

# 5th 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**

# Supporters



- **Funders (Past and Present):**
  - Emily Davie and Joseph S. Kornfeld Foundation
  - Y.C. Ho/Helen and Michael Chiang Foundation
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  - The Mill Park Foundation
  - The Olive Branch Foundation
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  - Betty and Norman Levy Foundation
  - National Institute on Aging
  - American Express Foundation
  - U.S. Cancer Pain Relief Taskforce
  - AAHPM
  - HPNA
  - **LIVESTRONG**
  - LORD Foundation (Pediatric Palliative Care Career Development Award)
  - Hearst Foundations (Hearst Scholar)
  - Anonymous donors
- **Partners:**
  - Center to Advance Palliative Care (CAPC)
  - Mount Sinai School of Medicine
  - AAHPM
  - American Cancer Society
  - Hospice and Palliative Nurses Association (HPNA)
  - **LIVESTRONG**

# Highlights of the First Five Years



- 17 NPCRC/ACS funded investigators, 17 subsequent NIH grants
- Publications in major biomedical journals
  - NEJM, JAMA, Lancet, Annals of Internal Medicine, Health Affairs, JCO
- Media attention
- NQF quality measures in palliative care
- Collaborations and Community

# Goals for 2020: The Next 8 Years

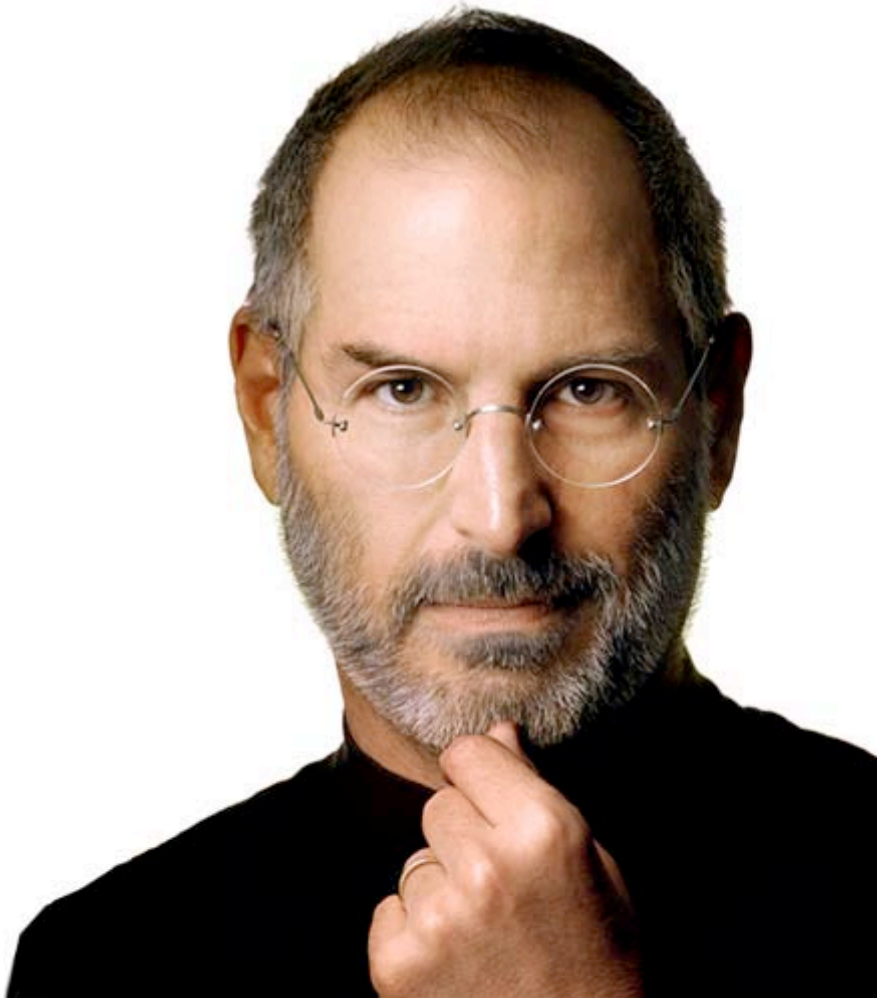


- All patients and families will know to request palliative care in the setting of serious and life-limiting illness
- All healthcare professionals will have the knowledge and skills to provide palliative care
- All healthcare institutions will be able to support and deliver high quality palliative care

