

# UKONS

Mission Statement  
*'Inspiring Cancer Nursing'*

## Oncology Nursing Society Newsletter

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### President's remarks

Summer holidays have come and gone and we look forward to the autumn and another excellent UKONS conference. The event will take place in Glasgow on 13–14 October. As in the past 2 years, the Friday will be a joint meeting shared with our colleagues in the British Oncology Pharmacy Association (BOPA), a collaboration that has allowed closer working and sharing of good practice and continues to go from strength to strength.

UKONS has been working hard to support nurses in oncology and general cancer care by delivering road shows to raise awareness of the UKONS telephone triage tool (developed by a team of enthusiastic nurses under the watchful eye of Philippa Jones). The success of these meetings has led to extra dates being added to the calendar to ensure access for a wider audience. The national tool is now readily recognised and is finding its way into emergency admission areas across the UK.

The joint UKONS/Royal Marsden Hospital cancer genetics meeting in June was a great success. It allowed nurses working in cancer genetics to hear some of the best speakers in the UK talk about the challenges and opportunities that we face when discussing cancer predisposition with families and patients. A full meeting report is on page 2 of this edition of the newsletter, and is also available to read on the website [www.ukons.org](http://www.ukons.org)

UKONS has collaborated with the British Journal of Nursing (BJN) to provide cancer information for general nurses who have contact with cancer patients. UKONS board members edit and encourage contributions to the oncology supplement that is published with the journal every 6 months. All UKONS members are automatically sent a free copy of the edition containing the oncology supplement.

UKONS continues to grow its membership and is proud of the work done by so many of you to sign up a friend in 2011. With access to study leave being so limited, I would encourage you to make the UKONS conference a 'must do' for this year. The UKONS board looks forward to welcoming you back or meeting you for the first time at the conference.

### Cheryl



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## Excellent speakers delight the delegates

**UKONS Genetics in Cancer Conference  
Royal Marsden Hospital, London, 20 June 2011**

The day of the conference coincided with day 1 at Wimbledon, and the morning was predictably overshadowed by storm clouds and the added challenge of an underground strike across London. Despite the weather and difficult travelling conditions, a lively band of hardy nurses turned out for the first 'Genetics in Cancer' conference hosted by the Royal Marsden Hospital (RMH) and sponsored by UKONS.

Audrey Arden-Jones, UKONS genetics forum member and part-time cancer and genetics lecturer at the Royal Marsden Hospital, had pulled out all the stops to coordinate the speakers for the day. True to form, she had called in many favours to ensure the best of the best were on hand. All speakers engaged with the audience and provided stimulating talks and interactive sessions.

Audrey opened the meeting by introducing **Cheryl Vidall, UKONS President** and Clinical Training Manager for Healthcare at Home. Cheryl set the scene, describing the planning and investment that UKONS has put into training for nurses working in cancer care in both the specialist and generalist settings. She encouraged more nurses to become members—to share the learning opportunities and maximise their exposure to a wide range of cancer training and educational events, including research grants and travel scholarships. She reminded everyone of the UKONS conference dates (13–14 October 2011) in Glasgow and encouraged them to attend.

The opening talk, '**Cancer Genetics—what do we do and how is practice changing?**', was delivered by **Dr Susan Shanley**, consultant in cancer genetics at the RMH. She described the various routes of referral and assessment currently used to ensure that patients and relatives receive safe, accurate assessment of the inherited risks of cancer. She described the various types of inheritance, and how carriers and affected individuals can be identified.

She explained how some cells can carry genetic mutations that act as either drivers or passengers in the development of cancers.

The next speaker was **Dr Helen Hanson**, Clinical Research Fellow at the Institute of Cancer Research. Her talk encompassed the spectrum of '**Breast and Ovarian Cancer Families—developments in assessing and managing risks**'. She described the research into identifying the genes responsible for inherited cancers, such as *BRCA1* and *BRCA2*, and the more common mutations that lead to an increase in familial cancers such as breast, ovarian and possibly prostate. She described the importance of mapping the family tree and how prophylactic mastectomy and bilateral salpingo-oophorectomy can significantly reduce the risk of cancer developing for those who carry key gene mutations. She also explained how some isolated communities show higher than average numbers of these mutations.

