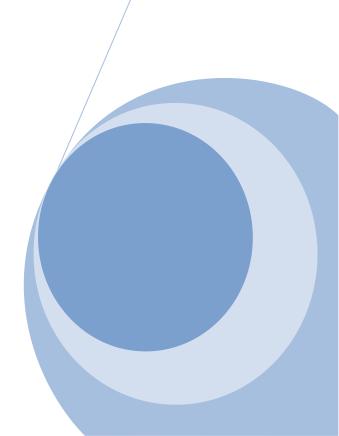
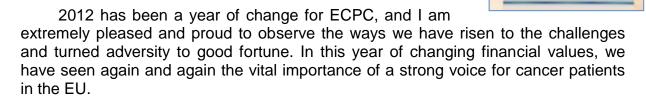


ECPC ANNUAL REPORT 2012



## Letter from the President

## Dear ECPC Members,



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This year has marked the appointment of a new Executive Director, Dr Erik Briers. As a patient and a scientist, he brings to the organisation a valuable and perhaps unique range of skills and experiences, and we are already seeing increased recognition from scientific and medical bodies in response to his expertise and diplomacy.

During 2012, we were very involved in the launch of a multi-stakeholder platform on personalised medicine, and provided the secretariat during most of the year. In the closing months of the year, this initiative was able to take its first tentative steps as a new movement in its own right. We are justly proud of the achievements of the Alliance and our involvement with it, and will continue to take a close interest in its development.

On more practical terms, we have moved offices. Our landlords in Brussels went into administration, and we were able to make this an opportunity to improve both our location and facilities in Brussels. Our new offices are only 300m from the European Parliament, both demonstrating and enabling the importance we place on ensuring that patient voices are heard in that institution, and we also now have meeting rooms for our use and for our members. The new premises mark another step in ECPC's development to a more sustainable, more professional organisation.

In the Spring of 2013 we will be holding elections for our new Board. I am sure this will be a vibrant and enthusiastic elections, and am confident that we will be able to hand over a strong and resilient organisation to our successors. I wish to thank my colleagues on the current Board, who have been extremely active and passionate and have made an enormous contribution to the growing recognition of ECPC and the importance of the work we do.

Tom Hudson, ECPC President

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## Letter from the Executive Director



Dear ECPC Members,

Being the Executive Director of an organisation such as ECPC is a challenge. It is even more of a challenge for a cancer patient as she or he knows first-hand the importance of a European level organisation.

Health is a mixed responsibility between the EU and national level. On some issues the EU is fully responsible for setting the agenda and issuing directives, on others it is the sole responsibility of the members states. This offers a complex situation for patient organisation such as ECPC.

At EU level the European Cancer Patient Coalition has to play its role as one of the major stakeholders in the healthcare debate. As major legislations are in the process of revision such as the Clinical Trials directive and the Medical Devices directive ECPC has been called to give its opinion and to eventually propose amendments on the pending proposals. This can only be done in cooperation with other stakeholders. At the same time, ECPC will maintain its privileged position with the EMA (European Medicines Agency) and other partners.

At the member state level the European Cancer Patient Coalition cannot act but only give support to the local organisations. Local organisations have to engage with their government in all aspects of health care but should play a major role in obtaining equal access to care in their country. They should be accepted as a stakeholder and equal partner in discussions on reimbursements and access to novel therapies.

These two levels are the two major arenas of activity for ECPC. ECPC has to develop a strong office team to participate in the EU level debate and to bring the "cancer" topic high up onto the agenda. Through collaboration with other stakeholders and our own FACE members of the European Parliament we need to work towards more awareness on cancer and to "personalise" it.

On the other hand ECPC has a responsibility towards its membership in helping them to act locally in their own member states. ECPC should give its membership the necessary tools to access their government and to build strong local organisations that need to have sustainability and professionalism. Through its "master classes", ECPC encourages the training of the membership even in areas such as Health Technology Assessment (HTA), the tool to decide on reimbursements for healthcare measures.

As a third point of action, ECPC has engaged in, and will further widen its participation in research at EU level. Today ECPC is already partner in several projects such as EPAAC, Rarecarenet, EurocanPlatform and others where we are acting as the voice of cancer patients, fulfilling our catch phrase "Nothing About Us Without Us".

