

## OUTRAGEOUS

## COURAGEOUS

### OUR SOCIETY IS JUST NOT READY

**I**t was a Tuesday evening, 6:30, and I was at the emergency room of a local New York City hospital. This was the second time in four months that my mother, who suffers from dementia, was in this emergency room. She had fallen at home and cut her forehead. Her home health aide had tried to have EMS take her to the hospital where she receives ongoing medical care, but EMS had refused.

I marveled at the chain of events that had brought us this far. My mother, who had been the matriarch of her family, a dedicated wife and mother, a working woman, a respected member of her community and church and a superb caregiver to her husband with Alzheimer's disease, succumbed to dementia shortly after his death in 1997.

In the emergency room, the home health aide had a difficult time advocating for my mother and I quickly came to understand how powerless even I (a professional social worker) was in negotiating decisions concerning her medical care. When I arrived at the emergency room, I

*Continued on page 5.*

### DEMENTIA UNIT OPENS CULTURE CHANGE IN ACUTE CARE

**C**abrini Medical Center (in Manhattan, at 227 East 19<sup>th</sup> Street: 995-6000) has opened a new sub-unit dedicated to individuals with dementia who require hospitalization while catering to the needs of their family caregivers. Nestled within Cabrini's Geriatric Unit, this sub-unit is named "Windows to the Heart" by its staff, and promotes an individualistic manner of care to each patient and respective families and caregivers.

The Unit's staff, which is composed of nursing staff and members of support services including social services, case management, chaplaincy, environmental services, homecare, and dietary, have completed eight months of specialized training. The training had two components. First, experts in organizational change management taught the staff on

how to promote teamwork and enhance the existing corporate culture to better serve the family-unit. Second, a clinical psychologist led eight months of training designed to understand and fulfill the biopsychosocial needs of the patients.

*Continued on page 5.*

*Hospitals are clearly another weak link in the system. Caregivers told numerous horror stories of trips to the Emergency Room (ER) where the caregiver was thrown out and the confused patient left to fend for himself in a chaotic urban ER environment. They told stories of hospitals that provided hard food that had to be cut, and when meals went uneaten, doctors assumed a decrease in appetites. They even reported experiences where patients were found tied to the bed, because "we have to keep her safe and we can't watch her." Nursing home administrators described nursing home residents with pneumonia being sent to the hospital, only to be moved from the ICU to the psychiatric ward because of their dementia. In every case, those relating these stories were careful to say that medical staff was trying to do the right thing - but were simply at a loss as to how to cope with a dementia patient.*

*From Carey Godell's external, review report to the Chapter's Long-Range Planning Committee, Spring 2000.*

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*Maureen Reagan,  
keynote speaker, Sept. 18  
Conference (see pg. 12)*

Alzheimer's Disease and  
Related Disorders Association  
New York City Chapter  
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## Director's Note



### World Alzheimer's Conference

If a cure or effective treatment for Alzheimer's isn't found soon, it is projected that by the year 2025, 22 million people will suffer from this disease.

Researchers and doctors are seeking to attack AD at any point where it may prove vulnerable—will the key be prevention, early detection, or a cure after the fact?

No one knows for sure, but at the World Alzheimer's Congress 2000, to take place in Washington, D.C. from July 9-18, an unprecedented concentration of strength, determination and expertise will be brought to bear upon the 21st century's greatest health challenge.

John Jager, executive director of the NYC Chapter, speaks of the conference goals: "World leaders in Alzheimer's research and care will unite at Alzheimer 2000 with change in mind—change that will lead to new, integrated ways of thinking about the entire spectrum of Alzheimer's disease."

Sharing knowledge and strategies can only bring us all closer to eliminating this threat. For registration information, see notice (below).

John Jager

*Executive Director*

#### World Alzheimer Congress 2000



With Change in Mind

Pivotal Research and Creative Care

JULY 9-18, 2000 WASHINGTON, D.C., U.S.A.

**World leaders in  
Alzheimer research  
and care come  
together with  
change in mind.**

Expected to attract some 5,000 attendees from around the globe, Alzheimer 2000 will mark the first time researchers, physicians, care providers, and other Alzheimer specialists have come together to identify strategies for improving care and for eliminating the threat of Alzheimer's to today's citizens and future generations.

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For more information, call the conference information line at  
312.335.5813, visit our Web site at [www.alzheimer2000.org](http://www.alzheimer2000.org),  
or e-mail us at [alzheimer2000@alz.org](mailto:alzheimer2000@alz.org).

ALZHEIMER'S  
ASSOCIATION

Alzheimer's Disease  
International

Alzheimer  
Society  
CANADA

# Welcome to the BOARD OF DIRECTORS



## ANNEMARIE TOBIN

Annemarie Tobin is a Senior Vice President with Marsh, Inc., a leading disk and insurance services firm. Prior to joining Marsh, Annemarie was with CNA Insurance in Chicago.

A Chicago native, Ms. Tobin moved to New York City in 1997 determined to contribute to the community in a meaningful way. Her mother passed away in 1998, yet the disease continues to affect her mother's sisters.

In 1998, Ms. Tobin met Nancy Morse and became interested in the activities of the NYC Chapter. The time and difficulty of finding out about resources to help her mother convinced Ms. Tobin that she wanted to work in raising awareness of the assistance available to family caregivers locally.

## MEMORANDUM . . .

**TO:** Friends, family members and professionals

**FROM:** Jean Marks  
(Retiring) Associate Executive Director



It is with great sadness (and pleasure for the work we succeeded in doing together) that I take my leave of this wonderful organization.

In lieu of the traditional farewell party, I am asking that our Board of Directors make a donation to The Minna Pollock Respite Fund.

The fund, created by a former President of the Chapter, Jack, in memory of his wife, directly and simply pays a small respite stipend to day care, home care, or overnight respite care providers to help families over some of the rougher spots during their caregiving lives.

A by-product of the fund is that it also helps our superb staff who experience parallel frustrations to yours as they confront, on your behalf, intractable problems and inadequate resources.

Should you wish to support our community through The Minna Pollock Respite Fund, please address your donation to my attention before July 30 or to Jed Levine's attention thereafter at the NYC Chapter: 360 Lexington Avenue, 5th Floor, New York, NY 10017.

## Editor's Note

Right about now, many of you are looking forward to your summer vacations. Of course, if you're involved in caring for someone with Alzheimer's, you know there's no time off. And every time you learn to cope with the demands of the situation, it changes, and not for the better.

