

# 3<sup>rd</sup> Annual Kathleen M. Foley Palliative Care Research Retreat and Symposium

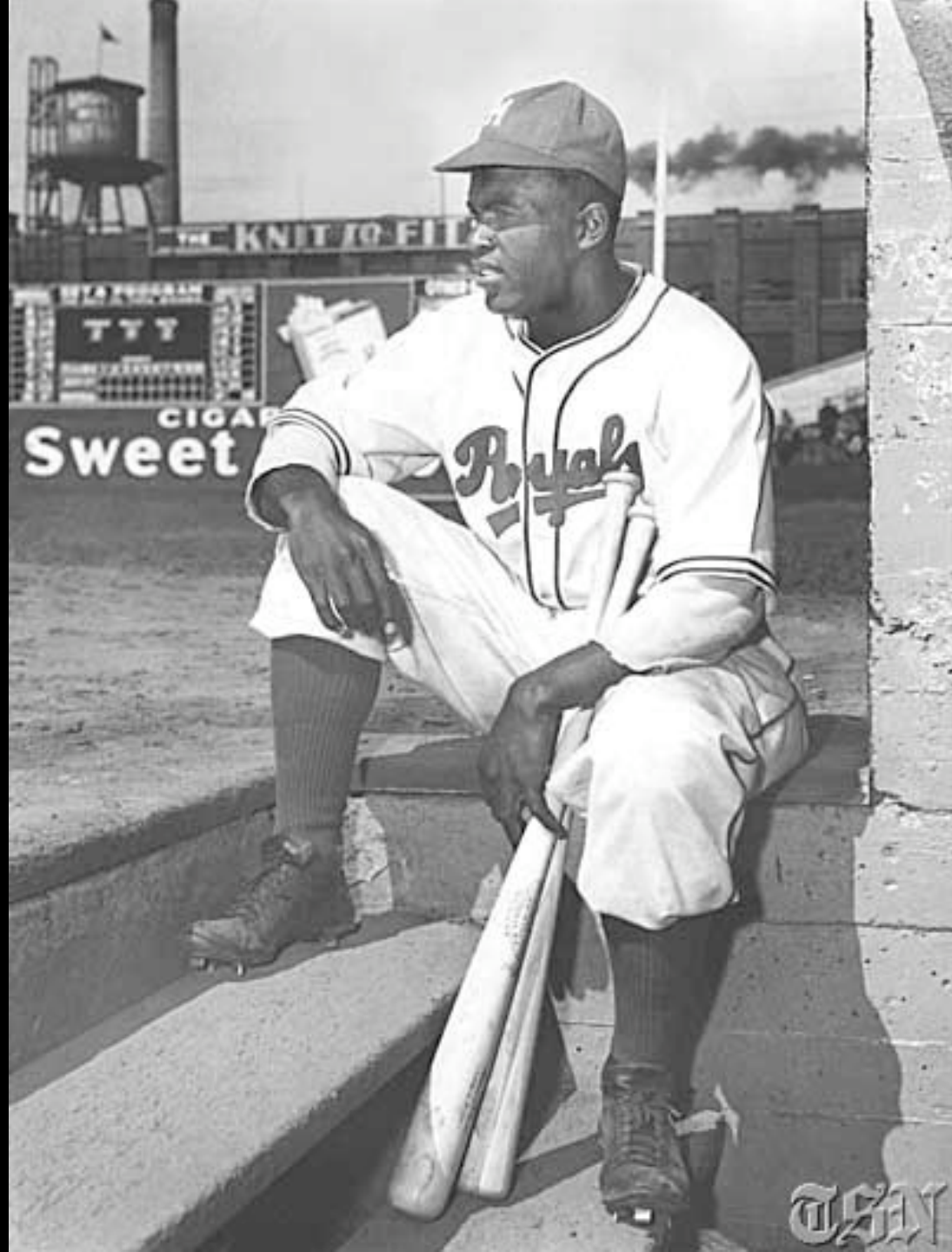


A collaborative meeting jointly sponsored by:

- The National Palliative Care Research Center
- The American Cancer Society
- The American Academy of Hospice and Palliative Medicine



American Academy of  
Hospice and Palliative Medicine



# National Palliative Care Research Center ([www.npcrc.org](http://www.npcrc.org))



- Center developed in response to the:
  - Shortage of palliative care funding structures;
  - Shortage of palliative care investigators;
  - Need for a national organizational home for palliative care research.
- Primary mission is to improve quality of care for patients with serious illness and meet the needs of their caregivers by promoting palliative care research and translating research results into clinical practice.

