



International Palliative Care Family-carer Research Collaboration

# Newsletter

April 2014

## Pre-conference workshop on family carers @ 8th World Research Congress of the European Association for Palliative Care

On 4th June 2014 from 1:30 – 4:30 pm, at La Llotja Congress Center (Meeting Room 1), Lleida, Spain, the IPCFRC is hosting a pre-conference workshop on methodological challenges associated with family caregiver research.

Professor Peter Hudson, Director, Centre for Palliative Care (St Vincent's Hospital Melbourne and a collaborative Centre of the University of Melbourne, Australia) and IPCFRC Executive Committee Chair provides an overview of this event:

### What can attendees expect from the Family Carer workshop at EAPC?

The purpose of this workshop is to discuss some of the methodological issues that arise when conducting research involving family carers of palliative care patients. Improving the evidence to underpin the support for family carers is a priority however research involving this population can be difficult.

This workshop will feature presentations from experienced researchers including Kevin Brazil (Professor of Palliative Care, School of Nursing and Midwifery, Queen's University Belfast, UK), Jean Kutner (Professor of Medicine in the Division of General Internal Medicine, Department of Medicine, University of Colorado School of Medicine, USA), Gunn Grande (Professor of Palliative Care, The School of Nursing, Midwifery and Social Work, The University of Manchester, UK) and Gail Ewing (Senior Research Associate, Centre for Family Research, Cambridge University, UK).

These internationally renowned speakers will provide candid accounts of some of the challenges they've experienced and what can be done to overcome them. The following topics will be discussed:

- Methodological challenges and strategies associated with rural family carer research.
- Enhancing capacity for rigorous family caregiver research: Development of the US Palliative Care Research Cooperative Group Caregiver Research One.
- Evaluating a Carer Support Needs Assessment Tool: trail design and challenges.

There will be ample opportunities to ask questions and make comments. We anticipate that attendees will leave this workshop with strategies to overcome methodological issues and hopefully feel inspired to commence or build on family carer research. It will also be a fantastic opportunity to establish networks and partnerships.

### Who is welcome to attend?

This workshop is open to everyone, not just IPCFRC members; however you do need to also be registered to attend the EAPC conference. Like our IPCFRC membership base, we expect a broad range of academics, medical specialists, nurses, allied health clinicians and students. We usually get experienced researchers and also people who are very new to family carer research to these types of workshops.

**To register for this free workshop and for further details, please copy and paste this link into your browser: [www.trybooking.com/EAAK](http://www.trybooking.com/EAAK) by 23 May 2014. Numbers are limited so early registration is recommended.**

## Want to know more about the IPCFRC?

If you are attending EAPC in Lleida in June, don't miss our open meeting to current and prospective IPCFRC members.

It's a great way to hear about what's happening in the IPCFRC community, meet the IPCFRC Executive Committee and your fellow IPCFRC members.

If you're not a member, you are welcome to come along and hear about what IPCFRC has to offer.

The open meeting will be held on:

**Date:** Thursday, 5<sup>th</sup> June 2014

**Time:** 13:30 pm - 2:00 pm

**Venue:** La Llotja Congress Center (Meeting Room 1-3), Lleida, Spain

**RSVP:** You are not required to register to attend the meeting

To become a member, please paste the following link into your browser: [www.centreforallcare.org/cpc\\_signup/](http://www.centreforallcare.org/cpc_signup/)

## Membership

The IPCFRC now has 132 registered members from many countries of the world, including; Australia, Bulgaria, Cameroon, Canada, Denmark, France, Germany, Ireland, Japan, New Zealand, Nigeria, Norway, Spain, Sweden, Thailand, UK & USA.

### Update your details!

We are now collecting information on members research interests and expertise.

Update your information: [www.centreforallcare.org/cpc\\_signup/](http://www.centreforallcare.org/cpc_signup/)

## Introducing IPCFRC Advocates

As part of the IPCFRC Strategic plan, advocates have been identified to promote IPCFRC and its mission within their region.

The advocates are a diverse group with established links to their respective fields and a strong interest and experience in family carer research. They will also make recommendations to the executive committee about the progression of the IPCFRC.