**Mr Gerald Gui**, Consultant Breast Surgeon at the RMH provided an insight into how breast surgery techniques have changed over recent years. In his talk, '**Developments in Breast Prophylactic Surgery for Women at High Risk**', he explained that breast tissue needs to be completely removed to minimise the risk of further tumour developing. Using photographs of reconstructed breasts, he also showed examples of older techniques, where the overall cosmetic effect was sometimes less than desirable. He explained that the decision whether or not to undergo prophylactic surgery must be made by the patient, once she has been given the facts about her disease and the perceived benefits of the intervention.

**Dr Astrid Stormorken**, RMH Consultant, presented '**Bowel Cancer—familial risk and implications for management**'. She explained the differences between acquired mutations (those that happen during a lifetime)



and hereditary mutations (where the fertilised egg carries a mutation that is passed into every cell in the individual). She included the more common familial conditions of familial adenomatous polyposis (FAP) and Lynch family syndrome, also known as hereditary non-polyposoidal colon cancer (HNPCC). Her talk also addressed the issue of bowel screening for those at increased risk, and the pathways for diagnosis. She stressed that patients have a right to know and a right not to know their individual cancer risk.

**Professor Shirley Hodgson** from St George's Hospital got the afternoon underway on the topic of '**Urological Cancers—when and why does family history matter?**' She described the various sites for urological cancers, including kidney, ureter, bladder and prostate. She described the symptoms and management of renal cell carcinoma (RCC), and some of the targeted therapies and monoclonal antibodies being used on the advanced form of the disease. She also pointed out that an increase in the rate of prostate cancer can be seen in those who carry *BRCA1* or *BRCA2* mutations.

**Dr Kate Tatton-Brown** from RMH and St George's gave a whistle-stop tour of '**Rare Cancer Syndromes**', and provided food for thought on how to

be more proactive in identifying some of the rarer conditions. She told the audience to 'think Li Fraumeni when you hear of sarcomas in the same pedigree [family]'. She also discussed a huge range of other very rare tumours with enthusiasm, and showed a phenomenal understanding of the unusual.

**Mick Mason** provided 'A Patient Perspective on Cancer Genetics', telling the audience how he came to terms with a bowel cancer due to FAP. The condition was diagnosed later than most cases of FAP tend to present—his symptoms had gone unnoticed or mismanaged for over a decade. He shared his experience of having one of his three children testing positive, and the impact of the genetic mutation on her life. He was delighted to report that his grandson, born last year, is free from FAP because his father (Mick's son) tested negative and therefore cannot pass the mutation on to the next generation.

The afternoon was rounded off by 'Challenging Case Studies—a

**learning perspective'**, delivered by the RMH genetics counsellors **Jennifer** and **Kelly**. They presented three pedigrees, and added useful information from various affected and 'worried well' members of each family tree. This talk led to discussion around the right to know or not know about one's genetic status, who should be tested, who should be told and, in the case of feuding families, who will talk to whom when there are positive findings.

Susan Shanley closed the meeting, and thanked Audrey Arden-Jones for organising the speakers, UKONS, and the UKONS educational partners for their support of what had been a very successful event.

The Genetics Forum is proposing to undertake an online survey towards the end of 2011 to find out what is being done by nurses working with cancer patients to alert the genetics team when there are family clusters or possible hereditary mutations that may need to be followed up and screened.

## Living With & Beyond Cancer Forum: Holistic Needs Assessment

Holistic needs assessment should be part of every cancer patient's care. It is important because it:

- Identifies people who need help
- Provides an opportunity for the person to think through their needs and, together with their healthcare professional, to make a plan about how best to meet these
- Helps people to self manage their condition
- Helps teams to target support and care efforts and work more efficiently by making appropriate and informed decisions

For further information, the National Cancer Action Team (NCAT) website can be accessed: <http://www.ncat.nhs.uk/our-work/living-with-beyond-cancer/holistic-needs-assessment>

## Chemotherapy partnership



The UK Chemotherapy Partnership was set up to help improve the quality and safety of chemotherapy services by sharing good practice, in the light of recommendations from the National Chemotherapy Advisory Group in England and Health Department Letter (HDL) 25 in Scotland.

