

# 4th Annual Kathleen M. Foley Palliative Care Research Retreat and Symposium



A collaborative meeting jointly sponsored by:

- The National Palliative Care Research Center
- The American Cancer Society
- The American Academy of Hospice and Palliative Medicine
- The Hospice and Palliative Care Nurses Association
- **LIVESTRONG**



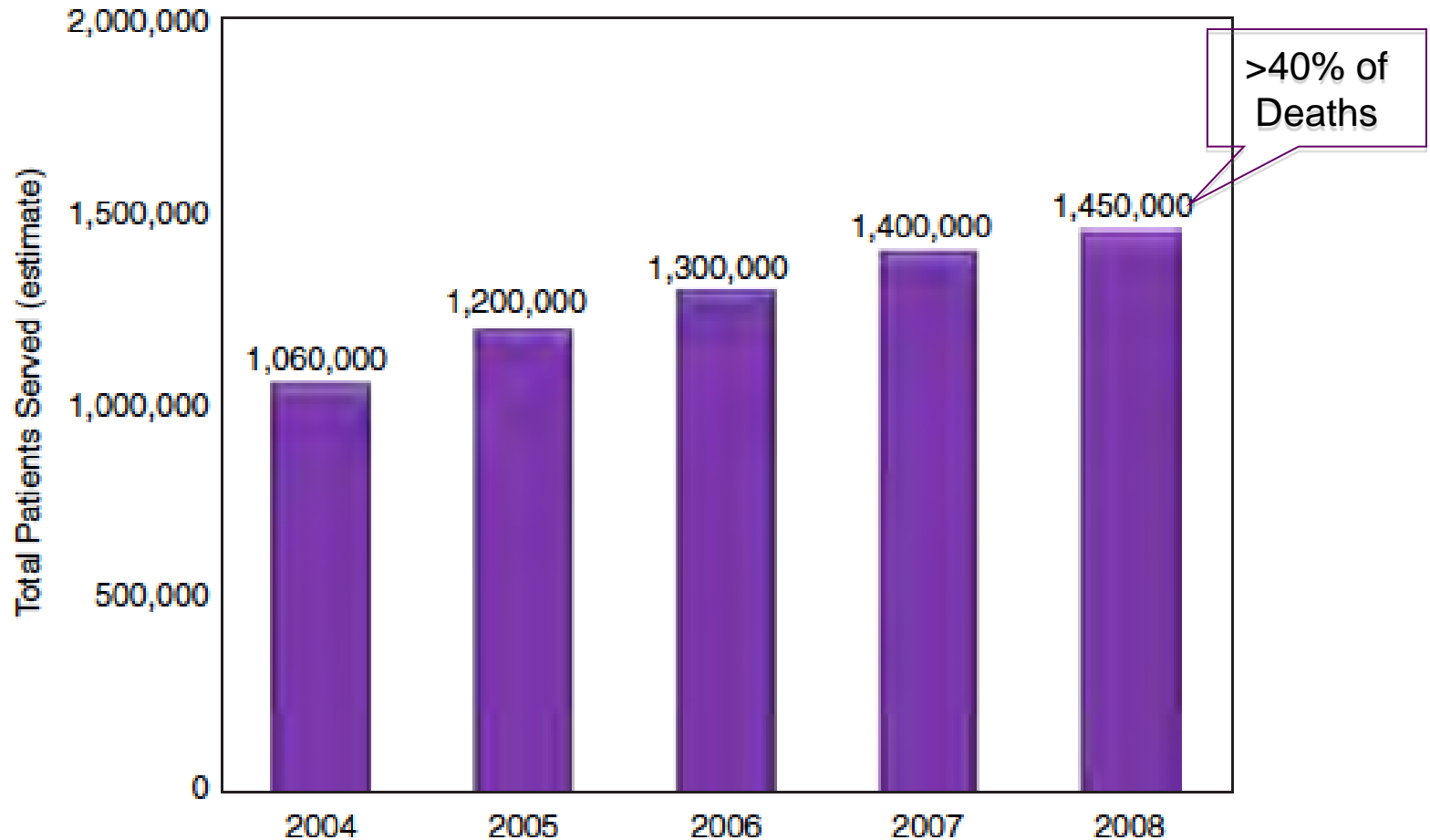
# Care For the Seriously Ill at the Turn of the Century (2000)



