

ECPC AGM 2011 Registration Open

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The ECPC Annual General Meeting 2011 will take place on 19th November. Register now online!

WALCE launches anti-smoking programme in schools

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ECPC Member Women Against Lung Cancer Europe have recently launched a national educational campaign to reduce the uptake of smoking, and hope to spread this out to other EU countries.

Patient Conference in Croatia

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ECPC member HULL, which stands for the Croatian Leukaemia and Lymphoma Society, hosted a conference for blood cancer patient advocates from Croatia and neighbouring countries.

Other ECPC members featured this week:
Diagnoza CML,
The Little People
Association.



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Personalised Medicine: The next big thing for cancer patients

Looking at the agendas of events, seminars or workshops in Brussels and the rest of Europe these days, it is quite easy to identify the hot topic in the health area: personalised medicine.

Everybody is talking about it and everybody has the feeling that there is a big shift coming for researchers, doctors, regulators and of course patients. That is why PM creates a great deal of hope among cancer patients, bearing in mind that oncology is the prime example when we talk about personalised medicine.

But what can we really expect from this concept and how realistic is it for patients that they can soon benefit from personalised therapies? What are the challenges for the politicians and healthcare providers to make personalised medicine a reality?

From the perspective of current and future cancer patients, the development of the field of pharmacogenetics is of immense interest. The encouraging vision that is now being established is that we may move from trial and error therapies to evidence-based personalised medicine in clinical practice.

It should be observed that the term "personalised" does not imply medicine tailored to the needs of each individual but rather an approach whereby populations of patients are stratified into groups of good and bad responders before treatment is

started.

Several challenges must, however, be managed in order for this vision to come true. In addition to scientific tasks, it will be critical to address the major gap in perception and knowledge between the scientific community and the lay public regarding drug development and pharmaceutical innovation. Well-informed cancer patients and their professional carers will play a key role in the implementation of personalised medicine. This will be in terms of developing a general understanding of the personalised medicines amongst the general public, and also at an individual patient level, ensuring that people know how to use medicines targeted to patient sub-groups in a safe, effective, cost-effective and timely manner.

Aware of the immense importance of the topic for cancer patients all over Europe, ECPC will focus on personalised medicine and will try, through its activities, to inform the European cancer patient community about the concept, developments and challenges of PM.

ECPC is hosting a workshop on personalised medicine in the European Parliament on 23rd November 2011. You can register on our website, and have your say through our online questionnaire: <http://www.surveymonkey.com/s/QHPZLQ3>.

By Martin Lohr, ECPC Policy Officer

**“Well-informed
cancer patients
will play a key
role”**



ECPC Members at the Cancer Summit

ECPC AGM: Register now!

The ECPC Annual General Meeting 2011 will be on November 19th, 2011, in Antwerpen, Belgium. Please register on our website: <http://www.ecpc-online.org/e-c/agm.html>

ECPC Board and staff will present activities and financial reports from 2011, as well as a report on the audit for 2010 which is being performed by KPMG Neth-

erlands. Proposed new statutes will also be presented to the membership for their approval.

Please note that full members who cannot attend can nominate another member to vote by proxy on their behalf. For more information, please contact us: info@ecpc-online.org; +32 28 88 89 43

Agenda

SESSION 1 : 11.00 - 12.30
 Welcome; confirm agenda
 Ratify co-opted Board members
 ECPC Progress Report
 Revision of ECPC Statutes

12.30 - 13.30 Lunch

SESSION 2 : 13.30 - 14.45
 Approve ECPC accounts 2010
 Update on ECPC accounts 2011

14.30 - 14.45 Coffee

SESSION 3 : 14.45 - 15.45
 Plan for 2012
 Partnership building
 Feedback from the members

Surveys
 Introducing the ECPC Office team

15.45 Close

Europa Donna Breast Health Day: Supporting key partners

On October 12th, 2011, ECPC supported Europa Donna's Breast Health Day event at the European Parliament. The event, which is part of an information campaign leading up to Breast Health Day on October 15th, brought the message of cancer prevention and awareness to the European Parliament.

Europa Donna, a partner with whom ECPC has worked on numerous projects, has made October 15th Europe's Breast Health Day. This year, the focus is on Making Healthy Choices, emphasising the importance of daily lifestyle choices on future breast health.

ABOUT BREAST HEALTH DAY

The 15 October 2011 Breast Health Day campaign is focused on raising awareness of lifestyle choices that can help prevent breast cancer later in life. Engaging in physical activity, maintaining a normal body weight and eating a healthy diet can help protect breast health.

Among other materials, it also includes a video and an online application for women to identify and commit to positive lifestyle resolutions related to physical activity. Campaign materials and further information, visit the Breast Health Day website.

<http://www.breasthealthday.org/>



The ECPC team join Europa Donna to promote Breast Health

This is your page. This is where you can share your success stories and the lessons learned, where you can share photographs of your events and where you can ask other members more about themselves.

Please think about what you could contribute to these pages. We very much hope that these pages will expand and take over the whole newsletter - because you are the whole reason that ECPC exists.

If you want to celebrate the contribution of one of your volunteers, or would like to write a letter to the Editor, we would be delighted to feature these here, on this page.

This week, these pages share some details of events hosted by various ECPC members.

Member



Don't forget that you can connect with ECPC through our social media pages: <http://www.facebook.com/ecpcfb> and <http://www.twitter.com/cancereu>.

Think of this page as a monthly noticeboard for members, and please submit something for the next edition. Contact: nicola.colson@ecpc-online.org, +3228888943.

LITTLE PEOPLE ASSOCIATION ROMANIA



Temerarii had a very special meeting this month with the Manchester United football team.

