

# NISCHR

## CANSER | CANCER



Ariennir gan  
Lywodraeth  
Cynulliad Cymru  
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## CANCER RRG NEWSLETTER

### Raising Awareness - The Roadshow!

The Cancer RRG have collaborated with WCRN and NISCHR CRC staff and Consumer Representatives to plan a series of roadshows with clinical teams around Wales. The aim was to provide a coordinated approach to ensure all specialist palliative care teams are aware of research development and research recruitment opportunities and thus maximise access to palliative care research for all patients in Wales.

The roadshows have taken place at locations selected by the local Clinical Lead, at lunchtimes, and have been 1-2 hours in duration. The panel of speakers take the audience through a research project from idea to completion, using a real life example.

Feedback from the audience, has been overwhelmingly positive so far. Several clinicians have contacted the RRG as a result of the roadshows with their research ideas and all clinical staff have been introduced to their NISCHR Regional Network Manager.

The roadshow promotes the NISCHR Cancer RRG and collaborations with the Wales Cancer Trials Unit, the Marie Curie Palliative Care Research Centre (MPCRC), NISCHR CRC and WCRN.

The Roadshow was piloted at the All Wales Palliative Care Conference at Gregynog in October last year and during Spring/Summer of 2011 the roadshow has been taken to all Local health Boards in Wales excepting Hywel Dda and Cardiff and Vale for which dates are currently being arranged.

### Focus Groups: Carer Support

Marie Curie  
Palliative Care Research Centre

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The physical care needs of patients approaching the end of life are considerable and require specialist knowledge and skills amongst those who care for them. However, when hospice patients are discharged back home families often express concern as they themselves receive no formal training or guidance on the practicalities of physical care. The MPCRC are currently organising a focus group study which aims to explore the views and experiences of:

- Hospice-based nurses on care provided to patients by friends/relatives at home.
- Carers on caring for relatives/ friends in the home setting at the end of life.
- Nurses and carers on the training needs of carers and how these might feasibly be addressed via interventions.

This information will be used to inform a submission to the Dimpleby Cancer Care research project call this coming Autumn. 1



Left to right: Emily Harrop, Research Associate MPCRC; Stephanie Sivell, Research Associate MPCRC; Annmarie Nelson, Deputy Director MPCRC; Anthony Byrne, Director MPCRC & Scientific Lead at WCTU; Kristen Thomas, Research Administrator MPCRC; Amanda Woodward, NISCHR Cancer RRG Palliative Care Portfolio Developer. Barbara Moore, NISCHR CRC (not pictured) was also present.

### 2 New Studies being led by members of the Palliative Care Research Development Group of the Cancer RRG

**QUALFRAG: A qualitative study exploring patients' experience on the FRAGMATIC lung cancer trial**

QUALFRAG is a qualitative sub-study of the largest lung cancer trial in the UK (WCTU's FRAGMATIC), which is investigating the effects of Fragmin (a self-injected anticoagulant, or 'bloodthinner') in patients with lung cancer. Few palliative lung cancer patients are recruited to clinical trials due to poor prognosis and symptom burden. As a result, their experiences of participating in these studies have not been studied. QUALFRAG will explore the experiences of up to 20 patients participating in the FRAGMATIC trial, its impact on their quality of life and how their symptom burden is managed over time. The results from QUALFRAG will help future studies target appropriate symptom control issues. QUALFRAG is funded by Stepping Stones via Velindre Charitable Funds and will fund a full time researcher and a full time research secretary. The study is led by Dr Simon Noble (sponsored by Velindre NHS and run out of MCPCRC / WCTU) at Velindre, Llandough and the Royal Gwent Hospitals.

For further information please contact Stephanie Sivell, Marie Curie Research Associate, Cardiff at [sivells2@cf.ac.uk](mailto:sivells2@cf.ac.uk).

**The role of exercise in patients with cancer cachexia: a study of preferences, motivation and outcomes of importance in patients with cancer.**

Studies of sufficient size and methodological quality are required to formally evaluate the role of exercise in sustaining daily activities in patients with cancer associated cachexia, a syndrome that has a profound effect on quality of life for both patients and carers. However, successful completion of an exercise study will depend on how acceptable and practical it is. Greater understanding is required of patients' life experiences of exercise as well as their current attitudes and preferences surrounding exercise types, preferred place of exercise and perceived benefits. The primary aim of this study is to determine the size and rate of decline of muscle strength and balance in a patient population with established cancer cachexia. The study will also examine preferences for, and motivation to, exercise in patients with established cancer cachexia and will look at the effect of perceived control, adjustment to illness and exercise history on potential barriers to exercise.