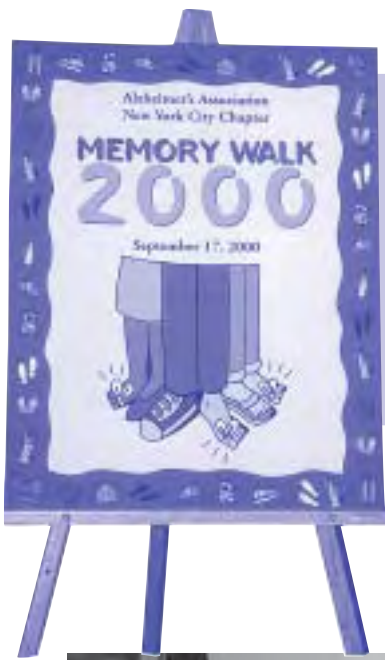


The Alzheimer's Association isn't just an organization. We are individuals who have been through what you're going through. This applies to the majority of our staff, volunteers, support group leaders and our Board of Directors. Don't feel that you must stoically accept the frustration, isolation and exhaustion that make caregiving so stressful; don't shoulder the burden alone. For 20 years, for thousands of families, we've been a lifeline when the bottom dropped out of their world.

Even if we can't banish all the clouds, we make it our business to celebrate the silver linings. One that will shine brightly is the involvement of persons with early stage Alzheimer's in "The Human Face of Alzheimer's, Breaking Through the Stigma" on Sept. 18. This will be the first conference which was planned with people with the disease and where they will have the opportunity to speak themselves; it's important for us to listen (see page 12.)

"Windows to the Heart" (see cover) represents a breakthrough in that it's the first acute-care unit designed for dementia patients. Cabrini Medical Center — where this eight-bed unit is located—worked in conjunction with our Chapter staff to create what will serve as a model for a new standard of care that, we hope, will ultimately be adopted (inter)nationally.

—Chris MacLeod



# MEMORY WALK *Kickoff*

At Gracie Mansion



*Mayor Rudy Giuliani presents the Alzheimer's Week Proclamation to Chapter co-president Irv Flinn.*



*Not everyone gets invited to Gracie Mansion for breakfast with the Mayor (center), here with Irv Flinn (left) and Herman Badillo (right).*

# VOLUNTEER LUNCHEON



*Left to right: Edith Rappy, Frances Decker, June Schofield, Lila Courtian, Angelina Memisha and Lucille Fischer.*



*Left to right: Pearl Goldfarb, Jack Pollack, Sophie Finkelman and Bernard Saper.*

# COURAGEOUS

*Continued from page 1.*

Families (or the patient's professional caregiver) are invited to spend time (including nights) in a special lounge area, which has a shower and kitchenette for their use. The staff will work with families to schedule X-rays and other tests and procedures at a time when the family caregiver is available to comfort and guide the patient during tests. In addition, the unit has open visiting hours, and families are welcome and appreciated whenever they are able to come. Patients will, of course, stay under the care of their usual attending physician.

Dr. Jeffrey Nichols, Chief of Geriatric Medicine and Palliative Care notes, "Family caregivers should not be an afterthought in the care of dementia patients. They should be involved throughout the entire care process--from the emergency room to inpatient care to education of the family before a patient is discharged. Dementia patients have very special needs and are part of a family unit."

"Windows to the Heart" was made possible through programmatic funding awarded by the United Hospital Fund. The recipients, Cabrini and its community partner, the NYC Chapter of the Alzheimer's Association, expect that this state-of-the-art (or should we say "heart") approach will become a new standard of care for dementia patients and their caregivers in hospitals.

Opened on April 5, 2000, "Windows to the Heart" is still in its initial stages of growth. As such, Cabrini seeks volunteers to help develop and lead activities and programs for the unit. For further information on the "Windows to the Heart," please call Dr. Jeffrey Nichols at (212) 995-6000. For more information about the United Hospital Fund's Families and Health Care Project, call (212) 494-0700 to purchase a copy of [Rough Crossings: Family Caregivers' Odysseys Through the Health Care System](#).



# OUTRAGEOUS

*Continued from page 1.*

was refused entry and a security guard threatened to arrest me when I attempted to speak to a nurse regarding my mother's condition and the fact that she had dementia. The threat of arrest and the security guard's menacing manner was a frightening experience that was uncalled for; I merely wanted to see her and to make sure that they were aware that she had dementia. Only after I demanded to have my mother either discharged or transferred to another hospital did the emergency room physician come to speak to me. This physician told me that she was to be admitted, would probably need a pacemaker and if I wanted to transfer her to another hospital I would have to go home and get a health care proxy. A pacemaker? She had come in for a fall and now they were going to give her a pacemaker? I rushed home and got the health care proxy. As a community advocate as well as a social worker, I had my documents in place knowing that they might be necessary at some future date. I had taken the advice that I had given to hundreds of families that I had counseled throughout the years.

I returned to the hospital armed with the health care proxy. By then two hours had passed before I was allowed to see her. After a change of shift, the doctor who got my mother's case sat at the nurse's station and exclaimed, "So she's the one," to the physician I had spoken to. To that I responded, "Yes, she is the one." That was the beginning of the end. Then he pointed his finger in my direction, silently signaling for me to come to him; when ignored he finally had to speak and say "come here." When I attempted to ask questions, he cut me off to show me an EKG. I acknowl-

edged his findings and reported that I had a health care proxy and that I wanted her transferred to the hospital where she received her ongoing care. He responded with "I don't care what you have, I'm admitting her." Shocked, I asked to speak to a social worker or a patient representative. He said I should call whomever I wanted and that I should get in touch with my lawyer. He then proceeded to pick up the phone and call Risk Management and yelled for security to get me away from the nurse's station. I said to him "This is not necessary! Why are you behaving this way?" He did not respond.

My mother was sedated with Ativan to secure a CAT scan (I was never consulted on her medical history or the medications she was currently taking.) Against my will, she was being prepared to be admitted. I was removed from the emergency room and I stood in the waiting area, overwhelmed, not knowing what to do. I made several calls and got voice mails and then I decided to call the Alzheimer's Association. I was so glad to hear a friendly and understanding voice. The helpline counselor's support and reassurance soothed me and helped me to gather my thoughts.

Shortly thereafter, I read the patient's bill of rights. Then I found a number to contact the hospital's patient representative. I explained my dilemma. The patient representative quoted a Cobra law that would not allow for a patient in an acute medical state to be moved. Further, she reported that my mother had said that she wanted to stay in hospital and therefore was deemed competent to make

*Continued on page 12.*

# PUBLIC POLICY UPDATE

## NYS Legislature Appropriates Monies for Alzheimer's

This year the joint Legislative Agenda of the NYS Alzheimer's Association Chapters and the Alzheimer's Disease Assistance Centers (ADACs) called for Alzheimer's 2000, a statewide funding initiative. Advocacy efforts focused on a state budget commitment to advance the work of the twelve Alzheimer's chapters, the nine ADACs which provide diagnostic and treatment services, and community agencies throughout the state. Funding was sought for programs that support early diagnosis, education, caregiver training, and essential support services. The Legislature heard us and responded.