# Funders and Partners



- **Funders:**
  - Emily Davie and Joseph S. Kornfeld Foundation
  - American Express
  - Atlantic Philanthropies
  - Brookdale Foundation
  - Ho/Chiang Foundation
  - Levy Foundation
  - National Institute on Aging
  - Olive Branch Foundation
  - Open Society Institute
  - Partnership for Palliative Care
  - U.S. Cancer Pain Relief
- **Partners:**
  - Center to Advance Palliative Care (CAPC)
  - Mount Sinai School of Medicine
  - American Cancer Society
  - American Academy of Hospice and Palliative Medicine (AAHPM)

# NPCRC Areas of Focus



- Exploring the relationship of pain and other distressing symptoms on quality and quantity of life, independence, function, and disability and developing interventions directed at their treatment in patients with advanced and chronic illnesses of all types;
- Studying methods of improving communication between adults living with serious illness with their families and their health care providers;
- Evaluating models and systems of care for patients living with advanced illness and their families.

# NPCRC Current Activities



- Pilot/Exploratory Grants
  - Goal is to provide experienced investigators with pilot/exploratory data that will support larger NIH/VA/Foundation funded research grants
- Junior Investigator Career Development Awards
  - Goal is to provide 2 years of protected time for junior investigators in palliative care
- Annual Research Retreat and Symposium
- Research Consultancy Program

# Research Consultancy Program



- Provides up to 10 hours of research consultancy to palliative care investigators
  - Biostatistics, qualitative methods, epidemiology, design, assessment, instrument selection
- Team of national experts in palliative care research
- Supported by NIA (K24 AG022345)

# NPCRC New Initiatives For 2010



- National Palliative Care Registry
- Palliative Care Compare (6/10)
- Research priorities in palliative care
- Users guide to palliative care research
  - JPM series focused on key issues in palliative care research
  - Led by Melissa Carlson (2007 NPCRC scholar)
  - Paired junior NPCRC and experienced investigators as co-authors
- Web-based guide to NIH submission
  - “What’s not in the RFA”
- Electronic library of successful NIH grants



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## National Palliative Care Registry

The Registry was created by CAPC and the NPCRC to help standardize structures and processes of care and demonstrate the reach and impact of palliative care in the nation's hospitals and beyond. This is a key step toward ensuring the long-term quality and sustainability of palliative care in the U.S. health care system.

Put your program on the map and help palliative care become part of the genome of American medicine!

Want to register your program?

[Register Now](#)

Already started your registration?

[Log In](#)

When you register your program, you'll be able to:

- Receive a premium listing in the [www.getpalliativecare.org](http://www.getpalliativecare.org) Provider Directory. Your listing will be highlighted and will have more complete information than a regular listing.
- Track your program's structures and processes of care, year after year, to guide the development and sustainability of your program.
- Be included in CAPC and NPCRC prevalence studies.
- Generate in-depth, customized reports comparing your program to your peers' through Palliative Care COMPARE™ (COMING 2010!). Use comparisons to peers' programs to help secure needed resources.