Dear members, in order to do all this, ECPC relies on a professional staff that I have been able to lead for almost a year now. The challenges are many. We live in a world with limited financial means so we are indeed very grateful for the support we have received from our sponsors. I am thankful to have been able to work with excellent collaborators who share the desire to make ECPC a sustainable and professional European Coalition.

Dr Erik Briers,
ECPC Executive Director

## **ECPC 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.



Tom Hudson President (Ireland)



Francesco de Lorenzo Vice-President (Italy)



Simona Ene Vice-President (Romania)



Ingrid Kossler Treasurer from Feb 2012 (Sweden)



Jana Pelouchova Secretary (Czech Republic)



Tom van der Wal Retired from ECPC, Feb 2012 Former Treasurer (Netherlands)



Sarunas Narbutas (Lithuania)



Henk Van daele (Belgium)

## Patient Advocacy: Building relationships

# **ECPC Patient Masterclass, Rieti, Italy**



ECPC was delighted to welcome cancer patient advocates, medical professionals and researchers, and industry representatives to our Masterclass in the beautiful city of Rieti in Italy, for a **two-day Masterclass in June 2012. The event was attended by 94 delegates and speakers.** The weather was beautiful and very summery, so the continued focus and participation of our delegates was much appreciated by the ECPC team.

Over the course of the two days, we heard challenging, thought-provoking and informative presentations, and the questions and discussions which followed indicated that the delegates found much to respond to throughout the event.

The event began with welcome speeches from the ECPC Board and the Sabina Universitas, before **Andrea Micheli (National Tumour Institute, Italy)** delivered a keynote speech on inequalities in cancer control. He identified a number of paradigms which need to be embraced, and proposed suggestions for addressing these issues.

Alojz Peterle, a Member of the European Parliament and former President of Slovenia who is also a cancer survivor, opened this session. Mr Peterle is very involved in the fight against cancer in the European Parliament and has collaborated with ECPC over a number of years. He spoke about his personal experience with cancer, and the lessons that we must learn from the disease, before inviting everyone to join him in Rome for the EPAAC Open Forum.

Milena Sant (National Tumour Institute, Italy) presented the EPAAC initiative and the ten work packages. The need to collaborate and cooperate in the struggle against cancer emerged from this session as a clear imperative, as Riccardo Capocaccia spoke about developing systems to manage and share information. Tit Albreht presented the role of national cancer plans and the challenge of involving patients more in this. The example of successful patient involvement in the Swedish national cancer plan was presented by ECPC Board member Ingrid Kossler and further developed by Nils Conradi. The session was wrapped up by Jola Gore Booth (EuropaColon) and Ian Gibson (EPAAC) with a challenging look at why screening is not being implemented fully.

The first session was chaired by Ian Banks (European Men's Health Forum) and Kathy Oliver (International Brain Tumour Alliance). After brief presentations from Gabriella Pravettoni (ecancer) on shared decision making and empowerment, and from Gordon McVie (ecancer) on the dynamics of doctors and patients making decisions, the session evolved in a very interactive and participatory form, as delegates focused on the question of how we as patients can help politicians, the media and other stakeholders to understand the issues and work with us better. Full details of this discussion will be included in the final event report.

**Personalised medicine** seems to be all jargon – what exactly is it and what does it mean for patients? ECPC Board Member Sarunas Narbutas presented the concepts of personalised medicine in a comprehensible way, comparing the complex diagrams to the Tokyo metro map – with only a little bit of explanation, you can begin to make sense of the patterns. With 75% of cancer patients undergoing chemo gaining no benefit from this, personalised medicine offers a better outlook for patients and for healthcare budgets.

**Ulrik Ringborg (Karolinska Institute) presented the EUROCANPlatform** and current efforts to coordinate cancer research in the EU. Fabio Gambini (Roche) presented the industry perspective on personalised medicine as a win-win situation. Paolo Casali (ESMO) addressed the problem of small numbers, where the benefit of a drug becomes harder to demonstrate in smaller sub-groups of patients. Angelo Paradiso addressed the challenge of biobanks and called on patients to support this issue.

