the



best of luck in their future endeavours. Both Sandy and Tom are involved with ECPC member organisations, and so fortunately they have not left the ECPC family. I look forward to meeting with them at our AGM and other events.

We are delighted to welcome Jana and Ingrid to the Board. Both are established and respected patient advocates in their disease areas, and coming from the Czech Republic and Sweden respectively, they contribute to an even distribution of Board members from different parts of Europe. They have quickly taken on key roles, with Jana becoming Secretary over the course of 2011, and Ingrid becoming Treasurer early in 2012.

I wish to extend my thanks to all of the individuals who work so hard to make ECPC what it is - the Board, the staff and everyone at our member organisations.

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.

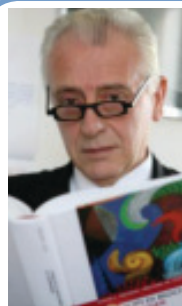
Tom is actively engaged in every stage of ECPC's development, liaising closely with both office and Board members on policy activities and strategic direction. He also has a keen interest in providing a platform to involve young people in shaping policies that will affect their health.



**Sandy Craine, Secretary
(resigned May 2011)**

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.



**Francesco de Lorenzo,
Vice-President**

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, and attended the UN high-level summit on non-communicable diseases in 2011.



**Jana Pelouchová, Secretary
(co-opted June 2011)**

Jana Pelouchová was co-opted to the ECPC Board in June 2011, and invited to take up the role of Secretary. After being diagnosed with CML, Jana founded Diagnostika CML in the Czech Republic. She is also a founding member of the CML Advocates Network.

Jana has focused on issues affecting rare cancer patients and is working to involve Central and Eastern European patient groups more fully in ECPC.



**Ingrid Kössler
(co-opted June 2011, appointed
Treasurer in March 2012)**

Ingrid Kössler was co-opted to the ECPC Board in June 2011. Since her diagnosis with breast cancer in 1988, Ingrid has been involved in patient advocacy, serving as President of the Swedish Breast Cancer Association and of Europa Donna. She has been a Member of the European Economic and Social Committee in Brussels since 2006.

Ingrid has supported the office's policy activities in Brussels and took up the role of Treasurer in early 2012.

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.

The current Board were elected in 2010, and will stand until the next elections in 2013.

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 three associations in Belgium.

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

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.

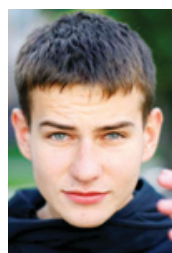
**Tom van der Wal, Treasurer
(resigned February 2012)**



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.

Šarūnas Narbutas



When he was diagnosed with CML in 2006, Šarūnas 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.

ECPC Staff



Denis Horgan, Head of External 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 (resigned August 2011): 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



Martin Lohr, Policy Assistant (resigned December 2011): 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, Office Manager: Nicola Colson initially began at ECPC with a Communications role, bringing editorial experience with a UK political magazine. In addition to developing ECPC's paper and online communications, she has taken over the financial and office administration (formerly managed by ECPC's Munich office). Her role also includes liaising with members, organising the AGM and liaising between Board and office.



Aukje Zijlstra, Intern (March - June 2011): Aukje Zijlstra was a graduate student in science communication at the University of Groningen. During her internship at ECPC, which formed part of her masters degree, Aukje wrote a number of articles for the ECPC newsletter and prepared materials for ECPC conferences. She went on to graduate from her degree.

