



### CANCER RRG NEWSLETTER

#### Roadshow Success

The series of Palliative Care Research Roadshows highlighted in the last newsletter have now been completed. The roadshow team from the Cancer RRG, NISCHR CRC, the Marie Curie Palliative Care Research Centre (MPCRC), Wales Cancer Research Network (WCRN) and Wales Cancer Trials Unit (WCTU) met with clinical palliative care teams across every health board in Wales to raise awareness of research development and research recruitment opportunities.

#### Roadshow Tour Dates

14 Oct 2010	Powys HB
06 May 2011	Cwm Taf HB
09 May 2011	Betsi Cadwaladr UHB
13 Jul 2011	Abertawe Bro Morgannwg
15 Jul 2011	Aneurin Bevan HB
12 Oct 2011	Hywel Dda HB
09 Dec 2011	Cardiff & Vale UHB



The contact details collected from those who attended the roadshows has helped to establish a palliative care database to keep the community up to date with research opportunities and identify clinical champions.

The roadshow initiative represents a unique approach in the UK to raising research awareness amongst clinical palliative care teams. It has introduced multidisciplinary clinicians to local research teams who can provide advice and support. The roadshows have been the first step in developing good communication links, and facilitating a coordinated approach to research governance and patient access across Wales.

#### NEW WEBSITE

For further information on the work of the Cancer RRG visit our new website at:  
[cancerrrg-palliativecare.org](http://cancerrrg-palliativecare.org)

#### Over £2.5 million funding approved for 2 new studies

A large and complex grant proposal for over £2million has been awarded to members of the Cancer RRG based at the WCTU/ MPCRC and is sponsored by Velindre NHS Trust. The CancerRRG collaborated with colleagues in Scotland and England, with specific methodological support from the CONDuCT MRC Methodology Hub in Bristol and logistical advice from NCRN and WCRN. The study will investigate the effectiveness of giving palliative radiotherapy with stent in patients with oesophageal cancer.

A grant of £611k has been awarded to fund a feasibility study to inform the design of a randomised controlled trial to identify the most clinically and cost effective length of anticoagulation with low molecular weight heparin in the treatment of cancer associated thrombosis.

Details of both studies will be announced in full at a later date.

## Studies being led by members of the Cancer RRG



### **CaNoPy: A study of the Care Needs of Idiopathic Pulmonary Fibrosis (IPF) patients and their carers.**

Marie Curie Cancer Care are funding this new study led by Dr Anthony Byrne which will address uncertainties in relation to the palliative care needs of patients with idiopathic pulmonary fibrosis (IPF), and their carers. Capturing patient and carer experience across the disease trajectory will provide key information for the development and evaluation of future service models. In particular, it will inform the definition of interventions and of meaningful outcomes. Specific aims are to:

1. Identify changes in patients' and carers' perceived palliative care needs over the progression of the disease in order to improve future service interventions.
2. Identify time-points or triggers at which palliative care services might effectively be introduced.
3. Define the specific information needs of patients and carers.
4. Evaluate specifically the experiences and roles of the carer.

Interviews will be held with 24-40 patients with IPF and their carers. Participants will be recruited from centres within Cardiff and Vale University Health Board, Abertawe Bro Morgannwg University Health Board and Nottingham University NHS Trust. The study is currently being set up, for further information contact Stephanie Sivell at [sivells2@cf.ac.uk](mailto:sivells2@cf.ac.uk).

## Conferences

Members of the Palliative Care RRG have attended several conferences in recent months and have given presentations about some of the work being carried out by the Cancer RRG.

At the Marie Curie Annual Palliative Care Research Conference in London in March Dr Michelle Edwards presented on patients' experiences and understandings of taking part in clinical trials for advanced cancer. This was based on a metasynthesis of findings from 3 qualitative studies linked to clinical trials exploring patients' motivations and understandings of the trials.

Dr Annmarie Nelson was an invited speaker at the 2012 British Psycho Oncology Society Annual Conference on Cancer Survivorship and Rehabilitation in Leeds. She delivered a presentation highlighting the qualitative work undertaken at the WCTU in the context of clinical trials, sharing a session with Professor Julia Brown.