The Alzheimer's Association chapters across the state will receive a total of \$235,000 for the Alzheimer's Community Assistance Program (AlzCAP); the Alzheimer's Community Service Program will receive \$300,000, and the ADACs, an increase of \$90,000 over last year's funding for a total of \$576,000. Additional monies from funds available to legislators individually ("Member Items") will go to various local programs and services that address Alzheimer's disease. All told, the needs of the Alzheimer's community have been recognized for a grand total of \$1,376,700. And our advocacy efforts are already underway to increase these monies in next year's state budget.

In addition, there are a number of other items of interest and importance to the Alzheimer's community. As a result of NYS Assembly efforts surrounding passage of the health care reform package by the Legislature and signed by Governor Pataki, there is to be a three-year "quiet period" for Medicaid. No new Medicaid cuts are to be proposed and there were none in this year's budget. This is very good news for all who have fought state cost containment proposals in recent years which involved reductions in home and community-based services and spousal protections.

This year's Legislative budget also provides one million dollars for social model adult day care. Funding has long been sought for this model of care, which can benefit many with

Alzheimer's throughout the state. This is a very important step in assuring needed funding.

In addition, the Legislature expanded the Elderly Pharmaceutical Insurance Coverage program (EPIC). Originally, this expanded coverage was to begin October 1, 2000. However, due to the cost of expansion (\$180 million when fully implemented) the expansion has been postponed until January 1, 2001.

There is also a commitment on the part of the Legislature to provide \$80 million in Temporary Assistance to Needy Families (TANF) surplus funds to address health workforce recruitment and retraining. Workforce issues are a major priority of the national Alzheimer's Association and of organizations and advocacy groups throughout NYS. Workforce issues must be addressed to assure quality care in nursing homes and the home. There must be better pay and training for those who do this important and too often unrecognized work on behalf of persons in need of long-term care.

Last, but far from least, Assemblywoman Helene Weinstein introduced legislation to make safety monitoring/assistance with health and safety needs due to physical or cognitive impairment part of the definition of personal care under state Medicaid law. This legislation would redress the Circuit Court decision last fall in the Rodriguez case. The Court had held that under the NYS task based assessment for personal care/home care under Medicaid, safety monitoring was not a task. Therefore, persons with Alzheimer's would not receive hours of personal care for conditions such as wandering. Without safety monitoring, persons who wander would be unable to remain in their own homes unless a family member or other person were to be available to supervise them.

Ann Berson  
Public Policy Coordinator  
May 2000

## ANNUALS AND PERENNIALS—a Gardening Approach to Giving

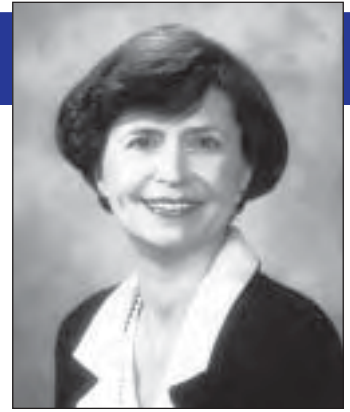
Whether you are an avid gardener or simply water the plants on your windowsill, you know that there are two kinds of flowers. "Annuals" are the ones you plant every year. They are beautiful and varied but, come autumn, they are spent. "Perennials" are those which, when planted once, reappear every year – a gentle reminder that some work pays off well into the future.

Our work at the Alzheimer's Association, New York City is thriving because donors like you provide a blend of "annual" and "Perennial" gifts. Perennial gifts may also be called "**planned gifts**" and include such things as gifts from retirement accounts, gift annuities, insurance, charitable remainder trusts, and will bequests. These are gifts that may require a little extra effort now, but they will continue to bloom well into the future.

For more information about the personal and tax benefits of a "perennial" gift, please call or e-mail Lynne Raymond for your free brochure entitled, "Planning Checklist." Telephone: (212) 983-0700; e-mail: [lynne.raymond@alz.org](mailto:lynne.raymond@alz.org)



# LEGAL INQUIRIES



## **Q. When should Medicaid planning begin?**

**A.** Planning for Medicaid should begin as soon as there is a possibility that an individual will need long term care. To be eligible for Medicaid, at home or in a nursing home, an individual's assets cannot exceed \$5,100. However, those individuals with assets in excess of that amount, should not be discouraged. There are strategies for protecting assets before they are spent down to pay for nursing home services. The strategies take into consideration the "look-back" period and also the penalty period which, in most instances, should not exceed thirty-six months. Note that in contrast to Medicaid nursing-home eligibility, there is no penalty period for accessing Medicaid home care and adult-day-care programs regardless of when resources are transferred or how much.

## **Q. What do I do when a Social Security beneficiary dies?**

**A.** A family member or other person responsible for the beneficiaries should do the following (1) Promptly notify Social Security of the beneficiary's death by calling the Social Security Administration at (800) 772-1213. (2) If monthly benefits were being paid via direct deposit, notify the bank or other financial institution of the beneficiary's death. Request that any funds received for the month of death and later be returned to Social Security as soon as possible. (3) If the benefits were being paid by check, do not cash any checks received for the month in which the beneficiary died or thereafter. Return the checks to Social Security as soon as possible.

## **Q. What is the difference between the Medicare and Medicaid home-care programs?**

**A.** To be eligible for the Medicare home-health-care program an individual must be confined to his home and require skilled nursing or rehabilitation services. Generally, the combined health-care services provided, including that of a home-health aide, do not exceed 35 hours per week. There are no financial criteria for eligibility. In contrast, the Medicaid home-care program does not require the patient to be homebound or necessarily in need of skilled nursing or rehabilitation services. The Medicaid program provides services to persons who may need assistance when performing some of the activities of daily living such as bathing, toileting, dressing, feeding and ambulating. Medicaid recipients may receive as much as 24-hours a day of custodial care, seven days a week. To be financially eligible, an individual may not have more than \$ 5,100 in assets; personal effects; an automobile; and a pre-paid burial contract. The recipient's primary residence - a house, cooperative apartment or condominium - is an exempt asset. Monthly income may not exceed \$620, but there are provisions for the spenddown of excess income. Persons eligible for Medicaid home care services are also eligible for adult-day-care programs which are becoming more widely available.