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# NPCRC Goals For 2020

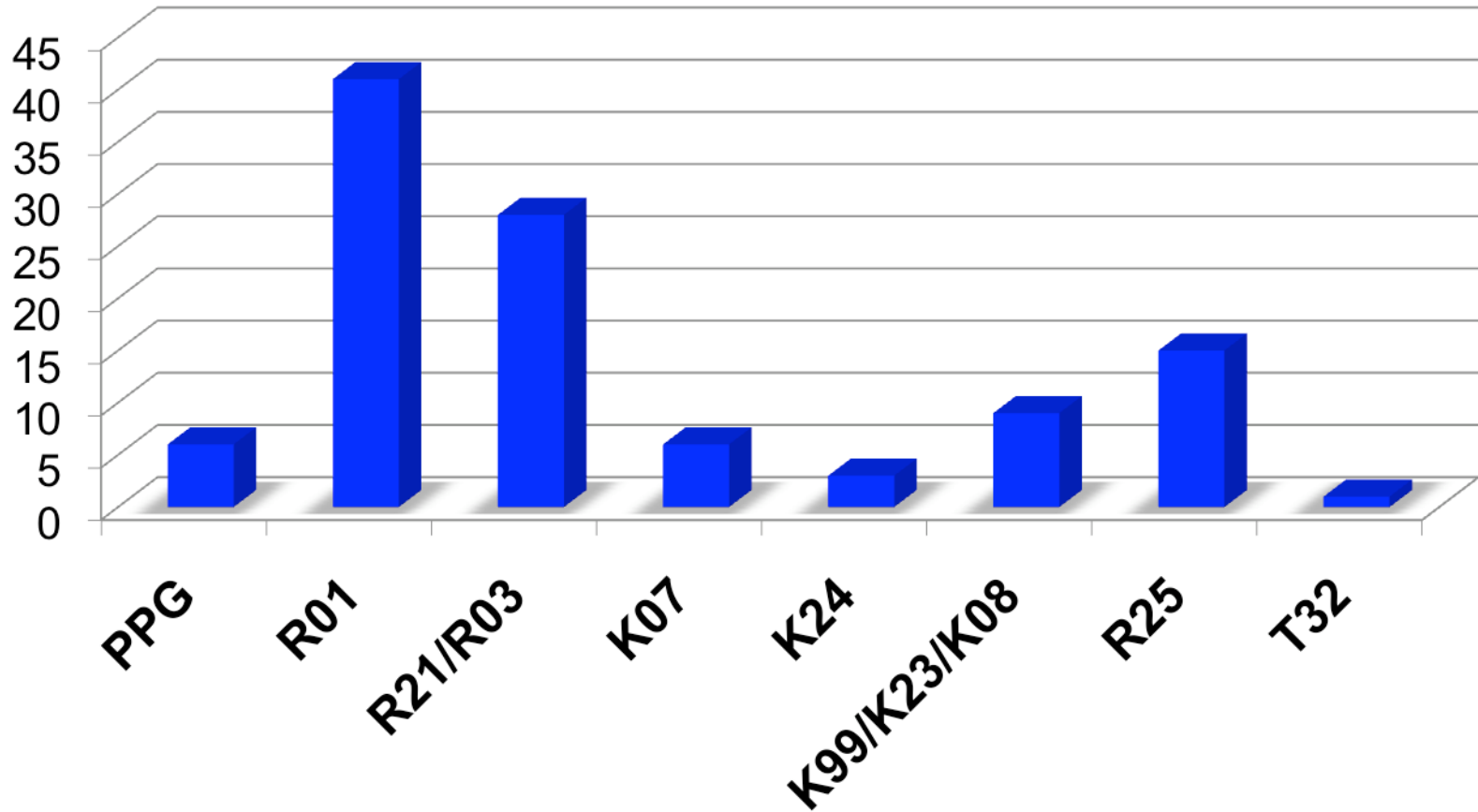


- **NIH funding for palliative care research will quadruple and all major Institutes will fund palliative care research.**
  - *Ensures adequate funding stream.*
- **All relevant NIH study sections will have  $\geq 2$  palliative care researchers.**
  - *Ensures appropriate peer review.*
- **The top 30 ranked medical/nursing schools in NIH funding will have  $\geq 3$  NIH R01 funded palliative care investigators.**
  - *Ensures adequate numbers of investigators and an adequate infrastructure to support new knowledge development and the development of the next generation of investigators.*

