Theme:
Childhood Cancer
Letter from the Editor

Dear Colleagues,

This issue of the EONS Newsletter is a collaborative work with one of our specialist nursing member societies, the SIOP Nurses Group. One of the aims of the SIOP Nursing Group is to promote communication and information exchange between nurses throughout the world caring for children and young people with cancer and their families. The progress which has been achieved in the treatment of childhood cancer is in many ways a remarkable success story.

Caring for a child with cancer is one of the most technically and emotionally difficult areas in nursing. Not only are you dealing with children and adolescents who hurt, you must reassure and educate families, balance a multitude of other health care professionals who are a part of the team, and keep up with ever-changing nursing practice and care. This issue of the Newsletter is an attempt to help specialist nurses stay abreast of the newest and most effective nursing practices and therapeutic approaches in pediatric oncology nursing.

The progress made in treating childhood cancer is astounding. From being an almost lethal disease 20-30 years ago, more than 70% of children with cancer can now be offered treatment with cure as the most likely outcome. This progress is the result of basic research and the testing of new knowledge through multi-institutional, multi-national clinical trials and multi-disciplinary collaboration. The development and implementation of the multidisciplinary team has been very successful in optimising the treatment of children with cancer. Mette Wested (Denmark) provides us with an excellent example of the importance of the team in her article, ‘The Multidisciplinary Brain Tumour Team at Rigshospitalet’.

Pediatric oncology nursing practice must incorporate both the science and the art of the discipline to foster positive physical and psychosocial treatment outcomes for paediatric oncology patients, especially those outcomes related to their health-related quality of life. Quality of care is influenced most directly by an increase in technical and clinical skills and by an increase of specialist knowledge. But it is effective ‘team-work’ that is known to make the real difference to the quality of care delivered. The paper from Jaklien Bistoen (BE) addresses the implementation of a pain protocol in a paediatric haematology.

Children diagnosed with cancer experience many complex physical, functional, psychosocial and behavioral problems during the course of their illness. Since there are large variations in symptom characteristics and distress, care providers cannot automatically anticipate what problems children are experiencing and consequently, what care is in their best interest. Cornelia M. Ruland from Norway gives us an example of best care in the article ‘SISOM: An Interactive, Graphical Tool to Help Children with Cancer Report their Symptoms and Problems’.

According to the article from Professor Michael CG Stevens (UK) “there is much to be gained if the achievements of the past 30 years can be used as a basis for further improvement. Nurses are central to these efforts. They can and should play important and better defined roles in leading aspects of clinical care and in undertaking clinical research”. Please take the time to read this article which supports the role of nursing in oncology.

As always, this issue contains updates on EONS projects and activities. In this issue is a brief description of the joint SIOP Europe and EONS special project ‘Collaboration Between Nurses and Doctors in Paediatric Oncology’ . This project, sponsored by ECCO, involves pairs of doctors and nurses from across Europe working collaboratively to improve patient care in their centres. In this issue you can also find more about the following projects: ‘The use of appreciative inquiry approach in pediatric oncology nurse education: single centre experience in Belgrade’, by Jelena Lazic (Serbia), and ‘Improving Phone Communication between Parents and Medical and Nursing Staff in a Pediatric Oncology Unit’, by Apostolos Pourtsidis and Perdikaris Pantelihmon from Greece.

Of course you can find much more in this issue of the EONS Newsletter then those pieces I have mentioned. So snuggle up with a cup of hot tea and enjoy! I hope that this Newsletter will give you, as always, a lot of information, ideas and energy.

My best wishes to all of you for 2009.

Jan Foubert
Our colleagues from...

SIOP (International Society of Paediatric Oncology)

Faith Gibson, Past Chair, On behalf of the SIOP Nurses Group

Many readers of the EONS Newsletter will be familiar with SIOP, the International Society of Paediatric Oncology, and the SIOP Nurses Group. For those of you who are not familiar with us, please let us take this opportunity to introduce our organisation.

The goals of the SIOP Nursing Group are to:
1. Promote communication and information exchange between nurses throughout the world caring for children and young people with cancer and their families;
2. Promote, support and assist in the development of educational programmes for paediatric oncology nursing in all SIOP countries;
3. Develop and promote standards of paediatric oncology nursing practice that can be adapted by all countries;
4. Initiate and support nursing research in paediatric oncology on a worldwide basis.

We try to meet many of our aims through our annual congress. This year over 210 nurses from 34 different countries met in Berlin for the congress. Although we have experienced consistent attendance at the meeting from some countries, we are excited that the number of participating countries steadily increases every year. The annual congress is our venue for presenting research and sharing new developments in clinical practice. We have witnessed a change over previous years in the type of presentations; there are now more presentations underpinned by research or clinical audit.

In addition to our annual congress, we are also involved in projects or initiatives that are in line with the overall aims of the SIOP Nursing Group. In this brief article we would like to introduce one project we are currently undertaking, some examples of which you can read about in this issue of the EONS Newsletter. This project, Collaboration between Nurses and Doctors in Paediatric Oncology, was jointly submitted for funding by SIOP Europe and EONS.

The principle aim of ‘Collaboration between Nurses and Doctors in Paediatric Oncology’ is to improve the way doctors and nurses in paediatric oncology centres work together for the good of the patient. More specifically the project aims to:
• Describe the level of integration between doctors and nurses in several areas of care;
• Improve the integration of nurses and doctors in specific areas of care;
• Promote the exchange and enrichment of theoretical and technical knowledge between professionals (doctors and nurses) in the same working environment.

Integrated and coordinated caring requires active involvement and commitment from all parties as well as continuous discussion of relevant therapeutic and caring decisions. It is naïve to think that the integration of nurses and doctors can develop spontaneously or through good will alone. Rather, it requires active organisational investment in professional development which should be fostered and implemented under the umbrella of the newborn science of “clinical governance”. Neither medical nor nursing educational curricula provide an in-depth knowledge of true collaborative working. Integration derives from and depends on cultural growth and is best promoted by the experience of working together while sharing common goals.

The project was funded by ECCO (the European Cancer Organisation) and was organised around three weekend seminars held in Europe over a period of two years. Ongoing support between seminars was provided by a designated mentor. The aim of the seminars was to promote the implementation of theoretical content, provide an opportunity to discuss and receive feedback on methodologies to be used to manage and sustain change, and to analyse the issues encountered in clinical practice and discuss the implementation of change in the real world of clinical practice using learned models of analysis and planning.

The participants have been active members of this ‘appreciative inquiry project’: an approach described as an exciting way to
embrace organisational change (Cooperrider et al 2005). Participants have planned and implemented a project in their own environment which deals with the promotion, integration, and collaboration of nurses and doctors in clinical care. To facilitate the implementation of their projects they used the theories and ideas which were provided in the seminars.

The project began with 15 pairs which included the following countries: UK (2 centres), Estonia (2 centres), Switzerland, Belgium, Greece, Lithuania, Serbia, Poland, Germany, the Netherlands, France, Spain, and the Czech Republic. All participants attended the first seminar. One pair from Spain left the project following the first seminar. Due to work commitments three further groups, the Czech Republic, one centre from Estonia, and Leeds in the UK, withdrew from the project following the second seminar. Eleven pairs continued with the project, working on a range of projects. Examples of the types of projects worked on by participants are: collaboration between doctors and nurses in providing information to the patients and their families during the course of treatment; improving phone communication between parents of ill children; medical and nursing staff in a paediatric oncology unit; and implementation of a paediatric pain protocol in the paediatric haematology/oncology ward.

Underpinning all of these projects, either implicitly or explicitly, are the principles of appreciative inquiry (AI). Appreciative inquiry makes a number of contributions to organisational development through innovation, change and sustaining achievement, by recognising that organisations, in this case, hospitals and hospital personnel, have strengths that can be built on (Reed 2007). The approach involves four stages (Figure 1).

Let me explain how we used AI in our project. Appreciate inquiry focuses on supporting people getting together to tell stories of positive development work which they can build on. Specifically it is about:

• Active input of those exploring change;
• Collective interaction to share and explore experiences;
• Affirming the telling process, encouraging people to express their ideas;
• Focusing on change and innovation, generating plans for the future;
• Focusing on the work place setting and understanding its context.

The cyclical nature of the AI process reflects the iterative nature of AI in that it is not a linear process that starts then stops when it’s completed (Reed 2007). This process was appealing to our project not only because of the iterative approach to change, but also because of its focus on organisational development which concentrates on what works well (i.e. a solution) as opposed to being problem-focused.

This is a very different language compared to the one we use in healthcare and that is a primary reason why it has been a challenge for participants in the project to apply the AI process as an underpinning framework for their individual projects. Nonetheless, you will see reflections on AI in the participant’s accounts that follow.

This has been an exciting project to be involved in. We anticipate reporting more to readers of the EONS Newsletter as this 2-year project moves into a further stage; that of sustaining change. Real-time strategic change is now required in the participating centres. Project participants will need to recognize patterns of the past and explore and agree on future directions. They will need to make a commitment regarding what needs to be done differently in order to get to where they want to be, decide on a plan, and make sure that change is sustained (Malby and Fischer 2006).

We are very pleased to announce that funding from ECCO for Collaboration between Nurses and Doctors in Paediatric Oncology has been secured for another year. This will support one more seminar to coincide with the ECCO 15 congress which will be held in Berlin, 20-24th September 2009.

We look forward to presenting further examples of our project to many of you there. See you in Berlin.

References:
As President of EONS I am often invited to many meetings but some invitations are unclear as to how nursing contributes. Recently I was invited to Paris to participate on behalf of EONS in discussions on “creating a European Cancer Centre platform” with other cancer organisations. This sounds mundane but in reality it was the start of a debate that may begin to see the way that cancer clinical trials are conducted in Europe. Why was I there? And how does this impact on nursing? Like a story this meeting had many plot lines and I was not clear at the beginning what role nursing played but often it is important to go, listen and participate to begin to see the relevance and see how the story unfolds. Situated at the UNICEF building in Paris members of the pharmaceutical industry, patient coalitions, cancer organisations, research funding bodies and multidisciplinary physician groups were all represented. I felt awed to be sitting in those historic seats where so much history has unfurled with so many eminent colleagues sitting around. Questions in my head were at the beginning what could nursing research offer cancer therapy development. This idea of a meeting didn’t come out of the blue but was started gradually because it is becoming harder to conduct cancer clinical trials within Europe. An analysis conducted by the Eurocan+ project concluded that the fragmentation between research, regulation and funding created consequences that undermined the future development of cancer research. Research is considered harder within Europe than the USA or Asia, not only because of the European Directive which regulates the ethics and processes of delivery of medical studies, but more fundamentally because of the inherent fragmentation within Europe between basic science and life sciences. This reduces the critical mass needed to carry out the large scale research needed to turn basic science into clinical innovation. However, the need for a new methodology for developing and testing new drugs and innovation requires a link between development and implementation. Europe has always had a strong basic science tradition and this is one of its strengths but this is not necessarily linked to the implementation phase and current cancer therapy is rapidly moving into a new era where co operation between disciplines is needed to make innovations possible in the move from “bench to bedside”. We have always worked in subject specific groups, radiotherapy research, immunological research, drug research, health and social research and these are often geographically and philosophically separated. Furthermore these boundaries have in the past been difficult to cross because of the way research is funded through uni-professional grants. To really move forward in the fight against cancer there is a need to bring these disciplines together. An analogy to this research dilemma is that we are all on separate roads going towards one destination but have to go over a bridge and as we converge the roads begin to join and merge and our single track lane becomes a motorway with multiple lanes as we cross that bridge.

An example of this was presented by M Piccart from the EORTC research group who used the example of current breast cancer research to illustrate the problems encountered and ways that as a discipline they have managed to address this. In breast cancer treatment the explosion of new concepts and technologies emerging from molecular and cellular biology has made it necessary to link the various fields. Understanding how different women with breast cancer react at a molecular and pathological level, changes the way we think about categorising the disease and what treatments we should provide. This moves away from the traditional model of a linear approach to drug development and randomised controlled trials to being one that is more comprehensive exploring epidemiological as well as biologically personalising therapy for the women. Developing groups of researchers who can begin to explore this complexity and develop this way of thinking is demonstrated in the TRANSBIG multidisciplinary research group (See article). So we are back to that question where does nursing fit in? Nursing research fits in around implementation and delivery, understanding the individual factors that influence their condition such as molecular, genetic as well as psychological and social parameters. Delivery requires implementation and it is often nurses who give the medications and supports the patient. It was also hard not to resist an “I told you so” as nurses have been saying for years that RCT trial methodology does little to capture the complexity or test clinical innovation in the reality of clinical care. Despite this we have also followed the uni-professional path in developing nursing research. Furthermore nurses need to be visible in clinical research contributing to clinical understanding not only as study nurses but shaping future implementation. As the future of cancer research emerges we are converging as professional disciplines and it is important that nursing is seen to be one of those tracks leading to comprehensive cancer care provision.
See you at the joint
ECCO 15 and 34th ESMO
Multidisciplinary Congress
BERLIN, 20-24 SEPTEMBER 2009

www.ecco-org.eu
EONS Grants
EONS established two research grant programmes in 2008 to support oncology nursing research in Europe. The EONS Mentoring Research Grant Program is a small research grant for inexperienced/novice oncology nurses and is intended to support oncology nursing research conducted by beginning and less experienced researchers. The grant provides the total sum of 10,000 Euros to fund a project for a duration of one year. Five grants were available for European oncology nurses with at least a BSN degree (preferably a Master’s degree) in nursing. Selected candidates must have been willing to become an individual member of EONS.

The EONS Major Research Grant has been established for European oncology nurse researchers with an academic degree beyond a Master’s level, to undertake research preferably of a multicentre nature. The study’s aims should fit within the research priorities identified by EONS. The grant is for two years and includes the total sum of 30,000 Euros. One grant was available for European oncology nurses with at least a Master’s degree (preferably a PhD) in nursing, willing to become an individual member of EONS, and have experience in conducting research.

