

## Monday, 24 September 2007

Opening Session (Mon, 24 Sep, 09:30–11:30)

### Cancer in Europe – sharing the responsibilities

8001

INVITED

#### Nursing on the political agenda

P. Rieger. *Oncology Nursing Society (ONS), Chief Executive Officer, Pittsburgh, USA*

In today's world, providing quality care to patients with cancer is both exciting and a challenge. Professional organizations and advocacy groups, having access to a solid and diverse network of members, are in a key position to impact quality care through changing health policy for the better. These groups are a crucial part of the process as governments seek to develop sound public policy. However, to be successful in the policy arena, organizations must dedicate time, resources, and processes to their efforts. Current issues that resonate worldwide include those of an adequate workforce, access to and payment for care, and education and regulation of nurses and nursing scope of practice. Educating members/volunteers on the issues and providing them with the leadership skills they need to move forward and make a difference is one way professional organizations and advocacy groups can help to shape policy. Not only can groups encourage their members/volunteers to speak up at the national level, but they also can educate them on how to successfully implement grass roots efforts close to home. Getting members/volunteers involved, however, can be challenging. Many may believe that their voice doesn't matter or they may be intimidated by the process and feel they lack the skills. Organizations must make a concerted effort to overcome these barriers and engage their members/volunteers in the advocacy arena. Current technology provides a quick, inexpensive way to reach out to members/volunteers through email alerts and online resources. These communications channels have great potential in disseminating information on advocacy and issues. Another way organizations can advance advocacy efforts is to establish partnerships with other groups with common interests to work toward change. Collaboration serves to conserve vital resources, provide a broader perspective on the issues when talking with policy makers, and drive the achievement of consensus on issues. By banding together, organizations can potentially have a greater impact than they might have individually. There are numerous examples of successful collaboration in the policy arena. Allocating financial resources, such as budgeting funds for staff positions or contracted services can also benefit advocacy efforts. Having a health policy agenda can help to focus efforts as finding adequate resources to fund policy efforts can be a challenge. Together, individual members/volunteers, working through their organizations – who in turn are working with other groups – can achieve greater political success together than they could working alone.

8002

INVITED

#### CARE: managing late and long-term sequelae of cancer and cancer treatment

C.P. Curtiss<sup>1</sup>, P.J. Haylock<sup>2</sup>. <sup>1</sup>*Curtiss Consulting, Consultations, Greenfield MA, USA;* <sup>2</sup>*Oncology Consultant, Consultations, Medina TX, USA*

As strategies advance to detect cancer early and treat it more effectively, the number of people living years beyond a cancer diagnosis increases. Many people now live with cancer as a chronic illness, with or without ongoing treatment. As people live longer after cancer treatment, new health-related challenges emerge. Physiological, psychosocial, spiritual and economic sequelae of cancer and cancer treatment vary from person to person but are substantial among many individuals. While some people experience a few minor long-term effects, others have permanent and disabling symptoms that impair function and quality of life. Once acknowledged, many sequelae can be prevented, treated or managed. Nurses can, and in many cases do have significant roles in promoting and delivering survivorship care. This presentation offers an overview of outcomes from a state of the science symposium on nursing's role in cancer survivorship and an organizational summit for national nursing organizations held in the United States in 2005 and 2006 respectively. Common long term and late effects affecting survivors of adult cancers will be identified; strategies and plans nurses can use to improve the care of survivors of adult cancers will be described; and the recently published "Prescription for Living" will be introduced, including a template that promotes routine survivorship care planning, facilitates formulation of a concise treatment summary, outlines follow-up care and guides planning for healthy lifestyles after cancer.

8003

INVITED

#### Research developing collaboration in cancer nursing research in Europe

C. Tishelman. *Karolinska Institutet, R&D unit Foundation Stockholms sjukhem, Stockholm, Sweden*

Nursing has a history of trying to establish itself as an independent academic discipline, often with resistance from other professions. The vast majority of definitions and descriptions of the field have been formulated within the discipline of nursing, and are often strongly influenced by theory and practice from North America.

The practice of nursing, including nursing research, often has different preconditions in Europe than in the US. In many parts of Europe, cancer nursing research is still conducted by a single researcher alone or with graduate students, often as a very isolated endeavour.

In this presentation, I argue that we need to critically examine our nursing heritage to constructively meet the future in Europe as a whole, as well as in our respective countries. New forms of research collaboration are developing, which will result in new benefits as well as new challenges. There is a need to collectively consider who we, as cancer nurse researchers, might choose to ally ourselves with, and how different types of collaborations are related to the visions driving our research.

### Special Lecture (Mon, 24 Sep, 11:30–12:15)

#### Is patient's information empowering?

8004

INVITED

#### Is patient information empowering?

K. Pollock. *The University of Nottingham, School of Nursing, Nottingham, United Kingdom*

The provision of comprehensive information about the diagnosis, treatment and outcome of illness is widely considered to constitute a key component of good quality health care. It is regarded as both an entitlement and a resource enabling patients to manage symptoms and cope with the challenges of ill health. In supporting patient autonomy and partnership working with health professionals information is seen to be 'empowering' and an important component of 'patient centred' health care. The 'expert patient' is at the heart of modern, responsive and professionally accountable health care provision. Nevertheless evidence is increasing that many patients are not ready, or do not choose, to embrace the role of 'expert patient' and that their responses to information are often more varied, complex, ambivalent and equivocal than the 'empowerment' discourse would suggest. The consequences of information are not always benign, particularly when patients confront life limiting and threatening diseases such as cancer. Moreover, laymen may differ from professionals in terms of the type and topics of information they deem most useful and relevant. Patient information continues to be written from a largely biomedical perspective. It provides the reader with information which professionals consider to be necessary or appropriate for uninformed laymen. This does not necessarily correspond with the lived experience of illness and associated concerns. Information tends to be viewed as a 'commodity' to be transferred unilaterally from professional to patient. Its purpose is to enable an appropriate degree of choice and participation in the management of illness that tends, in practice, to be equated with compliance with professional advice. This presentation critically scrutinises consumerist and professional discourses regarding information and the 'expert patient' and questions the relevance of 'empowerment' in relation to the normative role of patient which many people occupy whether through preference or tradition. Rather than aspire to emulate professional knowledge or expertise, or to claim autonomy in making decisions about treatment, patients seek to acquire agency through the achievement of shared understanding and professional acknowledgement. From this perspective information is valued primarily as a medium of communication rather than instruction