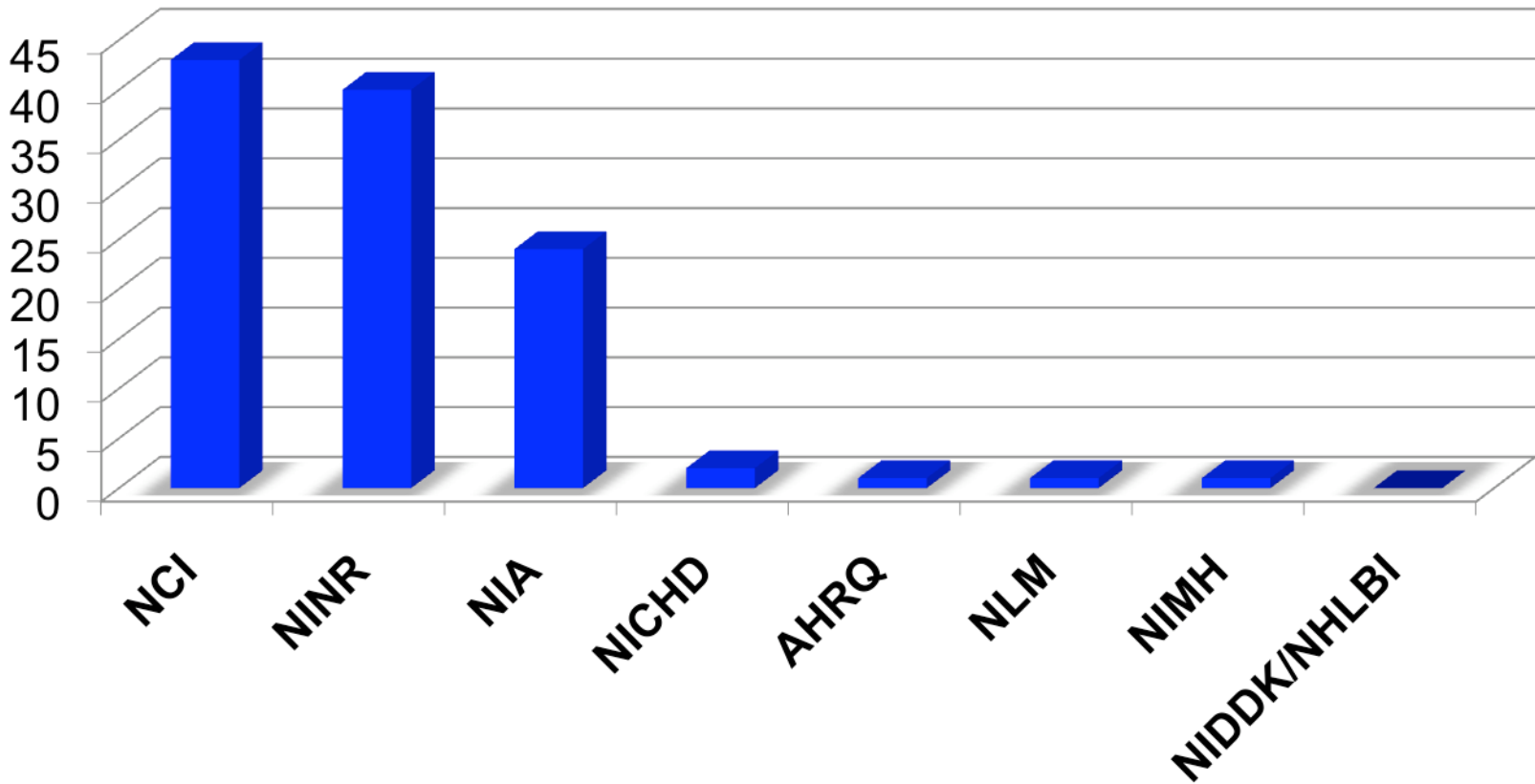
# 2009 Baseline: Grants

- 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)

# 2009 NIH Palliative Care Grants by Mechanism



# 2009 NIH Palliative Care Grants by Institute



# 2010 Baseline: Study section membership

- NIA-C: 1
- NIA-S: 1
- BMIO: 2
- HSOD: 2
- NCI – Career Development Subcommittee: 0
- NSAA: 2
- Others??