Cancer treatments are becoming more sophisticated and more successful. New agents, often targeted to subgroups of patients or used in combination with other drugs, are improving outcomes. However, these advances also exert increasing pressure on those who deliver the chemotherapy service. Recent reports have highlighted the threat this pressure is posing as the capacity of units fails to keep up with rising demand.

There are many examples of innovative practice introduced by frontline NHS staff that address safety issues and aim to improve the quality of patient care. These efforts often fail to gain widespread recognition in an organisation the size of the NHS. The UK Chemotherapy

Partnership aims to address this issue by sharing good practice through the UK Chemotherapy Partnership website and presentations at local and national meetings, and by facilitating visits to view examples of good practice. To visit the website, go to [www.ukchemotherapypartnership.org.uk](http://www.ukchemotherapypartnership.org.uk)

The UK Chemotherapy Partnership encourages contributions from anyone involved in chemotherapy delivery. Examples include streamlining patient pathways, on-treatment reviews by non-medical staff, acute oncology provision and patient education initiatives, but any change of practice that contributes to patient safety or aims to improve service quality would be of interest.

UK Chemotherapy Partnership activity is directed by a committee representing nursing, pharmacy and medical roles within the chemotherapy service, and supported by an unrestricted medical education grant from Pierre Fabre Oncology. UKONS fully endorses this site as a repository for good innovation and practice.

## Research nursing in experimental cancer medicine centres

Ruth Boyd, Belfast ECMC, Karen Doyle, Birmingham ECMC,  
Abigail Evans, ECMC Secretariat, Linda Jones, Cambridge ECMC,  
Alison Pass, Sheffield ECMC

Clinical Research Nurses play a 'pivotal role in enabling safe, ethical and scientifically sound research to take place.<sup>1</sup> Caring for patients in early phase cancer trials allows clinical research nurses to play a fundamental role in bringing benefits to patients faster. The Experimental Cancer Medicine Centre (ECMC) Initiative, which funds 45 research nurses, was established in 2007 to drive the development of new therapies. The Initiative is jointly funded by Cancer Research UK and the four UK devolved Departments of Health to fund infrastructure support for early phase clinical trials and biomarker research at 19 virtual centres of excellence across the UK.

All potential new cancer therapies must undergo initial testing through early phase clinical trials. The testing will determine the safety, side effects and correct dose of the treatment as well as whether it has the expected biological effects in patients. The development of new therapies is dependent on scientists finding new potential treatments which are then assessed in cancer patients in the clinic through participation in early phase clinical trials.

Tissue samples donated by patients provide the link from the clinic back to the lab and studies on these samples are utilised in future research including the development of biomarkers. Biomarkers are measurable properties in the body (i.e. tests) and can be used to diagnose cancer, indicate the likelihood of getting cancer, measure progression of disease and response to treatment. These studies are another important part of the work carried out at ECMCs.

### Caring for patients in early phase cancer trials and translational research studies

The demands of caring for patients entering an early phase cancer trial and translational research are both challenging and rewarding. Nurses are required to balance the need to deliver the highest possible standard of nursing care with the delivery of excellence in clinical research. It is therefore vital to



merge their specialist skills in these two areas to provide the best supportive environment for patients.

Historically the patients participating in early phase cancer trials have exhausted all treatment options and will often be in the palliative stage of their disease. When caring for patients in this position it is important to manage their expectations of how their tumour may respond. The trial team each play a role in managing these expectations through a robust informed consent and ongoing communication process. Early phase and translational research nurses are not only faced with the practical and ethical challenge of fully informing patients and their carers, but also fully involving them in the research process. This partnership approach enables them to

offer the necessary support and care.

Advanced communication skills are central to caring for patients on early phase cancer trials and translational studies and this is often put to the test when describing 'uncertainty'. "Indeed the uncertainty implicit in clinical trials is made more explicit by the process of information disclosure.<sup>2</sup> The early phase research nurse is ideally positioned to help address this uncertainty and will often meet with patients prior to their consultation with the doctor, identify key questions and concerns and will remain with the patient through the consultation and clarify concerns afterwards. This specialist support throughout the informed consent process is highly valued by patients and their carers.