# Our Themes For 2011

Research, Communication,  
Policy

# Steve Jobs, Entrepreneur (1955-2011)



- Founder and Re-inventor of Apple
- Singular focus on the needs of his customers
  - Understood his audience
  - Adapted designs to users not users to designs
  - Clear brand image

# Professional Communication is Key



- Current Problem

- Palliative care is linked to “end-of-life” care in the minds of the professionals and to a certain extent, policy makers
- Reinforced by all of us unwittingly and routinely
- Major barrier to ensuring access to high quality medical care for persons with serious illness – even those who are dying

# Efforts to Improve “End-of-Life” Care (1995-2004)



- Project on Death in America
  - *Soros’s OSI initiative to fund palliative care initiatives*
- Promoting Excellence in End-of-Life Care
  - *RWJ initiative to support research/education in palliative care*
- On our own terms: Moyers on Dying
  - *8 hour documentary series on palliative care*
- Approaching Death: Improving care at the end of life
  - *IOM report*
- Handbook for Mortals
  - *Consumer self-help book*
- Last Acts
  - *RWJ consumer advocacy organization*



# Language Matters

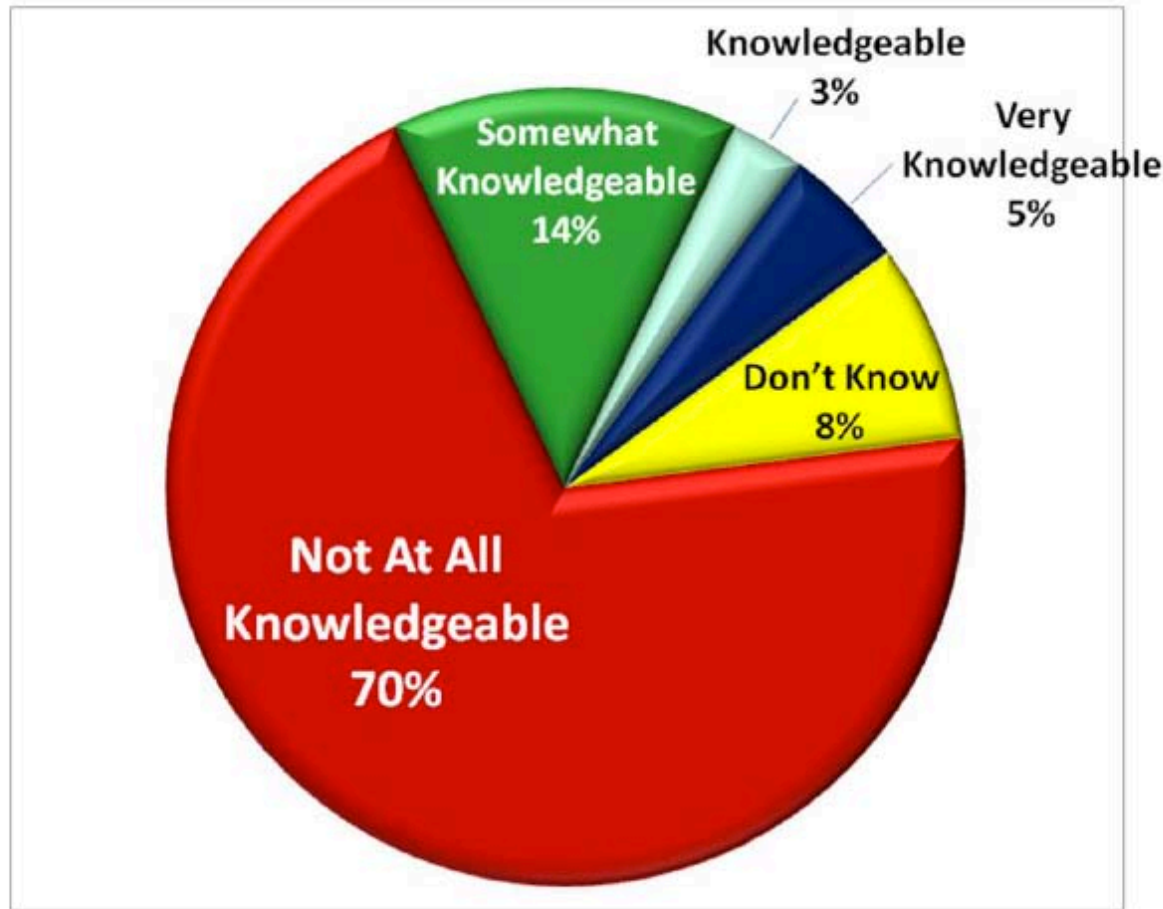
- If our goal is to improve care of the seriously ill the major barrier we face is self-imposed.
- Many people who need palliative care are not dying.
- Even among the subset that are, no-one wants to die, and very few, including clinicians, are able to accept that they are dying until death is imminent.
- We need to decouple palliative care from end-of-life care, terminal care, care of the dying

