



International Palliative Care Family-carer Research Collaboration

# Newsletter

March 2017

## Featured Member



**Dr Betty Ferrell**  
IPCFCRC Advocate  
*Director and Professor*  
*Nursing Research and Education*  
*City of Hope Medical Center*  
*CA, USA*

**Betty Ferrell, RN, PhD, MA, FAAN, FPCN, CHPN** has been in nursing for 40 years and has focused her clinical expertise and research in pain management, quality of life, and palliative care. Dr Ferrell is the Director of Nursing Research & Education and a Professor at the City of Hope Medical Center in Duarte, California. She is a Fellow of the American Academy of Nursing and she has over 400 publications in peer-reviewed journals and texts. She is Principal Investigator of a Research Project funded by the National Cancer Institute on “Palliative Care for Patients with Solid Tumors on Phase 1 Clinical Trials” and Principal Investigator of the “End-of-Life Nursing Education Consortium (ELNEC)” project. She directs several other funded projects related to palliative care in cancer centers and QOL issues. Dr. Ferrell was Co-Chairperson of the National Consensus Project for Quality Palliative Care. Dr Ferrell completed a Masters degree in Theology, Ethics and Culture from Claremont Graduate University in 2007. She has authored eleven books including the *Oxford Textbook of Palliative Nursing* published by Oxford University Press (4th edition published in 2015). She is co-author of *The Nature of Suffering and the Goals of Nursing* (Oxford University Press, 2008) and *Making Health Care Whole: Integrating Spirituality into Patient Care* (Templeton Press, 2010). In 2013 Dr Ferrell was named one of the 30 visionaries in the field by the American Academy of Hospice and Palliative Medicine.

### ***What lead you to a career in research?***

*I began my professional career in 1977, 40 years ago, as an oncology nurse. In 1984 I completed my PhD and my dissertation was on the topic of patients dying at home, which at the time was a new idea, and the impact on family caregiver bereavement. Since that time my research has continued to focus on family caregivers.*

### ***What are you currently researching?***

*My current research is largely focused on integration of palliative care into routine oncology practice. I have NIH funded studies integrating a palliative care intervention for patients and families in community settings in lung cancer and a study integrating palliative care for patients with solid tumors on clinical trials.*

*Continued...*

## Featured Member *continued...*

### ***What inspires your research?***

*What inspires my research is the ability to use our studies to be the voice of patients and family caregivers to advocate for their needs.*

### ***In what way does your work benefit the community?***

*I believe that our research has great benefit to patients and families at a time when care has shifted to the home and community. Family caregivers are the primary oncology workforce.*

### ***How did you get into the palliative care field?***

*I began my career in oncology and the transition to palliative care was a very natural fit as people facing cancer have such significant needs for support and palliative care.*

### ***What do you think makes you a good researcher?***

*I believe that being a good researcher is a combination of great passion for the work, dedication to rigor and integrity and a strong sense of how to best use research to impact clinical care.*

### ***What is it that you enjoy most about your research?***

*What I enjoy most about research is the opportunity to work with my colleagues across disciplines to look for real solutions to clinical problems. The greatest compliment is to meet clinicians who are using our research findings in their daily practice.*

### ***Tell us something that people might be interested to know about you?***

*When I began my career, there was no such thing as palliative care, no hospices in my state and only a few in the country, and few researchers with an interest in palliative care or family caregiving. It has been an enormous privilege to witness the development of these fields. I have heard the expression that we are "flying the airplane while building it" which I can identify with. I am honored to be among such great colleagues committed to this area of health care that can benefit so many.*

### ***How is being a member of IPCFRC relevant to your work?***

*The IPCFRC offers an opportunity to network and be connected to others who are committed to family caregiving research and care.*

## Review of literature related to family carer research

One of the initiatives of the IPCFRC is to compile a listing of publications related to family caregiver research in palliative care. This list is updated annually, and serves as a basic resource to aid those who are looking for peer-reviewed publications related to family caregiver research in palliative care. The 2017 version is available as a downloadable resource on the [\[IPCFRC website\]](#).

## Recent articles relevant to IPCFRC members

In each edition we will feature some recently published articles relevant to IPCFRC members.

If you have published in a peer-reviewed journal recently and the subject matter is relevant to the IPCFRC community, please email [centre.palliativecare@svha.org.au](mailto:centre.palliativecare@svha.org.au) with the subject 'IPCFRC Newsletter' and we will feature your publication in an upcoming edition.

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Aoun SM, Deas K, Kristjanson LJ, Kissane DW. (2017) 'Identifying and addressing the support needs of family caregivers of people with motor neurone disease using the Carer Support Needs Assessment Tool'. *Palliat Support Care* 15(1):32-43.

Aoun SM, Breen LJ, Oliver D, Henderson RD, Edis R, O'Connor M, Howting D, Harris R, Birks C. (2017) 'Family carers' experiences of receiving the news of a diagnosis of Motor Neurone Disease: A national survey'. *J Neurol Sciences* 372:144-151.

Ewing G, Penfold C, Benson J, Mahadeva R, Howson S, Burkin J, Booth S, Lovick R, Gilligan D, Todd C, Farquhar M. (2017) 'Clinicians' views of educational interventions for carers of patients with breathlessness due to advanced disease: findings from an online survey'. *J Pain Symptom Manage*. 55(2):265-271.