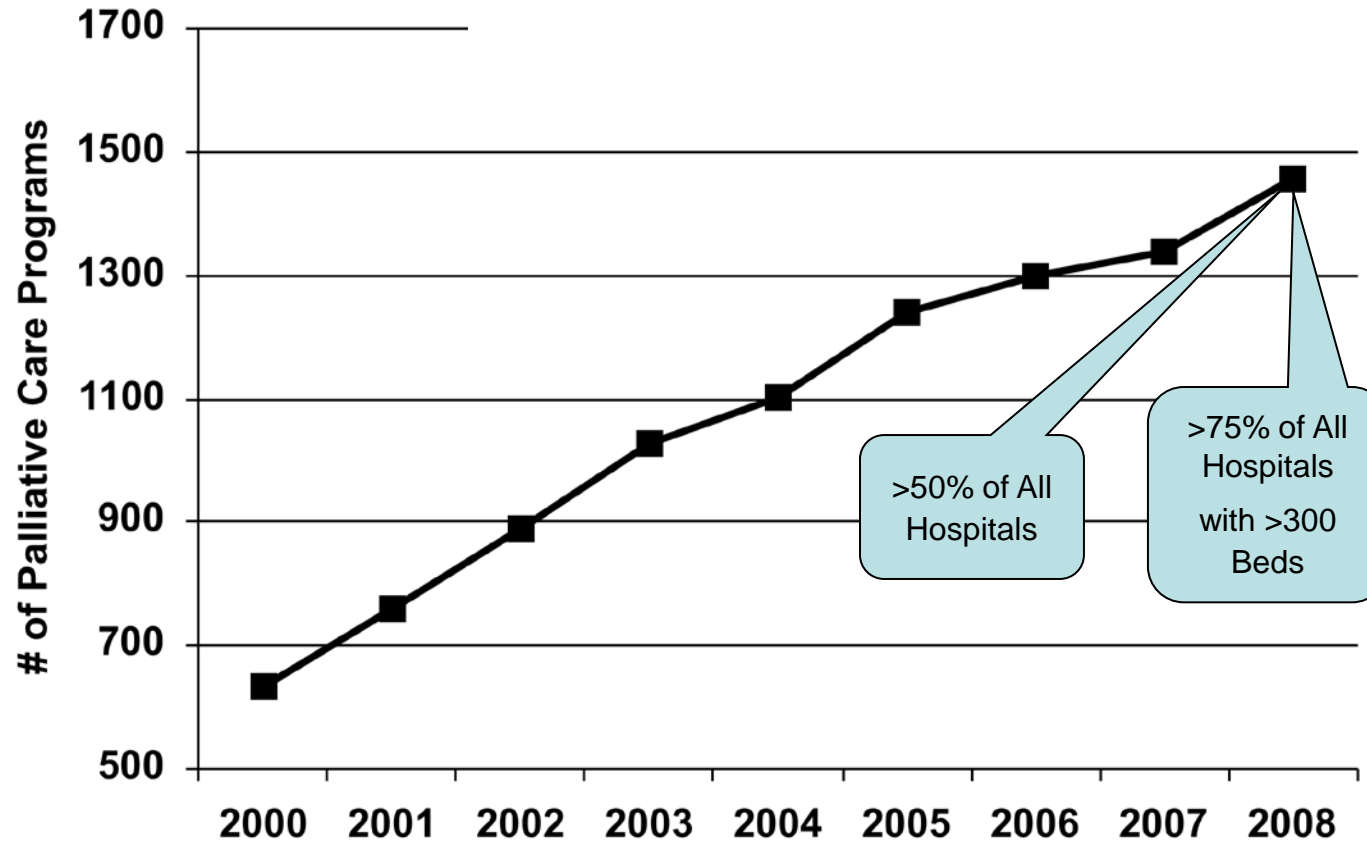
- Unprecedented gains in life expectancy: exponential rise in number and needs of frail elderly and their caregivers
- Cause of death shifted from acute sudden illness to chronic episodic disease
- Untreated physical symptoms
- Unmet patient/family needs
- Disparities in access to care
- Inadequately trained health care professionals
- An unresponsive health care system facing enormous and increasing expenditures

What a difference a decade  
makes...