# Our messages to the public



- “The doctor," she said, "should be saying to the patient, 'Even though we can do this, we shouldn't do this. Your loved one has a terminal illness we can't make better.' Someone has to step into the craziness and say, 'Even though the treatments are out there, they're not appropriate because they create suffering.' Nobody will do that, and it's sad.”...Philadelphia Inquirer
- For reasons both financial and compassionate, hospitals are enthusiastically launching palliative care programs whose specially trained personnel focus not on trying to heal or cure patients coping with life-limiting illness, but on alleviating their symptoms and offering emotional comfort, too...US News and World Report

# What About the Public?



\*Data from a Public Opinion Strategies national survey of 800 adults age 18+ conducted June 5-8, 2011.

# Palliative Care: New Language

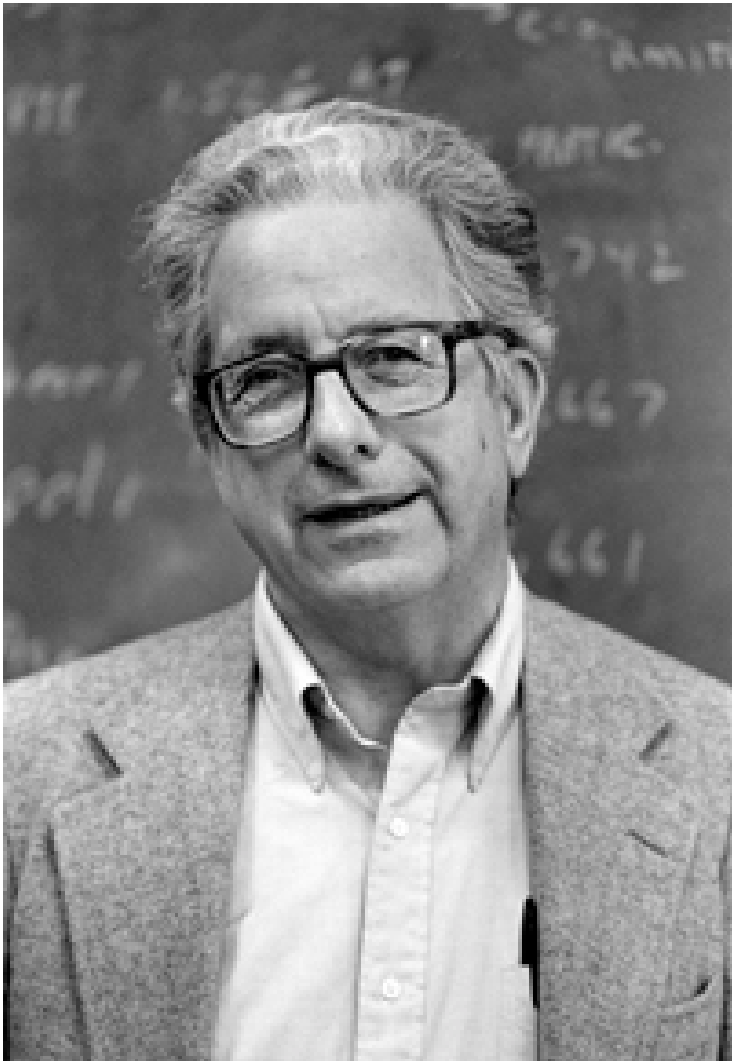


- Palliative care is specialized medical care for people with serious illnesses. It is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness - whatever the diagnosis. The goal is to improve quality of life for both the patient and the family.
- Palliative care is provided by a team of doctors, nurses, and other specialists who work with a patient's other doctors to provide an extra layer of support.
- Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.

# Once Informed...

- **95%** of respondents agree that it is important that patients with serious illness and their families be educated about palliative care.
- **92%** of respondents say they would be likely to consider palliative care for a loved one if they had a serious illness.
- **92%** of respondents say it is important that palliative care services be made available at all hospitals for patients with serious illness and their families.

# Paul Meier, Statistician (1924-2011)



- Kaplan-Meier Survival Curve
  - 35,000 cites
- Early and successful proponent of the RCT
