

# INVITATION

A unique, two-day patient advocates' educational course

## Understanding Cancer Clinical Research.

2014

February 28<sup>th</sup>  
and March 1<sup>st</sup>  
In Brussels



# Understanding Cancer Clinical Research.



**A unique, two-day patient advocates' educational course**

*“No matter how complicated the research, or how brilliant the researcher, patients and the public always offer unique, invaluable insights. Their advice when designing, implementing and evaluating research invariably makes studies more effective, more credible and often more cost efficient as well.”*

Professor Dame Sally Davies - Chief Medical Officer for England  
Director General of Research and Development and Chief Scientific  
Adviser for the Department of Health and NHS.

*“Patient Involvement in Clinical Research is a very welcome development. We need to involve patients in clinical trials at the design stage so that the relevance of what we do can be considered at the outset. In addition Patient Organisations are important helping patients understand what being treated in a clinical trial could mean to them. Together we can complete research more quickly and introduce new treatments faster.”*

Prof. Jean Yves Blay, leading European Sarcoma-Expert, Former President EORTC

Patients and their representatives offer a unique perspective of experiential knowledge acquired by dealing with their condition on a daily basis. They can help create more efficient trials, address issues expressed by those living with the condition, and help solve operational issues and ones that affect recruitment and compliance. Considering these elements in the early stages of trial design saves time and money in the long run. Patient organisations can play a key role.

The close cooperation between Patient Organisations, Medical Experts and Industry are one of the key elements of future Cancer Clinical Research. There is a high need for earlier and better patient involvement in clinical research to achieve effective cancer treatments more quickly. Patient involvement in cancer clinical research means research done with or by patients rather than doing research for, to, or about them.

“Patient-Reported Outcomes”, “Patient Centred Outcomes”, “Patient Relevant Endpoints”, “Quality of Life Aspects”. These are important factors in the clinical trial setting AND for the following HTA process. The right detection and selection of such factors early in the design process of clinical trials will have enormous influence on reimbursement decisions. Who could be in a better position than patients and patient organizations to help finding the right answers?

**In collaboration between the EORTC and different intl. Cancer Patient Advocacy Networks**

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But being able to act competent as a peer-to peer partners in clinical research, cancer patient advocates need knowledge. This means appropriate and independent training. A very welcomed and future opportunity will be EUPATI – the European Patient Academy for Treatment Innovations. But as time is moving forward fast and until EUPATI is ready to start we need solutions very soon to educate our patient advocates.

**So SPAEN took the initiative of bringing experienced European Cancer Patient Advocates with EORTC together to plan, organize and run the first international Training Course for Cancer Patient Advocates. A unique two-day cancer patient advocates' educational course. We would like to run this first pilot end of February 2014. If we will receive positive feedback from the participants more courses could follow – also open for representatives from countries outside Europe.**

Title of the Course:	Understanding Cancer Clinical Research. A unique, two-day patient advocates' educational course
Course Date:	1 <sup>st</sup> Pilot-Course: 28 <sup>th</sup> of Feb. – 1 <sup>st</sup> of March 2014 Arrival: 27 <sup>th</sup> of Feb. 2014 Networking Dinner: 28 <sup>th</sup> of Feb. 2014
Course Location:	EORTC Headquarters – Room Tagnon (max. 70 partic.) Avenue Emmanuel Mounier 83 1200 Bruxelles, Belgium
Target Audience:	<b>Course is open to all Cancer Patient Advocates Networks - representing all types of cancer!</b> Patient Group Leaders with min. 3 years of experience in patient advocacy/patient support. - High interest in understanding clinical research in cancer - Future interest in being involved in clinical research - Future level: Reviewer/Advisor to Medical Experts & Industry - Participants must have good English skills

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Main Course Objectives:	In this two-day course, participants will have the opportunity to learn basic knowledge about "Cancer Clinical Research" in an understandable way. This provides further opportunities - e.g. to attend other courses of EORTC (e.g. for young physicians or study nurses, etc.) or to do some self-studies on this topic. Participants will also learn more about the importance of "Patient Involvement in Clinical Research".
Number of Participants:	Max. 50 participants per course (Participants must complete an application form!)
Graduation:	EORTC Certificate
Course Directors:	Anastassia Negrouk (EORTC) Markus Wartenberg (SPAEN, IKCC, House of Knowledge)
Programme Committee:	Denis Lacombe, Laurence Collette, Anastassia Negrouk, Markus Wartenberg, Kathy Oliver (IBTA), Achim Kautz (ELPA), Jan Geissler (CML Advocates), Erik Briers (Europa Uomo), Peter Kaptein (Inspire2Live),
Trainers/Speakers:	- Experienced staff-members, researchers and medical experts from EORTC and the Cancer Medical Community. - Experienced Cancer Patient Advocates.
Participation Fee:	No fee for participants or their organisations/groups! (Travelling Expenses will be limited to max. 350,-- EUR and 2 overnight stays in Brussels.) Clear Reimbursement Policy!
Registration under:	Please register directly under: EORTC Website: <a href="http://www.eortc.org/conferences_and_courses">http://www.eortc.org/conferences_and_courses</a>

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