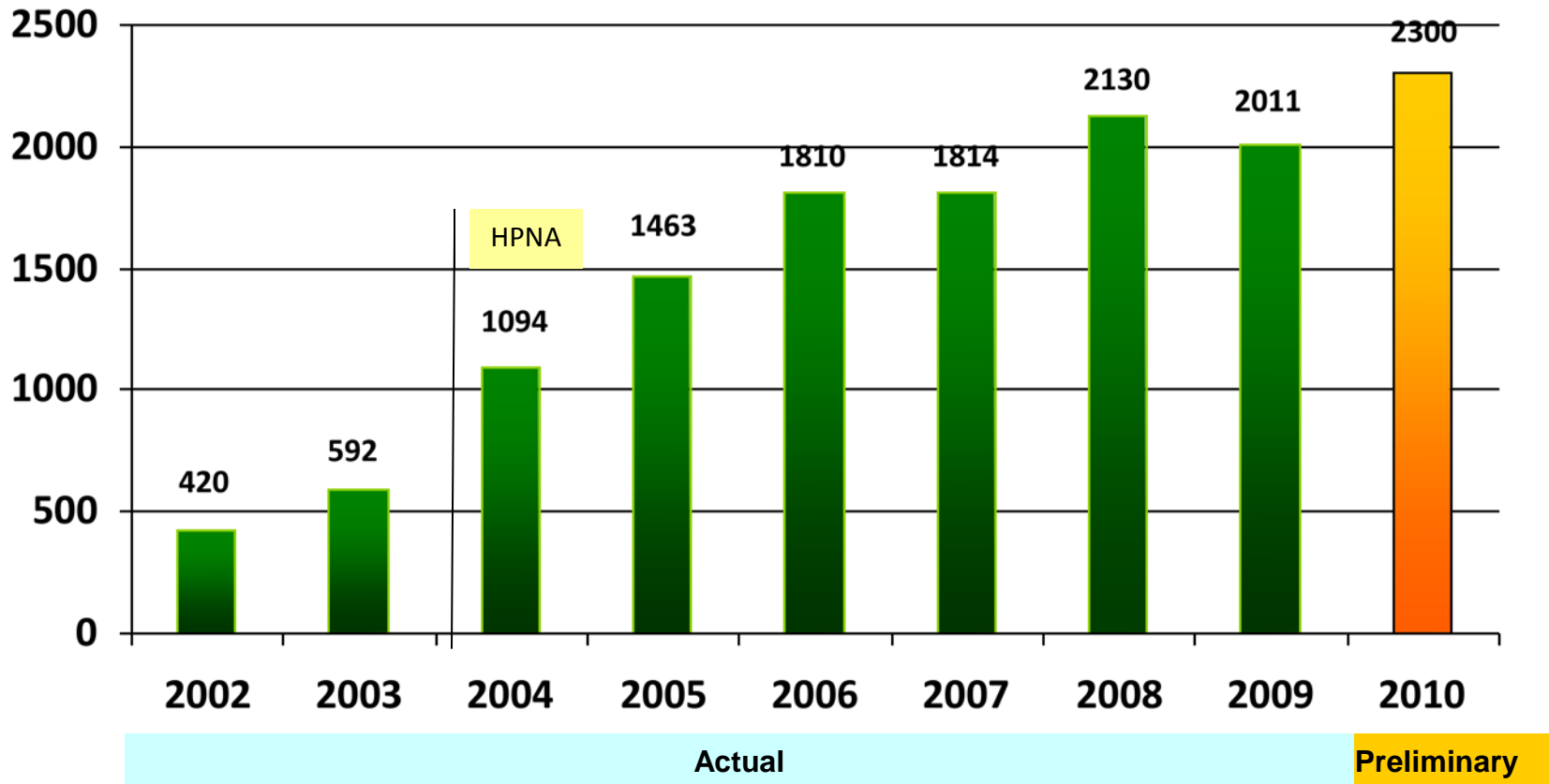
# Growth of Patients Enrolled In Hospice



