

What Stakeholders Can Do to Drive Clinical Research on Rare Cancers

Medical Practice / Clinical Research



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February 10, 2012



EONS

- ◆ European Oncology Nursing Society
- ◆ Represents 31 member societies, 28 European countries
 - ◆ Established in 1984
 - ◆ Promote practice of cancer nursing
 - ◆ Educational, **research and practice-based initiatives**
- ◆ Nurses represent approx. 33 % of the healthcare work force
- ◆ have the most contact with patients throughout all phases of the cancer journey



Awareness

- ◆ Rare Cancers can be addressed
 - ◆ by disseminating information to nurses where such cancers can be treated
 - ◆ in continuing education courses for nurses throughout Europe
 - ◆ in palliative settings where many of the patients will be cared for



Role of nurses in clinical trials

What we do, we can do

- ◆ Nurses can be of influence in the development and review of clinical trials.



Depending on the country, institution, internal structures :

- ◆ Nurses can
 - ◆ participate in the trial review board (is it feasible in the clinical setting?)
 - ◆ be involved in the recruitment of patients
 - ◆ help determine if the informed consent clearly formulated
 - ◆ can take a position about the number of test planned (acceptable for the patient?)



And as well can ...

- ◆ take an active part guiding the patients, carers understanding the protocol,
- ◆ support to understand ethical questions,
- ◆ help understand complicated therapy regimens
- ◆ educate patients about side effects of drugs and their management
- ◆ help patients and carers understand changes in daily matters
- ◆ encourage contact with special patient support groups



- ◆ Integrate nursing sub-studies within a trial to enhance the supportive care issues accompanying trial therapies



- ◆ Integrate existing symptom management guidelines



- ◆ consult and give information for patients carers re. self-management of taking drugs
- ◆ Nurses can help raise the compliance/adherence of the patients to continue in a study



Raising Awareness

Communication-Newsletter & Website

