



Patient Advocacy: Didn't we do well?

European Cancer patient group representatives are invited to submit a project application for the Advocacy Best Practice Sharing session at the European Cancer Congress

Application Form

Project application Submission Deadline: 30 June 2013

The applicant will receive a letter with the result of the review and the Committee's decision on the application by **first half of July 2013**.

For questions regarding the on-line submission process, e-mail francoise.vanhemelryck@ecco-org.eu

APPLICANT DETAILS

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Project Topic category

Please choose one main category and then select one sub category.

Main categories:

- Advocacy in Action
- Patient Support Services
- Awareness & Communication

Main category: Advocacy in action

Sub categories:

- Addressing a problem in access to state-of-the-art diagnosis, treatment and care
- Using patient stories to raise awareness of access problems
- Establishing a patient coalition to address a common advocacy issue
- Working collaboratively with different stakeholder groups, especially oncologists and research groups
- Using social media and the Internet as an advocacy tool
- Promoting the use of evidence-based guidelines to improve patient outcomes
- Promoting the establishment of reference centres/centres of excellence
- Conducting a patient survey
- Securing a patient voice in clinical trials
- Securing a patient voice in the development of health policy
- Establishing patient-driven registries and tumour banks
- Training advocates about cancer research and clinical trials

Main category: Patient support services

Sub categories

- Developing targeted, patient-friendly patient education resources
- Meeting the educational needs of patients with literacy problems
- Establishing a patient support group
- Running an online patient community
- Promoting wellness using complementary therapies
- Providing emotional support for patients' families/caregivers
- Providing financial support for patients/families in need

Main category: Awareness and communication

Awareness and communication sub categories

- Implementing a disease awareness campaign to promote early diagnosis/access to appropriate care
- Communicating about advances in cancer science to the public/patients
- Working with the media

Project description

The project description should not exceed 2.500 characters (including spaces).

Abbreviations may be used if standard or if spelled out and defined at the first use (put in parentheses immediately after the first mention of a term or phrase).

The application must be submitted in good English. The Patient Advocacy & Ethics Track Committee reserves the right to reject those applications which are presented in poor English, or may request an immediate revision by the presenter.

Title

Please provide the title of the project. The title should be brief, and in sentence case, objectively describing the initiative.

VOICE-Vision of information, confidence and engagement

Background

Please provide an introductory sentence indicating the purpose of the advocacy initiative (i.e. why your organisation decided to undertake the initiative)

Independent Cancer Patients Voice (ICPV) was started by women who, having undertaken Project LEAD breast cancer advocacy training in USA, were convinced this was the level needed in Britain. ICPV now provides education, mentoring and peer support to enable members to add an informed patient perspective to generic cancer research.

Methods

Please provide a brief description of how the initiative was implemented

ICPV now has over 40 members with a wide background of professional and cancer patient experience. Workshops are held at academic centres giving us geographic ability to recruit new members and promote interest from researchers. Mostly one day events, we have also held 3 two day residential workshops in Birmingham, Brighton and Glasgow. Our new venture "VOICE" is a 5 day intensive course in cancer biology and research methodology being run at St Bartholomew's Medical School. The content has been planned by Prof L Jones and Dr J Marshall together with ICPV members. We aim to run this course annually at different units.

Results

Please provide a summary of the main results you have achieved through implementing the initiative

We hope to give feedback from VOICE at European Cancer Congress. Previous workshops have proved both successful and popular with professional colleagues who volunteer to host/tutor us. "Dragons' Den" sessions enable researchers to present trials with potential recruiting problems for group discussion and receive constructive criticism and comments. This resulted in changing protocol for 1 trial and appointment of lay co-investigator. Protocols/papers can also be circulated via our on-line members only group with comments collated to return to researcher. ICPV is empowering advocates by education and support giving confidence to enable real partnership in cancer research.

Conclusions

Please provide a statement of the main conclusions

Effective patient advocacy requires quality education, training and support. This is best provided in partnership with the researchers needing an informed patient perspective in their work and as combination of intensive and one day workshops.

Keywords

Authors have to provide 3 keywords (different from category).

Education Effective Advocacy

Project application POLICIES AND REGULATIONS

With the submission of an application, the applicant

- Accepts responsibility for the accuracy of the submitted application (please proofread the application text carefully prior to submission).
- Accepts to present the project during the patient advocacy best practice session of the Patient Advocacy & Ethics track on Sunday 29 September 2013 between 09.00 and 11.00.

Project application SELECTION PROCESS

Projects submitted for presentation in the Patient advocacy best practice session will be reviewed by the Patient Advocacy & Ethics Track committee members and will be judged solely on the quality of the information supplied in the application.