

360 Lexington Ave., 5th Floor
New York, NY 10017
212-983-0700

Volume 15, Summer 1999



Someone to Stand by You

SOMEONE TO STAND BY YOU

A Conference for Persons with Alzheimer's Disease

By the time this newsletter reaches you, the first conference for people with Alzheimer's disease will have taken place in New York City, if not the world.

On June 9th, 40-50 people who participate in 11 early stage support groups in the tri-state area will have come together to hear the keynote speaker, a physician, speak about the status of diagnosis, treatment and research.

After lunch, the conference participants will have selected themselves into three workshops.

- Workshop 1. "It's on the tip of my tongue:" Ways to help communicate
- Workshop 2. The time of your life: Pursuing meaningful moments and meaningful endeavors
- Workshop 3. Raising Public Awareness: Becoming an advocate for research and services

The conference is an inevitable outcome for innovative professionals who urgently seek to change the culture of caring for persons who they see struggling daily with the effects of the disease.

As these professionals understand the physical and psychological environments in which people with the disease can flourish, their knowledge is becoming the basis for new approaches to care at home, in community settings and in nursing homes.

If you want to know more - - if you are responsible for a person or persons with a cognitive disorder - - and would want to join our efforts, call (212) 983-0700 and ask for:

- Rea Kahn - - for support group training
- Paulette Michaud - - for home care training
- Jed Levine - - for day care center training
- Jed Levine - - for hospital training
- William Senders - - for assisted living training
- Willian Senders - - for nursing home training



The Princess Yasmin Aga Khan receiving her "Metropolis" Tiffany crystal as the New York City Chapter's Humanitarian of the Year from NBC's Jack Ford, Gala Master of Ceremonies.

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Related Disorders Association
New York City Chapter
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New York, NY 10017
212-983-0700

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Director's Corner



Whose Newsletter Is This, Anyway?

Every three months or so the New York City Chapter prepares and distributes some 30,000 newsletters. In each edition we include articles about our programs and services, a quarterly calendar of activities, news about happenings at the Chapter and events, public policy updates, an *Outrage* column, and a variety of other items and articles hoping that you, our readers, will find it all helpful and interesting.

Although we, ably guided by our tireless volunteer editor, Chris MacLeod, prepare and publish this newsletter, it's really *your* newsletter. Once again, as we've done in the past, we'd like to encourage your responses to what we do and to what we print. Subject warranting and space permitting, we'd be delighted to share your thoughts and concerns with all of our readers.

So do send us your impressions, your comments, and your feedback. We've often been accused of trying to squeeze too much into these sixteen pages. Perhaps that's true. But if necessary, we'll squeeze a little more. We want to and we need to hear from you.

On another note, you should know that our Co-Presidents, Bill Brachfeld and Marilyn Cohen, who have ably piloted our Chapter's volunteer leadership these past two and a half years, will be leaving office (and the Board) at the end of June. By the time you receive our next edition we will be able to announce who will follow them in office. In the meantime, however, it is only fitting that I express our heartfelt thanks for the tireless energy and countless hours that Bill and Marilyn have invested into the life of the Chapter and the wellbeing of the community. Thank you both for a job well done. Do stay close. Undoubtedly we'll be calling on you again soon.

John A. Jager
Executive Director

ALZHEIMER'S DISEASE RESOURCES ON THE WEB:

Alzheimer's Association NYC Chapter – <http://www.alzheimernyc.org>

Alzheimer's Association National Office - <http://www.alz.org>

ADEAR Center - <http://www.alzheimers.org>

Alzheimer Page - <http://www.biostat.wustl.edu>

Alzheimer's Disease - <http://neuro-www.mgh.harvard.edu>

Alzheimer's Disease - <http://www.healthfinder.gov>

Alzheimer's Disease - <http://www.virtuallawoffice.com>

Alzheimer's Disease Review - <http://www.coa.uky.edu>

Alzheimer's Disease - <http://medlineplus.nlm.nih.gov>

Cognitive Neurology & AD Center - <http://www.brain.nwu.edu>

Doctor's Guide to the Internet (AD) – <http://www.pslgroup.com>

Head Injuries & AD - <http://www.columbia.edu>

Mini-Mental State Examination - <http://www2.kumc.edu>

Neurological Disorders (AD) - <http://neuroscience.miningco.com>

NMHA MHIC Factsheet Elderly - (AD) - <http://www.nmha.org>

Disclaimer: The Alzheimer's Association is not responsible for the quality or reliability of other sites.