The first day ended with an extensive question and answer session. ECPC President Tom Hudson concluded this by commenting that we have a great enemy in the disease we fight, but that our other enemy is the divisions between our organisations that divide and weaken us in this struggle.

The second day of the conference launched with a presentation from ECPC Board member Sarunas Narbutas on cross-border healthcare, presenting the recent Directive and the work of ECPC in the European Parliament to promote patient rights on this issue. Julio Celis (ECCO) presented the role of ECCO in promoting the cancer agenda in the Innovation Union and the policy instruments which enable them to work in partnership with stakeholders.

Gemma Gatta (National Tumour Institute, Italy) presented a brief overview of the RARECARE project which demonstrated that rare tumours account for 24% of total cancer prevalence in the EU. ECPC Board Member Jana Pelouchova presented the work of her organisation CML Diagnoza in the Czech Republic, supporting and informing patients about this rare cancer and treatment types. Paolo Casali (ESMO) addressed the difficulties in making clinical decisions for rare disease patients when information is lacking, and the obstacles to gathering and sharing that information. Susanna Leto di Priolo (Novartis) spoke on behalf of EFPIA, looking at how pharmaceutical companies can interact with rare cancer networks.

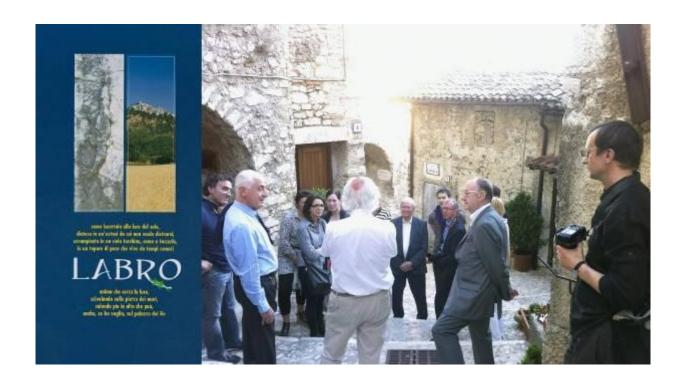
Annalisa Trama (National Tumour Institute, Italy) presented the next phase on the rare cancers project, RARECARENet, and invited participants to contribute through ECPC. This was followed by three national examples of managing rare cancer patient treatments – Jean Marie Brechot (National Cancer Institute, France) presented the network of national expert centres for rare cancers in France; Tom Kenny (National Specialised Commissioning Team, UK) presented the system of commissioning specialised services for cancer through the NHS; and Agnieszka Kowalewska (Bialystok Medical University, Poland) presented the Polish system for managing rare cancer patients.

**ECPC Vice President Francesco de Lorenzo** spoke about the UN High Level Meeting on Non-Communicable Diseases in September 2011. Following this, Andrea Micheli concluded the presentations with a look at cancer cost problems, and the challenge of considering health expenditure as investment rather than as a cost.

ECPC members made use of this opportunity to discuss the event and comment to the Board. There was a request for ECPC to create a space within the organisation dedicated to teenagers and young adults affected by cancer, which the ECPC Board responded positively to. Following enquiries about ECPC's social media presence, we were asked to create **an ECPC Facebook Group** for members to join and communicate. Delegates thanked the Board for affording them the opportunity to participate in an event like this, and for offering travel grants to make this possible. To conclude, each of the ECPC Board members presented themselves and their focus to the members.

The Board concluded by emphasising that they are keen to support members but they need input from the members to direct their efforts. ECPC is only as strong as its membership.

The ECPC Board wish to extend their thanks to all those who have contributed to the success of this event, including to the Sabina Universitas for the kind use of their historic space, and especially wish to thank Claudia di Loreto, who supervised and orchestrated the event from beginning to end.



# **ECPC Working Group: Teens and Young Adults (TYA)**



**ECPC launched its first working group in 2012**. We introduced this model to engage more effectively with our members, and to promote networking and collaboration between patient groups addressing similar issues in different contexts and countries.

Following requests from our members, our first working group was held in October 2012 and brought together organisations working with teenage and young adult patients from across Europe.

