



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

Mr

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 name **MORVAN**
 Organisation **"The survivors" association**
 Present Position **President**
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Project Topic category

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

Main category: Advocacy in action

Working collaboratively with different stakeholder groups, especially oncologists and research groups

Project description

Title

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

The first conference in France for the French childhood cancer survivors.

Background

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

On April 20th 2013, for the first time in France, health professionals and adults survivors from a childhood cancer met together around the medical, psychological and social questions they can experience throughout their life after the cure of a cancer

• Methods

This meeting is the result of an important research work led by the pediatric oncology department's of Gustave Roussy Institute, the INSERM, the National Institute of the Cancer and the Curie institute, who contacted by postal mail 2,500 former patients treated during their childhood between 1950 and 1985. This survey has triggered the creation of a clinic dedicated to these adults at Institute Gustave Roussy and Institute Curie.

To set up this meeting, the health professionals contacted the young Association " Les Aguerris ". This association was born last February by survivors from childhood cancer.

Members of the association worked with oncologists and a psychologist to set up the program of the conference.

Results

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

This first conference was a real success : Seventy-five survivors with 28 accompanying people, 24 doctors or researchers attended the meeting. Besides setting the program, members of the associations played a major goal during the day by sharing their experience. Medical questions were discussed such as risk of fertility impairment but reassurance about the health of the offspring, need of cardiac follow-up after anthracyclines based chemotherapy or thorax irradiation, possible mellitus diabetes after abdominal irradiation. Insurance coverage, health insurance and French policy for investigations of late effects of treatment were also presented.

The strong need of a survivors association was definitely confirmed.

Conclusions

Please provide a statement of the main conclusions

Many new subjects emerged during this first edition and since then, "The survivors" association has been working thoroughly with oncologists and other associations to promote their actions. A new date has already been decided; the second edition of the conference will take place on April, 5th 2014.

Keywords

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

Survivors, cancer, childhood

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.