Five projects were submitted this year for an EONS research grant: one project for the EONS Mentoring Grant submitted from the UK and four projects for EONS Major Grants, two from the UK and one each from Italy and Switzerland. We would like to thank those who submitted proposals. Each proposal was evaluated and ranked in terms of the scientific merit of the proposal related to the clarity of the problem, the significance of the problem, the international relevance, the adequacy of the methods and the feasibility of carrying out the study. Furthermore, the training, experience and research competence of the investigator(s) and team, the suitability of the facilities and availability of resources, the appropriateness of the budget, and the contribution to clinical cancer nursing in Europe were appraised.

It was agreed to award the Mentoring Grant to Amanda Shewbridge, a breast cancer Nurse Consultant at Guys and St. Thomas NHS Foundation Trust in London, who submitted the proposal “Enhancing the caregiver's role within ambulatory breast cancer surgery: supporting family members”. The mentor for this project is Dr. Teresa Wiseman who is a Nursing Research Fellow at the same institution and at Kings College, London. The co-investigator of this study is Prof. Alison Richardson from Kings College. The needs of carers is an important area of concern, however, the role and support needs of family members is less clear in the literature. The study will obtain information from carers to gain better understanding of the issues which arise when patients return home and the impact this event has on families. A sample will be chosen from carers of patients undergoing ambulatory surgery for breast cancer and will consist of 8 to 10 participants. The information generated will be used to help develop an intervention to enhance the information and support needs of carers. We believe this study will help to explore the support needs of family members and can serve as a foundation for future studies.

From the four applications for EONS Major Grants it was felt that the proposal entitled “Clarifying the cluster of symptoms related to chemotherapy induced nausea” was the strongest project, providing good background information and a robust team with previous work in the field. This project was submitted by Carole Farrell, who is a Nurse Clinician from Christie Hospital NHS Foundation Trust, Manchester. The co-applicants were Dr. Sarah Brearley and Prof. Alex Molassiotis from University of Manchester School of Nursing. This project builds on preliminary work which included qualitative interview with 17 patients at two cancer centers who had experienced nausea during chemotherapy. This first study found that patients described nausea as a distressing and complex symptom. The proposed project is a prospective, observational, descriptive study of 164 patients over two cycles of chemotherapy; the aim is to examine the relationship between nausea and other symptoms in order to determine if nausea exists as part of a symptom cluster. The next step will be to design an intervention to manage nausea as part of a cluster of symptoms. The results of the project are likely to produce findings of relevance to practice and to add to the body of knowledge in a European and international context.

We would like to congratulate the successful applicants and to thank all those who submitted proposals for EONS research grants. The results of these studies will be presented at ECCO or at the EONS Spring Convention and will also be summarized in the EONS Newsletter, as well as peer-reviewed journals.

Please look for further information on EONS-sponsored research grants on the EONS website.

Leadership Changes in Member Societies
A change in leadership in the governing bodies of some of our member societies has recently taken place. Maggie Crowe has replaced Annie Young as the President of UKONS (UK Oncology Nursing Society) and Cheryl Vidall will be the new representative of that organization on the EONS Advisory Council. Faith Gibson will hand over Chairmanship of the SIOP nurses group to Patti Bryon. On behalf of the EONS Board, we would like to welcome the newly elected officers to EONS and look forward to a fruitful collaboration with them. We would like to take this opportunity to thank Annie Young and Faith Gibson for their support and contribution to the activities of EONS over the past years.

New Member Society
EONS is pleased to welcome the Beaumont Hospital as a new Associate Member of EONS. The hospital, located in Dublin, has an active oncology department. We welcome them to the EONS community and look forward to a mutually beneficial collaboration.
Paediatric and Adolescent Cancer

Challenges for the future

Michael CG Stevens, CLIC Professor of Paediatric Oncology, University of Bristol, UK

Introduction

The optimistic prognosis for many children with cancer living in developed countries has been well documented and the extraordinary progress made in the cure of children with cancer over the past 30 – 40 years must be one of the most remarkable achievements for cancer care in the 20th century. Can this be sustained, and if so, how?

In a letter published in 2001, Parker and Craft commented on speculation that the improvement seen in childhood cancer mortality since the 1970s could, if it continued to show the same downward trend, be extrapolated to zero within 20 years [1]. In fact, the authors argued that this was unlikely although they also suggested that further improvements in survival would still be achieved.

Paediatric oncology can be justifiably proud of its heritage of collaboration and its commitment to clinical trials and to care in multidisciplinary teams. However, an unacceptable number of children still die of their disease and we are beginning to see that certainty about cure may take longer to be achieved than it once did. Perhaps some improvements in treatment merely prolong survival without the guarantee that all those who survive 5 years will ultimately be cured [2] Furthermore, the attention now shown to the needs of long term survivors also illustrates what price some young people pay for their survival.

Where then are the challenges for the future of paediatric oncology, and how will they be met?

Improving cure rates

It is generally estimated that, in developed countries, at least 75% of all children newly diagnosed with cancer will be cured [3]. This average figure incorporates a wide range of outcomes and there are certainly diagnoses which now achieve much higher cure rates, including, for example, standard risk acute lymphoblastic leukaemia, Wilms’ tumour and Hodgkin’s disease. In this context, the focus for the future should be on reducing the risks (short and long term) associated with therapy. Achieving this objective requires that attempts to reduce treatment intensity are evaluated in randomised clinical trials. This itself creates a problem as the design and implementation of a clinical trial where the end point is ‘equivalence’ in terms of survival but achieved by less therapy, poses significant statistical challenges about study design. Furthermore, in Europe, recent changes in the regulatory framework have disproportionately damaged the initiation and management of clinical trials in children [4].

For other diagnoses however, for example some brain tumours, metastatic neuroblastoma and sarcoma, current survival rates remain unacceptably low and more effective treatments are required [5]. The suggestion that ‘more should be better’ may not necessarily apply and the expectation that better results can be achieved by intensifying current approaches to treatment has not always achieved the hoped for benefit. It is here that the development of novel forms of therapy is required and paediatric oncologists may now look enviously at the scale of development of new small molecule, biologically designed drugs which are entering adult cancer practice.

A lack of priority in developing novel therapies for childhood cancer is apparent from the pharmaceutical sector because of the low potential for commercial return from the investment required.

Equality in prospects for cure

Despite the high cure rates achieved for patients in developed countries, it is clear that not all children worldwide have equal access to the benefits of modern therapy. This disadvantage is most obvious in the developing world [6] but there are important variations in survival rate even within Europe [7]. Reasons for this vary and although there may be differences in diagnostic accuracy and in the adequacy of cancer registration in certain geographical regions, much of the difference is likely to be real and reflect differences in the presentation of disease and in its pattern of care. Whilst referral to a specialist centre and treatment within a clinical trial are considered best practice in developed countries, the challenge is to ensure that children in countries with less well developed health care systems can benefit in similar ways. Remarkable results have been reported from international programmes which link specialist centres in developed countries with those established in low income countries [8] and it is clear that much can be achieved by addressing basic issues such as staff training and clinical service organisation, and by ensuring a secure supply of standard chemotherapeutic agents. Similar approaches may also benefit care in some of the newer countries of the expanding European Union.

Internationally there are also important differences in patterns of patient flow towards specialist centres and considerable variations in the extent to which children can be treated close to their home. In the United Kingdom, the National Institute for Health and Clinical Excellence (NICE) has published guidelines for improving outcomes in children and young people with cancer [9]. Whilst promoting the central role of specialist units (designated as Principal Treatment Centres), the guidance also incorporates an important philosophy about treatment close to home by stating that “the aim is for safe and effective services as locally as possible”. This approach endorses the concept of ‘shared care’, a model of care by which all patients are referred to specialist centres for diagnosis and treatment planning but at some point after that may be returned to their local health care community for some / all of their subsequent treatment. Achieving this depends on the complexity of the treatment required and on the availability of appropriately skilled and resourced local units. It is hoped that this approach will provide children, young people and their families with optimal treatment without unnecessarily damaging family integrity, educational opportunity and peer social contact. This needs to be further evaluated and it is a model which may merit wider consideration elsewhere [10].

Teenagers and young adults

It has been recognised for sometime that the outlook for older teenagers and young adults (TYA) with cancer is less favourable than that seen for younger children. This has precipitated a debate about optimal patterns of care for this age group [11] and, particularly in the United Kingdom, the development of specialist units for TYA patients. These units appear to best meet the needs of the patients [12] but the wider introduction of similar facilities will require careful evaluation and appropriate staff training. It is not yet known whether
the development of specialist TYA cancer units will deliver improved cure rates but this will be unlikely without a parallel commitment to clinical trial development for this age group. This has been identified as a priority issue [13] but few, if any, countries or collaborative clinical trial groups have yet established a comprehensive portfolio of studies for TYA patients with cancer.

Survivorship
It is estimated that there are already almost 300,000 survivors of childhood cancer alive in the United States and, with current survival rates, this population will grow. Similar statistics apply across European countries with established paediatric cancer services. Many of these individuals are at risk of long term consequences of their disease and its treatment and, compared with their siblings, are 10 times more likely to develop a serious disease in adult life, while their risk of premature morbidity and mortality does not appear to plateau [14]. This creates a significant challenge for the design and implementation of appropriate surveillance programmes and places an important additional demand on health care resources. It is likely that most survivors are not receiving appropriate, risk-based care and that most health care systems have yet to establish optimal programmes of care for all survivors [15].

How can nurses help to meet these challenges?
Paediatric oncology nursing is an area of specialised practise. It has been argued that the protocol driven approach to treatment, and the long term commitment made to an individual patient and his / her family, make paediatric oncology an ideal setting for the development of specialist nursing skills [16]. Advanced nursing roles have been explored in both acute care and, in particular, in the long term follow up of survivors [17]. In many centres, nurses already provide much of the care delivered to children in a community setting and are therefore often best placed to act as a coordinator for the wider aspects of care. The formal concept of a ‘key worker’ is defined in the UK’s improving outcomes guidance [9] and this role is most likely to be fulfilled by a senior and specialised nurse within the oncology team. These roles however largely remain in the existing province of the nurse and it is important to look further to see how nursing research can further progress care and outcome for children and young people with cancer.

Nurses are central to the achievement of higher standards of care and to the delivery of best outcomes and high quality patient / family experience. This can only be achieved if nurses actively engage in, and disseminate the results of, research. One important way to achieve this goal will be by focusing efforts on the application of best evidence to clinical practice. Despite some progress in recent years [18], there is still much that needs to be done to maximise the nursing contribution to research and development. Perhaps most obviously, nursing research should play a leading role in understanding and optimising how symptoms are best managed and in ensuring that the experience of children and young people and their families is enhanced by better care. Such efforts also need to be integrated into the work of the existing international collaborative clinical trial groups [19].

Conclusion
There is much to be gained if the achievements of the past 30 years can be used as a basis for further improvement. Nurses are central to these efforts. They can and should play important and better defined roles in leading aspects of clinical care and in undertaking clinical research.

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Scope
Further to the successes of the first Interconference Breast Cancer Meeting 2007, IBCM returns to bring the very latest in breast cancer research, treatment, care to the Balkan area, Central and Eastern Europe.

Within a truly multidisciplinary and multi professional setting, participants can expect a comprehensive review of cutting edge discovery from breast cancer biology and the clinic, the latest trends and developments in nursing care as well as updates on topical issues from the patient advocacy perspective.

To discover the many programme highlights of interest to the European oncology nursing community including the joint Europa Donna and EONS session on *What do we need to know about counseling and prevention?* and the Educational Session on *Nursing intervention in breast cancer* and so much more, EONS invites you to download your copy of the Advance Programme and register today at: [www.ecco-org.eu](http://www.ecco-org.eu) (select ‘congresses and conferences’ > ‘IBCM-2’).

Dates to Bookmark
- Abstract submission open: 01 November 2008
- Early rate registration deadline: 12 January 2009

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SiSOM

An Interactive, Graphical Tool to Help Children with Cancer report Symptoms and Problems

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Background

Children diagnosed with cancer experience many complex physical, functional, psychosocial and behavioral problems during the course of their illness. Since there are large variations in symptom characteristics and distress, care providers cannot automatically anticipate what problems children are experiencing and consequently what care is in their best interest. Less developed verbal skills, parents’ and clinicians’ communication styles, and attitudes toward the child might also prevent children from adequately communicating about distressing symptoms and problems with their care providers. Particularly for younger children it is difficult in a “traditional” conversation to talk about difficult topics. Children with cancer are therefore, at risk that their symptoms and problems remain under-diagnosed and treated.

To overcome these problems, our research team developed SiSom1, an interactive assessment and communication tool to provide children with a “voice”. SiSom is designed to help children with cancer between the ages of 7 and 12 report their symptoms and problems in a child-friendly, age-adjusted manner, and to assist care providers (nurses and physicians) in addressing and integrating children’s reported symptoms and problems into patient care.

The Development of SiSom

SiSom is based on a systematic review of the literature, focus groups with care providers, and participatory design methods where children participated actively in different stages of the design process. Because children have different perceptions of the world and ways to make sense of it than adults, developing a support system for seriously ill children poses a number of design challenges. Through participatory design, children helped us adapt SiSom to their cognitive and emotional developmental stage. Children contributed to the graphical design of the system’s interface; selection of understandable, child-friendly terms used in the system; iconic and graphical representations; and its usability.

SiSom

The resulting SiSom application uses spoken text, sound, animations and intuitively meaningful metaphors and pictures to depict symptoms and problems that even younger children who cannot read can respond to.

