

# NISCHR



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## CANSER | CANCER

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### CANCER RRG NEWSLETTER

#### Dear Colleagues

As lead for the NISCHR Cancer Registered Research Group it is my pleasure to be sending you the inaugural newsletter from the group. I thought I would start by giving a summary of the development of the new Cancer RRG and clarifying what was funded by NISCHR. Later on in the newsletter we will highlight some of our first steps in the development of the RRG and how it could help you develop research in Wales.

In July 2009 a bid was submitted to NISCHR to create a Cancer Registered Research Group (RRG) to increase the health research portfolio and



encourage development of cancer studies in Wales. The bid, led by myself, was developed by a group of individuals from the Wales Cancer Trials Unit (WCTU), Wales Cancer Research Network (WCRN), Wales Cancer Bank (WCB), Cardiff University, Swansea University, Bangor University, Velindre NHS Trust, Cardiff & Vale Local Health Board and the North Wales Cancer Centre. NISCHR awarded the status of Cancer RRG, to be hosted at WCTU, but only awarded

funding for a Palliative Care Research Development Group. The initially supported themes for development within the Palliative Care Research Development Group include:

- i) end of life methodologies
- ii) rehabilitation/cachexia
- iii) patient experience and
- iv) thrombosis

The funding for a two day a week palliative care portfolio developer was released earlier this year and I am very pleased to announce the appointment of Amanda Woodward into this post in September 2010. Amanda is located within the WCTU offices and will act as the main point of contact to the research community and her roles will be covered a little later in this newsletter.

The Cancer RRG was not awarded

any of the requested methodology posts. However there are research organisations based in Wales, such as the Cancer Research UK WCTU which works in developing studies in any cancer area and the newly formed Marie Curie Palliative Care Research Centre, who have methodological and other expertise and are interested in developing new study ideas with Welsh researchers. The NISCHR Cancer RRG has formed strong links with these two groups and so can signpost researchers on where help may be located. Further details on these two groups will appear later in this newsletter.

As a new RRG we are currently developing systems and processes, forming collaborations and developing a website so we can run efficiently and expand the palliative care study portfolio in Wales. Details of these will be given in future newsletters.

We look forward to working with you in the future.

Yours faithfully

**Gareth Griffiths**

Lead of the NISCHR Cancer RRG

## NISCHR CANCER RRG Palliative Care Portfolio Developer

Amanda Woodward was appointed as the Cancer RRG Palliative Care Portfolio Developer in September 2010.

Amanda has fifteen years broad experience in industry sponsored clinical



trials, ranging from management of Phase I Clinical Pharmacology Units through to management of large Phase III multi-national trials in a range of therapeutic areas.

The aim of this role is to act as a central point of contact to the Welsh palliative care community to facilitate high quality research activity in palliative care across Wales. We aim to:

- ◆ Build good communication links with existing and new Welsh palliative research groups and the NISCHR regional networks of research staff.
- ◆ Develop a database of palliative care research practitioners to facilitate a coordinated, collaborative approach to research across Wales.
- ◆ Direct Welsh palliative care researchers to the appropriate experts who can support the development of their research.
- ◆ Co-ordinate palliative care research development meetings to generate, discuss and review ideas for studies.
- ◆ Act as a central point of contact for non-Welsh

researchers looking to collaborate with Welsh centres.

- ◆ Register qualifying research projects within the NISCHR portfolio.

## Palliative Care Research Roadshow

A pilot roadshow was launched at the All Wales Palliative Care Conference at Gregynog, in October 2010. The aim of the roadshow is to ensure that all specialist palliative care teams around Wales are aware of research development and research recruitment opportunities. The roadshow promotes the NISCHR Cancer RRG and collaborations with the WCTU, the Marie Curie Palliative Care Research Centre, NISCHR CRC and WCRN.



The pilot roadshow was well received and produced some constructive feedback regarding format and content. A series of five or six roadshows around Wales are planned for early 2011.

## Networking

The NISCHR Cancer RRG Portfolio Developer attended a meeting of RRG Network Co-ordinators, Portfolio Developers and Research Fellows in November to begin the process of developing good communication links. Further contact has since been made with the Research Portfolio Development Fellow and Network Coordinator for

the Old People and Ageing Network (OPAN) to explore possibilities for collaboration.