## **Q. What is the "Nanny Tax" and do you need to pay it?**

**A.** Generally, if someone in your employ is paid \$1200 or more in a year for household work, such as a private nurse, health aide, caretaker or maid, then you must pay employment, state and federal employment taxes. This is sometimes referred to as the "nanny tax." Federal employment taxes are added to your income tax that you will report on your 1999 federal income tax return. These taxes may include Social Security, Medicare, federal unemployment tax, and federal income withholding taxes for your employee.

## **Q. What is the difference between a living will and health-care proxy.**

**A.** A living will is a written statement of an individual's wishes regarding medical treatment. The statement is to be followed if the individual is unable to provide instructions at the time medical decisions need to be made. The health-care proxy is significantly different from the living will in that it empowers another person (the agent) to make health-care decisions if the patient cannot do so herself. The living will, on the other hand, has no such provision but enables a person to express her own choices regarding medical treatment. It makes sense to utilize both a living will and a health-care proxy.

## **Q. What are the changes for HMO enrollment and disenrollment?**

**A.** Effective January 1, 2000, enrollments and disenrollments for Medicare health maintenance organizations that are made from the 1<sup>st</sup> to the 10<sup>th</sup> of the month are effective the first day of the following month. Thus, an election made on May 10<sup>th</sup> is effective June 1<sup>st</sup>. All elections made on January 11<sup>th</sup> to the end of the month are effective the first day of the second subsequent calendar month. For example, an election made on May 11<sup>th</sup> is effective July 1<sup>st</sup>. Prior to January, enrollment and disenrollment were both effective the first of the following month, no matter how early or late in the month the election was made.



*The NYC Chapter congratulates its good friend, Dr. Judah Ronch, on becoming the Executive Director of the Brookdale Center on Aging.*

**WEDNESDAY July 5**

Easing the Transition from Home to Nursing Home  
Time: 6:00 - 8:00 p.m.  
Place: Chapter office

**THURSDAY July 6**

Orientation Meeting for Family Members  
Time: 8:30 - 10:00 a.m.  
Place: Chapter office

**MONDAY July 10**

Education Meeting  
Time: 6:00 - 7:30 p.m.  
Place: Chapter Office  
Topic: Understanding and Coping With the Stresses of Caregiving.  
2 Workshops: Adult Children; Spouses and Siblings  
Speakers: To be announced

**MONDAY July 17**

Medicaid Home Care Seminar: A Practical Guide to the System  
Time: 12 noon - 1:30 p.m.  
Place: Chapter office  
Speakers: Sue Humphries, CSW, NYC Chapter Staff  
Joanne Spellane, Attorney  
Prior attendance at a Legal and Financial Planning Seminar required.

Legal/Financial Seminar  
Time: 5:30 - 7:00 p.m.  
Place: Chapter office  
Speaker: Anne Miles, Attorney

**WEDNESDAY July 19**

Orientation Meeting for Family Members  
Time: 5:30 p.m. - 7:00 p.m.  
Place: Chapter office

**TUESDAY July 25**

Orientation Meeting for Family Members  
Time: 12 noon - 1:30 p.m.  
Place: Chapter office

**THURSDAY July 27**

Legal/Financial Seminar  
Time: 5:30 p.m. - 7:00 p.m.  
Place: Chapter office  
Speaker: David Dorfman, Attorney

**WEDNESDAY August 2**

Easing the Transition from Home to Nursing Home  
Time: 6:00 - 8:00 p.m.  
Place: Chapter office

**THURSDAY August 3**

Orientation Meeting for Family Members  
Time: 8:30 - 10:00 a.m.  
Place: Chapter office

**MONDAY August 7**

Legal/Financial Seminar  
Time: 12 noon - 1:30 p.m.  
Place: Chapter office  
Speaker: Michael Long, Attorney

**WEDNESDAY August 9**

Orientation Meeting for Family Members  
Time: 5:30 - 7:00 p.m.  
Place: Chapter office

**ALL MEETINGS ARE FREE OF CHARGE**

The NYC Chapter office is located at 360 Lexington Avenue, between 40th and 41st streets, on the fifth floor. We extend our thanks to CAPE at the Samuel Field YM-YWHA for the generous donation of space for the Queens Orientation meetings.

**MONDAY August 14**

Education Meeting  
Time: 6:00 - 7:30 p.m.  
Place: Chapter Office  
Topic: Coping With Alzheimer's Disease: Early, Middle, and Late Stages  
Speakers: To be announced

**WEDNESDAY August 16**

Orientation Meeting for Family Members  
Time: 5:30 - 7:00 p.m.  
Place: Chapter Office

**MONDAY August 21**

Medicaid Home Care Seminar: A Practical Guide to the System  
Time: 12 noon - 1:30 p.m.  
Place: Chapter office  
Speaker: Sue Humphries, CSW, NYC Chapter staff  
Joanne Spellane, Attorney  
Prior attendance at a Legal and Financial Planning Seminar required.

Legal/Financial Seminar  
Time: 5:30 p.m. - 7:00 p.m.  
Place: Chapter Office  
Speaker: Douglas Chu, Attorney

**TUESDAY August 22**

Orientation Meeting for Family Members  
Time: 12 noon - 1:30 p.m.  
Place: Chapter office

**WEDNESDAY September 6**

Easing the Transition from Home to Nursing Home  
Time: 6:00 - 8:00 p.m.  
Place: Chapter office

**THURSDAY September 7**

Orientation Meeting for Family Members  
Time: 8:30 - 10:00 a.m.  
Place: Chapter office

Queens Orientation Meeting for Family Members  
Time: 12:30 - 2:00 p.m.  
Place: Samuel Field YM-YWHA Cape Conference Room, 59-28 Little Neck Parkway, Little Neck, NY.

**MONDAY September 11**

Legal/Financial Seminar  
Time: 12 noon - 1:30 p.m.  
Place: Chapter office  
Speaker: Martin Petroff, Attorney

**WEDNESDAY September 13**

Orientation Meeting for Family Members  
Time: 5:30 - 7:00 p.m.  
Place: Chapter office

**MONDAY September 18**

Medicaid Home Care Seminar: A Practical Guide to the System  
Time: 12 noon - 1:30 p.m.  
Place: Chapter office  
Speakers: Sue Humphries, CSW, NYC Chapter Staff, Joanne Spellane, Attorney  
Prior attendance at a Legal and Financial Planning Seminar required.

