



# PALLIATIVE CARE RESEARCH COOPERATIVE GROUP



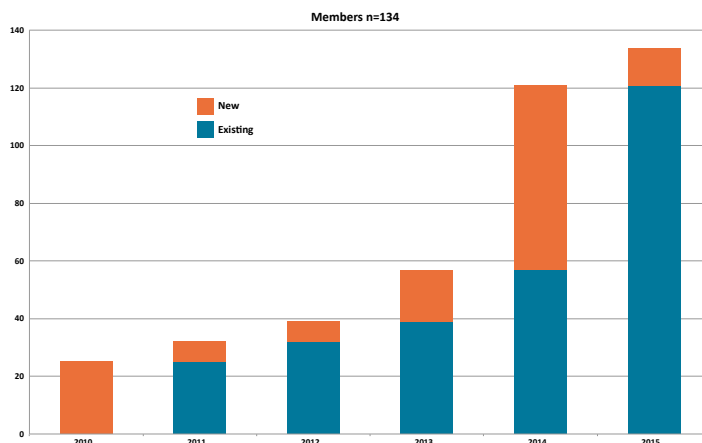
## PCRC STUDY LISTINGS

Study Title	Type	Status	Funding
Statin Discontinuation	Randomized Controlled Trial (RCT)	Closed; Manuscript published (Mar 2015)	National Institute of Nursing Research (NINR) UC4
Pharmacovigilance	Quality	Active enrollment; initial sites	CLHC, UC GIM & UCSF*
Best Supportive Care	Implementation	Active Enrollment	American Cancer Society (ACS)
QDACT-PCRC	Quality	Active Enrollment	Agency for Healthcare Research & Quality (AHRQ)
Statin Guidelines & Practice Patterns	Survey	Active Enrollment	PCRC 2014 Pilot Award
Pancreatic Care Planning	Intervention	Active Enrollment	PCRC 2014 Pilot Award
Anticoagulation Therapy	Retrospective Chart Review	Active Enrollment	PCRC 2014 Pilot Award
Family Experiences of ICU Transfers	Qualitative (Prospective interview)	Active Enrollment	PCRC 2014 Pilot Award
Caregiver Assisted Pain-Management	Randomized Controlled Trial (RCT)	Active Enrollment	NINR R01
Pediatric Social Support	Intervention	Active Enrollment	NINR R01
Caregiver Support for Pts w. Lung Cancer	Intervention	Active Enrollment	NINR R01

\* Duke University's Center for Learning Health Care, University of Colorado's Division of General Internal Medicine and University of California San Francisco's Division of Geriatrics

## Membership Committee Update

We are excited to share that the PCRC is now comprised of 134 members from 64 organizations. A full list of PCRC sites and members is available on the website under the "Current PCRC Members" tab. A warm welcome to all of our newest members – we look forward to working with you!



## Grant Application Resource for Protection of Human Subjects on PCRC Website

Part of any grant application utilizing NIH funds requires adequate attention to human subjects. To help with the process, NIH and NINR have some excellent resources that may be useful when preparing the sections concerning protection of human subjects, inclusion of women, minorities and children, and data safety monitoring plans in your grant proposal. This information is now available on the [PCRC website](#) under the "Resources" tab and the "Documents" subheading.

## NINR Updates

We want to express our sincerest gratitude to Dr. Donna Jo McCloskey and Dr. Sue Marden for their strong support of the PCRC over the past few years – thank you for the important roles you played as Program Officer and Scientific Officer! In their stead, we welcome our two newest colleagues from the NINR, Dr. Jeri Miller who will assume the NINR PCRC Scientific Officer role and Dr. Karen Kehl who will become the NINR PCRC Project Officer.

**Dr. Miller** is Chief of the Office of End-of-Life and Palliative Care Research (OEPCR) within NINR's Division of Extramural Science Programs. This new office will support ongoing efforts in end-of-life and palliative care science, including stimulating research initiatives, creating opportunities for collaborative activities and facilitating interdisciplinary science. A major program priority is to coordinate the development, implementation and evaluation of end-of-life and palliative care research in direct collaboration with other NIH Institutes and Centers, federal research agencies and outside constituencies. The office is staffed by several Health Scientist Administrators who support the Chief of the Office in programmatic oversight, science policy, initiative development, and assistance in translation of research for the public.

**Dr. Kehl** comes to NINR and the OEPCR from the University of Wisconsin-Madison, School of Nursing where she was an Assistant Professor. For more than 25 years, Dr. Kehl has specialized in hospice and palliative nursing and has served as a clinician, administrator, educator, and researcher. Her research focused on improving preparation of families for care in the last phase of life in the home hospice setting. Dr. Kehl participated in the Clinical and Translational Science Award program, which involved mentored research career development for clinical translational research. She also served on the Board of Directors for the Hospice and Palliative Nurses Association.

We are very excited to further strengthen our NINR collaboration with Jeri and Karen as new key members of our team – welcome and it is great to have you both onboard! The NINR is looking forward to the continued collaborative efforts to support the mission and vision of the PCRC! PCRC members are welcome to contact Jeri ([jmiller@mail.nih.com](mailto:jmiller@mail.nih.com)) or Karen ([karen.kehl@nih.gov](mailto:karen.kehl@nih.gov)) to assist with needs or questions.