The main navigation theme in SiSom is a “sailing from island-to-island” metaphor where symptoms and problems are placed on islands that children can visit with the help of a self-selected figure as illustrated in the pictures below.

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1 SiSOM is the Norwegian acronym for Si det SOM det er, meaning: “Tell it as it is”, or Selvrapportering Innen Symptomer Og Mestring, meaning: Self-reporting on Symptoms and Management.

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Figure 1: The child starts a journey into the island world in a boat from the lighthouse where the appearance of the child that comes along on the journey is selected. The child chooses the first island to be visited by touching it with a finger or a pen. The beam from the lighthouse points to that island. The helper, the little figure dipping in the water on the life raft in the right corner, follows along through the whole program and can be asked for oral advice by touching her.
Figure 2: In this example the child has chosen the island where difficulties with managing every day activities are explained. The child goes ashore, touches the section it wants to learn about, e.g. things that are difficult to manage in daily life.

Figure 3: When the child enters the section on daily life, a room is entered where each object represents a problem that the child can select. This opens a new animated picture that illustrates the problem in more detail (Figure 4). A touch on the magnifying glass to the right highlights all objects in the room that have not yet been selected.

Figure 4: Each symptom or problem is represented with a picture; trouble sleeping has been selected in this picture. On the left side a scale is displayed where the child can show how severe the problem is. The child can click on the ear and the text is read aloud if he or she does not want to read the text.

Figure 5: When the child has visited all the islands, a child-friendly report summarizes the reported problems and can be printed. This printed report can be used by health professionals during consultations with the child to tailor patient care to each individual child.

The interactivity and graphical and audiovisual functionalities made possible by the computer provide entirely different possibilities than questionnaires to capture children’s experiences of symptoms and problems from the child’s own perspective in a manner adapted to their developmental stage. This allows children to effectively report their symptoms and problems to their clinicians, and thereby help clinicians to provide individually tailored patient care.

In addition to the module for children with cancer, SiSom is also available for children with congenital heart disease.

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The eighth EANO congress was held from September 11 – 14, 2008 (hosted by the Spanish Group of Neuro-Oncology), at the Palau de Congressos de Catalunya, Barcelona, Spain.

On Thursday 11th September, prior to the main congress, a satellite event organised by non-profit organisations interested in brain tumour research was held. The session was suitable for an audience of lay people as well as health care professionals. Subjects covered included the incidence and aetiology of gliomas in adults and children and new treatment modalities. The International Brain Tumour Alliance (IBTA) (www.theibta.org), was represented by their Secretary, Kathy Oliver, who discussed what was important for the patient. She stressed the importance of maintaining hope and the importance of patients having equal access to treatment. A member of the audience had recently undergone surgery for an anaplastic astrocytoma and had set up the first support group in Lithuania (www.kartulengviau.lt). Her comment was that equity of care was aspirational rather than factual.

On Friday 12th September at 8am, the main conference began with a ’Meet the Experts Session’. I was honoured to be invited to speak, along with Dr B Muller from Kreischa, Germany, covering the topic of “Supportive care in brain tumours”. Professor F Graus, President of EANO, officially opened the Congress and the audience were welcomed by; Dr I Roussos, President of the local organising committee and writer and brain tumour patient Mr Baltasar Porcel.

The topics throughout the conference examined current treatments and novel therapies, gliomas, non-glial tumours and metastasis, neuro-imaging, pathology and cell biology. All of these topics were delivered with a focus on the patient and the importance of their quality of life. The full programme can be viewed on www.eano.eu.

During the coffee and lunch breaks it was possible to view the posters and exhibitions and mingle with colleagues and meet old friends. I, however, was anxiously preparing for the nurses session, which was held on the Friday afternoon. Anxiety and preparation paid off, as the session was well attended and organised. The presenters were from the UK, the Netherlands and Austria and the evaluation was favourable. The full evaluation and presentations along with the abstracts can be viewed on the EANO website.

On Saturday 13th September, in the afternoon selected posters were presented. I was delighted to support my colleague Dr S Erridge from the UK. She described the Edinburgh experience in the impact of changes in pathological classification and referral patterns on treatment and outcome of patients with a glioma 1988-2002 (1).

At the end of Saturday sessions the EANO General Assembly took place at the congress venue. New board members were elected and those retiring from the board were thanked for their work. Professor Frances Graus (Barcelona Spain) stood down as President and Dr Robin Grant (Edinburgh UK) was elected as the new President. Further information is available on the EANO website.

The Congress finished at lunchtime on Sunday 14th September. As usual it was slightly quieter than the rest of the conference but no less interesting. The weather remained sunny, as it had for the duration, for us to enjoy before departing homewards. At the congress there were commercial-funded Satellite Symposia and the opportunity to visit exhibition stands. The venue was a modern purpose-built facility and was in easy reach of the main attractions of Barcelona. Two social events were organised; the first of these was a Welcome Reception held in the beautiful gardens of the Rey Juan Carlos I Hotel, where we enjoyed local drinks and tapas. The congress dinner was held at the Marques de Comillas, Drassanes Reials de Barcelona. This venue was located near the port and dates back to the 13th Century. It was originally the royal shipyard. Following dinner we were entertained by Spanish folk singers, who sang with gusto and sentiment rounding off an excellent evening.

Barcelona was an ideal venue and the Congress a hit. I am looking forward to Maastricht, Netherlands in 2010, where I hope to expand the Nurses Session and provide translation for the benefit of non-English speaking nurses throughout Europe.

Meanwhile anyone with an interest in Neuro-oncology should look at the website and consider joining. Nurses have a reduced rate of 50 Euros for 2 years membership.

Shanne McNamara (EANO Executive Board Member for Nurses)

Reference
The Implementation of a Pain Protocol in a Paediatric Haematology-Oncology ward

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Background
Healthcare workers all over the world are challenged to improve and re-think their way of working due to the rapid advancement of clinical knowledge, multi-professional working and technical advancements. Quality of care is influenced most directly by technical and clinical skill-increase and increase of specialist knowledge, but it is effective 'team-work' that is known to make the real difference to the quality of care delivered.

This paper addresses the implementation of a pain protocol in a paediatric haematology-oncology ward using Appreciative Inquiry as methodology and research form. (1)

Aims and objectives
SIOP Europe, EONS and ECCO launched and funded a project: "Collaboration between Doctors and Nurses in Paediatric Oncology: a basic requirement for Quality of Care." (2&3)

Organizing this project will improve and integrate, as well as share, knowledge between physicians and nurses. Ultimately a constant process of growth for all parties will be promoted.

The implementation of a paediatric pain protocol is the centre project of the Paediatric Haematology-oncology Department of the Ghent University Hospital, Belgium.

Using a holistic approach,(4) this ‘pain project’ reaches for more accurate pain assessment, an improved knowledge of pain and a better organised and open communication concerning pain between all staff members and the patients, together with a consistent pain treatment plan. Subsequently an increase of quality of care and satisfaction of all parties involved should be achieved, although this will be difficult to quantify.

Methods and Design
The 'Appreciative Inquiry' method - a non-problem orientated form of action research, as previously explained by Dr. F. Gibson (1) - was compulsory for this project (cfr fig. 1)

In the Discovery Phase, an Appreciative Analysis based on SWOT-principles [5] revealed that the team’s strength and potential is found in its diverse constitution and its multiplicity of ideas, its awareness for the quality of care delivered, and the acquaintanceship and aptitude of working with written communication protocols.

Finally, setting up workgroups and round table discussions proved to be the best method for implementing new nursing strategies in the unit. “Our Dream” is to evolve from a strict hierarchical group of individuals to a smoothly working multi-professional team. A team that in all its diversity grows to an open dialogue with all parties involved and that promotes collaborative working. This dialogue should be based on an equivalent input and should result in a better understanding of different roles and a better appreciation of decision pathways made by the team.

To make that rather provocative statement applicable and relevant to the ward and due to some tensions at the time of the Project’s take-off, a more practical project regarding collaborative working was designed. Because of the need of a written pain treatment plan, consensus was easily gained to go for a ward specific paediatric pain protocol.

To reach that dream we had to focus on different levels: research, communication, education.

First a workgroup, representative of the whole ward, was set up to spread the workload and the basic principles were outlined. This “bottom up” approach together with the continuous interaction with the entire team ensured a strong involvement with the project.

Our motto: “Say what you do, do what you say and prove that you do what you say!” tried to emphasize this.

A few research steps were taken to define more concretely the need of a pain project. Articles about the implementation of pain protocols were reviewed; an inventory of available information about pain on the ward was made. Current pain practices in January 2007 were evaluated by a file survey (medical & nursing files) of 10 patients with a known pain episode for records of pain (type/intensity/treatment and response to treatment). An anonymous questionnaire of all team members, in the same period tried to reveal the knowledge and attitude towards pain and pain treatment.

In November 2007 a Joint Educational Programme was organised. The lecture covered three area’s related to pain: physiology, assessment and treatment, and was given by both doctors and nurses to both doctors and nurses. It was open to all team members but not compulsory.

Meanwhile the workgroup was enlarged with the addition of a clinical pharmacist to assist to write and edit a consistent and well structured paediatric pain protocol.

Because it is not useful to reinvent the wheel, different paediatric haematology-oncology centres were asked for information about a good working paediatric pain protocol and their experiences. The workgroup strived to develop a flowchart and a practical manual with theoretical background information and useful tips on pain and pain therapy to ensure a clear pain treatment plan adaptable to the individual needs of the patient.

The draft version of the protocol was critically reviewed by team members and the pilot trial is to be launched in November 2008, after the Belgian National Week of Pain.

The intention is to implement the protocol, after the final adaptations, in January 2009.
Results of the previous steps
A lot of information on pain and pain therapy seemed to be available on the ward but this was unstructured and mostly unknown to team members.

The file survey of 10 medical and nursing files of patients with a known pain episode showed a lack of systematic written information and discrepancies between medical and nursing files.

Although pain and pain treatment were frequently reported; 90% in nursing and 60% in medical files, it was seldom quantified or specified. Information on intensity, location and characteristics of pain were reported by respectively 20%, 60% and 20% in nursing files, and 0%, 50% and 20% in medical files. (Cfr fig. 2)

The response rate for the ‘team-potential’ questionnaire was 56% (30/54). Pain awareness was definitely sufficient (nurses 90%-physicians 70%); satisfaction about current pain practices on the other hand was not (55% both). Doubts about knowledge of pain were reported by 47 % of the nurses and 27 % of the physicians. The demand and enthusiasm for change and improvement was abundant (94% both). (Cfr. Fig. 3)

The conclusions of both survey and questionnaire were communicated to the team. Bearing Appreciative Inquiry in mind, particular emphasis was put on the positive results (awareness for pain and the enthusiasm for change). The statistic results and conclusions were gathered in a booklet and shown in a slide show as a computer screen saver for all the monitors in the staff room.

The evaluation of the Joint Educational Programme was very positive. A global attendance of 84% (48/57) of the target-population (physicians 50%, nurses 94%, others 83%) was obtained. In addition, it was also evaluated positive for theoretical contents and practical usefulness. Lecture schedule, dates and hours had been set after consulting uniquely the nursing team, this resulted in an unequal attendance rate and in a more time consuming organisation of the programme.

Whilst writing and editing the protocol a spontaneous enhancement of the use of pain measurement tools was noticed and although the draft version of the protocol was completed in the middle of the summer holiday period, the enthusiasm to review it was obvious.

Conclusion
Continuous interaction with the entire team led to a slow but steady progress of the project with an increasing interest in the subject of pain. This is a solid base for the implementation of a new paediatric pain protocol. Using Appreciative Inquiry and a bottom-up approach stimulated the group’s synergy and strength, lowered the threshold between physicians and nurses, and kept the motivation and enthusiasm for the project alive.

In conclusion, we are confident that pain treatment on the ward will be regarded as an example of smooth multi professional working which enables a better integration and communication between team members. This should optimize the human resources available and improve the quality of care on our ward.

Acknowledgements
We would like to thank all the team members of the Department of Paediatric Haematology- oncology of the Ghent University Hospital, Belgium for their enthusiasm and participation in this project.

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2. Faith Gibson, Senior Lecturer in Children’s Cancer Nursing Research, Institute of Child Health and Great Ormond Street Hospital for Children NHS Trust, London UK; basic principles op Appreciative Inquiry (FECS Special Project first Seminar Milan November 2006)
3. Federation of European Cancer Societies (FECS) Special Project: Nurses and Doctors in Paediatric Oncology working together. A multi-step action Research laboratory, a joint project between SIOP and EONS (November 2006- November 2008)
4. Holistic approach: In stead of charting one way links from psyche to soma or vice versa, a holistic approach aims at a systemic model where multiple biological, psychological social and spiritual factors are seen as interlinked. Like Aristotle had put it in the Metaphysics:’’The whole is more than the sum of its parts!’’
5. SWOT principles: SWOT analysis is a strategic planning method used to evaluate the Strengths Weaknesses Opportunities and Threats involved in a project. It involves specifying the objective of a project and identifying the internal and external factors that are favourable and unfavourable to achieving that objective (def.Wikipedia, the free encyclopaedia)
INTRODUCTION

The European Oncology Nursing Society (EONS) has provided support to cancer nurses across Europe since 1984. The mission of EONS is to add value to the work of its individual members and national societies in delivering care to patients with cancer. It aims to assist in the promotion of healthy communities through influencing, research and education.

The changing landscape of cancer management in relation to cancer treatments, new technologies, psychosocial care and health care provision has meant a significant shift in the way nurses apply their clinical skills and knowledge in the workplace. However, the professional development and status of cancer nurses across Europe is not uniform and EONS strategic agenda (CARE) aims to address this inequality by working with oncology nurses through their national societies.