Editor's Note

As the NYC Chapter looks back on 20 years of caring, the Association is rightfully



proud of all it has accomplished. Nationally there are more than 200 chapters, some 35,000 volunteers and countless support groups.

Due to the increased awareness of A.D. — and the potential number of baby boomers at risk in the next few decades—Federal funding for research has reached \$400 million. Almost weekly, we read of scientific findings that add to the body of knowledge about A.D.

Yet the puzzle remains unsolved. For those of us who have been involved with A.D. for the duration of those two decades (personally, it began 23 years ago) there have been too many cycles of hope and disappointment.

But the strength of this Association—and particularly this Chapter, has been its people. Our staff has provided real continuity of caring. John Jager, Jean Marks, Jed Levine, Rea Kahn, Gail Hoffmann—who exemplify our “Someone to Stand by You” motto—have all been with the Chapter for more than a decade.

And the fact that literally hundreds of volunteers, from the help-line operators to the Directors on our Chapter Board, have also achieved this distinction, is really something to celebrate. This is why, ultimately, we will triumph over A.D.

– Chris MacLeod

In Appreciation

Jeanette Coin recently stepped down as the facilitator of a support group for Adult Children of People with Alzheimer's. Her volunteer efforts made a tremendous difference to the members of the group. Maritza A. Nieves expresses what made Ms. Coin's contribution so special:

“I had tried two other Alzheimer's Support Groups before arriving at Jeanette's group in October 1996. I kept searching because something simply wasn't clicking for me in the previous groups. Jeanette creates an atmosphere of insight, nurture, respect, perception and kindness.

I desperately needed these qualities during my initial pains and challenges as a caretaker for my mother. I needed a place where I could “be real” with my emotions, be safe, be supported, offer support to other group members, get practical advice and build inner strength. Jeanette and the support group provided these gifts. Thanks Jeanette, I'll miss you.”

Adding their own thanks to Ms. Coin are Arlene Dubrow, Larry Fishman, Ilene Fox, Sandra V. Garvin, Leslie Gerber, Ina Gail Goldberg, Caryn Greenberg, Jo Ann Grossman, Gloria Seward, Charlotte Weil and Juliet Gumbs.

1999 Federal and State Legislative Priorities

The Alzheimer's Association's 11th Annual Public Policy Forum was held in March in Washington, D.C. Some 500 advocates from all over the country attended this year and had an opportunity to visit with their elected representatives to discuss the Association's federal public policy priorities. Our chapter visits this year included a meeting with the office of New York State's newly elected senator, Chuck Schumer, and we look forward to the senator's support in addressing the needs of the Alzheimer community. We were welcomed as well by New York City members of the House of Representatives and their aides.

This year the Association's federal public policy priorities focus on family caregiver supports; \$500 million for research (an increase of \$100 million over the fiscal year 1999 figure), a Medicare prescription drug benefit, adequate levels of Medicare home health care for persons with chronic illness, and a \$900,000 appropriation to continue Safe Return, the program for protection of persons with Alzheimer's who wander launched in New York City as the Helmsley Alzheimer's Alert Program.

Specifically, the family caregiver support priority seeks enactment of a \$1000 federal tax credit for persons with serious cognitive impairment/other disabilities. Certain family caregivers would also be eligible for the tax credit. This public policy priority also addresses the need for a national program to provide \$125 million a year to assist states and communities in development or expansion of caregiver support services, especially adult day care and respite. This program has been introduced in the Senate (S.707) and in the House of Representatives (HR 1341), and we will keep you posted

regarding any needed advocacy efforts as the proposed legislation develops.

In calling for the tax credit and \$125 million annually for a caregiver support program, the Association's priority essentially mirrors President Clinton's long-term care proposal outlined in our last newsletter. Neither the Alzheimer's Association Public Policy Division in Washington or our NYC chapter see this as the long term care solution, but it is a first step in recognizing the costs of care and the needs of family caregivers for support services.

