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International Palliative Care  
Family Carer Research Collaboration

## **International Palliative Care Family Carer Research Collaboration**

**Newsletter - Issue 11 - September, 2013**

***Welcome to the latest edition of the International Palliative Care Family Carer Research Collaboration (IPCFRC) newsletter.***

The IPCFRC vision is to improve evidence based support provided to family carers of palliative care patients via interdisciplinary and international research initiatives. The IPCFRC operates under the auspices of the European Association for Palliative Care (EAPC) and the administrative office is based at the Centre for Palliative Care, (c/o St Vincent's Hospital and collaborative Centre of The University of Melbourne, Australia). For information on the background to the establishment of the IPCFRC, its collaborators, and its objectives please refer to the IPCFRC website: [ipcfrc.centreforpallcare.org](http://ipcfrc.centreforpallcare.org)

### **The IPCFRC Executive Committee**

The IPCFRC has revised its governance structure with the establishment of a new executive committee. Chaired by Professor Peter Hudson (Australia), other members of the executive committee include: Gunn Grande (UK), Anette Henriksson (Sweden), Jean Kutner (USA), Kelli Stajduhar (Canada), Anna Ugalde (Australia) and Sheila Payne (UK) in an ex-officio role.

### **Membership**

As of September 2013, we are delighted to announce there are approximately 200 members of the IPCFRC, originating from a range of countries, including: Australia, Bulgaria, Cameroon, Canada, Denmark, France, Germany, Ireland, Japan, New Zealand, Nigeria, Norway, Spain, Sweden, Thailand, UK and USA.



## Special Edition of Palliative Medicine

A special issue of *Palliative Medicine* was published in July on Family Carers. Consisting of two editorials from IPCFRC Executive Committee members, two review papers and 11 original articles, this edition demonstrates the importance of research inquiry associated with this population. Congratulations to all IPCFRC members who contributed to this important edition.

- Hudson P. Improving support for family carers: Key implications for research, policy and practice. *Palliat Med.* 2013 Jul;27(7):581-2. doi: 10.1177/0269216313488855. PubMed PMID: 23780618.
- Payne S, Grande G. Towards better support for family carers: A richer understanding. *Palliat Med.* 2013 Jul;27(7):579-80. doi: 10.1177/0269216313488856. PubMed PMID: 23780617.

To read the full list of publications in this special edition, please click [here](#).

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### Upcoming IPCFRC Event:

#### PCFRC Open Meeting at the 8<sup>th</sup> World Research Congress of the European Association for Palliative Care, June 2014

Join us in Lleida, Spain, at the 8<sup>th</sup> World Research Congress of the EAPC for an open meeting of the IPCFRC.

This meeting is open to all members and those interested in finding out more information about IPCFRC. It will provide an opportunity to update you on the progress of IPCFRC and identify further areas for collaboration. Come along and meet some the IPCFRC executive committee and members from across the globe.

This meeting will be held on: Thursday, 5<sup>th</sup> June between 1330 – 1400 (room location announced in due course).



### Upcoming Conferences

#### 8<sup>th</sup> World Research Congress of the European Association for Palliative Care

This meeting will be held in Lleida, Spain on the 5-7 June, 2014. Abstract submission for the 8<sup>th</sup> World Congress on EAPC closes on the 15<sup>th</sup> October 2013. Abstracts can be submitted via the following link: [EAPC Abstracts](#)

#### 15<sup>th</sup> World Congress of Psycho-Oncology

The International Psycho-Oncology Society hosts this meeting in Rotterdam, The Netherlands on the 4-8<sup>th</sup> November 2013. To access the preliminary program academy workshops and lists of invited speakers, please go to: [IPOS Society](#)

#### Multinational Association for Supportive Care in Cancer – Save the date for 2014!

The MASCC International Symposium in Supportive Care in Cancer will be held over June 26-28<sup>th</sup> in Miami, USA. Stay tuned for abstract submission.