Promotional material has been produced to highlight the role of the NISCHR Cancer RRG Portfolio Developer, this has been made available at several conferences held recently by the NCRI, NISCHR CRC and Velindre R&D. This is available on request.

## Key Roles & Core Skills Consensus Development

In 2009 an NIHR Palliative Care Research Activity Survey of UK Research Networks was conducted. One of the key findings was that research networks required assistance in creating palliative care specific research roles for staff and understanding the training needs of research nurses in this area.

In September 2010 NISCHR CRC organised a Palliative Care Research meeting in Cardiff to define key areas for consensus development, focusing specifically on key roles and core palliative care research skills. Palliative care research study scenarios were assessed in terms of the function of the research practitioner, the challenges they would face, and the competencies that are core to their role.

Workshop participants included representatives from NCRN, CRUK, Wales Cancer Research Network, WCTU, Marie Curie Cancer Care and Marie Curie Palliative Care Research Centre Cardiff, together with other research nurses and palliative care consultants.

Several key themes emerged regarding the role of the palliative care research practitioner and a summary report is currently being generated.

## NISCHR Palliative Care Portfolio Studies

The studies listed below have met the NISCHR portfolio eligibility criteria. These studies are currently being carried out at Velindre Cancer Centre where a dedicated Palliative Care Research Nurse is in post.

Chief Investigator	Title
Prof Marie Fallon	Does the institutionalisation of pain assessment using the EPAT package reduce pain in cancer unit patients more than usual care: A cluster randomised trial.
Prof Marie Fallon	Double blind randomised control trial of pregabalin versus placebo in conjunction with palliative radiotherapy for malignant bone pain.
Prof Peter Hoskin	A randomised feasibility study of single fraction radiotherapy compared to multi-fraction radiotherapy in patients with metastatic spinal cord compression.

## Funding Applications

Tenovus have approved a recent application made by the WCTU and awarded funding to the following study:

Dr Anthony Byrne	The role of exercise in patients with cachexia: a study of preferences, motivation and outcomes of importance in patients with advanced cancer
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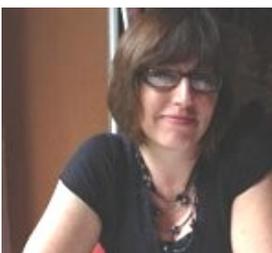
## Marie Curie Palliative Care Research Centre

The Marie Curie Palliative Care Research Centre is based at the Wales Cancer Trials Unit, Cardiff University. The aim of the Centre is to develop and support well designed research in palliative care, with the focus on design and conduct of pragmatic studies which will translate into better patient care.



Headed by Dr Anthony Byrne, Director, and Dr Annmarie Nelson, Deputy Director, the Centre is able to provide:

- ◆ Advice on how to develop a research idea
- ◆ Expert methodological advice
- ◆ Identification of funding routes and help with applications
- ◆ Direction on the right options for completing studies
- ◆ A vital trials unit function for study conduct



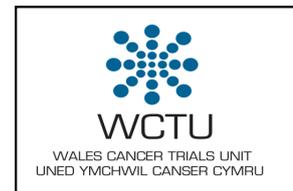
NISCHR Cancer RRG is part of the research infrastructure for Wales funded by NISCHR, Welsh Assembly government [www.wales.gov.uk/nischr](http://www.wales.gov.uk/nischr)

## Wales Cancer Trials Unit

Headed by Gareth Griffiths (Scientific Director) and Prof. Tim Maughan (Clinical Director) the WCTU is a one stop shop for a clinical trial, from the basic idea, to producing reliable evidence to change practice. The WCTU is an NCRI accredited and UKCRC registered Clinical Trials Unit and receives core funding from Cancer Research UK and Marie Curie Cancer Care.

The current WCTU portfolio of trials includes lung, bladder, breast, haematology, oesophageal, gynaecological, palliative care, primary cancer trials and other well designed studies.

The WCTU is staffed by a range of experts including Statisticians, Clinicians, Qualitative Researchers, Trial Managers, Data Managers, IT / Programmers, Safety Officers and Quality Assurance. These staff work with Oncologists, Clinicians, Scientists and research groups wishing to develop clinical trials.



[www.wctu.org.uk](http://www.wctu.org.uk)

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