Similarly, in calling for Medicare to provide for a prescription drug benefit and adequate home health care for persons with chronic illness and disabilities, the Association's public policy priority seeks recognition of Medicare's failure to address the very high cost of chronic illness. At the same time as we seek expansion of Medicare to address chronic care, Medicare, as we know it, is under tremendous challenge. Although the Bi-Partisan Commission on the Future of Medicare failed by one vote to formally approve a proposal to revamp Medicare, the so-called "Breux-Thomas" proposals are expected to be introduced in Congress. If the legislative proposals were enacted, they would have very serious consequences for Medicare beneficiaries. The proposals include raising the age of eligibility to 67, a co-pay for home health care, and most threatening of all, a premium support system. Premium support would mean that Medicare would pay in part for the costs of a private insurance plan, and beneficiaries, depending on the plan chosen, would pay the remainder. In effect, beneficiaries would receive a voucher toward purchase of their service plan. It is not clear that all plans would have to provide a defined

set of benefits. Those opposing this proposal believe that traditional Medicare would not likely remain a viable option, as rising costs would force beneficiaries to choose the premium support plan.

The Report of the Bipartisan Commission does include a modest prescription drug proposal for low-income beneficiaries. But the proposal is much more limited in its applicability than the drug benefit sought by advocates. There is no clear resolution immediately ahead for long term care, prescription drug coverage, or for Medicare itself, but the chapter will do its best to continue to inform you and will ask for your help in advocacy efforts in the time to come.

On a final note, as of this writing, the New York State budget for the coming year is still not finalized, but we are hopeful that Governor Pataki's proposals to reduce Medicaid reimbursement to home care and nursing home providers and to eliminate the right of spousal refusal for home care will not be enacted. The legislature is also expected to provide funds for social model adult day care. We are hopeful as well that funding will be made available for the Alzheimer's Community Assistance Program (AlzCAP) to enable the chapters statewide to strengthen their tele-

phone helplines, counseling services, training and public and professional education efforts.



Ann Berson
Public Policy Coordinator
April 1999

United Hospital Fund Awards \$1.15 Million in Grants to Develop Critical Resources for Family Caregivers

The United Hospital Fund has awarded seven New York City hospitals \$1.15 million in grants to develop innovative programs and resources to assist family caregivers. This initiative, is the first effort of its kind in the country to address the daunting needs of family caregivers—relatives, spouses, partners, and friends – during hospitalization and afterwards at home.

More than 25 million Americans currently provide care for a family member or friend, according to the Fund's Families and Health Care Project. Their work, if it were part of the market economy, would have an economic value of nearly \$200 billion—equal to 20 per cent of the total for all health care expenditures. This figure dwarfs total expenditure for paid home health care (\$30 billion) and nursing home care (\$79 billion) combined.

The burden on family caregivers is increasing because of converging demographic, policy, and technological changes. Families are smaller and tend to be geographically dispersed. More medical procedures are performed on an outpatient basis and hospital stays are being shortened.

At the same time, cost cutting and staff reductions have drastically decreased time hospitals can spend on discharge planning and support services that would serve the needs of family caregivers. In the face of these challenges, caregivers often feel isolated and alone.

“We know that family caregivers are facing increasing, sometimes intolerable, pressures,” said Carole Levine, Director of the Families and Health Care Project.

Photographed at right are personnel from three of the seven medical centers awarded grants, which include a focus on families of persons with Alzheimer's disease.



From Left: Jeffrey Nichols, MD, Medical Director, Cabrini Center for Nursing and Rehabilitation and Chief of Geriatrics; Sarah Walters, Assistant to the President, Cabrini; James R. Tallon, Jr., President, United Hospital Fund; Carol Levine, Director, United Hospital Fund Families and Health Care Project; Jean Marks, Associate Executive Director, NYC Chapter, Alzheimer's Association; Randi Mednick, Sr. Planning Associate, Cabrini, Jacob Victory, Planning Associate, Cabrini, and Mary Purcell, a family caregiver.



Left to Right: (Back Row) Esther Chachkes, Director of Social Work, NYU Hospitals Center, Judith Dobrof, Assistant Director, Social Work Services, The Mount Sinai Hospital; Carol Ann Young, a caregiver associated with the grant project at, Mount Sinai; James R. Tallon, Jr., President, United Hospital Fund; Jean Marks, Associate Executive Director, Alzheimer's Association NYC; Cynthia Epstein, a caregiver associated with the grant project at NYU Hospitals Center; and the Principal Investigator for the grant, Mary Mittelman, DRPH, Director of Caregiver Research, NYU Hospitals Center. (Front Row) Jacqueline Bier, Director of Medical Nursing, NYU Hospitals Center, and Carol L. Levine, Director, United Hospital Fund's Families and Health Care Project.