### **Alison Pass: My role as an early phase research nurse**

I am currently a Research Sister within the Cancer Research Centre at Weston Park Hospital where I have a responsibility for the execution of Phase 1 trials. I work within the Rare Tumour team, covering various disease sites but I have the ultimate responsibility for early phase (1 and 2) trials.

My role as a research sister is very diverse and my duties include:

- Leading phase 1 and 2 studies within the portfolio
- Assessment, screening and recruitment of patients
- Obtaining informed consent
- Administration of experimental treatments
- Key contact and advisor for patients
- Collection and processing of biological samples
- Coordination of patient care - from treatment to follow up, liaising with the MDT and sponsors

- Educator for patient groups and peers
- Counselling for patients/carers
- Data collection
- Resource management (finances, staff and equipment)
- Maintaining high standard of record keeping
- Supporting junior members of staff

The role therefore requires specialist knowledge in areas such as informed consent as well as research regulation and guidelines. In addition a good understanding of specific cancers and standard treatments is needed. To carry out this role it is necessary to have excellent communication skills, be well-organised and be able to manage the workload as well as use reflective practice. IT skills are important as is an ability to lead, teach and present.

I have been a qualified nurse for 23 years, mainly within the field of oncology. I am now working within a specialised role which is fascinating and rewarding as well as stimulating and each day presents new challenges. This makes my role exciting and enjoyable.



### **Linda Jones: My role as a translational research nurse**

I currently work as Senior Translational Research Sister at the University of Cambridge, based in Addenbrookes Hospital, Cambridge where I am solely funded by the ECMC Initiative. Having been an oncology nurse since the late 80's I moved into research in the mid 90's working at University College London and now here in Cambridge. My current role is within the field of breast oncology.

The number of nurses working within translational research has increased over the last few years. The role involves collecting blood, tissue and other specimens from patients with breast cancer and this includes women who are in the process of being diagnosed, those who have been diagnosed and those who go on to get metastatic disease. Samples may come from the operating theatre, wards, clinics, scanning departments or even by post. These samples may be individual or we ask patients to undergo serial biopsies or bloods so that we can look at the effect of treatments.

My role is very diverse and involves communicating and liaising with a vast array of other hospital and university staff

including surgeons, oncologists, ward staff, nurses, trials staff, laboratory personnel and families of patients. Duties include:

- Screening patients for suitability for studies
- Offering trials and studies to patients and their families
- Informed consenting of patients
- Counselling of patients
- Collection of bloods and tissues
- Preparation, storage and handling of bloods and tissues
- Teaching and educating nurses about translational research
- Assisting scientific personnel in the writing of studies (the nurses write all the patient information leaflets and do all the ethics applications)

One of my main roles is to act as a resource across the other ECMC centres (and other hospitals) to help obtain good quality and standardised samples which can be used to further research. Speaking at meetings, study days and conferences are a regular part of the role.

Each day brings a new challenge. I meet many people in the course of a day and especially enjoy the diversity of the role. Many of the patients I approach are very grateful to be asked to help with translational research; something which often will not affect their care, but the care of others in the future. I have found my role in nursing and wouldn't work anywhere else.

The safety of the patient entering an early phase cancer trial is fundamental to the trials team. The research nurse is central in their role for detecting, managing and recording expected or unexpected side effects. The unpredictable nature of this research reinforces the importance of the research nurse's assessment during the clinical trial phase. When caring for those participating, attention to detail is vital in

determining the safety, side effects and correct dose of treatments. The early phase cancer trials and translational nurses have these specialist skills and are able to assess and support the patient and their carers during these crucial study visits.

Early phase research nurses are also now caring for an increasing number of

patients entering translational studies. These patients may not be at the end stages of their disease, but equally require specialist nursing support as they consider participation in a translational study. Caring for those donating tissue requires the provision of support and advice on how these samples will be utilised in future research, helping them to understand the world of biomarker development and

tissue collection. Many of these samples will be collected and stored for such a time in the future when technological advances allow for more specialist tests to be performed. Therefore ECMC research nurses will be required to provide information and support to those entering such tissue collection studies, when they do not have a clear answer as to how the tissue will be used.