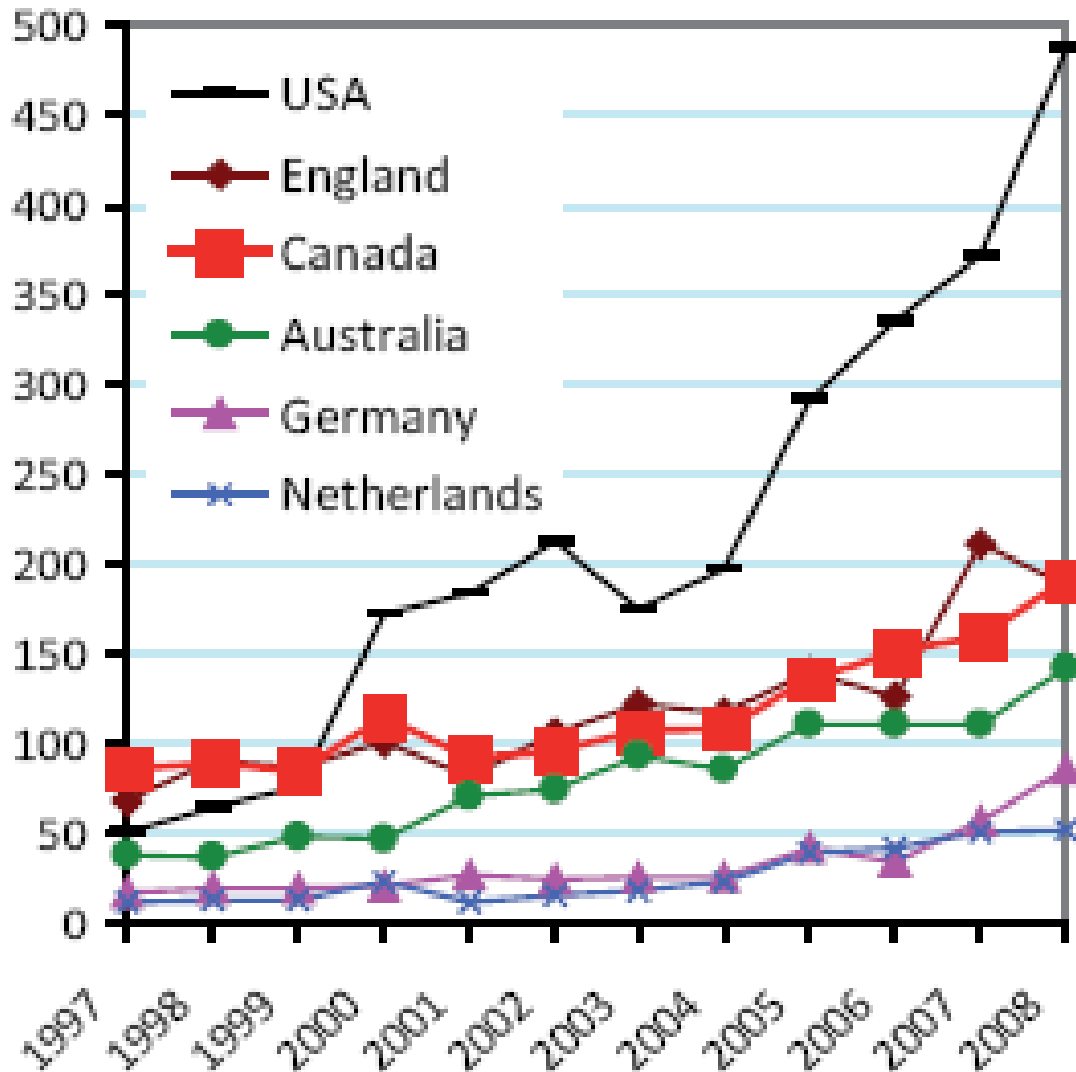
# Growth of Non-Hospice Palliative Care Programs



# Growth of Annual AAHPM/HPNA Meeting Attendance



# Palliative Care Research Publications



Slide courtesy of Neil Hagen, MD



# Palliative Care 2010



- Dramatic increase in the number of clinical palliative care programs
- Increasing public and professional awareness and acceptance of palliative care
- Recognition of palliative care as a distinct medical specialty
- Enhanced professional training and educational efforts in palliative care
- Increasing evidence of the benefit of palliative care
- Major quality and policy initiatives

# How Did We Get Here?

- Technical assistance to hospitals, institutions, and educators to translate this research into practice
- Focused educational programs that addressed the needs of learners
- A clear body of research that demonstrated palliative care:
  - Improves clinical quality
  - Addresses patient and family preferences
  - Helps hospitals, hospices, healthcare systems address their fiscal pressures
- Targeted and strategic media outreach
  - Moving research into the public and policy domain

# Palliative Care Research: 2010



The NEW ENGLAND  
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JCN *Journal of*  
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# Palliative Care Research