STRATEGIC PRIORITIES

Communication

Communicating with and to oncology nurses across Europe remains a challenge. Developing diverse communication pathways is complex and EONS is committed to doing this by continuing to produce and distribute (through the national societies) a newsletter four times a year. The EONS website (part of Cancerworld) is an established forum for cancer nurses and EONS will be developing multi-language sections within the site as well as options for interactive forums to promote professional discussion, information and networking. The European Journal of Oncology Nursing continues to be one of the leading cancer journals and celebrated 10 years of publication in 2006.

Political Agenda

EONS is one of the professional cancer societies that form part of the umbrella organisation renamed ECCO in 2007 (European CanCer Organisation) previously known as FECS – Federation of European Cancer Societies. The organisation provides a collective political voice in Europe. EONS is also a member of the European Specialist Nurses Organisation (ESNO) which consists of associations from both European Nursing Specialist and Nursing Interest Groups. The organisation acts as a platform to represent nursing in the wider political forum.

Research

Promoting evidence-based clinical practice through research has always been a core function of EONS. Various grants are distributed through EONS to promote and facilitate research initiatives. One of the priorities is to develop a European cancer nursing research network which will enable wider collaboration, participation and sharing of research evidence as well as build a body of research and development expertise.

Education

The themes as priorities in education are to develop cancer nurse educators to develop and accredit teaching programmes which have education quality standards as part of the review process. Inequality in accessing post-registration cancer nursing education exists across Europe. Alongside this work is the commitment to develop specialist education and leadership programmes which can be viewed in www.cancerworld.org/eons

Notwithstanding the busy agenda the patient experience lies at the heart of the CARE Strategy. By utilising and working in collaboration with patients, EONS will continue to provide a unique contribution to the agenda of cancer care in Europe, whilst promoting the unique contribution of cancer nursing in this process.

For more information on EONS, please contact the secretariat at eons.secretariat@skynet.be
Update on European Commission Cancer Policy activities

The latest news from the European Commission indicates that the long-awaited EU Communication on Cancer that was initially expected for early 2009 has been postponed. According to the European Commission, the planned Cancer Platform originally foreseen for early 2008, will now be launched in mid 2009 and involves a variety of stakeholders including Member State representatives and industry. Following the conclusions of this platform, the Cancer Communication could then be issued by the end of 2009. However, no specific timeline for the initiative has been decided by the Commission.

In October 2008 the Commission published the internal version of the report on the implementation of the Council recommendation on cancer screening.

World Cancer Declaration sets ambitious targets for 2010

On 31 August 2008, the World Cancer Declaration 2008 was presented at the World Cancer Congress in Geneva which was organised by the International Union against Cancer. The Declaration sets out 11 targets to be met by 2020 and calls on all relevant parties to take immediate steps to slowdown and ultimately reverse the number of deaths from cancer. This should be achieved by committing to targets and by providing resources and political backing. The targets set out by the Declaration include:

• Effective implementation of cancer control programmes;
• Better measurement of the global cancer burden and the impact of cancer control interventions;
• Significant reduction of global tobacco consumption, obesity and alcohol intake;
• Access to universal HPV vaccination programmes;
• Increased public awareness of cancer;
• Earlier diagnosis of cancer through the provision of better screening and early detection programmes;
• Improved access to accurate cancer diagnosis, appropriate cancer treatment and rehabilitation services;
• Increased availability of effective pain control measures;
• Improved training opportunities for healthcare professionals on all aspects of cancer control;
• Significant improvements in cancer survival rates in all countries.

To achieve these ambitious targets, the Declaration sets out a number of priority actions. These actions focus on putting cancer as a priority on health policy agendas, improving cancer prevention and early detection, as well as facilitating access to cancer treatment. Of particular interest, the Declaration aims at closer collaboration with the ‘pharmaceutical industry to increase access to cancer medicines that are affordable and of assured quality’.

Parliamentary Question on Information to Patients and the Cochrane Initiative

Dr. Dorette Corbey MEP (Dutch/ PSE) submitted a parliamentary written question on the access of EU citizens to the Cochrane Library, which publishes independent reviews on treatment methods. In her question, Dr. Corbey referred to the recently published CONCORD study ‘Cancer survival in five continents: a worldwide population-based study’ by Prof. Michel Coleman et al and the CONCORD Working Group. This study, published online in Lancet Oncology in in July 2008, reported that there are significant inequalities and differing survival rates for different cancer types across Europe. These differences may be due to varying diagnostic techniques, limitations in access to care, and the different degrees of effectiveness of screening and treatment. Since 1993, information on health and the effectiveness of treatment methods have been gathered by the Cochrane Collaboration, which publishes independent reviews in the online Cochrane Library. This information can be used by treatment providers, clinicians and patients alike. At present, free access to the online library is not granted to all EU citizens. The European Union Alliance for Dissemination of Evidence has therefore submitted a petition to the EU Health Commissioner asking for universal access to the Cochrane Library.

Cancer Research in Europe: What Next?

The September issue of the European Journal of Cancer featured a questions and answer section with Prof. Richard Sullivan (London School of Economics and Political Science and Kings College Integrated Cancer Centre, London) on ‘Cancer Research in Europe’. Prof. Sullivan outlines three ‘eras’ of cancer research in Europe, and highlights the political effects of this research. The first era started with the first EUROCARE studies in the mid to late 90s. While the players involved failed to agree on a ‘single vision’ on cancer at this point in time, various organisations (e.g. FECS (now ECOO), UICC, ESMO and ECL) got closer aligned in the years that followed, thereby initiating the ‘second era’. The third era starting in 2005 marked a shift of focus with big institutions and cancer facilities taking cancer research forward. This lead to more cooperation and collective efforts on research and the linking of hospitals and universities. The author also mentions that “it remains to be seen how the future of National Cancer Control Programmes will work with the multiple parties involved”. Prof. Sullivan concludes by saying that there will never be a “European Cancer Institute” like the National Cancer Institute (NCI) in the United States, as this would conflict with the heterogeneous approach that adds strengths and creativity to European cancer research. He nevertheless does envisage the creation of a discussion forum to coordinate cancer research and thereby drive innovation. A cooperative voice at European level would be needed from a political perspective.

European Patients’ Forum (EPF) launches Patients’ Manifesto

In September the European Patients’ Forum (EPF) launched a Patients’ Manifesto with a call for action to improve the quality of healthcare across Europe. This is ahead of the upcoming European Parliament elections in June 2009. The EPF is an umbrella organisation representing 37 pan-European patient organisations active in the field of European public health. In total, the EPF represents over 150 million patients across the EU. The Patients’ Manifesto calls for vital new measures in 3 fundamental areas:

• Equal and timely access to safe, effective diagnosis, treatment and support;
• Better information and resources for patients to be partners in determining their care;
• A patients’ voice to be heard in Brussels and throughout the European Union by promoting patient empowerment, increase allocation of funds to EU health policy and support European Patient’s Right Day on 18 April.

The EPF calls on the European Parliament to commit to the rights of patients and reflect the above priorities in their activities and initiatives. The Patients’ Manifesto is intended to make patients’ rights a cornerstone of current and future health-related initiatives.
Over the last two years, 40 TARGET courses with over 700 participants have been conducted by 14 of the EONS member societies. The feedback from the evaluations has been very encouraging and the invited lecturers have only highest praise for the course and the accompanying documentation. In 2008, TARGET courses have been organised in Austria (September), Belgium (October), Germany (March, June), Greece (October 2008), Israel (May, June), Sweden (February, April) and Switzerland (April) with very positive feedback from participants with regard to the quality of the presentations and the course material. One of the participants noted that „this is a very well planned course with a perfect transmission from theory into practice“. A participant at the Swedish course pointed out that „this is a very important lecture for patient care. I hope there will be more of this kind of courses in the future, I understand more, I became motivated and my work becomes more pleasant“. At date of this article, further courses will be organised in Germany (November), and Italy (November, December).

For those who have not yet delved into this subject, TARGET is an educational initiative that aims to give nurses a greater understanding of the science behind targeted therapies in general and specific understanding of the use and efficacy of EGFR- targeted therapies. The TARGET course covers following topics:

- the molecular biology of cancer
- how new therapies are targeted at specific molecules or pathways
- how these therapies are used in clinical practice
- nursing considerations when caring for patients on targeted therapies
- supporting the needs of the patients and their carers

The rapid developments in medical oncology are affecting our daily clinical practice. Regardless where one works, whether in larger university hospitals or private oncology practices, the molecular targeted therapies have been registered for a wide range tumors and are continually expanding to others following further clinical trials. The number of such therapeutic agents has exponentially increased over the last years so that the newer therapy regimens are not seldom a combination of a monoclonal antibody or signal transmission inhibitor and the conventional chemotherapy regimens. We have also seen that for some tumors, the new drugs are also being employed as monotherapy.

The "original" TARGET program was geared towards the EGFR / TKI inhibitors. This sector has remained of medical importance. The position however, of other pathways such as VEGF, proteosome inhibitors and multikinase inhibitors caused the necessity for an update in the TARGET materials. The trend in the pharmaceutical branch towards new oral tumor therapies, although not at all new, has definite implications for nursing practice. This too, was a topic that had to be addressed in the new material. To provide input for the new material, a task force has been called together.

The task force includes:

- Liesbeth Lemmens, Belgium
- Clementine Molin, Sweden
- Maggie Uzzel, UK
- Annie Young, UK
- Jan Foubert (EONS CEO), Belgium
- Jan Hawthorn (medical writer), UK
- Anita Margulies (Chair), Switzerland

Many of the members of the group were involved in compiling the first edition of the TARGET material.

The TARGET project was first supported with an unrestricted grant from Merck, Darmstadt Germany. This support and the possibility of developing the first TARGET course materials cannot be underestimated.

With the change in product availability, EONS decided it was important to take a multi-pharma approach for support of the update. We found willing partners with Amgen and Novartis. Other companies were approached, and we hope for support from them at some point. This policy also allows the content of the TARGET material to be not only broad spectrum, but neutral in the presentation. Nurses are involved with all drugs, all tumor entities, all patients and all health economic situations.

It is EONS goal to give their member societies as much information and educational support to be able to meet the continually growing demands of the oncology health sector. If your society has not yet run a TARGET course, consider one for 2009 with the TARGET Update.

You will be giving your members one of the best possible courses to understand this dynamically growing treatment area and will give them the knowledge to improve the care and support for the patients and their carers. EONS grants can be applied for should you wish to translate into your native language, 2 grants have been awarded for this purpose. At present TARGET is available in English, Dutch, French, German, Italian and Spanish.

To apply for the TARGET course or for translation grants please contact EONS secretariat, Mr. Rudi Briké (eons.secretariat@skynet.be). Information is available on the EONS website at www.cancerworld.org/eons.
Cancer Prevention in Young People
HPV Vaccination

Dr. Daniel Kelly, Reader, School of Health & Social Science, Middlesex University, London

Introduction
Cancer prevention initiatives are normally directed towards adults. Smoking cessation, breast and testicular self examination and healthy eating advice are examples of health education campaigns that have encouraged adults to adopt more healthy choices. The recent launch of the HPV (Human Papilloma Virus) vaccination programme is a new step in cancer prevention as it is targeted at girls and young women prior to them becoming sexually active. Once engaging in unprotected intercourse there is an increased risk of exposure to the HPV virus that is implicated in the promotion of cellular changes and, eventually, cervical cancer. However, this prevention initiative has not been without critics and has provoked controversy as some claim that it may encourage promiscuous behaviour and go against religious teachings. This article considers some implications of the HPV vaccination for cancer nurses.

HPV and Cancer
Cervical cancer is the second most common cancer in young women (aged 15-44) after breast cancer. In the European Union it is thought there are approximately 33,000 cases of cervical cancer and around 15,000 deaths. Importantly, cancer of the cervix is also a major public health concern in the developing world: 83% of all new cases of cervical cancer are now being reported in these countries (Parkin & Bray 2006).

The genital tract is susceptible to infection by the HPV virus, especially important are the high-risk strains of the virus which include HPV 16 and 18 (Cancer Research UK 2008). HPV is also implicated in anogenital cancers in both sexes. However, not all forms of HPV cause cancer which is an important point as almost 80% of all new cases of cervical cancer are now being reported in these countries (Parkin & Bray 2006).

Immunisation promotes protection by alerting the body’s defences to the presence of potentially damaging invasion by particles such as viruses. There are two HPV vaccines currently available (Gardasil produced by Sanofi-Pasteur and Cervarix produced by GlaxoSmithKline) but it is claimed that neither can offer complete protection against all possible strains of HPV. As both vaccines target HPV 16 and 18, it is claimed that approximately 70% of cervical cancers will be prevented by their use. Gardasil also protects against HPV 6 and 11 which are responsible for genital warts.

The choice of product used in recent vaccination campaigns instigated across Europe appears to have been guided by the available scientific evidence and related issues of the costs and benefits. In addition to the vaccination programme there is also a well-established cervical cancer screening programme that has been thought to reduce overall incidence of this disease by up to 80% (European Centre for Disease Prevention and Control 2008). The difference with the vaccination approach is that it is specifically targeted at girls prior to them becoming sexually active. Aside from any concerns about the relative risks associated with immunisation itself, the age of the target group has raised a number of controversies.

Controversies
The controversies associated with the HPV vaccination programme revolve around the concern that is associated with future sexual activities in an age group who are still under the legal age of consent. This is compounded by the concerns of some parents that it should not be administered in schools but that those wishing to receive the vaccination should be required to approach their family doctor. In the UK this has led to some school governors refusing permission for the vaccination programme to be instigated. Further concerns have been voiced about the use of the vaccine itself, the risks of possible unknown side-effects in the longer term and prophylactic exposure to an agent that some parents feel would not occur within the context of a monogamous relationship.

