

# NYCARE

**New York Consortium for Advancing  
Alzheimer Research and Education**



# Partners

## Alzheimer's Disease Centers

### Columbia University

 Karen Bell, MD

### Mt. Sinai Medical Center

 Margaret Sewell, PhD

 Mary Sano, PhD

### NYU School of Medicine

 Mary S. Mittelman, Dr.PH

 Christine M. Weber, PhD

## Alzheimer's Association, NYC Chapter

 Jed Levine, MA

 Della Frasier Rios, RN, MS



# Goal of NYCARE

- The goal of the Consortium is to promote awareness and advance knowledge of people with Alzheimer's disease, family caregivers and health care providers regarding current research, treatments, clinical trials, and services



# Aims of NYCARE

- To conduct collaborative educational activities
- To develop methods to evaluate the success of outreach and education
- Expand the audience for our educational efforts.



# Results of NYCARE

- Monthly meetings
- Closer affiliation of 3 ADC's
- Closer affiliation of ADC's with the NYC Chapter of the Alzheimer's Association
- Wider audience for education
- Collaboration in many educational endeavors






# Memory Walk

- Participate as a team
- Visibility for NYCARE
- Joint fundraising for Alzheimer's Association



# Alzheimer's Association Quarterly Newsletter - 4 page centerfold

## Wide circulation and visibility

-  Mailed to 35,000 readers
-  Sent electronically to 2,000 readers
-  Available online at [www.alznyc.org](http://www.alznyc.org)

## Articles written collaboratively

-  Rotating responsibility
-  Reviewed and edited by all NYCARE participants

## List of studies and clinical trials currently enrolling participants in each ADC



# Newsletter Research Articles

- Brain Donation: The Gift of Knowledge
- The Role of Genetics in Alzheimer's Disease
- What is Mild Cognitive Impairment?
- Participating in Clinical Research: What you need to know
- Winter 2001: Speaking with your Doctor about Treatments for Alzheimer's Disease: What to Ask and What to Expect to Hear
- Spring 2002: The Importance of Support for Family Caregivers
- Summer 2002: Clinical Trials
- Fall 2002: Does Estrogen Have a Future in Treating Alzheimer's Disease?
- Winter 2002: The Caregiver's Dilemma
- Spring 2003: The Role of Cholesterol and Cholesterol-Lowering Medications for Alzheimer's Disease
- Summer 2003: Dementia with Lewy Bodies
- Fall 2003: Cholinesterase Inhibitors: Answers to frequently asked questions about their use
- Winter: Behavioral Symptoms of Alzheimer's Disease
- Spring 2004: NYC ADC's Participating in the NIA Alzheimer's Disease Genetics Initiative
- Summer 2004: Maintaining Quality of Life: A Delicate Balance





# CME Courses for Physicians

- Joint responsibility for design and content
- Joint responsibility for funding
- Rotating responsibility among 3 medical schools for accreditation
- Joint responsibility for presentation
- Joint responsibility for recruiting
  - High prescriber list of 1100 doctors
  - Intranet web messages at medical centers



# Development of Evaluation Tools

- The effectiveness of education seminars for the general public
  - Before and after questionnaires responded to by audience raising hands
  - Rated by representatives of 3 Centers and Alz. Assn.
  - Established inter-rater reliability of independent raters
  - Provided evidence for the effectiveness of our outreach programs
    - Seminar series at NYUMC
    - Outreach in community settings



# Development of Evaluation Tools

- The effectiveness of CME courses for physicians in the community
  - Used audience response system
  - Assessed change in willingness to refer patients and family members for evaluation, participation in clinical trials and services of the Alzheimer's Assn.



# Annual Mayor's Conference on Alzheimer's Disease

- Increase visibility to many service providers who attend
- One table for NYCARE rather than 3 tables for 3 centers
  - Shares cost
  - Advertises collaboration



# Our New Partner

## New York City Department for the Aging (Our local Area Agency on Aging)

- Builds on 20+ year informal relationship
- Facilitates sharing resource information
- Potential for new funding opportunities
- Broader base for potential client contact
  - Caregiver programs - National Family Caregiver Support Program
    - 15 Community Partners
    - serving people who speak 13 languages (besides English)
  - Case management.
- Experience providing services to the underserved
- Experience negotiating the system
- Experience with non-English speaking elderly
- Familiarity with issues unique to different areas and cultures
- Linkage to groups advocating for benefits for the elderly with dementia and their families.



# Challenges to Collaboration

- What to share and what to keep for ourselves.
- How to fund development of evaluation tools
- How to reach a wider audience
  - Health care providers
  - Elderly with undiagnosed dementia
  - Families with no formal services



# Why We Want to Continue NYCARES

- We can reach a larger audience
- We can appeal to a wider set of sources for potential funding
- Collaboration brings new ideas
- It's more fun to work together than to go it alone.