**JOURNAL OF CLINICAL ONCOLOGY**  
Official Journal of the American Society of Clinical Oncology

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**Place of Death: Correlations With Quality of Life of Patients With Cancer and Predictors of Bereaved Caregivers' Mental Health**

Alexi A. Wright, Nancy L. Keating, Tracy A. Balboni, Ursula A. Matulonis, Susan D. Block and Holly G. Prigerson

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This Article  
Published online before print  
September 13, 2010, doi:  
10.1200/JCO.2009.26.3663  
JCO October 10, 2010 vol. 28  
no. 29 4457-4464

» Abstract  
Full Text  
PDF

**JOURNAL OF CLINICAL ONCOLOGY**  
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**Impact of Hospice Disenrollment on Health Care Use and Medicare Expenditures for Patients With Cancer**

Melissa D.A. Carlson, Jeph Herrin, Qingling Du, Andrew J. Epstein, Colleen L. Barry, R. Sean Morrison, Anthony L. Back and Elizabeth H. Bradley

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10.1200/JCO.2009.26.1818  
JCO October 1, 2010 vol. 28 no. 26 4371-4375

» Abstract  
Full Text  
PDF

## Annals of Internal Medicine

Established in 1927 by the American College of Physicians

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### Article

## Brief Communication: Management of Implantable Cardioverter-Defibrillators in Hospice: A Nationwide Survey

Nathan Goldstein, MD; Melissa Carlson, MBA, PhD; Elayne Livote, MPH, MS, MA; and Jean S. Kutner, MD, MSPH



## The NEW ENGLAND JOURNAL of MEDICINE

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### ORIGINAL ARTICLE

## Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer

Jennifer S. Temel, M.D., Joseph A. Greer, Ph.D., Alona Muzikansky, M.A., Emily R. Gallagher, R.N., Sonal Admane, M.B., B.S., M.P.H., Vicki A. Jackson, M.D., M.P.H., Constance M. Dahlin, A.P.N., Craig D. Blinderman, M.D., Juliet Jacobsen, M.D., William F. Pirl, M.D., M.P.H., J. Andrew Billings, M.D., and Thomas J. Lynch, M.D.  
N Engl J Med 2010; 363:733-742 | August 19, 2010

# Palliative Care Media Highlights 2010



**The New York Times**



THE WALL STREET JOURNAL.



**Newsweek**



**msnbc**

60 MINUTES



THE NEW YORKER

**Los Angeles Times**

**The Philadelphia Inquirer**



# Temel et al/Kelley & Meier, 2010

*New England Journal of Medicine*, August 18, 2010

**419,193,994 impressions**



**Helping cancer patients live better,  
longer**

**Cancer strategy: Easing the burden**

*Boston Globe* (8/19/10)

*NBC Nightly News* (9/10/10)

**Palliative care can help cancer patients live longer**

*USA Today* (8/18/10)

## **Palliative Care Extends Life, Study Finds**

*The New York Times* (8/18/10)

**Study shows value of quality-of-life cancer care**

*The Washington Post* (8/18/10)

**New Studies in Palliative Care**

National Public Radio, *The Diane Rehm Show* (8/24/10)

**Study: Advanced Cancer Patients Receiving Early Palliative Care Lived Longer**

*The Wall Street Journal* (8/18/10)

# NPCRC Grantee Accomplishments



- Career Development: 9 of our 16 junior investigators have already secured NIH/additional foundation funding as a result of their NPCRC awards
- Pilot/Exploratory: 6 our 11 investigators have leveraged NPCRC funding for larger NIH awards including an NIH program project grant

# Palliative Care Research Cooperative



*RESEARCH PROJECT*  
Department of Health and Human Services  
National Institutes of Health  
NATIONAL INSTITUTE OF NURSING RESEARCH

Notice of Award

**Issue Date:** 09/30/2010

THIS AWARD IS ISSUED UNDER THE AMERICAN RECOVERY AND REINVESTMENT ACT OF 2009 AND IS SUBJECT TO SPECIAL HHS TERMS AND CONDITIONS AS REFERENCED IN SECTION III

**Grant Number:** 1RC4NR012584-01

**Principal Investigator(s):**

Amy P. Abernethy (contact), MD  
JEAN S KUTNER, MD

**Project Title:** Creation and demonstration of a palliative care research cooperative group

Case, Cynthia O.  
Dir, Office of Research Admin  
2200 West Main St.  
Suite 820 Erwin Square Plaza  
Durham, NC 277050000

**Award e-mailed to:** gcmal@mc.duke.edu

**Budget Period:** 09/30/2010 – 09/29/2013

**Project Period:** 09/30/2010 – 09/29/2013

Dear Business Official:

The National Institutes of Health hereby awards a grant in the amount of \$7,175,320 (see "Award Calculation" in Section I and "Terms and Conditions" in Section III) to DUKE UNIVERSITY in support of the above referenced project. This award is pursuant to the authority of 42 USC 241 42 CFR 52 and is subject to the requirements of this statute and regulation and of other referenced, incorporated or attached terms and conditions.