Our working group brought together members from as far apart as Ireland, Norway and Turkey. Each participant introduced himself and briefly presented the work of their organisation. Many groups organise activities for young people affected by cancer, often activity camps or social and cultural events, offering patients a

chance to meet one another and to share non-cancer-specific activities as well as sharing experiences.

Many groups are also increasingly advocating for more recognition of the specific needs of this age group and particularly in Eastern Europe there is a heavy emphasis on raising the funds to pay for treatment. In all parts of Europe, knowing which treatment centres can offer the best care for your specific cancer is critical for young patients, so identifying specialised centres of expertise would be of great value.

As well as providing networking opportunities, the meeting included an introduction on how to get involved in the European project ENCCA. This age group is something of a 'lost tribe' – the available data shows that teenagers get an unusal spectrum of cancer types that no one hospital or department would usually specialise in, and survival data shows that survival is often poorer than in children with the same disease. We believe that this is because the age group is not served well by either children's services or adult services working alone, but that collaboration across that division and across political and professional boundaries is the key. Outcomes improve at a slower rate than in other age groups, and access to clinical research is much lower among young adults than in children.

ECPC Board member Sarunas Narbutas presented on his experience attending the first global congress of young cancer patients and survivors which took place earlier in 2012 in Ecuador. He commented on the very different model of engagement than in Europe – young people were asked to draft a declaration of patient rights and were fully involved at all stages.

This was followed by an extended discussion/brainstorming session, which threw up many areas for possible further collaboration. We hope to explore these more in the 2013 meetings.

# Participation to the 5<sup>th</sup> International Oncology Days "A blooming Plant" and Youth Training "Global Youth Action against Cancer"



ECPC Vice President Simona Ene was invited in Mush, Turkey on 13 - 20 May 2012 by ECPC Turkish membership: Youth Accumulation Association, Onco Serv and Hand in Hand against Cancer Federation. She was a speaker at the 5<sup>th</sup> International Oncology Day Conference held on 14-15 May and one day trainer at the training "Global Youth Action against Cancer".

She spoke on the first day of the conference in the opening session and attended at the end of the day the march on the main street of Mush with the final destination the building of Mush Government, organized by the conference organizers in order to raise awareness of the public and politicians regarding the conference and training and also regarding cancer. On the second day she chaired the Session on EU Health 2020 and had a presentation in the same session with the title "How EU influences the national health policy and how we can influence the EU Health Policy?"

One very important issue raised at the end of the conference by Mrs. Feray Ertmel from Pink Ribon Organization was the domestic violence against breast cancer women that happens often and is not punished by Turkish justice. She asked ECPC guidance and support to try to settle this issue.

The most interesting session in Simona Ene's opinion was the one on nutrition and cancer that emphasized the connection between the processed food and increase of cancer risk. The message from this session was "as long as there is a healthier choice, choose it even it needs some individual efforts to achieve".

The most emotional sessions were the two last sessions where patients told their stories, how cancer had impacted their life and their successful battle against cancer. There were two persons from the public sharing their stories of a journalist and an actress who are now cancer advocates supporting cancer patient organizations.

Denis Horgan, the ECPC Head of Policy Affairs (until November 2012) also attended as a speaker and made a presentation on EU Cancer Control Policy and ECPC contribution and on EU Health 2020 programme.

The mammo-mobile project was launched on the first day of conference. This project was developed based on sharing the good practices from Romania regarding access to diagnose facilities (mammography) by disadvantage communities and communities living far away from available facilities in the area. Simona Ene had shared this idea with ECPC Turkish membership and they implemented this with financial support from the Japanese Embassy and the Ministry of Health in Turkey.

On 13 May and 16-19 May, Simona Ene attended the youth training course bringing her contribution and experience and hold a session on breast cancer awareness for both genders. She also had different meetings with local stakeholders to raise awareness of cancer, cancer control, home and palliative care and health promotion.

## **Policy Achievements**

## **ECPC** in the European Parliament



ECPC launched the **Forum Against Cancer Europe in June 2010**, as a platform for European Parliamentarians from different countries and parties to join in support of cancer patients and actions against cancer. We have built on that with successive events and projects over the last years.