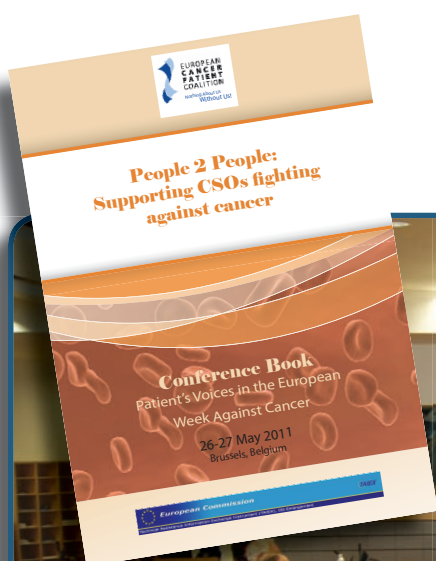
Emilie O'Herne, Intern (October 2011 - March 2012) Emilie O'Herne came to ECPC following her graduation from the University of York to work on ECPC's activities with young people. With her experiences working with the THIMUN network and other voluntary work on youth issues, she helped to develop ECPC's capacity



Vesta Ratkeviciute, Volunteer (October - November 2011): Vesta joined us on a brief release from her work at the EU Affairs Co-ordination and Preparation for the Presidency Division in the Lithuanian Ministry of Agriculture. With her background working for the national parliament, the European Parliament and the Lithuanian delegation to the EU, she was able to make a strong contribution to ECPC's work.



Patient Advocacy: Building Capacity

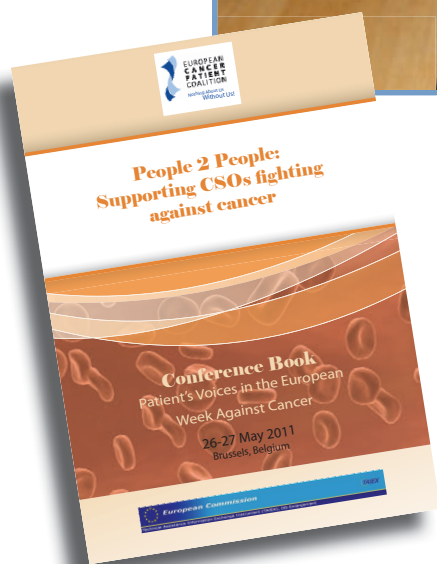


People2People Conference: European Week Against Cancer, May 2011



Delegates at the People2People Conference

People2People: Supporting CSOs fighting against cancer



The People 2 People: CSOs fighting against cancer event was a four-day workshop for cancer advocacy groups in EU-candidate and -neighbouring countries, and was held to coincide with the European Week Against Cancer. ECPC was invited to organise two days of the event, which was funded by the European Commission (Technical Assistance Information Exchange Instrument, DG Enlargement).

The event was held in the Committee of Regions and the European Economic and Social Council, and took place on May 26-27 2011.

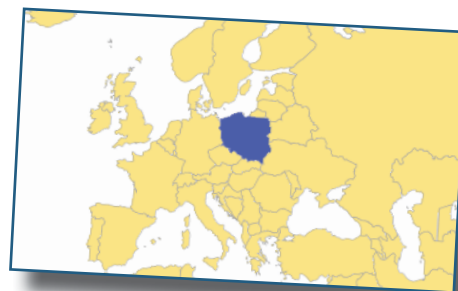
Including speakers from Europa Uomo and Europa Donna, and from advocacy groups in Romania, Greece, Turkey and Poland, the event focused on the exchange of best practice between patient advocacy organisations. Organisations were invited to present successful projects, particularly those making use of social media.

The key points which came out of this conference were the importance of collaboration and networking, and of building long-term relationships with advocacy groups across national borders and disease groupings. This was summed up by speaker Prof. Louis Denis (above right), who is both oncologist and cancer patient:

"This disease does not stop at borders, nor do calamities and problems faced with cancer morbidity or mortality. We have a common fight across our countries."



ECPC President Tom Hudson speaking to delegates at the People2People Conference



ENAN: European National Advisory Networks

Poland

ECPC launched the ENAN initiative as a way of linking up more effectively with patient groups active at the national level - both ECPC members and non-members.