**\$7,175,320**



# 2010: A Very Very Good Year for Palliative Care



# Where Do We Go Next?



- 2020 Goals
  - All patients and families will know to request palliative care in the setting of serious and life-limiting illness
  - All healthcare professionals will have the knowledge and skills to provide palliative care
  - All healthcare institutions in the US will be able to support and deliver high quality palliative care

This will require changes in  
state and federal policy...

# How Do We Get There?

- Workforce
- Access and Quality
- Evidence base
- Public and professional misconceptions

# Workforce

- Current problem:
  - 1 palliative medicine MD for every 1,000 persons with serious and advanced illness
    - Compare to 1 oncologist per 145 newly diagnosed cancer patients or 1 cardiologist per 71 MI victims
  - 20 states have no GME fellowship training programs in palliative medicine

# Access and Quality

- Current problem
  - 50% of hospitals (27% of hospitals with over 300 beds) lack a palliative care program
  - Standards for palliative care programs are voluntary
  - Business model = cost savings + MD reimbursement (difficult to demonstrate and sustain)

# Evidence base

- Current problem
  - Inadequate evidence base to support appropriate care of persons with serious and life-limiting illness
    - NIH Funding in 2009
      - 114 active NIH grants in palliative care
      - \$30,031,914 in FY 09 (.098% of total NIH budget)
        - » NCI: \$13,179,833 (0.27% of NCI budget)
        - » NINR: \$10,679,930 (7.5% of NINR budget)
        - » NIA: \$5,534,584 (0.8% of NIA budget)
    - Lack of junior and mid-career investigators
    - Lack of sustainable research centers

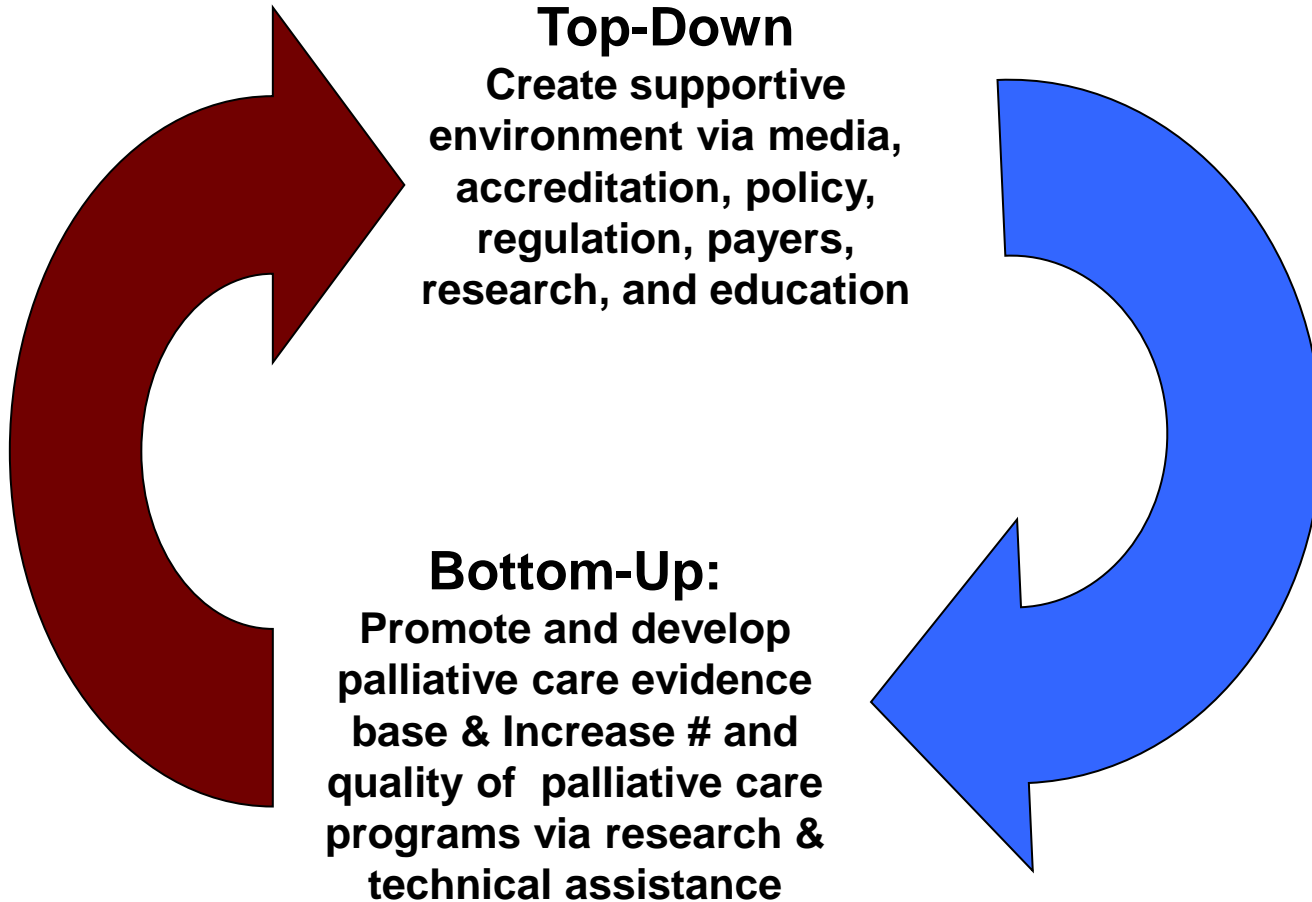
# Public and Professional Misconceptions