## Active PCRC Studies

### Study Title: QDACT Feasibility

**Principal Investigator: Arif Kamal MD**

The QDACT Feasibility protocol titled, *“Testing the feasibility of a point-of-care quality monitoring infrastructure for the PCRC,”* is currently being rolled out at 5 PCRC sites. The team is conducting a formal feasibility study of the *qdact.pcrc*, a point-of-care electronic data capture tool to measure quality of care in the PCRC. The team will use mixed quantitative/qualitative measurements through electronic surveys and semi-structured interviews to obtain feedback; participants are palliative care clinicians who will evaluate feasibility in usual palliative care clinical settings. Pre-specified thresholds for success will establish feasibility and this infrastructure, if proven feasible, can then become integrated into usual palliative care delivery across the PCRC. Additionally, palliative care can conduct the same types of collaborative quality improvement activities, based on data collected at point of care, as other medical disciplines like general surgery and cardiology.

### Study Title: Best Supportive Care

**Principal Investigator: Yousuf Zafar MD MHS**

This protocol titled, *“Implementation of consensus-based standards for best supportive care in a clinical trial: a pilot study,”* is currently being rolled out at three PCRC sites. Because many cancer clinical trials are designed to evaluate the benefits of experimental anticancer drugs against Best Supportive Care (BSC); many drugs have been registered based on very modest survival advantages when compared with BSC. When reporting of BSC in trials is incomplete, the resulting data have uncertain internal and external validity. In line with the CONSORT statement on reporting of clinical trials, this study seeks to generate consensus-based standards for BSC definition (allowing this to be updated as new evidence becomes available), operationalize, and measure outcomes in a clinical trial setting.

### Study Title: Pharmacovigilance Project

**Principal Investigators: Amy Abernethy MD PhD and Jean Kutner MD MSPH**

Surveying PCRC palliative care clinicians, this international project is focused on assessing how palliative care interventions are performing in real world situations, summarizing clinical benefit and harm. For example, how are medications like gabapentin and pregabalin used in the palliative care setting, and with what benefit or toxicity? Data are being gathered from over 40 sites worldwide, including the PCRC. Currently, the PCRC study team is in the process of finalizing the protocols and data collection process. Keep your eyes open for opportunities to participate.

## Steering Committee Updates

On behalf of the PCRC, we would like to welcome Dr. Marie Bakitas to the Steering Committee! Dr. Bakitas received her ADN/RN from the University of Bridgeport, post-Master's certification as an adult nurse practitioner from the University of New Hampshire. She is certified as an Adult Nurse Practitioner, Advanced Certified Hospice and Palliative Care Nurse (ACHPN) and Advanced Oncology Certified Nurse (AOCN). While working as a clinician and researcher, in 2001 she embarked on formalizing her research training by completing a doctorate (DNSc) and post-doctoral fellowship at Yale University. Dr. Bakitas is an internationally recognized scholar who has focused on conducting innovative pain and symptom management and palliative care intervention clinical trials to improve the quality of life and care for people with serious, life-limiting illness and their families through improved management of distressing symptoms. Dr. Bakitas has participated in over 30 funded research grants and served as the principal investigator on 15.



We look forward to the breadth of knowledge and valuable insight that Dr. Bakitas will bring to the PCRC Steering Committee!

## 2015 PCRC Pilot Award Update

A number of well-crafted Investigator Development Pilot Applications have been submitted to the PCRC and the review process is currently underway, with a review orientation and webinar scheduled for April (exact time TBA). Six pilot applications will be awarded and applicants will be notified in June. Exciting times for the PCRC!

**Connect with us!**

[www.palliativecareresearch.org](http://www.palliativecareresearch.org)



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## NINR's 30<sup>th</sup> Anniversary

### Poster Abstract Submission

The National Institute of Nursing Research (NINR) is accepting abstract submissions for a poster session that will be held during NINR's 30th Anniversary: Advancing Science, Improving Lives kickoff symposium. The symposium will take place October 13, 2015 at the National Institutes of Health (NIH) campus in Bethesda, MD. NINR invites you to submit an abstract for consideration as a poster presentation that is based on NINR-supported completed work, work-in-progress, work presented at other meetings, or work that has previously been published.

NINR seeks submissions on topics related to:

- Symptom Science: Promoting Personalized Health Strategies
- Wellness: Promoting Health and Preventing Illness
- Self-Management: Improving Quality of Life for Individuals with Chronic Illness
- End-of-Life and Palliative Care: The Science of Compassion

The submission topics are based on the themes of NINR-supported science. For more information on the themes, visit [www.ninr.nih.gov/keythemes](http://www.ninr.nih.gov/keythemes). Submission Deadline: **May 15, 2015**. The corresponding author will be notified about abstract acceptance by July 1, 2015.

To learn more about poster abstracts and the submission instructions, please visit <https://ninr30poster.ninr.nih.gov/>.

## Upcoming important dates

### Face-to-Face PCRC Investigator Meetings

- Spring: March 26-27, 2015 (Chicago IL)
- Fall: October 7-8, 2015 (Bethesda MD)

*For those going to Chicago in a few days, we are looking forward to seeing you all soon for exciting updates, innovative presentations, new connections, and generative discussions!*