In 2012, we began the year with a joint-workshop with EURORDIS on patient registries and the essential role they play in improving patient services.

In the spring, we hosted the second annual conference for the Melanoma International Community Advisory Board and have worked with the members of this initiative to produce and launch a White Paper in the European Parliament, drawing attention to the issues faced by patients affected by this cancer and highlighting actions to improve their access to treatment.

We worked with numerous partners to build the **European Alliance for Personalised Medicine**, which was a focus of our policy work during the year.

We look forward to building on this work over 2013, and continue to collaborate closely with partners from all sections of the health policy arena.

## **ECPC-EURORDIS: Patient Registries**



The European Cancer Patient Coalition (ECPC) and Rare Diseases Europe (EU-RORDIS) joined forces in January 2012 to hold a workshop in the European Parliament on the importance of patient registries for patients with rare cancers and rare diseases.

Accurate and detailed data is essential for planning and providing quality healthcare, and without efficient registries we cannot have accurate data. With over 20% of all cancer patients in the EU affected by a 'rare cancer' – including all children and teenagers with cancer – this is an issue affecting a large number of people across the EU. (The European Commission defines a rare disease or cancer as one that affects less than 1 in 2000 people).

With the support of Nessa Childers, Irish MEP, ECPC and EURORDIS presented to European legislators and regulators exactly why registries and data are important not only for healthcare professionals but for patients.





# The European Alliance for Personalised Medicine

In the spring of 2012, ECPC was a major partner in the launch of an innovative new partnership. The **European Alliance for Personalised Medicine** brings together patient groups, researchers, clinicians, pharmaceutical companies, the diagnostics industry, regulators and politicians to address the obstacles to patient access to personalised medicine.

The launch in the European Parliament and successive meetings were organised by ECPC as the Secretariat. The Alliance is fortunate in its Chairs, former MEP John Bowis and former Commissioner David Byrne.

Towards the end of 2012, the Alliance gained enough momentum to become a fully independent organisation. As we observe the Alliance making its first steps we are proud to have been such a facilitator in its creation and we will of course continue to play a role in the evolution and focus of the organisation.

## **ECPC's participation in the Rare Cancers Europe**

ECPC shall continue to play an active role in the multi-stakeholder platform RARE CANCERS EUROPE, providing patient input into the discussion and involving in RCE projects. The output of Rare Cancers Conference which took place in Brussels in February, 2012 was to provide a set of consensus statements on new methods of clinical studies in rare cancers (RareMeth Consensus Paper) dealing with design and end-points of clinical studies, methods for combining available evidence and organizational and regulatory aspects of clinical studies.

The project of Rare Cancers Europe Goal 3 – Improving Access to Rare Cancer Treatment and Care in the EU consisted of two parts: Access Index research followed by case studies. The case studies are intended to complement and illustrate some of the Access Index findings, carried out by the Swedish Institute for Health Economics. Case studies should compare data from 2 countries including viewpoints from healthcare professionals and patient advocates, by video interviews and texts. Jana Pelouchova, ECPC Secretary and ECPC representative in the RCE platform, took part in the Czech Republic case study.

## ECPC's representation at EMA during 2012

ECPC Board member Henk Van daele represented ECPC in different activities of the "European Medicines Agency" (EMA) in London in 2012. PhD Pauline Evers (NFK, Nederlandse Federatie van Kankerpatiëntenorganisaties) was also confirmed as ECPC representative, status shared with Henk Van daele.

 Public Declaration of Interests and Confidentiality Undertaking of EMA members and experts.

In order to work for EMA every patients' representative (= expert) must sign a declaration that is published on the EMA website.

This declaration consists of three parts: a) Personal details (full name, name of organisation, country, etc.), b) Public declaration of interests in the pharmaceutical industry within the past 5 years, c) the Confidentiality Undertaking. This third part mentions: "I understand that I may be invited to participate either directly or indirectly in certain EMA activities and hereby undertake: - to treat all Confidential Information and Confidential Documents under conditions of strict confidentiality; - not to disclosure in any way to any third party any Confidential Information or Confidential Document; - not to use any Confidential Information or Confidential Document other than for the purposes of my work in connection with EMA activities; - to dispose of Confidential Documents as soon as I have no further use of them".