Across Europe there appears to be consensus that vaccination should be made available, although the mode of delivery varies in each country (World Health Organisation Europe 2008). In some countries, for instance, there is a catch up programme for young women up to the age of 18. Social deprivation and associated cancer risk factors such as cigarette smoking also have to be considered in cervical cancer prevention programmes.

For cancer nurses this raises a number of implications which are outlined below. Clearly low income EU countries will be disadvantaged and the pricing of vaccines may need to be tiered to allow access to widespread vaccination. The same issue will also arise to an even greater degree in the developing world where the majority of cervical cancers occur.

Implications
It is important that cancer nurses across Europe are aware of the HPV vaccination adopted programme in their own country. By raising awareness of the importance of HPV in relation to cervical cancer prevention nurses working in public health or school settings are likely to have an influential role on the decision made by parents as well as young women about whether to accept the vaccine. In some settings young men are also being offered the vaccine. HPV is transmitted sexually and the vaccine could provide additional protection against other cancers including those arising in the penis or anus (Parkin & Bray 2006). At present, however, there is less published evidence available on the effectiveness in boys.

However, there are also important ethical and legal concerns about the ability of young people to participate in vaccination programmes against HPV, or for their parents or guardians to do so on their behalf. In the majority of the press coverage in the UK the voices of young people have not been as obvious as those of politicians, parents or religious leaders. Whilst consensus is probably the preferred approach in such circumstances, this may not always be possible when sexual activity is part of the debate.

There are a number of useful web resources available for those who wish to direct young people or parents to learn more about HPV vaccination. This includes an on site forum in the UK that addresses key questions in a tone that is both informative and non-judgemental. It is also possible to download a number of leaflets for different age groups across the adolescent range. Information for school teachers, parents and health professionals is also available. The web address is: http://www.immunisation.nhs.uk/Vaccines/HPV
**Summary**

The HPV vaccine has been hailed as a significant breakthrough in the prevention of cervical cancer. It is now being adopted in public immunisation campaigns for young women across Europe and it is the responsibility of cancer nurses to be aware of the biological, financial, ethical and political dimensions attached to this important public health initiative (Wright et al 2006). There is also a need for colleagues to share their experiences of implementation of the programme and ensure they have a voice in ongoing debates about HPV vaccination in a measured and balanced way. For many years nurses have administered other vaccines to young people, cancer-related vaccines, however, raise additional concerns especially when associated with discussions about the risk of cancer in the future, sexual activity and the lifestyles of young people.

There are also opportunities to learn from each other and to influence health policy at a national and European level when debates about HPV vaccination are taking place. In EONS we are well placed to continue the debate about the role that sexual health plays, both in the prevention of certain cancers as is the case with HPV as well as during treatment and beyond.

**References**


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**7th BUON Congress and Oncology Nursing Program**

**Report**

**Sultan Kav, President Elect**

The Balkan Union of Oncology held the 7th Conference of the Balkan Countries in October in Kusadasi, Turkey. This year the Turkish oncology professional community was host to this interdisciplinary conference. Approximately 550 doctors and nurses attended from seven Balkan countries.

The program for nurses was organized by the Turkish Oncology Nursing Association (TONA) in collaboration with the Hellenic, Serbian and Bulgarian Oncology Nursing Societies. This was the first 3-day conference for oncology nurses to be held in one of the Balkan countries. In total, 70 oncology nurses and 24 invited speakers were in attendance from six of the Balkan countries (Armenia, Bulgaria, Greece, Macedonia, Serbia, and Turkey). The nursing program consisted of oral and poster presentations. International speakers at the nursing sessions included Sara Faithful from the UK, current president of EONS, and Dr. Judi Johnson from the U.S. who spoke on behalf of MASCC. This was a unique opportunity for the Balkan nurses to share experiences, think about their practice, and network in order to establish contacts for future collaborative work.

Some of the main topics of the nursing program were:
- Oncology nursing in Europe and EONS activities
- The future of oncology nursing in the Balkan countries
- Dilemmas in concepts: supportive, palliative and end of life care
- Developing the nursing role in radiation oncology
- Mentorship in oncology nursing
- Overlooked side-effects and neglected issues in oncology nursing
- Oncological emergencies: nursing implications for prevention, detecting and management
- Non-pharmacological therapies for symptom management
- Changing paradigms in cancer care: oral agents
- Stress in oncology nursing and strategies to support nurses
- Caregivers and family burden: can it be measured?
- Development of educational programs for cancer patients and their families
Policy Perspectives

Cancer services for young people in England

Louise Hooker, Project Manager, Children and Young People IOG Implementation, National Cancer Action Team, London

Introduction
The needs of young people with cancer are receiving increased attention, and changes in health and psychosocial support services for this group of cancer patients are starting to emerge. Health policy areas that influence services for these patients are those that relate to children and young people in general, as well as cancer-specific policy initiatives, with national strategy on health and social care, education and families providing the broader policy context within which young people’s cancer services operate. This brief article summarises some recent health service policy initiatives and the implications for the development of service models for young people with cancer within the National Health Service (NHS) in England.

There is considerable variation between the terminology and age ranges encompassed in policy and practice models for young people. The key policy document underpinning policy in children and young people healthcare includes young people up to their 19th birthday, past the usual age of transition from paediatric to adult services. However, the specific guidance on cancer services for young people included young adults within its scope, and subsequently this has been more closely defined to include those diagnosed before their 25th birthday. This article refers to all 13-24 year olds as ‘young people’, but the phrase ‘teenagers and young adults’ (TYA) is the phrase often used in relation to service models and here the terms are interchangeable.

National Service Framework for children and young people
A National Service Framework (NSF) for children, young people and maternity services was published in 2004 (1). This heralded a 10-year programme of service reform and established national standards for services for children and young people (CYP). The NSF is in three main parts, Part 1 provided a set of underpinning standards for the services required by all children and young people and their parents or carers. Part 2 addressed children and young people and their parents who have particular needs, including services for CYP who are ill, in hospital, or who have disabilities, complex health problems or mental health needs. Part 3 covers maternity care and the first three months of parenthood.

Three components of the NSF have had a particular influence on the subsequent development of cancer care for young people

Age-appropriate services: Key to the future development of cancer services for young people is the NSF requirement for all young people up to age 19 years to have access to age-appropriate services that are responsive to their particular needs, in care settings that are well-suited to their age and stage of development. These may be provided either in an adolescent unit or alongside others their own age in a specified area within a ward.

Specialist care delivered locally: The NSF requires that all CYP are to have access to the knowledge and expertise of specialised services when required, and that the most complex assessment, treatment and care should be delivered in tertiary centres. However it states that tertiary (specialised) care should also be delivered more locally by establishing clinical network arrangements and supported by outreach services, including peripheral clinics, nursing support services, telephone support lines and teaching programmes for staff.

Transitional care: The NSF particularly stressed the need for the transition from child to adult services be planned, and coordinated by around the needs of each young person. The NSF stipulated that transition should be to “An interested and capable adult clinical service, which has close links with the children’s service, an understanding of the developmental needs of young adults, and participates actively in the transition.”

National Cancer Policy
In 2000, the NHS Cancer Plan (2) was published, a national strategy for the reform of cancer services. This has initiated a programme of large scale service reconfiguration and changes in organisation and practice in cancer care. One of the key drivers for change has been the development by the National Institute of Health and Clinical Excellence (NICE) of a series of evidence-based guidance on the commissioning and provision of cancer services, called ‘Improving Outcomes Guidance (IOGs). These have predominantly been concerned with the provision of services for patient groups defined by their disease e.g. colorectal cancer, but the publication of guidance on ‘Improving Outcomes in Children and Young People with Cancer’ was published in 2005 (3). This reflected the high level policy direction of the NSF and incorporated this into specific recommendations for the provision of cancer services for children and young people, having undertaken a systematic review of the available evidence base and consulted with clinical specialists and service users to achieve consensus expert opinion based upon the evidence where this existed. The CYP IOG sought to provide a framework for service provision in designated specialised centres and local hospitals through managed clinical networks, and ensure that these services would have a critical mass of patient workload to be both clinically and financially sustainable for the level of care they provide. The emphasis is on “safe and effective services as locally as possible, not local services as safely as possible.” Elements of the CYP IOG that are proving to be particularly significant for services for teenagers and young adults include the following:

Principal Treatment Centres (PTCs): The IOG defines core components of Principal Treatment Centres for teenagers and young adults and states that referral pathways are to be agreed for young people with each type of cancer. Each PTC must be able to sustain the full range of services and defined levels of appropriately trained staff. All care for patients less than 19yrs of age will need to be provided in age-appropriate facilities, and patients aged 19yrs and over must have unhindered access to age appropriate facilities and support when needed.

Multidisciplinary teams (MDTs): Care will be delivered throughout the pathway by MDTs, with all patients having access to both tumour-specific expertise and age-appropriate care. MDTs for TYAs will need to ensure they have within their core membership the skills and experience to meet the age-related needs of young people with cancer.

Shared care: Clinical networks should be developed to establish shared care arrangements between PTCs and identified local services, with clinical leadership at local level, agreed treatment and care protocols, defined areas of responsibility agreed with the
PTC and clear lines of communication with the MDT at the PTC and primary care in the local community.

### Supporting change

The implementation of this IOG is to be completed by 2010/11, a deadline reinforced in the NHS Cancer Reform Strategy (4). It was recognised that due to the complex nature of the guidance and the amount of rapid change required, additional leadership and co-ordination of effort was necessary both at national and at local level. Further guidance (5) has been issued for commissioners to provide a clear direction on what is required in cancer services for young people to fulfill the requirements of both the NSF and the IOG. The key principles of this guidance are outlined in Box 1.

A unique partnership initiative has also been developed between the Cancer Action Team, and a national charity, Teenage Cancer Trust to establish TYA cancer service programme manager posts at regional level to provide a focused resource and support local service transformation and to share good practice regarding new models of care as they develop. A set of quality measures will be developed for TYA cancer services, to be incorporated into the NHS Manual for Cancer Services. This will give hospitals providing these services the opportunity for developmental self-assessment against the measures as the new models are implemented, prior to formal external peer review in the future.

### Challenges and opportunities ahead

There are numerous challenges in implementing the service change required, as this guidance crosses the traditional boundaries between child and adult services, and requires the development of teams and approaches to care that can also function across cancer disease-site specific teams. Although some specialist TYA cancer units are already in existence, a national baseline assessment in 2006 highlighted that only a minority of young people with cancer had access to age-appropriate facilities and the expertise of a TYA MDT. Although shared care in paediatric oncology services is well-established in some areas of the UK, it is not a model that is familiar in adult cancer services. Whilst the provision of age-appropriate care for children is available in every paediatric unit that may provide shared care, this will not currently always be the case in adult cancer services that could provide local shared care for young people. However, there are numerous exciting opportunities for TYA services and specialist young peoples teams. They will be able to work with both paediatric and adult service colleagues to facilitate age appropriate care in specialist centres, and the development of outreach teams provides an opportunity to support local age-appropriate cancer care. TYA teams also are uniquely well-placed to develop programmes for transition of care as outlined in the NSF between child, TYA and adult services either for patients receiving cancer therapy, surveillance immediately after treatment or those who are in need of long-term follow up and support. TYA teams will need to work in partnership with colleagues in other services to provide person-centred care that can improve the outcomes and experience of young people with cancer.

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**Box 1**

**Key Principles for services for young people with cancer**

- All patients aged 16-18 years inclusive should be referred to a Principal Treatment Centre (Young People) for treatment.
- All patients aged 19-24 years inclusive should be offered referral to a Principal Treatment Centre (Young People) for treatment.
- All patients aged 16-24 years inclusive should be discussed at both a site-specific MDT meeting and a TYA MDT meeting.
- Referral of patients to a PTC (Young People), or review by both a site-specific and a TYA MDT should not be allowed to delay the start of urgent cancer treatment.
- For each patient, a lead medical clinician should to be identified, who will have overall responsibility for their treatment.
- The provision of treatment on a shared care basis is not precluded in delivering CYPIOG-compliant services for young people. These arrangements should be developed in partnership with the PTC (Young People) and agreed by commissioners.
- The TYA MDT at the PTC (Young People) should have a role in coordinating treatment, psychosocial care and peer contact/support for young people wherever they are treated.
- It is recognised that all the core defining services required of a PTC (Young People) may not be available in a single location. Provision of PTC services may involve more than one Trust, but these should not cross city boundaries.
- Robust arrangements should be in place for planned transition between children and young people’s services and between young people’s and adult services.
When children are diagnosed with cancer, it means an enormous change in the life of the children and their families. The families are about to live a very different life from what they are used to, with a large number of restrictions placed upon everyday lives. The parents have to live with constant anxiety, fear of serious illnesses and the side effects the treatment may cause – and perhaps most of all the risk of losing a child.

In Denmark, cancer is the most frequent medical cause of death in children older than one year. About 160 children are diagnosed with cancer in Denmark every year. About one third present with a brain tumour, one third develop leukaemia and one third develop solid tumours. The approximate survival rate is 80 %. Children with a brain tumour have a lower recovery rate.

Treatment of childhood cancer is very intensive and consists of chemotherapy and/or surgery and radiotherapy. Children with a brain tumour are at high risk of having a large number of problems later in life because the treatment also often includes brain surgery and radiotherapy.

In Denmark, treatment of childhood cancer is centralised in four paediatric oncology centres. At the Paediatric Oncology ward of the University Hospital Rigshospitalet in Copenhagen approximately 80 newly diagnosed children with cancer are admitted every year.

Children suspected of having cancer, are referred from local hospitals to Rigshospitalet for diagnosis, treatment and care. Rigshospitalet’s catchment area is within a distance of 100-140 km. Compared to other countries in Europe, distances in Denmark are very short so no family will have to travel very far. But as the children are going to Rigshospitalet quite often for both treatment and follow up, a hundred kilometres may still be a long way to travel on a regular basis. In spite of this, however, the majority of families prefer going to Rigshospitalet – in part because they grow familiar with both staff and surroundings.