The first ENAN trip was made to Poland in April 2011. The trip was a great success, strengthening ECPC ties with patient groups and also helping us to identify new partnerships. It was also a great opportunity for the ECPC team to see the activities of our members first-hand, and to meet the people behind the achievements.

During the trip, we were able to attend the Congress of Contemporary Oncology in Poznan. The patients' panel focused on good relationship between patients and doctors, and during the event, a Memorandum was composed and signed by all patient organisations present, including ECPC.

The Poznan Memorandum, dated 14 April 2011, called upon the key stakeholders to review and improve the

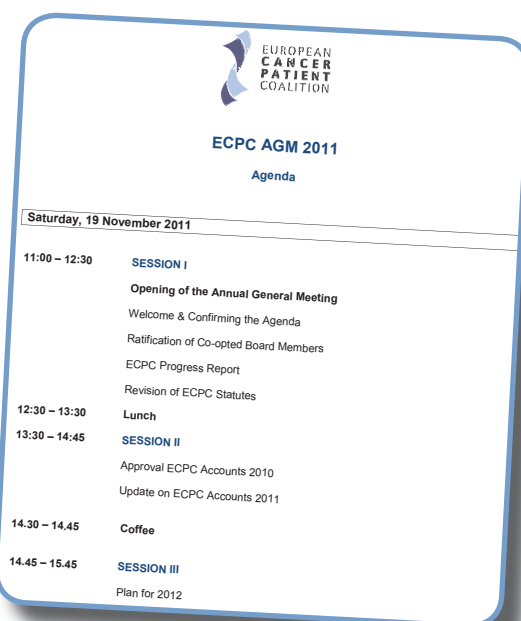
National Cancer Plan; to provide all patients with quality diagnostics and care; guarantee patient involvement in related decision-making; make cancer a priority of the Polish Presidency of the EU; and fight against discrimination in access to treatment.

On the last day of our visit, we participated in a conference on patients' rights in Poland, to link up with European Patients' Rights Day.

We would like to thank all the organisations who welcomed us and shared their work with us.

Organisations we met:

- Polish Association Supporting the Myeloma Patients;
- Association of Men with Prostate Cancer "Gladiator";
- Polish Society of Clinical Oncology;
- Polish Union of Oncology;
- KRWINKA, Foundation for Children with Cancer Diseases;
- The Fulfilled Dreams Foundation;
- Association Supporting Sarcoma Patients;
- Polish Ostomy Association POL-ILKO;
- Polish Cancer Patient Coalition;
- Nationwide Association for CML Patients Aid;
- Polish Federation of Breast Cancer Survivors "Amazonki";
- "Let's Win Health" Foundation;
- Association supporting GIST patients;
- Patients' Rights Ombudsman;



ECPC Annual General Meeting 2011

The ECPC Annual General Meeting took place on 19th November 2011, at the Oncology Centre in Antwerp, Belgium. The minutes can be read below:

Session I: Progress Report; Statutes Revision

- Members noted the passing of Board member Arthur Masny with sadness, and paid tribute to his contribution to this field.
- The appointments of co-opted Board members Jana Pelouchová and Ingrid Kössler were ratified unanimously.
- ECPC Board and staff reported on recent activities.
- It was noted that all would like ECPC to become more closely involved with professional medical groups, and were pleased to hear about the collaboration with EHA on a workshop in August.
- ECPC will continue to lobby on the issue of how the Commission funds patient organisations who also receive funding from pharmaceutical companies.
- There was consensus among the membership that ECPC is the main voice for patients in Europe, as well as a request for ECPC to formalise its relationships with other key stakeholders such as Europa Donna through a Memorandum of Understanding.
- The proposed statutes were present-

ed to the membership, who approved them by a strong majority. However, it was proposed and unanimously agreed that the statutes would be distributed to all full members for consultation and voting.