 Representing ECPC in the activities of EMA consisted of three different tasks.

#### 1. SAG

EMA establishes Scientific Advisory Groups (SAGs) to provide advice in connection with the evaluation of specific medicines or treatments. They consist of European experts (including patients' representatives) selected according to the particular expertise required on the basis of nominations from the Committee for Medicinal Products for Human Use (CHMP) or the EMA. These meetings in London are strictly confidential.

## 2. PCWP Meetings

The PCWP (Patients' and Consumers' Working Party) was established to provide recommendations to the EMA and its human scientific committees on all matters of interest to patients in relation to medicinal products. The activities of the PCWP are focused on four main areas: transparency and dissemination of information, medicinal product information, pharmacovigilance, and interaction with EMA and its scientific committees.

In 2012, Henk Van daele participated in PCWP meetings in London on: 27-28 February, 22-23 March, 7-8 May, 25 May, 24-25 September, 8 November, and 29-30 November.

The Minutes of the PCWP meetings are published on the EMA website.

#### 3. Review of draft package leaflets

As representative of ECPC, one is asked to review SmPC (Summary of Product Characteristics) and PL (Package Leaflet) of medicinal products that are being assessed for new marketing authorisation. The SmPC is the text describing the properties of a medicinal product and will be made available to all prescribing physicians in the EU.

The PL contains the same information as the SmPC but is written in a patient friendly language. Each document (SmPC + PL) is about 30 to 50 pages. Usually doctor Pauline Evers makes more remarks about the SmPC, while Henk Van daele makes more remarks concerning the PL.

# Plenary Meeting of Quality Criteria for Health Checks



The Plenary Meeting of Quality Criteria for Health Checks, part of EPAAC project took place on 31<sup>st</sup> of August 2012.

This project was raised from the concern that health checks, including those provided by private companies for commercial purpose and those involving joint collaboration between the private and state health care services are subject of alleged failures (misdiagnose, overdiagnose, overtreatment etc). Beside this, the last decade has noticed a continued increase in the number of different checks and screenings offered by private companies and in the number of these companies themselves, resulting in a real new market that led also to increase of self-medication or medicine procurement via internet pharmacies.

Cancer patients are, as most of chronic disease patients, the most frequent consumers of healthcare services, including health checks.

This project aims to prepare a standard regarding Quality Criteria for Health Checks in order to:

reflect the overall need of all health care consumers, including patients:

- assure evidence-based, appropriate, qualified, safe and good/best quality heath checks;
- health checks services to comply with consumers and patient rights regarding transparency of information provided to consumers/patients, personal data protection, informed consent, reports of health checks provided in an appropriate manner etc.;
- prevent unnecessary health checks to be performed.

The meeting aimed mainly to review the draft document and the comments received in order to decide on the comments that will be included in the text. ECPC Vice President Simona Ene sent some comments and attended the meeting. These comments were very welcomed and agreed by majority.

Simona Ene succeeded to get the Romanian Ministry of Health involved in this project as Romania is one of the countries that face a very high commercial purpose of health checks leading to corruption in healthcare system. The final draft of this document will be subject of public consultation, meaning that it will be spread nationally where there is any interest in it.

At the kick-off meeting ECPC had submitted a document prepared by Denis Horgan, ECPC Head of Policy Affairs (until November 2012) and presented by Tom van der Wal, Former ECPC Treasurer (until February 2012) regarding the responsibilities assumed in this project and the dissemination of this document is one of them.

## **European Oncology Nursing Society – 8 Spring Convention**

The European Oncology Nursing Society (EONS) – 8 Spring Convention took place on 26<sup>th</sup> - 27<sup>th</sup> April 2012 in Geneva, Switzerland.

**ECPC Vice President Simona Ene was invited to attend this event and made a presentation at the workshop "How to reach disadvantage groups?".** She talked about the good practice from the projects that she had implemented in Romania regarding this issue together with nursing and social worker students and nurses. She emphasized the importance of working together not only to reach the disadvantage groups but also on other tasks regarding public awareness and cancer patient education and empowerment.