Because of strict isolation rules, patients and families are not allowed to use public transportation. They can either use their own car or benefit from transportation by taxi paid for by the hospital as a part of the Danish public health system.

We believe that the care and the safety provided for by their parents are vital to the children, so one parent is always admitted to the hospital together with the child. We know that the parents are the children’s best representatives. They take part in the care of the child and they obtain knowledge and information about the disease and treatment. They are of course fighting for the most precious thing they have – their child.

At Rigshospitalet, The Paediatric Oncology Ward consists of 20 inpatient beds. There is a day care unit and an outpatient clinic with approximately 40 visits per day. In the outpatient clinic special care teams consisting of a doctor and a nurse focus on a specific cancer diagnosis. By focusing on one particular diagnosis in a comparatively limited number of patients, staffs are able to acquire special knowledge, professional expertise and understanding, which will give the staff a better knowledge of each patient and improve the treatment.

In order to optimize the treatment of children with a brain tumour we established The MDBT-Team at the Outpatient Clinic of The Paediatric Oncology Ward of Rigshospitalet. In The MDBT-Team all involved professionals work together and benefit from each other’s expertise. We are convinced that both children and families benefit from our joint efforts. And we find our efforts indispensable, considering the fact that the specific treatment which the children receive may give them serious health problems later in life, e.g. lack of puberty, heart problems, lung problems, secondary cancer and fertility problems.

Later in life the children may also suffer from late effects of radiation to the brain: Learning disabilities, decreased memory, problems with concentration, distortion of emotion, decreased final height, disturbed body proportions, growth hormone deficiency and social isolation. Children often feel alone and are often increasingly dependent on their parents. These serious problems, which, normally, other children with cancer will not suffer from to the same degree, really emphasize and justify the existence of The Multi-disciplinary Brain Tumour Team.

The Purpose of The Multidisciplinary Brain Tumour Team (The MDBT-Team)

Due to the treatment with surgery, and radiotherapy in particular, children with brain tumours have some very special needs, not only during the treatment but also during the rehabilitation period.

More about The MDBT-Team

The MDBT-Team is very dedicated. The team consists of two doctors, one nurse, one neuropsychologist, one social worker, three physiotherapists and two occupational therapists.

We have meetings twice a month – each meeting lasts about 45 minutes. The agenda for the meetings is focused on children with special needs, terminally ill children and new patients.

During the period when the child is admitted to the inpatient clinic, the nurses in the ward, the doctors and The MDBT-Team currently discuss the care and treatment in order to secure the best care and complete treatment. This could be a matter regarding the child’s rehabilitation period after an operation or a family with a special problem or need.

The MDBT-Team also convenes network meetings with external partners: The social service authorities, schools, kindergartens and rehabilitation professionals in the child’s home area. The purpose of these meetings is to inform the external partners about the specific problems the children may face once they are discharged from hospital. In this way we hope to improve the quality of the care and treatment.
Twice a year The MDBT-Team arranges a special team-day. We discuss new guidelines, ideas and new written instructions which apply for the outpatient clinic as well as for the ward. We invite external keynote speakers and other involved professionals from outside the hospital to teach and inspire us. Our purpose is to gain common understanding and to increase our joint work with other professionals who we cooperate with both internally and externally.

Because the treatment is centralised in one place, we have a unique access to cooperate with a number of other involved professionals and medical experts present at Rigshospitalet during and after treatment. They include educationalists, teachers, dieticians, nurses specialised in pain relief, the ward priest, neurosurgeons, GP’s educated within growth hormone deficiency, neuropaediatrics, ophthalmologists and ENT-specialists.

What are the tasks for the nurse in The MDBT-Team?

I have 12 years experience as a paediatric oncology nurse at Rigshospitalet, and for the last eight years I have been working at The Outpatient Clinic of The Paediatric Oncology Ward. In my daily work I focus primarily on children with brain tumours.

When the families attend the outpatient clinic, I observe the children and inquire about their common conditions. Do they have any special needs or problems which the doctor needs to take care of or take into consideration? As a contact person for the patient and the family I get to know them all very well. The families can always call me, and I am the contact from the patient to the doctor. It is important that the families feel secure that their problems are taken care of in a serious, respectful and determined way.

I make sure that the children have a treatment plan made out for them. In respect of the children’s examinations and tests elsewhere at Rigshospitalet, I do the following up and coordinate these activities. A lot of the correspondence between the different members of The MDBT-Team comes to me. This gives me a unique insight in the function of the team.

When children with brain tumours are about to be discharged from the inpatient clinic, I always introduce myself to the families and tell them that I have a special focus on the children with brain tumours. They can contact me when they are at home.

In situations where the families are caring for a terminal child at home, there is, in order to secure the best care for the child and the families, a very close cooperation between the doctor, specialised in brain tumours, me and sometimes other nurses from the ward, involved in the care of the child. We make sure that either the doctor or the nurse is in contact with the family on a daily basis.

Other professionals in The MDBT-Team.

The social worker applies for parental leave (for one parent) during the child’s treatment, stays in contact with the social service authorities and applies for grants to the children. Other arrangements, for instance extra expenses relating to the child’s illness and help to siblings, are also taken care of by the social worker. Often, the families do not know much about their rights, and they are not aware of which benefits they can claim in this respect.

The physiotherapist’s main task is rehabilitation. Especially in the first acute period after the child has had surgery where rehabilitation is vital. In The MDBT-Team we find it important that the physiotherapist meets the child and the parents before the operation in order to estimate the child’s physical capacity and to inform the parents about the physical changes they may expect to see after an operation. The physiotherapist will give the family some guidelines for rehabilitation which they can use at home. The physiotherapist also stays in contact with the external physiotherapist in the child’s home area.

The neuropsychologists job is neuropsychological testing of the child. After the child has been tested, we can see what kind of difficulties and specific problems the child may have, both cognitively and emotionally. The neuropsychologist has meetings with the child’s school teachers and the family in order to find the best school or other solution for the child. The neuropsychologist also has therapeutic conversations with the parents, the child and siblings as needed.

The doctor has the superior responsibility for the medical treatment of the patient.

The benefits for patients and their families of The MDBT-Team

Everyone who is a part of The MDBT-Team has considerable knowledge of all the patients and families at The Paediatric Oncology Ward at Rigshospitalet. The patients and the families do not have to repeat their health story over and over again. Furthermore, we believe it to be an important message to the parents, that there is consensus in The MDBG-Team in respect of treatment and care of their child.

The fact that we have a very good working climate in The MDBG-Team and that each professional group respects each other is of course a motivating factor for the team members. We are also happy with the fact that every child diagnosed with cancer is taken care of psychologically, physically and socially. Finally, The MDBG-Team appreciates having the specialized expertise of all other clinical professionals at close hand – and we are sure so do the families.

The nid on the physical changes they may expect to see after an operation. The physiotherapist will give the family some guidelines for rehabilitation which they can use at home. The physiotherapist also stays in contact with the external physiotherapist in the child’s home area.
Improving Phone Communication between Parents and Medical and Nursing Staff in a Pediatric Oncology Unit: Project Report

Apostolos Poursidis and Perdikaris Pantelehmon, Oncology Department, Aglaia Kyriakoy Children’s Hospital, Athens, Greece

Introduction
With as many as 700 long-term survivors, 200 patients receiving active therapy, and about 65 to 70 new patients each year, we became aware of a high workload burden and severe time pressures during both regular work hours and after-hours service on our in-patient ward and the outpatient clinic. In addition to providing direct patient care, a substantial portion of our practice consists of answering telephone calls from caregivers of children who call to ask advice on how to manage clinical problems; some calls are of an urgent nature. As there is no standardized telephone triage practice and the nurses in our unit are not involved in many issues of patient care, the majority of calls are sent to the physician in charge. Answering calls from the parents of sick children is sometimes frustrating and often times challenging. Family practice physicians, pediatricians, and other specialty clinical practices are incorporating telephone calling systems as part of the services available to their patients, either during regular work hours or as an after-hours service (Black, 2007). At our institution, calls from parents have been answered primarily by physicians although nurses are capable of providing accurate information. Some parents however are hesitant to trust advice given by a nurse and prefer to talk directly with the physician although physicians often don’t have time to thoroughly address the questions posed by parents.

Project Planning
The purpose of our project was to create a new telephone calling system which allowed nurses to answer patient calls for two hours per day. Emergency calls made at any time were to be answered by the physician in charge. Further, questions which could be easily answered were recorded and replied to on the following day and a list of frequently asked questions was created.

Our goal was to organize the team responsible for answering the calls so that the number of in-coming calls could be decreased by 50%. To accomplish this, it was necessary to gain the acceptance and trust of both parents and young patients for the new system. The health care team provided parents with important information about the way the system works, types of questions which were appropriate to ask using the telephone system, and the times to place calls. Brochures with written instructions about assessing problems which required a phone call to the hospital were developed and distributed. Furthermore, the team provided education to parents about emergency situations and routine problems and we improved the instructions we provide to parents before patient discharge. We also interviewed parents to find out what ideas they had for improving the telephone call system. Our goals for all these initiatives were to: 1) ensure that calls were made during appropriate times; 2) increase parents’ trust in the information they received from physicians and nurses over the telephone; 3) decrease the time needed by nurses and physicians to answer calls; 4) create a more calm environment for the families; and 5) improve the integration of the nursing staff in the call system.

We wanted the new call system to be more flexible and more accessible than the old system. We also wanted to improve the consistency of information delivered by staff, to reduce the number of unnecessary calls and to identify frequently asked questions as secondary aims of the project.

Project Implementation
The first step of implementing our project was to identify the type of calls received. We randomly assessed the calls made by caregivers for 10 days including weekdays and holidays. Each phone call was reported in a specific form containing the diagnosis, the disease status, the time of call and the main reason for the call. Further, calls made during both regular work hours and after-hours service on our in-patient ward and the outpatient clinic. In addition to providing direct patient care, the majority of calls are sent to the physician in charge. We initially set up a team consisting of two nurses and two physicians. Using nurses as the first point of contact for callers and to allow nurses to provide advice is a new and growing practice in pediatric oncology. There is much support in the literature that nurses are the best health care professionals for giving telephone advice (Briggs, 2002). The team must be experienced and have knowledge of their patient population, the disease process, and appropriate to ask using the telephone system, and the times to allow nurses to provide advice is a new and growing practice in pediactric oncology. There is much support in the literature that nurses are the best health care professionals for giving telephone advice (Briggs, 2002). The team must be experienced and have knowledge of their patient population, the disease process, and the times to place calls. Brochures with written instructions about assessing problems which required a phone call to the hospital were developed and distributed. Furthermore, the team provided education to parents about emergency situations and routine problems and we improved the instructions we provide to parents before patient discharge. We also interviewed parents to find out what ideas they had for improving the telephone call system. Our goals for all these initiatives were to: 1) ensure that calls were made during appropriate times; 2) increase parents’ trust in the information they received from physicians and nurses over the telephone; 3) decrease the time needed by nurses and physicians to answer calls; 4) create a more calm environment for the families; and 5) improve the integration of the nursing staff in the call system.

Reason for call:
- Fever 26
- Pain 24
- Bleeding / problems related to low platelet count 14
- GI problems, vomiting 6
- Questions about drugs, vaccines, appointments, catheter care 32
- Blood count, drug adjustment, GCSF 34
- Others (rash, exposure to infections, mouth sores) 12

Table 1: Analysis of calls made during the 10 day assessment
Further, because there is a shortage of nursing staff, each step for change goes slowly. We need to involve a larger group of people in this project but we have experienced difficulty in getting more colleagues to participate. We have implemented weekly meetings to increase involvement in the project. It will be necessary to increase the visibility of the framework of Appreciative Inquiry as used in this study.

References

Project Limitations
We have faced numerous problems in implementing this project. Firstly, the stressful situation in our institution continues and we have encountered members of the health care team who are not very cooperative although members were enthusiastic during the initial planning phases of the project.
The goal of the European Specialist Nurses Organisations’ (ESNO) is to facilitate and provide an effective framework for communication and co-operation between the European Specialist Nurses Organisation and its constituent members in order to represent the mutual interests and benefits of these organisations to and within the European Federation of Nurses (EFN) and the wider European community.

**Mission Statement**
To promote and contribute to the health and wellbeing of people in Europe: ESNO will facilitate and enable the political voice of nurses, through collaboration with key stakeholders to strengthen the professional status and evidence based practice of nursing as a specialty. Secure the recognition of specialism in nursing in the EU and the greater Europe.