Legal/Financial Seminar  
Time: 5:30 - 7:00 p.m.  
Place: Chapter office  
Speaker: Robert Freedman, Attorney

**WEDNESDAY September 20**

Orientation Meeting for Family Members  
Time: 5:30 - 7:00 p.m.  
Place: Chapter office

**THURSDAY September 21**

Home Care: An Introduction for Family Caregivers  
Time: 5:30 - 7:00 p.m.  
Place: Chapter office

**TUESDAY September 26**

Orientation Meeting for Family Members  
Time: 12 noon - 1:30 p.m.  
Place: Chapter office

**THURSDAY September 28**

Legal/Financial Seminar  
Time: 5:30 - 7:00 p.m.  
Place: Chapter office  
Speaker: Ronald Fatoullah, Attorney

## VOLUNTEER POSITIONS AVAILABLE:

**Development:**

POSITION AVAILABLE: Assistant to the Development Associate with inputting data, clerical phone work, preparing and organizing reports. Knowledge of word processing a plus.

**Hours: 4-8 daytime hours per week.**

**Alzheimer's Public Awareness/Educational Meetings and Training Programs:**

POSITIONS AVAILABLE: Assistant to the Education Coordinator with 1) Videotaping educational seminars, 2) Preparing packets and informational materials to be distributing at the seminar.

**Hours: 2-4 hours bi-weekly.**

**Telephone Receptionist and Educational Meeting Center**

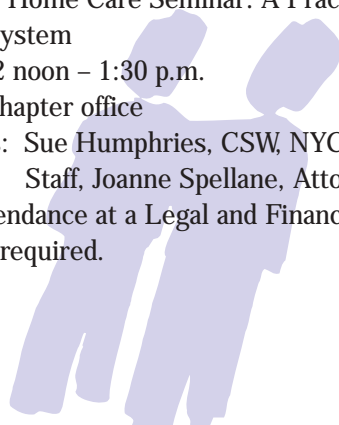
POSITION AVAILABLE: Assistant to the Helpline and Administrative staff for callers after hours and to welcome guests to educational meetings and support groups after 5 pm.

**Hours: 5:00pm - 7:00pm Monday-Thursday**

*FOR ALL POSITIONS PLEASE CALL THE COORDINATOR OF VOLUNTEERS AT (212) 983-0700 EXT. 212*

**PLEASE NOTE: Orientation Meetings for families new to Alzheimer's disease are held five times a month in the Chapter office and once a month in Queens, with the exception of July and August. The dates are listed above.**

**All meetings subject to change. Please call (212) 983-0700 for more information, and to reserve a seat. Reservations are mandatory for all meetings.**



# Memory Problems Don't Always Mean Alzheimer's

You've heard older adults jokingly refer to an occasional memory lapse as a "senior moment." And indeed, more often than not, this is no cause for alarm. Dr. Deborah Marin, Chief of Geriatric Psychiatry at Mount Sinai Hospital has the statistics to show that "successful aging" is the norm.

Still, as Dr. Marin points out, aging brings subtle changes in our thought processes, including memory. "It's common to experience the 'tip of the tongue' syndrome, which indicates some difficulty in retrieving the information.

"However, even though it may take more attempts to learn a phone number, they will be able to learn it, and recall it, along with other new information," Dr. Marin continues. "What's not normal is to consistently forget appointments, or forget what movie they've just seen."

Fifty percent of persons over the age of 65 are worried that they are losing their memory. "There's still a gray area between normal aging and being able to identify a memory disorder," says Dr. Marin. "Testing will reveal whether someone has a greater risk of developing a memory disorder. The tests measure the recall of newly learned information--for example, after reading a story, we see if they can answer questions about it 10 minutes later."

An older person's internist is less likely to notice changes in his patient's cognitive functioning than people he or she interacts with more regularly. If the family notices a change, they should try to take the initiative, as the older adult "may not be forthcoming about needing help or having a problem."

"Often, early stage patients are in denial about having a problem. Others have tremendous insight into their illness," says Dr. Marin, who is also Medical Director of the Department of Psychiatry. The threat of Alzheimer's disease--a diagnosis that is devastating to patient and family alike--is the unspoken fear that grips those who notice changes in their memory.

Chances are, though, that what they're suffering from is a condition which ranks much lower on the scale of public awareness. "MCI" or Mild Cognitive Impairment," is consistent forgetfulness, without the additional deficits in other areas of thinking or functioning that are the hallmark of more serious memory disorders and Alzheimer's disease.

"MCI is that gray area between the normal forgetfulness associated with aging and dementia, or Alzheimer's," observes Dr. Marin. Those with MCI are often overly concerned about their memories--in fact, she estimates that 60 percent of people over 60 fit this description--these she calls "the worried well." At the other extreme, "most A.D. patients don't run to their doctors; it's their spouses or friends who bring them to be tested. Those who do have Alzheimer's tend to be already far along in the process when they are finally diagnosed."

"Since 10-15 percent of people with a clear-cut memory deficit convert to from MCI to Alzheimer's every year (50

percent over five years). Mount Sinai's research division is interested in identifying individuals who are mildly cognitively impaired," says Dr. Marin. "We are doing ongoing clinical research on MCI--the isolated memory problem--testing to see whether a high dose of Vitamin E or Aricept can protect people [with MCI] and prevent Alzheimer's. Mount Sinai is a site for a National Institute of Aging (NIA) study on this condition."

"When we screen people for these studies, we use a cognitive test given by a neuropsychologist, along with a face-to-face interview. But since people with MCI are generally doing well, we don't always pick MCI up."

Participants in these studies should be at least 55 years of age, reasonably healthy, but concerned about their memories. They should have a spouse, friend or neighbor who can observe them at least 10 hours a week. They also cannot be on antidepressant medication or already be taking a Vitamin E supplement (the amount of E in a multiple vitamin is not a disqualifier).

If they become part of this three-year study, they will get free medication, free monitoring and have their cognitive skills evaluated every three months. Spouses can also enroll in the study, since normal controls are needed.

Current studies are testing Aricept (FDA-approved for persons with mild to moderate symptoms of Alzheimer's) in combination with Vitamin E and with anti-inflammatory medications. In another study limited to female participants, estrogen is taken in addition to the established therapeutic dose of Aricept. Mount Sinai is also testing the efficacy of Nimesulide, an anti-inflammatory drug, in combination with Aricept (FDA-approved for persons with mild symptoms of Alzheimer's); as well as Aricept and Guanfacine, which is known to improve the functioning of the nerve cells in the brain that produce norepinephrine, a neurotransmitter.

Alzheimer's patients who are taking Aricept may participate, unless their condition has already progressed too far--beyond the mild to moderate stage. "We can't enroll people if they can't communicate their needs verbally or interact socially," says Dr. Marin, "First, because we wouldn't be able to evaluate them, and also because the medication won't help with so few functioning brain cells."