Simona Ene had another presentation on 27<sup>th</sup> of April at the Farewell Plenary on "How can be improved the cancer services by collaboration between nurses and cancer patients?". She focused the presentation on the EU 2020 in order to emphasize the huge opportunities and the need to work together to build strategic partnerships. Later she had an interview with e-cancerty and talked about how she became a cancer advocate.

## **ECPC** participation in **EC**-funded projects



RareCareNet project aims at building an information network in order to provide comprehensive information on rare cancers to the community at large (e.g. oncologists, general practitioners, researchers, health authorities and patients). Within this project ECPC will build a network of patients' organizations and treatment centres and will provide information material to cancer patients in order to facilitate prevention, diagnosis and treatment.

This project was launched in mid 2012. ECPC representatives participated in the kick-off meeting of this project which took place in July in Luxembourg and various meetings afterwards. At the ECPC Masterclass held in June in Rieti, Italy, ECPC organized a dedicated session to introduce this project to the participants and asked inputs from participants for a questionnaire designed to collect preliminary information and data in order to start building the database of the information network. ECPC will focus on building this database in 2013.

If you are or know a patient organization working with rare cancer patients, please get in touch with us. For further information please see:

http://www.rarecarenet.eu/rarecarenet/index.php/project/aims



EurocanPlatform aims at decreasing cancer mortality by dealing with three main areas of strategic research: prevention, early detection and improved treatments. There will be a strong focus on translational cancer research in five selected tumours: breast, head-neck, lung, malignant melanoma and pancreatic cancer. In this project, ECPC's role lies in contributing to the construction of a knowledge system explaining cancer, its origin, prevention mechanisms, treatment and outcomes to the patient community and to the general public. In 2012, ECPC participated in meetings and liaised with different partners to discuss ways to carry out dissemination activities. ECPC plans to assist the platform members in organizing public outreach activities during ECCO congresses, ECPC masterclasses and patients' workshops. For further information please see: <a href="http://eurocanplatform.eu/">http://eurocanplatform.eu/</a>



The general objective of the "European Partnership for Action Against Cancer" (EPAAC) for the period 2010-2013 is to contribute to the reduction of cancer burden in the EU by actions in the areas of health promotion and prevention, screening and early diagnosis, cancer related health care, coordination of cancer research and cancer information and data. The overall objective is to support Member States (MSs) in the development of their National Cancer Plans (NCPs). Integrated NCPs are public health programmes designed to ensure coordinated and centrally managed implementation of evidence-based strategies for prevention, early detection, diagnosis, treatment, rehabilitation, palliation and research for innovative solutions, and to evaluate outcomes. EPAAC will help to raise awareness about cancer promotion and prevention, especially among target groups in Europe, by disseminating the European Code Against Cancer using proven communication strategies and messages, and by engaging policy-makers at the European, national, and sub national levels. **ECPC is involved in several work packages of this project**.

## **ECPC Financial Report 2012**

#### **Expenditure**

Office and activities costs: € 267.272,00 Cost of personnel: € 161.831,00 Equipment depreciation: € 5.147,00 Financial charges: € 541,00 Extraordinary expenses: € 3.370,00

**TOTAL expenditure:** € 438.161,00

#### Income

From European projects:  $\leqslant$  45.688,96 From industry grants:  $\leqslant$  377.160,00 From honoraria:  $\leqslant$  5.700,00 Others:  $\leqslant$  10.230,88

**TOTAL income:** € 438.779,84

We would like to thank the following organisations for their financial support in 2012:

Amgen; Boehringer Ingelheim; Daiichi-Sankyo; Eli Lilly; F. Hoffman - La Roche; Genomics Health; GlaxoSmithKline; Novartis; Pfizer; Merck.



#### **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 healthcare 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.

#### How to contact us

Rue Montoyer 40 1000 Brussels Belgium

Tel: +32 (0) 2 342 01 04 Email: <u>info@ecpc.org</u>

#### **ECPC Website**

http://www.ecpc.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.org if you are interested in learning more about ECPC.