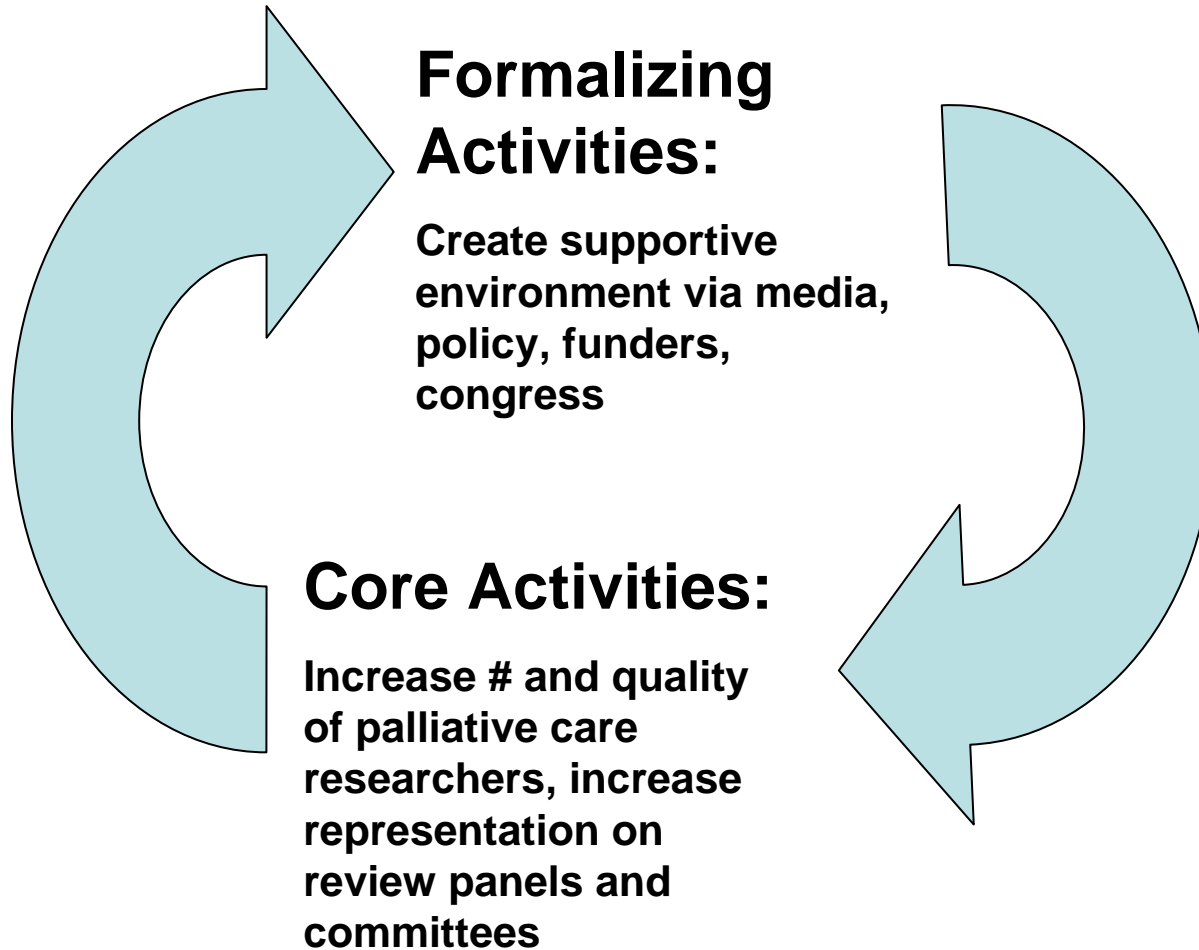
# 2010 Baseline: Medical/Nursing Schools with R01 Funded Investigators



- Three or more
  - Brown, Harvard, Duke, MSSM, UCSF
- Two
  - CWU, City of Hope, Dartmouth, MSKCC, University of Nebraska, University of Pennsylvania, University of Rochester, Yale University



# How do we get to our 2010 goal?



# Bottom-up

- Grant submissions:
  - High quality: science and “grantsmanship”
  - Targeted
  - Audience specific
- Peer review
  - Increase representation of palliative care on key NIH, AHRQ, VA review panels
    - Proactively refer
    - If asked, serve
    - Don’t eat our young
    - Avoid the circular firing squad

# Top Down

- Policy – make the case in DC and at the state level
- Demonstrate how palliative care research can help solve the healthcare crisis
  - Media, outreach, technical assistance
- Insert palliative care into VA/AHRQ/NIH funding priorities
- To be continued on day 3....

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, and develop new research ideas and collaborations.

# 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, 52 MD/DOs, 15 PhDs (psychology, health services research, behavioural medicine), 3 SW, 1 DDS
- 29 Junior investigators, 57 Experienced investigators

# Our Schedule...

# Tonight



- 4:45 - 5:00 pm: ACS Pathfinder Award Presentation
- 5:00 - 6:00 pm: Opening Plenary
  - XXX, Judith A. Paice, PhD, RN, FAAN
- 6:00 - 6:30 pm: Networking Reception
- 6:30 – 9:00 pm: Dinner



# Wednesday

- 7:00 – 8:00 am: Continental breakfast
- 8:00 – 9:45 am: Moderated poster session
- 9:45 – 10:00 am: Break
- 10:00 – 11:45 am: Research in progress presentations
- 11:45 – 1:00 pm: Lunch with Panel
  - “Successfully managing a modern academic career”
- 1:00 – 5:00 pm: Networking/Free time
- 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: “Taking action to advance palliative care: Why public policy matters” (experienced investigators)
- 7:30 – 9:00 am: Grant workshop part I: Mock study section (junior investigators)
- 9:00 – 9:15 am: Break
- 9:15 – 10:15 am: Closing Plenary
  - “xx’, Anthony Back, MD
- 10:15 – 10:30 am: Goodbyes and evaluations
- 10:30 am: Shuttle departures to ATL

# A Final Note...