**Objectives**
- Be a network for communication and collaboration between the European Specialist Nurses organisation and specialist interest groups in Europe
- Promote the recognition of and the professional status of the specialist nurse at the European level
- Represent the interests of the member organisations
- Provide expert advice on issues shaping specialism in nursing
- Promote the development of specialist nursing education, practice and research

**Member organisations**
List of member organizations as of July 2008:
- ACENDIO - Association for Common European Nursing
- Diagnoses, Interventions and Outcomes
- EDTNA/ERCA - European Dialysis and Transplant Nurses Association / European Renal Care Association
- EFCCNa - European federation of Critical Care Nursing associations
- ENDA - European Nurse Directors Association
- EONS - European Oncology Nursing Society
- EORNA - European Operating Room Nurses Association
- FINE - European Federation of Nurse Educators
- FEND - Federation of European Nurses in Diabetes
- FOHNEU - Federation of Occupational Health Nurses within the European Union
- Horatio - European Psychiatric Nurses
- EANN - European Association for Neurosciences Nurses
- IFNA - International Federation of Nurse Anesthetists

**Observers**
- PNAE – Paediatric Nursing Associations of Europe

**Reports from April and October ESNO Council Meetings**
ESNO Council (ESNO Board of Officers and representatives of member organisations) meet twice a year in Brussels. These meetings took place in April 21-22 and October 20-21 2008. At the April meeting the following issues were discussed:
- The registration process was discussed and a decision taken to be registered in the Netherlands. This process has been completed.
- The constitution was agreed with amendments. Name “specialists” is decided to change as “specialist”.
- The need for clear statements about criteria for membership to ESNO was debated during the meeting. The reasons are to enhance the professional status of the organization, to ensure quality of selection of new member organizations and to inform potential new member organizations. The criteria are now on the ESNO website.
- The group worked on the PEST analysis with Liz Ollier and developed an action plan.
- The financial status of the organisation was reported. At the October Meeting each member organisation presented a short report. Here are some of their activities reported at the meeting.
- FINE: Mrs Anne Lekeux reported that 7th FINE Conference took place in Plovdiv, Bulgaria and had representation from 23 Countries. The new President of the organisation is now Prof. Nedyalka Krasteva, from Bulgaria and Anne is vice-president for the next two years. FINE has two Leonardo Projects: The first is the “Virtual Hospital” which is an online construction using ICTE (Information and Communication Technologies for Education) allowing a learner in nursing to get in contact with multiple virtual patients. The second project is IENE-Intercultural Education of Nurses in Europe which aims to create the approaches, methods and tools for intercultural education of nurses and other medical staff participating in European mobility or working with patients with different cultures and languages. The purpose is to facilitate their participation in the European labour market and their integration in different cultural backgrounds.
- ACENDIO: Mr. Walter Sermeus presented a report about the activities of ACENDIO (Association for Common European Nursing Diagnoses, Interventions and Outcomes) which is a membership organisation established in 1995 to promote the development of nursing’s professional language and provide a network across Europe for nurses interested in the development of a common language to describe the practice of nursing. He explained that the organisation is now looking for a new scope which will include documentation, supporting data, outcome data and EFMI (European Federation of Medical Informatics) trying to combine this organisation. The ACENDIO pre-conference meeting will be held on 26-27 of June, 2009 in Helsinki, Finland just before 10th International Congress on Nursing Informatics. Walter gave information about 2nd Summer School on Clinical/Critical Pathways. The information about these activities can be reached on ACENDIO website: http://www.acendio.net/
- EFCCNa: Mrs Bronagh Blackwood has talked about their recent Congress in Florence, Italy. She explained about a two week exchange program to promote greater cooperation between member associations helping to share expertise to develop nursing care throughout the European countries.
- EANN: Mr. Paul van Keeken gave a report on Leonardo project called “NeuroBlend” which aims at creating a European blended learning framework for competence based life-long learning of neuroscience nurses (www.neuroblend.eu).
ENDA: Mrs. Jacqui Filkins pointed that their organisation now focused on nutrition in hospitals and joined to The European Nutrition for Health Alliance which is a united effort to raise awareness of the importance and the urgency of the issue of malnutrition and to build an agenda for action at the European level.

To increase membership of ESNO, European nursing organisations were searched, listed and presented at the meeting. Potential members will be approached and invited to join.

As a part of the agenda, EU issues (Directive 36, Bologna Process and Green Paper on Health Professionals in Europe) were discussed at the both meetings. At the April meeting, it was agreed that ESNO will formally respond to the roadmap of the Green Paper.

ESNO Board of Officers was elected for next two years:
President: Pascal Rod
Vice-president: Jacqui Filkins
Secretary: Wouter de Graaf
Treasurer: Paul van Keeken

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ESNO Strategic Plan
Work towards recognition of specialist education in the EU
• Mandatory post basic education for specialist nurses
• Focus on developing infrastructures for continuing professional development
• Collaborate with EFN on a position paper on life long learning for nurses

Influencing EU social and health policy
• Provide specialist expert opinion in EU social, health, nursing education and research policy
• Respond actively to EU White and Green papers
• Respond to EU Recommendations and Directives

Promote effective strategies in recruitment and retention of nurses
• Contribute to the discussion on the impact of the nurses moving from one country to another on the specialist nursing practice
• Collaborate with key stakeholders on relevant position papers

Improve collaboration between interest groups
• Develop collaboration with key stakeholders within Europe
• Disseminate information on relevant actions to the members of ESNO (website and internal communication structures)

Evaluate the collaboration with EFN and other stakeholders
The next ESNO Council Meeting on April 20th -21st, 2009.

We are pleased to announce that EONS have appointed an expert panel to develop a European breast care nursing curriculum to build on the European basic cancer curriculum. This will be led by Dr Debbie Fenlon from the University of Southampton, who has many years of experience nursing breast cancer patients. She is now working in full time research to explore the problems that survivors of breast cancer face and to find ways to help women cope with these problems. Other members of the panel are all expert nurses in breast cancer. They include Manuela Eicher from Switzerland, Ilana Kadmon from Israel, Emma Pennery from the UK, Yvonne Wengstrom from Sweden, Saskia Claassen from the Netherlands and Sara Marquard from Germany.

The panel aim to draw on expertise from around Europe to draw up a basic minimum standard of training for nurses working with women with breast cancer. They will then bring this knowledge together to develop learning outcomes and clinical competencies and design a curriculum to equip nurses with the skills and knowledge necessary to provide best care for women with breast cancer all across Europe.

If you would like to contribute to this process we would be delighted to hear from you. Any information that might inform the curriculum, such as research evidence, standards, policies, learning outcomes, competencies or local curricula, would be very welcome. Please contact Debbie Fenlon on dfenlon@soton.ac.uk. We hope to be announcing the final document next Spring, so watch this space!

Debbie Fenlon, Senior Research Fellow, Macmillan Research Unit, School of Health Sciences, University of Southampton.

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Use of Appreciative Inquiry
in paediatric oncology nurse education

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Introduction
We joined a special research project to look at collaborative working between nurses and doctors in paediatric oncology, supported by Federation of European Cancer Societies (FECS), International Society of Paediatric Oncology (SIOP) and The European Oncology Nursing Society (EONS). Fifteen participants, from fourteen European countries, joined the project. Every team was represented by a nurse and doctor, working together in the same paediatric oncology centre. The project was designed to develop the collaboration between doctors and nurses with an aim to improve the basic requirements for quality of care. The project philosophy was based on Appreciative Inquiry (AI) principles 1, which significantly differs from the usual problem perception and solving approach. The AI approach consists in the basic assumption that organisation is not a problem to be solved, but a mystery to be embraced 2. AI method steps are introduced through 4-D cycle: Discovery – appreciating, Dream – envisioning the results, Design – co-constructing and Destiny – sustaining 3.

Choosing the project of local interest
Our team represented the University Children’s Hospital, the oldest children's hospital in Balkans, founded by the King’s decree in 1924, with a long history as a teaching base. In the hemato-oncology department, diagnosis and treatment of all malignancies, except brain tumours is performed, as well as non-malignant hematological diseases in childhood. Employees include four paediatric specialists, three clinical doctors, fifteen nurses and two laboratory technicians. The average number of new diagnosis of malignant diseases per year is about 60. Although our nursing staff is very dedicated to the patients and their parents, we were aware of a lack of systematic clinical education for these staff. We decided that our local task would be to devise a program of education for staff, using an AI approach.

Project aims
The main aim was to develop more self confident and self sustaining staff, strongly aware of quality of care and best practices. In addition, improved nursing will motivate doctors, so benefit will be seen through better collaboration, professional relationships and improving patient care. Finally, the creation of a model of collaboration and education to be followed by future generations of doctors and nurses with possibility to offer it to other hospitals that treat paediatric malignancies in our country.

Methods to reach our endpoint
Because of a lack of an official nurse paediatric oncology education program, we consulted foreign centres, which are experienced in this field and made modification to our operational methods. We mostly relied on St. Jude Children’s Research Hospital - Nursing education, Patient Care Services (PCS), Gen Foley and UC Davis Medical Center - UC Davis Health System; The Center for Nursing Education (CNE).

Demonstrating the use of Appreciative inquiry

Discovery
Analysis of our work helped us to appreciate the membership of the BFM group, the application of current protocols and good interpersonal relations. We also concluded the following: young nurses are only in a position to be instructed by senior nurses, despite them having a higher level of education and a degree. Motivation for teaching sometimes depends on personal relations which can lead to omissions in standardising education. Since there is a lack of supportive services (psychologists, social workers), which results in overworking, doctor-nurse communication and team working is often strained which makes professional relationships strained.

Dream
By envisioning the results, we discovered that our dream is to evolve from a traditional model of nurse doctor relations to a more productive multi-professional team with greater possibility of open dialogue between all its members. Standardised education will optimise the knowledge, skills and approach of each individual, regardless of their function, age and position. Good quality of care and overall results of treatment will be achieved more easily with better understanding and patterns of communication. Greater nursing involvement in clinical work will improve the medical research strategies and open the door for new projects. The model of instruction giving should be replaced with more close collaboration, which will result in proper involvement in patient’s care.

Design
Considering what should be ideal, we constructed the project schedule with specific key timelines and events:

From November 2006 until February 2007 we made the presentation of the purpose of FECS-SIOP project, illustrating the AI concept as well as the chosen topic of local interest. We noted the strong opinions about the chosen topic which revealed the possible challenges in realising the project.

From March 2007 until May 2007 we made the final agreement about the course model. Chosen topics cover basic essentials concerning the nursing role in paediatric hematology and oncology, manual manipulation procedures, medical preparation and administration of medications, nutrition, hygiene and care, most common diseases (malignant and non-malignant), most common therapy-related toxicities, postoperative follow-up, management of pain, psychological perspectives, palliative care and ethical and legal issues.

From June 2007 until August 2007 we divided the topics among all team members, provided the logistic support for the course to be realised and once again reminded the team members of 4D cycles and AI concept.

From September 2007 until April 2007 the educational program was undertaken and we summarised our results in an abstract for SIOP congress.

From July 2007 until September 2007 we repeated the lectures and gathered all lectures into a nurse education guideline. The project schedule is shown in Table 1.

Destiny
The creation of new model of function and communication, standardisation of knowledge, and sustainability of co-workers.
**Project realisation**
The time needed to spread the idea of appreciative enquiry was longer than expected, considering we were in position to establish a completely new approach. We realised that changing the conventional way of thinking was one of the biggest steps and we wanted to be sure that all team members would adopt a different manner of communicating and acting.

It should be pointed out that operational steps, as well as lecture giving, were made by all members of team.

During the project, we were concerned about possible lack of enthusiasm, interest, logistics or support. In a majority of cases, the team member’s enthusiasm gradually dropped after realising the necessity to undertake overtime work to ensure the project completion. Despite the difficulties to keep the project to schedule due to different shifts, congresses, seminars, holidays and health problems, we followed the education plan twice a week with attendance of almost the whole staff as well as external consultants.

After every lecture session, there were interesting discussions which resulted in paper forms of the evaluation of the day’s topics were completed which was as reliable source of information.

The evaluation analysis was through an anonymous questionnaire, which was designed to evaluate the content of the course and the benefits of the acquired knowledge and the new approach to training.

The questionnaire data showed that 90% of staff was female, with an average age of 36.5 years and average work experience of 16.5 years. Complete satisfaction of the project organisation, chosen topics and lecture attendance was found in more than 80%, but surprisingly, complete satisfaction with the lectures overall outcomes was only seen in 50%. For that reason, we postponed the project completion date and repeated the more challenging lectures. Interestingly, the best rated lectures were ones considering life threatening situations in our patient group.

**Project outcomes**
We adopted a different manner of communication based on Al concept and developed an educational course using an interactive and positive approach. Our experience showed that replacing the model of instruction giving, with more close collaboration with other health care teams led to an evolvement from a traditional model to a team with a greater possibility of open dialogue between all its members.

The benefits of participation in the FECS/SIOP project were noticed even before the end of the project with an upgraded and standardised knowledge among staff and the creation of more self confident and self sustained team members. This raised the awareness of quality of care and best practices, which led to greater involvement and motivation for team work and more productive results in more satisfied surrounding.

A few lessons were learnt during local task realisation in that new and innovative ideas are met with fear and replacing a traditional model of working is harder for senior members of staff. Nurse’s involvement in what had been traditionally doctors work, and the other way around, was limited, and accepting different opinions doesn’t necessary lead to conflict.

Our major discovery is that after the course completion, nurses are showing great initiative for further education, which is why we have agreed to have the next lecture sessions when some interesting cases occurs or when preparing to introduce new protocols.

Further steps are already planned with the aim to share the positive goals that we achieved. Offering the project to other pediatric hemato-oncology centers in the country and publishing a book for paediatric oncology nursing are our first priorities.

We noted that collaboration profoundly influenced the working atmosphere and resulted in staff being receptive to new challenges. With improved knowledge, nurses are actually more involved in quality-of care and aware of best practices. Improved nursing motivates the doctors, so benefit is also seen through better collaboration improved professional relationships and in the patient’s treatment and care.

**Conclusion**
We are grateful for opportunity to participate in FECS-SIOP project, and especially proud that we completed the project on time and successfully answered our project goals.

We have stressed the importance of collaborative working throughout and used this model of nurse/doctor collaboration to improve the quality of care in our centre. Hopefully, the model of collaboration and education which is created will last longer than the project itself and be followed by future generations of doctors and nurses.

**Acknowledgments**
We express our gratitude to Dr Faith Gibson and Dr Momcilo Jankovic, MD, for their sincere support and inspiration in every step of our project. We also appreciate the help of Prof. Paola Di Giulio and Dr Martin English, MD, as well as all team members involved in FECS-SIOP project. And last, but not least, we are thankful to all nurses, doctors and laboratory technicians from our department for patience and hard work in project realization.