—Chris MacLeod

Note: The MIS study will be recruiting participants through 65-80 centers in the United States and Canada. In New York City, the centers, at this writing, are:

**Brooklyn:** Maimonides Medical Center, Linda Morgante, (718) 283-7470

**New York:** Columbia Presbyterian Medical Center, Evelyn Dominguez, (212) 305-2371;  
Mt. Sinai School of Medicine, (212) 241-8329  
NYU Medical Center, Martha Shapiro, (212) 263-5708

For additional information call 1 (888) 455-0655, or visit their web site at [www.memorystudy.org](http://www.memorystudy.org)

## One-Man Crusade to Raise Alzheimer's Awareness

In 1997, Matthew Phillips decided that he was going to get actively involved in fighting Alzheimer's disease, which had stricken his mother and one of his aunts.

Last summer, he set himself the challenge of cycling from Boston to St. Louis--a 22-day marathon--to raise money for the cause. Matthew's commitment is praiseworthy in itself; but all the more impressive because Matthew suffers from cerebral palsy. He needs crutches just to walk.

Yet that didn't stop this Bronx native. One of Curtis and Lizzie Phillips's 11 children, Matthew, 41, and his brothers (Cecil, Fonso, Sammy, Curtis, Perry, and Elmer) have performed as gospel singers at many area churches.

The kind of vehicle Matthew needed for his journey--a quadricycle--was donated by the Rhoads company of Hendersonville, Tenn. Fordham University held a benefit in his honor. New York University has also offered support. Others donated their legal expertise to set up "Matthew's Challenge" as a not-for-profit organization. The Face of America Bike-a-Thon is being sponsored by World T.E.A.M. Sports.

On May 15, a fundraiser for Matthew's Challenge took place at Mickey Mantle's restaurant on Central Park South. Bright and early the next morning, the kickoff for the next leg of Phillips's ride took place in Riverside Park, City Hall Park. To arrive in New York City on schedule, Matthew had to hand-pedal his quadricycle 85 miles daily. The same day that Matthew left Boston, (May 13) another team of riders left from San Francisco. By the time all 100 team members met in St. Louis (June 3), it was clear that Matthew's own physical challenges were no match for his determination. You can check his progress on his web site: [www.matthewschallenge.org](http://www.matthewschallenge.org).



## AMBULETTE COMPLAINTS

**M**any Alzheimer's patients and their families rely on Ambulette services for transportation to adult day programs, doctors, physical therapy and other appointments. It has come to our attention that the quality of service is declining. At a recent meeting of the Manhattan Geriatrics Committee of the New York City Department of Mental Health, Mental Retardation and Alcoholism, Paul Feuerstein, Director of Barrier Free Living, and co-chair of the Disabilities Committee reported on a new advocacy campaign to improve transportation for the disabled and the elderly.

If you are experiencing problems with an ambulette service, such as late pick-up, driver was unhelpful, or driving in an unsafe manner, you can register a complaint with the New York Taxi and Limousine Commission, which regulates ambulette services. If the ambulette was obtained through your doctor's office, or day care program, let them know, as well, that you had a bad experience. Be specific when registering a complaint, have the date and time of the incident, the name of the ambulette service, the name of the driver (if known), and specifics about the service that was unsatisfactory. The number to call is (212) NYC -TAXI, (212) 692-8294 and press 1 to make a complaint.

The Taxi and Limousine Commission does not regulate Access-A-Ride. It is regulated by the Department of Transportation. If you have a complaint about Access-A-Ride, you can call 1-877-337-2017. Persons, providers or consumers, interested in participating in either the Geriatrics Committee or Disabilities Committee can call Judy Stein at the New York City Department of Mental Health, (212) 442-4994, for more information about these meetings.

# “Vintage” Art Improves Over Time

## Monuments Attest to Sclar’s Staying Power

Recently, our Chapter Office has been enhanced by two striking bronze sculptures fabricated by artist Harold Sclar. One is an imposing yet whimsical aggregation of geometric forms that harks back to the era of the Russian Constructivists. Painted a bright red, it’s prominently displayed in our reception area. Sclar’s other sculpture, with its venerable green patina, brings to mind an open book, inverted.

Sclar, a prominent metal sculptor, created interior pieces as well as site-specific constructions. Gallery shows (he had more than 20 solo exhibitions) drew media interest, and the attention of architects of office buildings and shopping malls from New York to Ohio. Sclar’s work also graces some 38 churches and synagogues.

Whether Sclar worked on a grand scale or along more intimate lines, he imbued every piece with his characteristic dynamism. Sclar’s bronzes found favor with collectors as prominent as Jacqueline Onassis, Salvatore Dali and Miles Davis.

In 1964, Sclar was commissioned to fashion a monumental welded bronze construction, “Resurrection,” which was installed above the entrance to the Vatican Pavillion at the New York World’s Fair.

A lifelong New Yorker, Harold Sclar turns 70 this year. Alas, the birthday celebration will be bittersweet, as Sclar has been diagnosed with Alzheimer’s disease. We are grateful to Elizabeth Potter-Sclar for a glimpse of this great talent.



## OUTRAGEOUS

*Continued from page 5.*

decisions on her own behalf. I doubted that this occurred questioned the patient representative’s veracity, first on the grounds that my mother spoke only Spanish (was there a translator present?) and second, that she did not have the capacity to make a decision about her medical care (on her last mini-mental status exam, she scored a ten.) I got a lot of double talk. I finally told the patient representative that I did not want this doctor caring for my Mother and that I had a right to ask for another doctor based on the patient’s bill of rights. He was removed from the case.

In speaking to his replacement, a sane and empathic human being, I determined that she did not even have a list of my mother’s current medications. The following day the doctors assigned to her case reported that she could have been transferred since she had not been in an acute medical state.

Finally my mother was moved to the hospital of our choice and was treated. It was determined then that she did not need a pacemaker and was treated with medication for her arrhythmia. I was relieved to spare her any type of invasive procedure and glad to have her back home. However I live in dread of another hospitalization and possibly repeating a similar scenario.

As I reflected on all that had occurred, I noted some disturbing trends throughout these hospitalizations. There is an obvious shortage of staff hospital-wide that makes difficult

work all the more difficult. There are sometimes only two nurses per twenty-five patients in a unit. Overworked staff therefore looks to control any behavior that is deemed out of the ordinary. That control comes either through drugs or restraints. My mother was not only given Ativan but anti-psychotics like Haldol and Resperidol. Once I was told, she put on her coat and said, “I want to go home.” After that, she was given Resperidol. I suppose a 5-foot tall, one hundred-pound, frail and elderly woman poses a risk of flight? On another occasion, she was restrained because she wanted to get up out of bed. I had tried to avoid this by hiring a private duty aide during the day and myself sleeping over. However, during a twenty minute interval between the time the aide arrived and I left to dress for work, they restrained her, concerned that she would fall out of the bed with no one to watch her for a mere twenty minutes.

