

The Power of Social Media – Patients Can Lead the Way Together

27th January, 2011 European Cancer Patient Coalition (ECPC)

*“From the success of my campaign to get all eligible patients in Lithuania access to the lifesaving drug GIST, I understand how important the internet, social media and general opinion is. Promoting public awareness is the key to successful patient advocacy. In media, patients must play an active role – **Sarunas Narbutas, OHLB Kraujas** and ECPC Board Member*

The internet has made communicating across distances and sharing information easier than ever before. Many ECPC members have dynamic websites which offer useful information in a range of languages, along with opportunities to volunteer, contacts for further information, and advertising events or campaigns.

ECPC and Social Networks

ECPC intends to use the social networking sites Facebook and Twitter to link up some of these organisations and sites, and to raise awareness of cancer issues among other internet users, particularly young people. While language differences, lack of familiarity with computers or limited internet access might prevent such a facility from being equally accessible to all, these sites will enable us to develop the links between ECPC and our membership.

ECPC hopes that Facebook and Twitter will enable us to share the work and news of ourselves and our member organisations with a wider audience. We would love to see you on the site, and invite you to send us your stories, photographs, videos and links to be featured on the site. There is also a Discussion Board where you can post your thoughts and findings relevant issues – perhaps you would like to see a FACE Workshop on a particular topic. Whatever your contribution, we at ECPC want this Facebook page to be a place where our members and their members can communicate freely with us and with one another, sharing ideas, experiences and advice as we work together for a better future for cancer patients.



ECPC TV

You can also tune into the ECPC TV channel at www.youtube.com/ecpctv, which will be officially launched in March in Dublin at the European Partnership for Action Against Cancer. In these videos, you can see what goes on at a FACE Workshop. We are planning to bring the ECPC TV camera team

on a tour to some of our member states, so we can show MEPs, other decision-makers and everyone who is watching exactly what you do, how essential it is for cancer patients, and how they can help you do it better.

ECPC wants your help

28th February 2011 is Rare Disease Day. We will be running a number of initiatives for this day, but one of the most ambitious is the One Million Faces For Action Against Rare Cancers. We are hoping to collect photographs of people's faces accompanied by a message of support for rare cancer patients and organisations, which we can use in our awareness-raising campaigns.

Please, take a five-minute break from whatever you are doing, and take a photograph. If enough people take a brief moment to show their support, then we will be communicating a powerful message to decision-makers at local, national and European levels.



Please visit our new Facebook site: www.facebook.com/ECPCfb, or follow us on Twitter, where you can find us under @cancereu. Any contributions for the site can be sent to the Nicola Colson, the Communications Assistant, at nicola.colson@ecpc-online.org. Please do send us your stories and suggestions, as we are always keen to hear what you are up to and how we can support you.

For further information please contact:

Denis Horgan
ECPC Head of External Affairs
Ph: + 32 472 53 51 04
Email: denis.horgan@ecpc-online.org

Nicola Colson
Communications Assistant
Ph: + 32 478 83 98 40
Email: info@ecpc-online.org

About ECPC – The European Cancer Patient Coalition

The European Cancer Patient Coalition was founded in 2003 under the slogan "Nothing About Us, Without Us". It is committed to improving cancer prevention, screening, early diagnosis and best treatment, reducing disparity and inequality across the EU. ECPC seeks to ensure that policy makers, politicians, health professionals, the media and the general public recognise the serious nature of cancer and the need for concerted action to reduce unnecessary death and suffering. Further information can be found at <http://www.ecpc-online.org>