Supplemental Needs Trust

There is a little-known, but helpful benefit for persons on Social Security Disability (SSD), who are applying for, or receiving, Medicaid or Medicaid Home Care. If the Alzheimer's person is under 65 years of age, is disabled under criteria for SSD, and has monthly income over the \$612.00 allowed by HRA, that surplus income can be transferred to a Supplemental Needs Trust, which would not disqualify them for Medicaid, nor would it have to be paid back to the home care vendor.

The Supplemental Needs Trust can utilize the surplus income to pay directly for a need not met by Medicaid. It is called a Supplemental Needs Income Trust.

Although this benefit applies to only a small percentage of Alzheimer's clients, it is another useful tool in planning for those few. As with any legal or financial planning, the chapter encourages clients to consult with their elder law specialist. If you need a referral to a lawyer who concentrates in elder-law, please call the chapter helpline at 212-983-0700. You are also invited to attend one of the Legal and Financial Planning Seminars held twice a month in Manhattan, or in the Bronx, Brooklyn and Queens in June. (See the educational calendar.)

Jed A. Levine and Jeffrey G. Abrandt



Chapter Executive Director, John Jager and Associate Executive Director, Jean Marks greet Olga Lipschitz of Cobble Hill Nursing Home, Inc.



Chapter Co-President-elect Dr. Eugene S. Callender (left) greets guests during Gala reception.



Brenda Siemer, producer of the award winning Alzheimer's video, "I Know a Song" being introduced by her husband actor Roy Scheider.



Humanitarian of the Year recipient, the Princess Yasmin Aga Khan being introduced to Gala Vice Chair, Barbara Cohen by John Jager, Executive Director.



Gala Chair, Nancy B. Morse, Director of Development, Lynne Raymond, and Chapter Board member, Dianne Zimmerman of Pfizer Inc enjoying the reception.



Honorary Chapter Director, Keith Hernandez being interviewed by Dr. Frank Field for Channel 9 News.

1999 Forget-

An "Unforgettable" 20th Anniversary

On May 4, 1999 at The Plaza in New York City, over 400 guests helped celebrate the Chapter's landmark Anniversary, and recognize several very special people in our community for their outstanding dedication and achievements in the ongoing battle against Alzheimer's.

Jack Ford, NBC TV's "Today Show" weekend edition anchor, and our Master of Ceremonies, had the enviable task of presenting five beautiful Tiffany "Metropolis" full-lead crystal vases to our honorees. They were: Princess Yasmin Aga Khan, *Humanitarian of the Year*; Carol J. Parry, Executive Vice President of Community Relations, The Chase Manhattan Bank, *Outstanding Community Leadership*; Louis Davis, long-time Chapter Board member, *Lifetime Achievement*; Karen Katen, President, US Pharmaceuticals, Pfizer Inc, and Soichi Matsuno, President, Eisai Inc., 1999 corporate co-honorees who directed the pioneer research that discovered Aricept, and the innovative strategic marketing efforts that introduced it to the public.

Popular cabaret artist Susannah McCorkle entertained before guests took to the dance floor for the rest of the night.

We all were reminded why we were at the ball by viewing an abridged version of Brenda Siemer's award-winning video "I Know a Song." Roy Scheider, Brenda's actor husband introduced her as producer of the vivid work that lets the viewer journey with Brenda through a



Eisai Inc. President, Soichi Matsuno and US Pharmaceuticals, Pfizer Inc President, Karen Katen receiving their Tiffany crystal awards from Nancy B. Morse as Gala Corporate Honorees.



Gala Chair, Nancy B. Morse accepting the Mayor's Proclamation from New York City's Department for the Aging Commissioner, Herbert W. Stupp.



Jack Ford, looking on as Carol J. Parry, Executive Vice President for Community Development, The Chase Manhattan Bank receives her Outstanding Community Service Tiffany crystal award from Chapter Co-President, Marilyn L. Cohen.



Jack Ford presenting the Tiffany crystal award to Lou Davis.

Me-Not Ball

Celebration for the New York City Chapter

collection of vignettes depicting her life as it was – growing up a healthy child with healthy parents – and the personal changes she experienced through fourteen years of caregiving for a mother with Alzheimer's. The film is her affirmation of the power of love to effect acceptance.