François K, Lobb E, Barclay S, Forbat L. (2017) 'The nature of conflict in palliative care: A qualitative exploration of the experiences of staff and family members'. *Patient Educ Couns*. doi: 10.1016/j.pec.2017.02.019. [Epub ahead of print]

Nichols LO, Martindale-Adams J, Zhu CW, Kaplan EK, Zuber JK, Waters TM. (2017) 'Impact of the REACH II and REACH VA Dementia Caregiver Interventions on Healthcare Costs'. *J Am Geriatr Soc*. doi: 10.1111/jgs.14716. [Epub ahead of print]

Nielsen MK, Neergaard MA, Jensen AB, Vedsted P, Bro F, Guldin MB. (2017) 'Pre-loss grief in family caregivers during end-of-life cancer care: a nationwide population-based cohort study'. *Psychooncology*. doi: 10.1002/pon.4416. [Epub ahead of print]

Nielsen MK, Neergaard MA, Jensen AB, Vedsted P, Bro F, Guldin MB. (2017) 'Predictors of Complicated Grief and Depression in Bereaved Caregivers: A Nationwide Prospective Cohort Study'. *J Pain Symptom Manage*. 53(3):540-550.

Phongtankuel V, Paustian S, Reid MC, Finley A, Martin A, Delfs J, Baughn R, Adelman RD. (2017) 'Events Leading to Hospital-Related Disenrollment of Home Hospice Patients: A Study of Primary Caregivers' Perspectives'. *J Palliat Med*. 20(3):260-265.

Robinson CA, Bottorff JL, McFee E, Bissell LJ, Fyles G. (2017) 'Caring at home until death: enabled determination'. *Support Care Cancer*. 25(4):1229-1236.

Sankhe A, Dalal K, Agarwal V, Sarve P. (2017) 'Spiritual Care Therapy on Quality of Life in Cancer Patients and Their Caregivers: A Prospective Non-randomized Single-Cohort Study'. *J Relig Health*. 56(2):725-731.

Tanco K, Vidal M, Arthur J, Guay MD, Hui D, Liu D, Chisholm G, Bruera E. (2017) 'Testing the feasibility of using the Edmonton Symptom Assessment System (ESAS) to assess caregiver symptom burden'. *Palliat Support Care*. doi: 10.1017/S1478951517000098. [Epub ahead of print]

## Conferences relevant to IPCFRC members

12<sup>th</sup> Annual Conference on Palliative and End of Life Care

Date: May 5, 2017

Location: Toronto, Canada

Website: [[12<sup>th</sup> Annual Conference on Palliative and End of Life Care](#)]

2017 Australian and New Zealand Society for Geriatric Medicine Annual Scientific Meeting

Dates: May 10-12, 2017

Location: Rotorua, NZ

Website: [[ANZSGM 2017](#)]

3<sup>rd</sup> Victorian Integrated Cancer Services Conference

Dates: May 11-12, 2017

Location: Melbourne, Australia

Website: [[VICS 2017](#)]

15<sup>th</sup> World Congress of the European Association for Palliative Care

Dates: May 18-20, 2017

Location: Madrid, Spain

Website: [[EAPC 2017](#)]

2017 International Death, Grief & Bereavement Conference

Dates: June 5-7, 2017

Location: Wisconsin, USA

Website: [[DGB 2017](#)]

19<sup>th</sup> International Conference on End of Life Care

Dates: June 18-19, 2017

Location: Dubai, UAE

Website: [[ICELC 2017](#)]

2017 MASCC/ ISOO Annual Meeting on Supportive Care in Cancer

Dates: June 22-24, 2017

Location: Washington DC, USA

Website: [[MASCC/ISOO 2017](#)]

Victorian Comprehensive Cancer Centre Leadership Development Program

Dates: July 26-28 & August 24-25, 2017

Location: Melbourne, Australia

Website: [[VCCC LDP 2017](#)]

21<sup>st</sup> IAGG World Congress of Gerontology and Geriatrics

Dates: July 23-27, 2017

Location: San Francisco, California, USA

Website: [[IAGG 2017](#)]

19<sup>th</sup> World Congress of Psycho-oncology and Psychosocial Academy

Dates: August 14-18, 2017

Location: Berlin, Germany

Website: [[IPOS 2017](#)]

14<sup>th</sup> Australian Palliative Care Conference

Dates: September 6-8, 2017

Location: Adelaide, Australia

Website: [[PCA 2017](#)]

2<sup>nd</sup> National Symposium for Academic Palliative Care Education & Research

Dates: September 28-29, 2017

Location: San Diego CA, USA

Website: [[2<sup>nd</sup> National Symposium for Academic Palliative Care Education & Research](#)]

2017 Marie Curie Annual Palliative Care Research Conference

Date: October 6, 2017

Location: London, UK

Website: [[2017 Marie Curie Annual Palliative Care Research Conference](#)]

5<sup>th</sup> Australian Palliative Care Research Colloquium

Dates: October 26-27, 2017

Location: Melbourne, VIC

Further details to follow – please keep a look-out on the Centre for Palliative Care [[website](#)]

44<sup>th</sup> Clinical Oncology Society of Australia Annual Scientific Meeting

Dates: November 13-15, 2017

Location: Sydney, Australia

Website: [[COSA ASM 2017](#)]

## Upcoming IPCFRC Event

An open meeting for current and prospective IPCFRC members at the [10th World Research Congress of the European Association for Palliative Care (EAPC)] in Bern, Switzerland in May 2018 is currently under planning. We will update you once the details are confirmed.

Open meetings provide the opportunity for members and prospective members to hear about what is happening in the IPCFRC community and what IPCFRC has to offer, as well as meet the IPCFRC Executive Committee and their fellow IPCFRC members.

## Membership

The IPCFRC has 220 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.

Individuals from all continents with a genuine interest in palliative care research related to family carers may become individual members of the IPCFRC. Membership is free. To formalise your membership please complete the [online form] on the IPCFRC website.

### Forward IPCFRC to a friend!

Please forward this newsletter to friends or colleagues interested in family carer research. They can also sign up for [free membership]!

### Update your details!

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

[Update your details now]

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