The study is led by Dr Anthony Byrne (and sponsored by Velindre NHS Trust) at Llandough and Velindre NHS Trust. For further information please contact Nichola Gale, at [GaleNS@cf.ac.uk](mailto:GaleNS@cf.ac.uk).

### Introducing ...



#### Stanley Dylan Griffiths

Congratulations to Gareth Griffiths and his wife Jacqui who are the proud parents of baby Stanley who arrived on 1st August weighing 8lb 4oz. We wish them all the best!

### Palliative care research to be showcased in Japan

Research from the Marie Curie Palliative Care Research Centre, Cardiff, led by thematic leads, Simon Noble (Thrombosis) and Annmarie Nelson (Patient Experience) was presented at the International Society of Thrombosis and Haemostasis Annual Conference in Kyoto. Their qualitative research on thrombosis will signpost the future research agenda in the management of blood clots in hospice patients.

### 11th Annual All Wales Palliative Care Conference, Gregynog, November 2011

This year's conference will take place on 3-4 November at Gregynog Mansion House Conference Centre. Abstracts include a summary of the palliative care infrastructure and processes that have been put in place by Dr Anthony Byrne and the Wales Cancer Research Network to enable patients in SE Wales to have the opportunity to be involved in high standard UK wide palliative care research studies. In 2009 four patients had been recruited to palliative care studies from across Wales. Since the initiative in SE Wales 120 patients have been recruited to five studies.

## Other Developments:

- ◆ In 2010 the NISCHR Cancer RRG was only awarded funding to develop palliative care. A request for uplift has been submitted to NISCHR to enable resources to be available to develop solid tumours.
- ◆ The NISCHR Cancer RRG was approached and supported a number of AHSC applications.
- ◆ The NISCHR Cancer RRG reviewed and supported a NISCHR fellowship application by Jo Zabkiewicz in Haematology, Cardiff University.
- ◆ The Palliative Care Research Development Group of the NISCHR Cancer RRG has formed more formal links with the NCRI Palliative Care Clinical Studies Group so the Cancer RRG acts as the point of contact for palliative care researchers from the rest of the UK who are interested in undertaking studies in Wales.

Marie Curie  
Palliative Care Research Centre

CARDIFF

Dr Annmarie Nelson, Deputy Director, Marie Curie Palliative Care Research Centre Cardiff, will be holding monthly Research Clinics as a forum to discuss research ideas and potential studies.

Currently the clinics will be held monthly at the Marie Curie Hospice in Penarth and bimonthly at Y Bwthyn Newydd Palliative Care Unit, Bridgend.

## NISCHR Palliative Care Portfolio - Summary of Study Status:

Study	Opened	Due to Close	Recruitment target	Recruitment to date	PI & Site
MODAFINIL Modafinil for the treatment of fatigue in lung cancer: a multi-centre randomised, double-blinded, placebo controlled trial	Oct 2010	Dec 2011	5-20	3	Anthony Byrne Llandough
	Jul 2011		8	1	Dr Haq Withybush
PREGABALIN Double-blind randomised controlled trial of pregabalin versus placebo in conjunction with palliative radiotherapy for malignant bone pain	Oct 2010	Dec 2011	10	6	Anthony Byrne Llandough
SCORAD III A randomised phase III trial of single fraction radiotherapy compared to multifraction radiotherapy in patients with metastatic spinal cord compression	Aug 2010	May 2015	4-5 yr	1	Jason Lester Velindre
EPAT Edinburgh Pain Assessment Tool - Does the institutionalisation of pain assessment using the EPAT® package reduce pain in cancer unit inpatients more than usual care: A cluster randomised trial.	Jul 2009	Mar 2011 (closed)	100	100	Nikki Pease Velindre
The role of exercise in patients with cancer cachexia: a study of preferences, motivation and outcomes of importance in patients with advanced cancer.	Due Sep 2011	Sep 2012	50	Due to open Sep 2011	Anthony Byrne Velindre Llandough



For further information regarding palliative care research, contact:

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