Session II: ECPC Accounts

- The financial report was presented. Explanations were provided about changes made to ECPC's internal administration, as well as further anticipated changes over the next year. The members agreed that great progress was being made in growing ECPC into a strong and sustainable organisation.
- The financial report was approved unanimously by the members, with all Board members abstaining from this vote.
- The membership fee was discussed. Members were in favour of introducing at least a nominal fee as a means of indicating commitment to the organisation. It was agreed that this item should be on the agenda of the next AGM.

Session III: Feedback from Members

- Little People Association Romania representative Shajjad spoke about an issue that had arisen over recent work there. Young cancer patients had been featured in a fundraising video for hospi-

tals, and their images had been treated inappropriately. It was agreed that ECPC would work together with corporate donors, European lawyers and media/PR sources to develop a Code of Ethical Conduct which could be launched in the European Parliament and could be used by corporate donors as leverage for good practice.

- The difficulty in getting responses from members via surveys was reported and discussed. The ECPC Board and Office are very keen to be able to investigate and report on the views and priorities of the member organisations.
- It was confirmed that the newsletter is open to all who wish to access it. It was also agreed that there would be no more than 10 newsletters a year to avoid overloading members with emails.
- Members will also be invited to submit an annual report of activity, to provide a regular opportunity to update their contact details and to inform ECPC about their projects.
- It was suggested that in each country, we would identify an active member to assist the office in updating our database and identifying active organisations to invite to join ECPC and/or participate in our activities.

The ECPC AGM 2012 will be held in Brussels in October next year. We look forward to seeing you there.



Policy Achievements





FACE Workshop on Health Inequalities, January 2011

ECPC in the European Parliament



The Forum Against Cancer Europe was launched in June 2010 in the European Parliament. It brings together Members of the European Parliament from different countries and political groups to support cancer patients.

Under the auspices of FACE, ECPC organised a number of workshops in the European Parliament. By bringing together the different stakeholders face to face, we can identify obstacles and difficulties, and discuss potential solutions.

Patients, clinicians, researchers, regulators, politicians and the pharmaceutical industry are invited to participate in these workshops.

In 2011, ECPC organised or co-organised six workshops. We began the year with a workshop on rare cancers, and the particular difficulties faced by patients with a rare cancer. With greater risk of a wrong or late diagnosis, often

fewer treatments available, and small populations which make clinical research very difficult, rare cancer patients face a very great challenge.

Later in January, a second workshop looked at health inequalities, at how differences in income and lifestyle affect the risk of developing cancer. Speakers underlined that health cannot be seen as an independent policy area - the long-term health implications of policies in areas ranging from environmental to urban planning to employment regulations

need to be considered.

In March, to coincide with International Women's Day, we focused on issues primarily affecting women with cancer, and looked at what lessons can be learned from patient advocacy among cancers predominantly affecting women, such as breast cancer.

Following the focus on women and cancer, in June we were delighted to hold a workshop on men's health. It marked the launch of a report on men's health in Europe which showed that men are dying younger and faster than



FACE Workshop on Personalised Medicine, November 2011

women for every major cancer that should be affecting men and women equally. This worrying report draws attention to the need to address gender inequalities in healthcare, particularly in awareness of risks and willingness to seek medical help.

In August, ECPC joined forces with the European Hematology Association (EHA) and a number of our members to organise a workshop in the European Parliament to look at the needs of haematology patients, including cancer patients.

In November, we linked up with the Organisation of European Cancer Insti-



FACE Workshop on Men's Health, June 2011

will be announced in the European Parliament plenary and discussed.

We would like to thank FACE Champion MEPs Marisa Matias (Portugal), Jo Leinen (Germany), Michele Rivasi (France), Herbert Reul (Germany) and Antonyia Parvanova (Bulgaria), who submitted the Written Declaration.

Written Declaration 80, inspired by a FACE workshop held in June 2010, aimed to improve the coordination, co-operation and coherence of pan-European, national, regional and local cancer research activities, avoiding duplication and focusing on unmet needs in cancer treatment. We are delighted that the declaration received so much support.