### Support for early phase and translational research nurses through the ECMC Nurse Network Group

ECMC nurses are supported through the ECMC Early Phase and Translational Research Nurse Network which focuses on providing training and support for what are often isolated nurses, who require unique skills within nursing. The group is led by an enthusiastic and forward thinking steering committee made up of nurses from within the ECMC community, and topics for training come from within the group as a whole. Often one training session will lead on to topics for further training.

Examples of study days include topics such as biomarkers, communication in early phase trials, ethics, consent, risk assessment and out-of-hours patient safety. Events are usually hosted and

run by nurses in ECMC centres which allows us to ensure lower costs but at the same time allowing us to use the wealth of expertise and knowledge that each individual ECMC specialises in.

The Nurse Network Group shares best practice through face to face meetings and discussion forums and has led to the sharing of SOP's, job descriptions and nursing roles as well as the development of guidance. As a result of a group workshop with other ECMC Network Groups to discuss issues around the handling of tissue samples, the Nurse Network led on the publication of the 'Sample Handling Guidance Document for Research Nurses and Junior Clinical Laboratory Staff'.

The Nurse Network is also keen to be part of and join in with other national and international groups. Recent examples of this include Network members joining in discussions with the UK Clinical Research Facility Network and the Wellcome Trust. Members attended the 'Think Tank' meeting in Manchester in June 2010, to represent Early Phase and Translational Research Nurses in discussions of general research nurse career pathways, role definition and educational needs and the differing role of our research nurses.

The group continues to go from strength to strength and hopes to continue to improve the profile and quality of Early Phase and Translational Research for the benefit of our patients.

More information about the ECMC Initiative can be found at <http://www.ecmcnetwork.org.uk/>

The sample handling guidance can be downloaded from the ECMC website at <http://www.ecmcnetwork.org.uk/news-events/news/ecmc-sample-management-guidance?view=rss>

To join the ECMC Early Phase and Translational Nurse Network Group please register at <https://www.ecmcnetwork.org.uk/utilities/register/>

### References

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2. Cox K. Informed consent and decision-making: patients' experiences of the process of recruitment to phases I and II anti-cancer drug trials. *Patient Education and Counselling* 2002. 46; 31-38.



*"The nation's cancer nurses"*

## What's in it for you?

- A prominent, collective voice for cancer nursing that is based on fully consultative and interactive membership
- Your views and expertise will be sought and shared with peers, cancer nurse leaders and national strategic policy makers in every country of the UK
- Your collective voice will influence the future of cancer nursing to ensure nursing practice is informed and developed by practising nurses
- Local and national study days, conferences and local fora to promote excellence in nursing and influence cancer policy
- Educational awards are available to members
- New interactive website, offering members only areas
- Associate membership available to AHPs (no voting rights)
- Associated member of European Oncology Nursing Society (EONS) which qualifies UKONS members for certain EONS membership benefits
- Payment can be made by direct debit

**Join or renew your membership ONLINE at [www.ukons.org/join](http://www.ukons.org/join)**

## Network round-up

### Northern Ireland

The Northern Ireland Assembly elections have resulted in Edwin Poots becoming the Minister for Health. His first major decision was to confirm that the proposed radiotherapy centre in the west of the province will go ahead, as will the purchase of another linear accelerator at the cancer centre in Belfast. Various healthcare issues have been raised with him, notably the shortfall in the cancer drugs budget in Northern Ireland compared with the rest of the UK, and the need for investment in acute oncology services. The latter has been brought to a head by the need to rationalise A&E services, and the likely closure of the A&E department at Belfast City Hospital, where the Regional Cancer Centre is located.

The review of the Northern Ireland Cancer Network (NICaN) has resulted in a radically altered network configuration, with some network groups being absorbed into areas of generic regional work, such as the regional review of urology services. This change has caused considerable concern among clinical staff and service providers alike, which have been raised with commissioning groups and the Chief Executive of the Health and Social Care Board.