  - Actions, writings, and influence on policy makers led to wide-scale adoption of the RCT as the standard for FDA clinical trials
  - Millions of lives saved

# Enhancing Care for Those with Serious Illness: Next Research Steps



- High quality targeted pragmatic research
  - Symptoms, communication, models of care delivery, measures
- Policy initiatives
  - Education
  - Quality
  - Funding
  - Implementation

# 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.



What will the next 2 days  
hold?

# 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
  
- 16 RNs, 60 MD/DOs, 20 PhDs (psychology, health services research, behavioural medicine), 1 SW
- 32 Junior investigators, 53 Experienced investigators

# Our Schedule...

# Today



- 9:30 - 10:30 am: Opening Plenary
  - “*Building a Palliative Care Journal*”, Charles Von Gunten, MD, PhD
- 10:30 - 10:45 am: Break
- 10:45 - 12:00 pm: Poster presentations
- 12:00 - 12:30 pm: Lunch
- 12:30 - 1:00 pm: ACS Palliative Care Pathfinder Award
- 1:00 – 2:30 pm Work in progress presentations
- 2:30 – 5:00 pm Free and networking time
- 5:00 – 6:30 pm Research Challenges and updates
- 6:30 – 7:00 pm Wine and cheese reception
- 7:00 - Dinner

# Wednesday

- 8:00 – 9:00 am: Continental breakfast
- 9:00 – 10:30 am:
  - A) Mock study section: Junior investigators
  - B) Mentorship challenges: Experienced investigators
- 10:30 – 10:45 am: Break
- 11:45 – 12:00 pm: National Policy and Research Updates in Palliative Care
- 12:00 - 12:30 pm: Lunch
- 1:00 – 2:00 pm Plenary
  - *“Research Priorities in Pediatric Palliative Care”*, Christina Ullrich, MD
- 2:00 – 3:30 pm: Free time
- 3:30 – 5:00 pm: Research Consultancies
- 5:00 - 6:00 pm: Closing Plenary
  - *“Early Palliative Care-Improve Life Quality and Survival”*, Neil MacDonald, MD
- 6:00-6:30 pm: Reception
- 6:30 pm - Dinner

# Wayne Gretzky, “The Greatest” (1961- )



- “I skate to where the puck is going to be, not where it has been.”