We would also like to thank the MEPs who participated in our workshops this year: Marisa Matias (Portugal), Petru Luhan (Romania), Sidonia Jędrzejewska (Poland), Gay Mitchell (Ireland), Nessa Childers (Ireland), Jo Leinen (Germany), Robert Sturdy (UK), Peter Liese (Germany), and Philippe Juvin (France).



MEP Petru Luhan signs the Written Declaration on cancer research

tutes (OEI) to organise a workshop on personalised medicine and the potential this offers to cancer patients. Looking at the obstacles to access, the meeting concluded with a very positive and hopeful message. ECPC will be taking forward the issue of personalised medicine in 2012.

As well as the workshops, FACE is also a platform which enables ECPC and cancer patients generally to access MEPs more easily, and facilitates MEP support for patient issues when passing legislative dossiers.

In January, the support enjoyed by ECPC in the European Parliament was made very evident when the Written Declaration on Cancer Research, actively supported by ECPC, was passed with XX votes, an overall majority of MEPs. A Written Declaration used to launch a debate on a particular subject. If this short text is signed by a majority of MEPs, it



Nessa Childers



ECPC-EHA Workshop on Haematology, August 2011



Melanoma ICAB

On Tuesday, 22nd March 2011, the launch of the Melanoma Independent Community Advisory Board (M-ICAB) marked a historic moment in cancer advocacy, and in particular melanoma.



The Independent Community Advisory Board model is adapted from the model of engaging different stakeholders involved in the treatment of people with HIV/AIDS. The model was very successful in this disease area and ECPC believes it can serve a role in the field of cancer.

Stakeholders and members of the melanoma community gathered to identify and adopt concrete actions to improve the situation for melanoma patients. The event was hosted by ECPC and moderated by Prof. Patricia Garcia Prieto, founding member of M-ICAB and stage IV melanoma patient. The M-ICAB initiative

was inspired by her battle for access to treatment and to clinical trials.

Participants in the interactive workshop included representatives from pharmaceutical companies, academic researchers, practising clinicians, MEPs, representatives from the European Commission and from the regulatory body the European Medicines Agency, as well as patients, relatives, carers and advocates. This is the first time other stakeholders have been invited by patients to an event where patients shape the agenda. M-ICAB offers a new model of connectivity to improve communication between stakeholders and to ensure a patient-centred approach at all times.

Patients and advocates spoke of the need for more information about available treatment and support to be disseminated. Catherine Poole, from Melanoma International Foundation in the USA, said that "an educated patient becomes very empowered – they live longer and happier." The pharmaceutical industry agreed that there was a willingness among different companies to collabo-

rate with one another and with other stakeholders, but that the problems, from their perspective, begin after regulation, with differences in Health Technology Assessments and a lack of EU support for patient access to drugs immediately after authorisation. Researchers called for half of future FP7 funding to be allocated through open calls and for biological sample collection to be made integral to future clinical trials, allowing the identification of biomarkers in the future. The final input came from the European Medicines Agency, who expressed frustration with the lack of focused targets for many drugs, and agreed that tissue collection is crucial.

The event was a very positive one, a welcome step in the path for fair access to treatment for all. ECPC hopes to apply the ICAB model to other cancer communities with difficulties accessing treatment.





Financial Report 2011

ECPC funding during the financial year 01 Jan 2011 - 31 Dec 2012

From European projects:	€ 19.926,00
From European grants:	€ 1.499,90
From industry grants:	€ 245.287,16
From honoraria:	€ 232,00
Total income 2011:	€ 266.945,06

We would like to thank the following organisations for their financial support:

Amgen; Bristol-Myers Squibb; Eli Lilly; F. Hoffman - La Roche; GlaxoSmithKline; Novartis; Pfizer; Sanofi Pasteur.



How to contact ECPC

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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 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.



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