- Current Problem
  - Palliative care is linked to “end-of-life” care in the minds of the public, professionals, and policy makers
    - “Death Panels”
  - Major barrier to ensuring access to high quality medical care for persons with serious and advanced illness



# It Will Take All of Us



What will the next 2 1/2  
days hold?

# Goals For Our Retreat



To provide an opportunity for interdisciplinary palliative care researchers to come together to network, learn from each other, discuss the science of palliative care, develop new research ideas and collaborations, and develop the knowledge and skills necessary to meet our 2020 goals.

# Who is in the room?



- NPCRC
  - CDA grantees and their mentors
  - P/E grantees
  - Scientific Advisory Council Members
- American Cancer Society
  - Grantees
  - Program Directors
- AAHPM
  - Scholars
  - Board members and Committee Chairs
- Palliative Care Research Leaders
- Funders and Supporters
  
- 17 RNs, 48 MD/DOs, 16 PhDs (psychology, health services research, behavioural medicine), 1 SW
- 31 Junior investigators, 51 Experienced investigators

# Our Schedule...

# Tonight



- 4:45 - 5:00 pm: ACS Pathfinder Award Presentation
- 5:00 - 6:00 pm: Opening Plenary
  - *“Be at the Table or Be on the Menu: My Year in Washington”*, Diane E. Meier, MD
- 6:00 - 6:30 pm: Reception
- 6:30 – 9:00 pm: Dinner

# Wednesday

- 7:00 – 7:30 am: Continental breakfast
- 7:30 – 9:00 am: Moderated poster session
- 9:00 – 9:15 am: Break
- 9:15 – 11:00 am: Research in progress presentations
- 11:00 – 12:00 pm: Plenary
  - *“The Ten Commandments of Building a Successful Research Career”*, Christine Miaskowski, PhD RN
- 12:00-12:30 pm - Lunch
- 12:30 – 3:30 pm: Networking/Free time
- 3:30 – 5:00 pm: Media training 101
- 5:00 – 6:30 pm: Research Consultancies
- 6:30 – 9:00 pm: Dinner

# Thursday



- 7:00 – 7:30 am: Breakfast
- 7:30 – 9:00 am: Advanced Media Training” (experienced investigators)
- 7:30 – 9:00 am: Grant workshop part II: Investigators Responding To Pink Sheets (junior investigators)
- 9:00 – 9:15 am: Break
- 9:15 – 10:15 am: Closing Plenary
  - *“Dignity and Palliative Care: The Long and Winding Road,”*  
Harvey M Chochinov, MD PhD
- 10:15 – 10:30 am: Goodbyes and evaluations
- 10:30 am: Shuttle departure to SLC