Please join us in congratulating and welcoming the advocates.

The newly appointed IPCFRC advocates include:

- A/Prof Deborah Parker, The University of Queensland/Blue Care, Australia ([deborah.parker@uq.edu.au](mailto:deborah.parker@uq.edu.au))
- Dr Richard Harding, Cicely Saunders Institute, UK ([richard.harding@kcl.ac.uk](mailto:richard.harding@kcl.ac.uk))
- Prof Elizabeth Hanson, Linnaeus University, Sweden ([elizabeth.hanson@lnu.se](mailto:elizabeth.hanson@lnu.se))
- Dr Betty Ferrell, City of Hope, USA ([bferrell@coh.org](mailto:bferrell@coh.org))
- Dr Robin Cohen, McGill University, Canada ([robin.cohen@mcgill.ca](mailto:robin.cohen@mcgill.ca))

## Articles relevant to IPCFRC members

Each edition we will feature some articles relevant to IPCFRC members and by IPCFRC members.

If your work is relevant to the IPCFRC community, please email [centreforallcare@svhm.org.au](mailto:centreforallcare@svhm.org.au) with the subject 'IPCFRC Newsletter' and we will feature your publication in an upcoming edition.

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Mc Veigh C, Reid J, Hudson P, Larkin P, Porter S, Marley AM. The experiences of palliative care health service provision for people with non-malignant respiratory disease and their caregivers: an all-Ireland study. *J Adv Nurs*. 2014 Mar;70(3):687-97.

Gadoud A, Macleod U, Kane E, Ansell P, Johnson M. A palliative care approach for people with advanced heart failure: recognition of need, transitions in care, and effect on patients, family carers, and clinicians. *The Lancet*. 2014 Feb;383:S50.

Bentley B, O'Connor M, Breen LJ, Kane R. Feasibility, acceptability and potential effectiveness of dignity therapy for family carers of people with motor neuron disease. *BMC Palliative Care*. 2014;13(12).

Giesbrecht M, Wolse F, Crooks VA, Stajduhar K. Identifying socio-environmental factors that facilitate resilience among Canadian palliative family caregivers: A qualitative case study. *Palliat Support Care*. 2013 Nov 11:1-11,

O'Brien MR, Preston H. Family carer perspectives of acute hospital care following a diagnosis of motor neuron disease: a qualitative secondary analysis. *BMJ Support Palliat Care*. 2014. Online first.

Funk LM, Stajduhar KI, Outcalt L. What family caregivers learn when providing care at the end of life: A qualitative secondary analysis of multiple datasets. *Palliat Support Care*. 2014 Feb 13:1-9.

Sampson C, Finlay I, Byrne A, Snow V, Nelson A. The practice of palliative care from the perspective of patients and carers. *BMJ Support Palliat Care*. 2014. Online first.

## Conferences relevant to IPCFRC members

### World Research Congress of the European Association for Palliative Care (EAPC) - 8th Congress

Dates: 5-7 June 2014

Location: Lleida, Spain

Website: [www.eapcnet.eu/research2014/](http://www.eapcnet.eu/research2014/)

Featuring a IPCFRC workshop and meetings. Visit [www.centreforallcare.org/index.php/research/ipcfrc/events/](http://www.centreforallcare.org/index.php/research/ipcfrc/events/)

### 20th International Congress on Palliative Care (Montreal Conference)

Dates: 9-12 September 2014

Location: Montreal, Canada

Website: [www.palliativecare.ca/en/](http://www.palliativecare.ca/en/)

### 16th World Congress of Psycho-Oncology and Psychosocial Academy (IPOS 2014)

Dates: 20-24 October 2014

Location: Lisbon, Portugal

Website: [www.ipos2014.com](http://www.ipos2014.com)

### 2014 World Cancer Congress

Dates: 3-6 December 2014

Location: Melbourne, Australia

Website: [www.worldcancercongress.org](http://www.worldcancercongress.org)

## Forward e-news to a friend!

Please forward this newsletter to friends or colleagues interested in family carer research. They can also sign up for free membership at: [www.centreforallcare.org/cpc\\_signup/](http://www.centreforallcare.org/cpc_signup/)

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