A total of 15 abstracts from the Cancer RRG have also been accepted for poster presentation at the following conferences:

- 10th Annual British Thoracic Oncology Group Conference. 26-27th January 2012. Dublin.
- 9th Palliative Care Congress. 14th-16th March. Gateshead.
- Marie Curie Annual Palliative Care Research Conference. 23rd March 2012. London.
- 7th World Research Congress European Association for Palliative Care. 7-9th June 2012. Trondheim, Norway.



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

This study, funded by Tenovus and led by Dr Anthony Byrne, opened to recruitment in September 2011 and has so far recruited 22 patients from Velindre and Landough Hospital. 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 also examines 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. For further information please contact Nichola Gale, at [GaleNS@cf.ac.uk](mailto:GaleNS@cf.ac.uk).



### **QualFRAG: A qualitative study exploring patients experience on the FRAGMATIC lung cancer trial.**

Ten patients were recruited to QualFRAG before recruitment closed to the main FRAGMATIC study in December 2011 investigating the efficacy of low molecular weight heparin in lung cancer patients. Patients were interviewed to explore their experience of participating in the FRAGMATIC study, its impact on their quality of life and how their symptom burden is managed over time. The final round of interviews have now been completed, the results will help future studies target appropriate symptom control issues. QualFRAG is funded by Stepping Stones via Velindre Charitable Funds and is led by Dr Simon Noble. For further information contact [sivells2@cf.ac.uk](mailto:sivells2@cf.ac.uk).

## Other Developments:

1. The MCPCRC are coordinating a Delphi process to assess the training needs of adult hospice staff working with young people transitioning from paediatric care. This will be followed up with focus groups with young people, their parents and staff.

2. The Cancer RRG co-hosted two meetings on the future direction of upper GI cancer radiotherapy in the UK, held in Bristol in October and Cardiff in March. The meetings were hosted in collaboration with the WCTU and NISCHR AHSC. Discussion points arising from the meeting will be used to inform the trial design of future NCRI oesophageal cancer studies in addition to working towards a consensus paper on chemoradiation in oesophageal cancer.

3. The UK wide NCRI Palliative Care Clinical Studies Group has been reformed into the NCRI Palliative Care and Supportive Care Clinical Studies Group and will have sub-groups in the area of Palliative Care, Supportive Care and Complementary Therapies. Members of the previous NCRI CSG included NISCHR Cancer RRG representation and we are currently applying to be members of this new NCRI CSG.

## I Want Great Care

The iWGC questionnaire survey was commissioned by the Wales Palliative Care Implementation Board to measure satisfaction with palliative care received in Wales from 2009 onwards. It was implemented in response to awareness of unmeasured variation in quality of care, the challenge of defining and measuring palliative care, the economic context of service delivery, and the need to ascertain the patient and family perspective on what constitutes good palliative care service. When patients or carers were given the opportunity to comment on any aspect of palliative care experience as part of the iWGC questionnaire, they used the free text response box extensively. Analysis of this data forms the basis of four papers currently in preparation examining:

- The skill sets associated with palliative care.
- The emotional experience of palliative care patients.
- Questionnaire methodology.
- Language: Use of metaphor, how patients use narrative.

## 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	May 2012	5-20	4	Anthony Byrne Llandough
	Jul 2011		8	3	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 2012	10	7	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	4	Jason Lester Velindre
	Aug 2011		4-5 yr	1	Kate Parker Singleton
SOB-LC II A randomised trial of high versus low intensity training in breathing techniques for breathlessness in patients with malignant lung disease: early intervention	Jul 2011	Dec 2012	30	11	Anthony Byrne Velindre Llandough
RECC The role of exercise in patients with cancer cachexia: a study of preferences, motivation and outcomes of importance in patients with advanced cancer.	Sep 2011	Apr 2013	50	22	Anthony Byrne Velindre Llandough
NCRN177-ACE At Home Evaluation of Two Pneumatic Compression Devices in the Treatment of Lower Extremity Lymphoedema (ACE: At home Compression Evaluation)	Dec 2010	Dec 2012	20	18	Melanie Lewis Singleton

For further information contact: **Dr Amanda Woodward** Palliative Care Portfolio Developer

Tel: 029 2068 7268 / Fax: 029 2068 7501 email: [woodwardaj@cardiff.ac.uk](mailto:woodwardaj@cardiff.ac.uk)