Temerarii members from Cluj, Iasi and Bucharest spent the evening watching the team train, talked with Manchester United legends Brian Robson and Denis Irwin, and met Sir Alex Ferguson, Wayne Rooney, Ryan Giggs, Michael Owen and the rest of the Manchester United team.

Everybody had a great time, as you can see from the photographs.



WOMEN AGAINST LUNG CANCER EUROPE (WALCE) ITALY

WALCE (Women Against Lung Cancer in Europe), in collaboration with Carthusia Publishing has initiated the project named "I do not smoke it - we shall try to see things clearly in the smoky speeches", an information and awareness campaign on damages of smoking and on the healthy lifestyles, aimed at ten-year-old pupils, consisting of an educational kit for the classroom.

Epidemiological studies show a steady increase in the number of teens starting to smoke cigarettes. In Italy, 18% of young people start smoking before the age of 15, and 38% are adolescent and often begin between the age of 15 and 17.

The campaign has been made possible thanks to an educational grant from Autostrade per l'Italia and it is sponsored by the Institute of Health and the Piedmontese Institutions. The project was officially launched in Turin, and was created with the aim of helping children to understand the world they live in and to learn more about tobacco, one of the most serious current problems.

Dr Silvia Novello, the President of WALCE, said "We have chosen to address the campaign to ten-year-old pu-

pils, because we think it is important to implement prevention and information measures on the damage caused by smoking and focus the attention on children who are in their age of development, a phase during which learning is faster and more immediate. We would like to plant the seeds of good habits among children when they are still young and particularly receptive and able to set behaviours and approaches that then persist into adulthood".

The text of the story consists of four tales, told by four children with whom all the pupils could easily identify themselves. Inside the educational kit you can find:

- the big book for the class is the magic tool that helps teachers to capture chil-



dren's attention on issues not always connected to everyday experiences of their age but only with some of them;

- 24 notebooks: one per student with a dossier for parents to fill in at home;
- a guide for the teacher.

For more information on this campaign, please contact Raffaella Ronchetta on ufficiostampa@womenagainstlungcancer.eu, or via +39-8129272.

CROATIAN LEUKAEMIA AND LYMPHOMA SOCIETY (HULL) CROATIA



ECPC Board Member Jana Pelouchova with other participants



In parallel with the 2nd Leukaemia and Lymphoma Meeting – a scientific congress taking place from 17th to 21st September in Dubrovnik, Croatia, the Croatian Leukaemia and Lymphoma Society organised a Patient Conference with international participation, from 16th to 19th September.

The language similarities enabled participants from neighbouring countries to understand the lectures, share best advocacy practices and benefit from intense networking. Patient advocates from Slovenia (Milena Remic), Macedonia (Pepo Levi) and Bosnia-Herzegovina (Ismet Kodro) introduced the activity of their societies. In the medical programme, leading Croatian experts on leukaemias, lymphomas, myelomas and myelodysplastic syndrome presented treatment updates in patient-friendly form.

In the patient advocacy section, Jana Pelouchova, ECPC Board member, leukaemia patient and chair of Diagnoza CML support group in the Czech Republic, presented current ECPC achievements. In view of the audience consisting en-



tirely of haematology patients, she highlighted the joint ECPC-EHA conference in the European Parliament at the end of August. Raising awareness of ECPC activities, especially on behalf of blood cancer patients, was highly welcomed and appreciated both by patients and healthcare professionals attending the session.

The Croatian Leukaemia and Lymphoma Society “HULL”, an ECPC member, took the opportunity to host this unique patient event partly thanks to the effort of Jadranka Santini, Secretary of the Society. The event was innovative in inviting patient advocates from neighbouring countries, who understand each other’s languages as well as the challenges of access to effective treatment options in blood cancer: Croatia, Slovenia, Macedonia and Bosnia-Herzegovina.

DIAGNOZA CML CZECH REPUBLIC

The Diagnoza CML patient society conference took place in Prague on 22nd October. Nearly 70 members gathered in Prague to benefit from a CML educational programme consisting of four lectures focusing on CML treatment and monitoring updates, current legislative changes in the Czech healthcare system and patient advocacy sessions.

During coffee breaks, patients used the opportunity for friendly networking as well as informal debates with leading CML clinicians and a molecular laboratory expert from the Prague Institute of Haematology.

During the Patient Advocacy Session, Jana Pelouchova, founder and chair of Diagnoza CML, and ECPC Secretary and Board member, highlighted ongoing activities both on Czech national level and at the European level, particularly recent ECPC cooperation with the EHA.



ECPC Board Member Jana Pelouchova presents the organisation

UPCOMING EVENTS

November 2011

- 19 - ECPC Annual General Meeting, Antwerpen, Belgium - REGISTER NOW
- 23 - ECPC Workshop on Personalised Medicine, Brussels - REGISTER NOW
- 23-24 - European Cancer Control Summit, Brussels, Belgium
- 28 - ENGAGE 2011: The future of healthcare in Europe, Brussels, Belgium
- 29 - European Voice debate: Health Technology Assessment, Brussels
- 29-02 Health Technology Assessment World Europe, London, UK

December 2011

- 8 - European Forum on Patient Adherence to Medication, Brussels, Belgium

January 2012

- 19 - Presentation of report on stratified treatment of breast cancer, London
- 24-25 EFGCP Annual Conference: Informed Consent, Brussels, Belgium
- 25 - Later Life: Quality Care Mattres, London, UK
- 26-27 - EPAAC event on palliative care, Milan, Italy

You can subscribe to the ECPC newsletter on our website.
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**EUROPEAN
CANCER
PATIENT
COALITION**



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