What I concluded from these experiences is that our society is definitely not ready for our aging population and much less for our demented aging population. The system dictates that the elderly “be seen but not heard” and they will restrain and they will drug to ensure that our most fragile and most vulnerable elderly are “manageable.” The system needs change and that change can only come from the raised collective voices of those who are concerned for the well being of our elders.

# BULLETIN BOARD

## Bill Moyers on PBS

A four-part television special, "On Our Own Terms: Moyers on Dying in America," should be of great value to every family that finds itself dealing with end-of-life care issues. Covering everything from hospice to pain management to emotional support for the dying, the series will be broadcast on PBS from Sunday, September 10 through Wednesday, September 13 (9:00-10:30 P.M.).

## Widows/Widowers of A.D. Patients

Will you share your experiences (in a confidential questionnaire) to assist a graduate student with research that will help caregivers of A.D. spouses. If you are over 60 and have been widowed for one year or more, please contact Karen Gleeson, 500 Dean St., Apt. 3L, Brooklyn, NY 11217. You may also call (718) 783-4196 or e-mail her at <kgteach@aol.com>.

## New Drug Approved for A.D.

In May, the FDA approved a new drug treatment, rivastigmine (Exelon) for Alzheimer's disease. This drug helps increase levels of active acetylcholine (the neurotransmitter that is deficient in people with AD) by blocking two enzymes which break it down. The more drugs that are available means that families have better odds of finding one that benefits the patient without major side effects.

## NYU Drug Studies

The efficacy of treating Alzheimer's with Aricept plus exercise will be analyzed in a four-month program at NYU. Otherwise healthy persons with moderate AD are the optimal candidates. The Silberstein Aging and Dementia Research Center at NYU is currently enrolling participants into clinical drug trial for people with Alzheimer's Disease (AD).

- 1) Neotrofin: For those with mild to moderate AD -- may help nerve cells thrive.
  - 2) Rofecoxib and Naproxen: For those with mild to moderately AD -- may help prevent deterioration.
  - 3) Olanzapine and Risperidone: For those with behavioral problems associated with AD.
- Call Study Coordinator, Martha Shapiro, at (212) 263-5708 for more information.

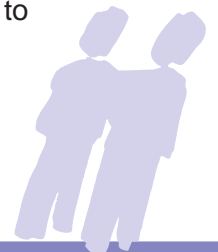
Also at NYU, clinical drug trials to treat AD as well as for mild cognitive impairment are getting underway. Call (212) 263-8088 for more details and an application form.

## CAREGIVER SURVEY

The Cornell University Gerontology Research Institute and The Department of Public Health-Weill Medical College are sponsoring a study of how the number and quality of social supports and social networks affect the physical and mental health of caregivers over the age of 65. Volunteers are needed to complete a self-administered, anonymous questionnaire. We hope that the results will help identify needed services, which will make the caregiving role easier. If you would like to help with this project please contact: Sonia Austrian, DSW, Weill Medical College, (212) 746-5890.

## Spanish-Speaking Volunteers Needed

We are seeking Spanish-speaking volunteers who are interested in presenting programs on Alzheimer's disease at Senior Centers in NYC to increase awareness of Alzheimer's in the Latino community. In November 2000, as part of the NYC Latino Alzheimer's Taskforce, volunteers will be trained to present *Keepsake*, a comprehensive program designed to provide information about aging, memory and Alzheimer's, developed by Pfizer, the Alzheimer's Association and the National Council on Aging. Interested persons who are bi-lingual and preferably bi-cultural, please contact Jed Levine, Director of Programs at the Alzheimer's Association NYC chapter, at (212) 983-0700.



# A Week to Remember . . .

ANNOUNCING OUR FIFTH ANNUAL

## “A WEEK TO REMEMBER ALZHEIMER’S”

Monday, September 11 – Monday, September 18, 2000

### SCHEDULE OF EVENTS

September 11-16 Empire State Building, Zeckendorf Towers, Con Ed Building and Lincoln Center Fountain are all lit in the Chapter’s signature color, purple

September 13 Mayor’s Official Proclamation of “A Week to Remember Alzheimer’s” September 11-18 and Safe Return “Good Samaritan” Awards Ceremony Howard Safir, NYC Police Commissioner; Press Room: 10:00 a.m. One Police Plaza

September 11-18 Barnes & Noble Stores feature AD-related literature Memory Walk posters and registration brochures

September 17 **MEMORY WALK**  
South Street Seaport Piers 16, 17  
**SUNDAY, SEPTEMBER 17**  
Registration 9:00 a.m.  
Walk 10:00 a.m.  
Honor those with the disease, their families and caregivers. Remember those who have been lost to the disease.  
Call 1-800-MetLife for more information.

September 18

Alzheimer’s Association, New York, New Jersey and Connecticut Chapters will host a **ONE-DAY CONFERENCE** at the Hyatt at Grand Central Station  
*“The Human Face of Alzheimer’s—Breaking Through the Stigma”*  
**KEYNOTE SPEAKER:**  
**MAUREEN REAGAN**  
Featuring: Persons with early stage Alzheimer’s as speakers/participants, along with notable physicians, other health professionals, and family caregivers.  
Invited: Persons with mild cognitive impairment or in the early stages of Alzheimer’s disease, professional caregivers, families and friends...Call Judy Louie at: (212) 983-0700 for more information

## SAVE THE DATE

In June 1999, the Alzheimer’s Association, New York, New Jersey and Connecticut Chapters held a conference for people in the early stages of Alzheimer’s disease--**the first ever!** The small by-invitation-only conference, attended by early stage individuals, caregivers, support group leaders, and professionals, fueled the start of an advocacy group--an initiative that continues to grow. The **Early Alzheimer’s Alliance**, comprised of individuals who attended the conference, has since met periodically to plan and pave the way for a next, larger, conference. With an expanding group and renewed effort, the Early Alzheimer’s Alliance and the tri-state Alzheimer’s chapters are pleased and excited to announce our next symposium.