## Recent Family Carer Publications

Due to the special edition of family carer research in *Palliative Medicine*, there has been a substantial list of family carer publications from March – July 2013. Other seminal publications not include:

The Melbourne Family Support Program: An overview of evidence based interventions successful of improving caregiver outcomes has been published and profiled widely in Australia: Hudson P, Aranda S. The Melbourne Family Support Program: evidence-based strategies that prepare family caregivers for supporting palliative care patients. *BMJ Support Palliat Care* doi:10.1136/bmjspcare-2013-000500

Family carers of patients with motor neuron disease: A literature review has demonstrated the progress made in assisting family carers of MND patients: Aoun SM, Bentley B, Funk L, Toye C, Grande G, Stajduhar KJ. A 10-year literature review of family caregiving for motor neurone disease: moving from caregiver burden studies to palliative care interventions. *Palliat Med.* 2013May;27(5):437-46.

A protocol for qualitative research: Qualitative research is important in understanding the experiences of family carers, and a substantial piece of qualitative research is underway, aiming to understand how both patients and carers recover or maintain psychological wellbeing: Roberts D, Appleton L, Calman L, Large P, Grande G, Lloyd-Williams M, Walshe C. Protocol for a longitudinal qualitative interview study: maintaining psychological well-being in advanced cancer--what can we learn from patients' and carers' own coping strategies? *BMJ Open.* 2013 Jun 20;3(6).

A new instrument for family carers: Anna Ugalde, an IPCFRC Executive Committee member, published the final results from her PhD which developed and tested a self-efficacy measure for caregivers: Ugalde A, Krishnasamy M, Schofield P. Development of an instrument to measure self-efficacy in caregivers of people with advanced cancer. *sychooncology.* 2013 Jun;22(6):1428-34. PubMed PMID: 22941754.

Methods and Ethics: Recently there have been numerous publications on ethical and methodological issues in palliative care research; including the following four papers:

- Gysels M, Evans CJ, Lewis P, Speck P, Benalia H, Preston NJ, Grande GE, Short V, Owen-Jones E, Todd CJ, Higginson IJ. MORECare research methods guidance development: Recommendations for ethical issues in palliative and end-of-life care research. *Palliat Med.* 2013 May 21. PubMed PMID: 23695828.
- Preston NJ, Fayers P, Walters SJ, Pilling M, Grande GE, Short V, Owen-Jones E, Evans CJ, Benalia H, Higginson IJ, Todd CJ; on behalf of MORECare. Recommendations for managing missing data, attrition and response shift in palliative and end-of-life care research: Part of the MORECare research method guidance on statistical issues. *Palliat Med.* 2013 May 7. PubMed PMID: 23652842.
- Evans CJ, Benalia H, Preston NJ, Grande G, Gysels M, Short V, Daveson BA, Bausewein C, Todd C, Higginson IJ; MORECare. The Selection and Use of Outcome Measures in Palliative and End-of-Life Care Research: The MORECare International Consensus Workshop. *J Pain Symptom Manage.* 2013 Apr 26. PubMed PMID: 23628515.
- Higginson IJ, Evans CJ, Grande G, Preston N, Morgan M, McCrone P, Lewis P, Fayers P, Harding R, Hotopf M, Murray SA, Benalia H, Gysels M, Farquhar M, Todd C; MORECare. Evaluating complex interventions in end of life care: the MORECare statement on good practice generated by a synthesis of transparent

expert consultations and systematic reviews. BMC Med. 2013 Apr 24;11:111.  
PubMed PMID: 23618406.

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### **Contributions**

**We look forward to promoting the work of IPCFRC members in upcoming newsletters. Please email [centreforpallcare@svhm.org.au](mailto:centreforpallcare@svhm.org.au) with the subject heading 'IPCFRC' to let us know about any newsworthy items, including: achievements, awards, publications or presentations, promotions or completion of PhD or masters theses. We look forward to hearing about the progression of family carer palliative care research in your team.**

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The IPCFRC is auspiced by the Centre for Palliative Care, part of St Vincent's Hospital and collaborative centre of The University of Melbourne, Australia.

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