On a positive note, all of Northern Ireland's cancer service providers will adopt the National Patient Safety Agency (NPSA)-UKONS telephone triage tool this autumn in an integrated and coordinated project with help from UKONS' Philippa Jones.

### Scotland

Before the Scottish National Party (SNP) secured an overall majority in the Scottish government it pledged it would launch a 'Detect Cancer Early' initiative, aiming for a 25% increase in the amount of cancers detected at the first stage. The SNP states that the aim will be achieved by raising cancer awareness and increasing diagnostic capacity in the NHS in Scotland. To further improve the health of the people of Scotland, the SNP has also pledged

to make progress with the introduction of a 'Minimum Pricing Bill'. In November 2011, the Scottish government voted against the SNP proposal to introduce minimum alcohol pricing, despite support from many healthcare professionals in Scotland.

Other initiatives to encourage healthy lifestyle choices and tackle health inequalities include plans for a new tobacco control policy, and a strategy for tackling obesity in Scotland. Cancer remains a significant challenge for the people of Scotland and for the new Scottish government. Nurses in all care settings across Scotland will continue to play a vital role in all healthcare settings in the prevention and earlier detection of cancer.

### England

Autumn has seen announcements of awareness campaigns on sigmoidoscopy (screening programme), the Cancer Drugs Fund and expanded radiotherapy capacity, and the refreshed Cancer Reform Strategy will continue to shape cancer services up to 2015.

The Spending Review outcome for NHS was announced. Though there is no cut in its budget, the NHS is still expected to contribute to meeting the deficit, and organisations are making efficiency savings. In tandem, the British Association of Day Surgery has endorsed the 23-hour breast model, and the enhanced recovery programme is gaining momentum. To support organisations preserving the cancer nurse specialist (CNS) role, Excellence in Cancer Care: the Role of the CNS has been published.

The Peer Review programme report has been issued, and clinicians are being sought for the next round.

Other activities include:

- Consultation on the 'information revolution'
- £50m fund for stratified medicines innovation
- Launch of GP practice profiles
- Publication of six National Cancer

Intelligence Network data briefings

- Publication of the Cervical Screening and Cancer e-Atlas, with new statistics on cancer registrations and cervical screening
- Forthcoming conferences
  - National Cancer Research Institute, Liverpool, 7–10 November 2011
  - Survivorship, Winchester, 2 December 2011

### Wales

The new Welsh government has tasked The Cancer Services Co-ordinating Group to produce National Standards for Teenagers and Young Adults (aged 16–24 years). These draft national standards have been released for a 3-month period of consultation ending 27 September 2011.

Cancer patients with depression will receive more support and treatment, thanks to new measures being introduced by the Velindre Cancer Centre in Cardiff as part of the Welsh government's 1000 Lives Plus initiative. When undergoing routine clinical assessment, patients will be asked two key questions to ascertain whether they have been feeling down, depressed or helpless during the past month, or if they have little pleasure or interest in doing things. If a patient answers 'yes' to either question, they will be asked to participate in further assessment to determine what treatment or support mechanisms are needed.

The Welsh Cancer Intelligence and Surveillance Unit (WCISU) discussed plans for a new cancer registry for Sierra Leone when Dr Simeon Owizz Koroma, Head of the Sierra Leone Cancer Registry and Consultant Pathologist, visited Cardiff on 28 June. The registry will provide data and give much needed help in the planning of services for prevention, diagnosis, cure and care of cancer. More information on cancer registries and surveillance is available from the WCISU website. <http://www.wales.nhs.uk>. More information on the Wales for Africa programme is available at <http://walesforafrica.org>

# DON'T FORGET TO REGISTER

## UKONS Annual Conference

The Scottish Exhibition and Conference Centre, Glasgow  
13–14 October 2011



# UKONS

ANNUAL CONFERENCE  
GLASGOW 2011

For more information and to register, please visit:

[www.ukons.org](http://www.ukons.org)

**Key topics include:**

- Key note speaker: Ros Moore, Chief Nursing Officer, Scottish Government
- Models of care in Acute Oncology Services
- Regulation, public protection and leadership in cancer nursing
- Improving cancer outcomes - A perspective from the Cancer Action Team
- Impact of the NHS reforms on the care of patients with cancer



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