# THE HUMAN FACE OF ALZHEIMER'S: BREAKING THROUGH THE STIGMA

A One-day Interactive Symposium for People with Early Stage  
Alzheimer's Disease, Caregivers, and Professionals  
on MONDAY, SEPTEMBER 18, 2000

## GRAND HYATT NEW YORK

Park Avenue at Grand Central

This one-day conference will be open to early stage persons, family members, caregivers, professionals, and the general public with the continued goals of breaking through the stigma of Alzheimer's disease, increasing sensitivity, and public awareness through dialogue and education, and bringing to the forefront the voices and experiences of individuals with Alzheimer's disease. Here's the voice of Zan White, an individual with early stage Alzheimer's disease, and Judy Louie:

**Judy:** *What is the purpose of the conference?*

**Zan:** *The purpose is to bring together people affected by Alzheimer's disease so that we can discuss our particular perspectives on the disease. People with Alzheimer's disease want to continue to be active and useful. We want to use our minds and do what we can for as long as we can.*

**Judy:** *What is the goal of the conference?*

**Zan:** *The goal for those of us in the early stages is to break through the stereotypes surrounding the disease. We are NOT poor, pathetic souls waiting to die, nor should we be considered to have little capacity for interaction and no capacity for usefulness. Our goal is to break through this stigma.*

**Judy:** *What would you like to see accomplished at the conference?*

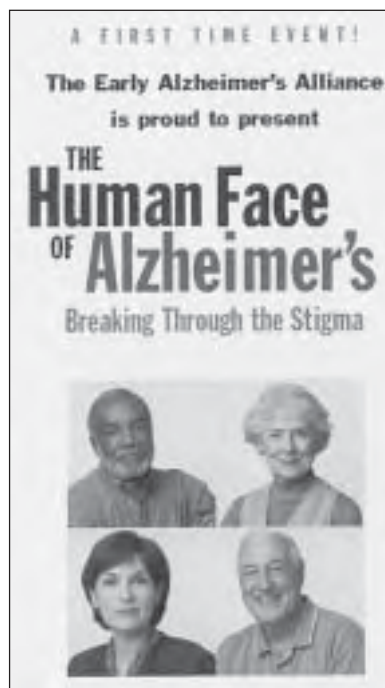
**Zan:** *The conference ought to educate people, especially caregivers, as to the needs of individuals with Alzheimer's disease. Caregivers need to know that there are support networks/support groups for people with the disease as well as for them. **Also, I want people with the disease to know that they should not be afraid to come out of the closet.** We need to deal with the disease and to show the public that people with AD can function and live with dignity. HIV people have managed this, but the Alzheimer's community has not, yet.*

**Judy:** *Why do you think a conference like this is important?*

**Zan:** *There is a growing awareness that the numbers of people with Alzheimer's disease are growing by leaps and bounds...and yes, we need to continue searching for a cure, but we don't have a cure yet. In the meantime, we need to make people aware that AD shouldn't be a hidden issue. We need to go public and focus our recruitment efforts at places like senior citizens groups, retirement communities, hospitals, and nursing homes; we should reach out to at least one religious leader in every denomination so they can get the word out in their community. We need to organize by networks. We need allies.*

**Judy:** *How has the diagnosis of AD changed your life?*

**Zan:** *I wake up every day having to decide on what I'm going to focus on, what I'm going to do—it has given me great clarity. I want to embrace life; I live intensely in the moment and live one day at a time. I make the most of each day, each experience and each moment. I may have Alzheimer's disease but I can still make decisions about how I want to live and I have precious little time left to have a voice in the community which will shape my future.*



The urgent driving force behind the conference continues to be early stage persons along with the help and support of professionals and staff persons working in the field of AD. By harnessing the strengths of persons with Alzheimer's disease, we have a first-hand account of what they are facing. Their voices can make a significant contribution to our understanding of the impact of the disease on the individual and on their caregivers.

Our continuous effort to shape and build on this initiative requires your expertise, your compassion, YOUR VOICE! Please join us in shaping the future of Alzheimer's disease by volunteering your time in this advocacy effort and in the conference. For more information, please call **William Senders** or **Judy Louie** at (212) 983-0700.

*It's time to mark your calendar for September 17*

# MEMORY WALK 2000

*Check Out Our New Route!*

Memory Walk is a Sunday morning walk sparkling with entertainment, and highlighting notable New York sites and personalities. Mayor Giuliani, our **Memory Walk 2000** Chairman, along with Mets great Keith Hernandez, are expected to lead off over 2,000 participants. This year, we will begin and end the walk at Piers 16 and 17 at South Street Seaport where we can picnic and enjoy the views from both piers, as well as fantastic entertainment from the stage on Pier 17.

Each registered walker is eligible for prizes and all walkers receive refreshments identifying wristbands, tee shirts, and other goodies.

**Memory Walk 2000** provides a terrific opportunity for family members, caregivers and friends to demonstrate their love for those afflicted by Alzheimer's disease, and for those who are working to manage and conquer it. The Chapter will provide badges that can be personalized to honor a loved one. Again this year, we are positioning our **Memory Walk** at the Seaport at the end of the walk. During your picnic lunch (while you enjoy the entertainment); your badges, posters, photographs and other mementos can be displayed on it.

Join us and celebrate the special people in your life!

Last year the top three fundraisers turned in a total of more than \$15,000 to fight Alzheimer's disease. Congratulations and thank you!! The top corporate team to 'walk the Walk' fielded a team of over 200 members...*more* congratulations and thank you, *too!*

In addition to the \$17.50 registration fee for each member of **Memory Walk 2000**, walkers are encouraged to collect contributions and obtain pledges in support of their participation.

Set a goal for yourself. **And join us on September 17, 2000 at South Street Seaport!**

## MEMORY WALK 2000 REGISTRATION FORM

To register, please complete this form. Make your check payable to  
**The Alzheimer's Association, New York City**

Alzheimer's Association, NYC Memory Walk  
360 Lexington Avenue - 5<sup>th</sup> Floor  
New York, NY 10017

I wish to pay by credit card:

American Express # \_\_\_\_\_

Visa # \_\_\_\_\_

MasterCard # \_\_\_\_\_

Exp. Date: \_\_\_\_\_

Signature: \_\_\_\_\_

Enclosed is my \$17.50 registration fee.

I am not able to participate in Memory Walk, but want to make a donation. Enclosed is my check for:

\$1,000  \$500  \$250  \$100

I wish to contribute by credit card:

American Express # \_\_\_\_\_

Visa # \_\_\_\_\_

MasterCard# \_\_\_\_\_

Exp. Date \_\_\_\_\_

Signature: \_\_\_\_\_

My company has a matching gift program.

Name/address of company \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Signature \_\_\_\_\_

— Watch your mail for a Memory Walk 2000 Brochure or call 1/800/MetLife to request one! —



*Someone to Stand by You*

New York City Chapter

360 Lexington Avenue  
5th Floor  
New York, NY 10017

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