**References**

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**Table 1. Project schedule and results summary**

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EONS Newsletter celebrates Seven Years of Progress
And bids farewell to Jan Foubert and Emile Maassen

The first issue of the EONS Newsletter, in its present format, was launched in September 2001 during the ECCO conference in Lisbon. That issue, which contained a meagre eight pages, looked and read much different than the 44-page Fall 2008 issue. The title page of the retired EONS Newsletter was white, the print font was large, and it contained no articles related to state of the art issues in cancer nursing. That rather plain version was dressed up and the issues that followed became more sophisticated in appearance, layout, and content. Emile, Carol and Jan joined the EONS News Team what seems like ages ago and were instrumental in the changes that have taken place in the scope and content of the Newsletter over the years. Cath Miller joined the team in 2007 and her contributions have proved invaluable.

Recent issues of the Newsletter have been theme-based. Themes covered in previous issues have included: prostate cancer, lung cancer, psycho-social oncology, colorectal cancer, cancer screening, and education and childhood cancer. Observant readers have surely noticed that each issue also contains recurrent features such as ‘Our colleagues from’ which has spotlighted over 20 societies, ‘EONS News’ and updates on projects and EONS-related activities. Our ambitious colleagues at the AIIO (Associazione Italiana Infermieri di Oncologia) translate each issue of the EONS Newsletter into Italian and a Spanish version of the newsletter was available at the ECCO conference 2007 in Barcelona.

The members of the News Team are quite pleased with the product they produce on a quarterly basis. The process of transforming the Newsletter into a high-quality publication has been one of trial and error with some downs but many ups. We have learned not to look for mistakes but rather to focus our energies on making corrections that will make the Newsletter a true vehicle of communication between EONS and its members.

On this occasion of celebrating seven years of publishing the EONS Newsletter, the News Team would like to thank all members who have taken the time to write articles or to relay suggestions to improve the Newsletter. Gratitude is also extended to all our corporate sponsors, especially Amgen Europe and TopoTarget, who have provided financial support for the last two years. This support has enabled the News Team to implement new ideas and publish a newsletter that not only gets better with every issue but reaches more oncology nurses in Europe with each issue.

It is our sincere hope that readers find something of interest in every issue – and if they do, then we are fulfilling our goal. With this issue, Jan Foubert and Emile Maassen will retire their involvement with the News Team. Although the future is always uncertain, both Jan and Emile are able to look back with pride and personal satisfaction on their accomplishments and contributions to EONS.

EONS Clinical Travel Bursary Grant 2009

Aim
To support nurses who are working in oncology to obtain clinical experience by visiting another cancer centre/unit.

Description
The EONS clinical travel bursary is awarded towards costs incurred (clinical site fee, travel, accommodation and expenses) by the successful applicant during the clinical site visit. The applicant is responsible for organising their clinical site visit. The clinical site visit must be a minimum of one week in duration.

Funding
Single payment of €2,500 travel grant. Two grants will be awarded. The applicant must use the grant within one year of the award.

Closing date
Application forms must be completed and sent to EONS Secretariat by 1st March 2009

Restrictions
Applicants must be an individual member of EONS or willing to become individual member and working in cancer nursing. The applicant must complete the application form (see www.cancerworld.org/eons) including a proposal of how they will disseminate the knowledge and experience acquired (maximum 1000 words). If you receive a travel grant you are expected to write a final report of your clinical site visit for the EONS newsletter.

Contact
All applications to be forwarded to: EONS Secretariat:
Avenue Mounier 83/8, 1200 Brussels, Belgium
Tel: ++32(2)779 99 23
Fax: ++32(2)779 99 37
For further information contact EONS Secretariat at eons.secretariat@skynet.be
The TRANSBIG Workshop

Yvonne Wengström, EONS past-president

The key to individualising treatment lies in finding a way to quickly “translate” the discoveries about cancer biology made by laboratory scientists into tools that physicians can use to help make decisions about the way to treat patients. This area of medicine that links basic laboratory work to the treatment of patients is called “translational” research.

TRANSBIG is an international network that was created to promote this kind of translational research and international collaboration in that area: the goal is to bring the best minds and resources together in order to reduce the wasteful duplication of efforts. The network includes 39 world-class institutions present in 21 countries and is managed by the BIG-TRANSBIG Secretariat based in Brussels. Each participating organisation brings with it expertise that ranges from being specialised in cutting-edge biomedical technologies and cancer treatment programs to lobbying governments on behalf of patient groups and supporting cancer societies.

The extent to which researchers are collaborating with experts outside their field is a key indicator of research practice patterns, and may have implications for the likely impact of such research in clinical practice. As a network, TRANSBIG is dedicated to high-level collaboration that will contribute to advancing individualised treatment for breast cancer patients. Among its many strengths is the fact that it is linked to an already existing network of groups around the world that conduct clinical breast cancer research together – the Breast International Group (BIG). In this way, the connection is guaranteed between what scientists learn in the laboratory and what physicians and patients decide together about treatments in the clinic.

EONS was invited to represent the nurses role in a workshop at the last EBCC meeting with the theme “Patient-Physician-Researcher-Nurse: a key partnership on the road to a cure for cancer?” This is a hot emerging topic as the complexities of cancer and its treatment, rapid advances in biomedical science and technology, growing concerns about the quality of health care, and intense competition for limited research dollars contribute to the urgent need for interdisciplinary collaboration in cancer research. Collaboration in the design and implementation of significant research initiatives will advance the discovery of knowledge to improve outcomes for patients and care providers, with both medicine and nursing standing to benefit from close collaboration.

Research collaboration between physicians and nurses is slowly starting to change and the traditional hierarchical nurse-physician relationship is gradually evolving into a collaborative model. Historically, physicians have assumed the lead role in many collaborative research initiatives. However, contemporary research collaboration between physicians and nurses is more often non-hierarchical in nature, with the implied assumption that power is based on knowledge and expertise, rather than role or function.

Nurses roles in clinical trials have often been described as clinicians; direct caregivers, coordinators of care, educators and patient advocates. By others also as, research nurses; facilitators, liaisons, data collectors and playing a major role in identifying eligible patients. Lately however, also members of International Research Boards and as primary investigators which we all see as a welcome development. At times this may well be a struggle for nurses since responsibilities and expectations can be overwhelming since the role as patient advocate and researcher has rather conflicting goals, one can ask the question is it possible to advocate on behalf of the patient while being interested in recruiting?

In sum, many clinical and scientific exigencies demand new cultures of physician-nurse research collaboration and communication based on mutual respect, trust, shared interests, and commitment. Although research collaboration holds great potential to improve oncology outcomes, it is a complex and sophisticated process requiring a significant investment of time and effort. The resulting advances in science, however, should far outweigh the investment. Benjamin Franklin stated when the Declaration of Independence was signed, “We must all hang together or, assuredly, we shall all hang separately.”

Nursing has played a major role in informed consent. The single largest group of consent forms are used in oncology and oncology nurses have for some time argued that this does not mean that patients understanding or decision making is improved, but this also has implications for the importance of the role of the nurse as educator and advocate in this process.

Collaboration in clinical research a complex phenomenon and it offers great potential the sharing of ideas and goals will of course foster a vibrant intellectual examination of the research problem at hand. But if this is to occur there needs to be a willingness to share expertise and resources by all involved in the collaboration. The Clinical Trial Nurse has become an integral element of the clinical trial process and is fast evolving as a new and challenging specialty and the identification of caring practices and clinical skills unique to this specialty will allow the boundaries of this new area to be further defined. I believe that future challenges entails to increase nurse participation in cancer clinical trial networks to facilitate trans-disciplinary research. If we learn from the good examples where communication and collaboration between clinical trial nurses and clinicians have been developed we are on the road to succeeding this venture.

In order to reduce the wasteful duplication of efforts, it is important for interdisciplinary collaboration in cancer research. Collaboration in the design and implementation of significant research initiatives will advance the discovery of knowledge to improve outcomes for patients and care providers, with both medicine and nursing standing to benefit from close collaboration.

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The first time I attended an EONS meeting was in 1995. In 1997 I was elected to the Executive Board and became Treasurer of the Society. For four years I served on the Board, was elected and served for six years as president-elect, president and past-president of the Society. For the past 18 months I have held the post of Executive Director of EONS. After 14 years, I have decided to say farewell to EONS.

Throughout those 14 years, I have worked with many Board Members and Presidents. I have had the opportunity to meet a lot of oncology nurses and to visit almost all the countries who are members of EONS. My travels took me to many places in the world where I have spoken about cancer and cancer nursing. Some of the personal highlights during my time with EONS were the birth of my “kids” TITAN and TARGET and receipt of the ONS Distinguished International Award which I received in 2007.

EONS has developed very much in the last 14 years. The Society has been very productive and innovative in the design of educational projects and cancer-related curricula. Based on a learning needs analysis, designed by experts in the field, pilot tested and implemented with the support of local national oncology societies, projects such as TITAN and TARGET have really had an impact on the practice of cancer nursing in Europe. I have also witnessed the growing importance of the EONS Newsletter and the EONS website as a means of communication not only to the EONS membership but also to practicing cancer nurses throughout Europe.

I think EONS has gained a well-recognised position in a European context. The CARE strategy gives attention to the four pillars that support the existence of EONS. In the area of research, I think EONS can still develop further by making research more practical and accessible. Influencing the political agenda in Europe will always be the most difficult part of the CARE strategy because of the low profile of nurses in the EU and the lack of knowledge nurses have about politics.

Education is the main business of EONS and further development of our educational offerings should focus on future trends. Distance learning, for example, and other models of education should be considered. EONS should drive quality cancer care through education, research, leadership and advocacy and advance excellence in oncology nursing through professional and organisational vitality. Topics like palliative care and clinical leadership need more attention in the future. The diversity of the make-up of EONS has always been a challenge and this will not change in the future – perhaps diversity can also be viewed as one of the elements that make EONS excel and stand out in the crowd of international nursing organisations.

I believe that EONS has now reached a stage where it is in a good position to become “independent” although this means that we have to work on an organisational structure that allows us to remain independent in the future. Being independent means that we must have the resources to lead and to govern the society. EONS now has a sound financial basis: in 2000 we had a capital of 68,000 €, an amount that has been multiplied by 20 in 2008! Becoming independent of other societies and institutions will not be easy; we are dependent on the support provided by others especially from the income of the ECCO conference. The good news is that we have been very successful with our own Spring Conference in the past years and we have established some ongoing support from the industry for several of our activities.

I have worked hard for EONS over the past years and I have enjoyed the work immensely. A secret of my success was that I did the things that I was able to do and sought more information (or help) with the tasks that I was unfamiliar with. Liking the job you are doing is critical to achieving success.

Many people have approached me and asked, ‘what will EONS do without you?’. This is quite a moving question but, in truth, I will be happy and pleased if EONS continues to become stronger and more successful without me. I wish each of you and EONS the very best for the future.
The Hungarian Cancer Society, Oncology Nursing Section organized its first independent national conference in the city of Eger in June 2008. It was a pleasure and an honour for us that Professor Dr. Edit Oláh, past-president of the Hungarian Cancer Society and Honorary president of the Oncology Nursing Section, was the main patron. Other persons involved in the Hungarian Cancer Society who served as patrons of the conference were Prof. Dr. Zoltán Szentirmay, current president, Dr. László Landherr, general secretary, and Dr. Károly Pólus, Honorary Nurse of the Section Oncology Nursing.

There were 209 colleagues from 37 institutions from different parts of Hungary who attended the 1st Travelling Oncology Nursing Conference and Exhibition. The scientific program was divided into five sections with five remarkably interesting and varied symposia. The topics of the symposia included state-of-the-art information on rehabilitation following breast surgery, pediatric oncology, oncology nursing in Hungary, guidelines and new opportunities for the safe handling of hazardous medicines, and the role of oncology nurses in chemotherapy and biological treatments. In addition to these topics, topics such as the major issues in patient education and the latest guidelines on oncologic treatments were presented.

The invited speakers and presidents of the Hungarian Nursing Directors Association and the Council of the Hungarian Paramedical Professionals spoke about the declining number of oncology nurses in Hungary, the implications of this problem, and possible solutions for dealing with the shortage. In keeping with obtaining the goals of the Nursing Section, the representatives of the Hungarian Dietetic Association, the Hungarian Physiotherapist Society and the Hungarian Psycho-Oncology Society introduced ideas for future collaboration between their societies and the Nursing Section of the Hungarian Cancer Society.

We also included information and updates on EONS activities and discussed the implications of these activities from a Hungarian perspective. We are pleased to announce that we have made significant progress since joining EONS in November 2007. The welcome speeches and opening ceremony were followed by the opening of the exhibition area and a reception. Afterwards the participants went on a lamp-lit walk in remembrance of Florence Nightingale, “The Lady with the Lamp” through the historical stonewalks of Eger up to the castle. The participants were rewarded for their efforts with a wine-tasting in the castle. It was good to see relaxed and happy faces, and listen to the never-ending discussions and conversations throughout the evening. This was an excellent opportunity to build new relationships and to refresh existing ones both on a personal and professional level. It is our society’s firm belief that organizing academic and recreational programs is vital in maintaining professional relationships.

We hope that our supporters will continue to help us in achieving our future goals. I would like to mention that our 1st Travelling Conference and Exhibition was sponsored by 16 companies, of which 12 participated as exhibitors and 4 supported symposia at the conference. In total, 34 companies, foundations, and institutes took part in the sponsorship of the conference. The Hungarian Cancer Society will host its next XXVIII national conference in Budapest between 12-14 November 2009. An international forum on oncology nursing is planned for the conference.

The Oncology Nursing Section of the Hungarian Cancer Society is still very young and very interested in learning about cancer nursing in other European countries. We would very much appreciate hearing first-hand about the role and activities of the cancer nurse in different countries from other EONS members. If you would be willing to speak at our conference, please contact us at: csabaavramucz@yahoo.com.
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