All of us at the New York City Chapter realize that "old friends are silver and new friends gold..." Therefore, many thanks to all of our old corporate friends, including Eisai Inc., Pfizer Inc, The Chase Manhattan Bank, Lyons Lavey Nichols Swift, Inc., RR Donnelley, Hill & Knowlton, Offitbank, Aging in America/Morningside House, Montefiore Medical Center, Maimonides Medical Center, Columbia University, the multitude of "Friends of Lou Davis and Barbara and Arnold Cohen," as well as to Gala board and committee members who with their families and friends helped make the evening sparkle and glow! The "Metropolis" crystal vases – especially etched for each of our honorees – were donated by Tiffany's.

We also warmly welcome new friends to the "Forget-Me-Not Ball," including Alpha Plastics, Inc., Janssen Pharmaceuticals, American Home Products, The Equitable, Concorde Records, Jade Systems Corporation, R.H. Donnelley, Mutual of America, Mellon Bank, and Merrill Lynch.

Together we raised over a HALF-MILLION DOLLARS in support of the Chapter's services, educational programs and research.



The Princess Yasmin Aga Khan enjoying a moment during the Gala with Mr. and Mrs. Howard Rubenstein.



From left to right, Nancy B. Morse, Roy Scheider, Brenda Siemer, Peter and Frances Luffman, Gala committee members, and others applauding entertainer Susannah McCorkle.

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. The dates are listed below.
All meetings subject to change, please call 212-983-0700 for more information, and to reserve a seat. Reservations are mandatory for all meetings.

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 June 14

Education Meeting
 Time: 6:00 - 7:30 p.m.
 Place: Chapter office
 Topic: Anticipatory Grief: Coping with the Loss in Alzheimer's Disease
 Speakers: Benyamin Cirlin, CSW

WEDNESDAY June 16

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

THURSDAY June 17

Bronx Education Meeting
 Time: 1:30 - 3:30 p.m.
 Place: To Be Announced
 Topic: Legal/Financial Seminar

MONDAY June 21

Medicaid Home Care Seminar:
 A Practical Guide to the System
 Time: 12 Noon - 1:30 p.m.
 Place: Chapter office 360 Lexington Ave.
 Speaker: Adeena Horowitz, CSW, NYC Chapter staff
 Joanne Spellane, Attorney
 Prior attendance at a Legal and Financial Planning Seminar required.

MONDAY June 21

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

TUESDAY June 22

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

THURSDAY June 24

Queens Education Meeting
 Time: 1:30 - 3:30 p.m.
 Place: SelfHelp Clearview Center
 208-11 26th Avenue
 Bayside, NY 11360
 Topic: Legal/Financial Seminar
 Speaker: Ronald Fatoullah, Attorney

WEDNESDAY July 7

Time: 6:00 - 8:00 p.m.
 Place: Chapter office
 Topic: Easing The Transition From Home to Nursing Home

THURSDAY July 1

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

THURSDAY July 1

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.

FRIDAY July 9

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

MONDAY July 12

Education Meeting
 Time: 6:00 - 7:30 p.m.
 Place: Chapter office
 Topic: Coping with Alzheimer's Disease: Early, Middle and Late Stage Issues
 Facilitators: To be announced

WEDNESDAY July 14

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

MONDAY July 19

Medicaid Home Care Seminar:
 A Practical Guide to the System
 Time: 12 Noon - 1:30 p.m.
 Place: Chapter office 360 Lexington Ave.
 Speaker: Adeena Horowitz, CSW, NYC Chapter staff
 Joanne Spellane, Attorney
 Prior attendance at a Legal and Financial Planning Seminar required.

MONDAY July 19

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

WEDNESDAY July 21

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

TUESDAY July 27

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

MONDAY August 2

Legal/Financial Seminar
 Time: 12:00 Noon - 1:30 p.m.
 Place: Chapter office
 Speaker: Marc Crawford Leavitt, Attorney

WEDNESDAY August 4

Time: 6:00 - 8:00 p.m.
 Place: Chapter office
 Topic: Easing The Transition From Home to Nursing Home

THURSDAY August 5

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

THURSDAY August 5

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 August 9

Education Meeting
 Time: 6:00 - 7:30 p.m.
 Place: Chapter office
 Topic: Coping with Alzheimer's Disease: Early, Middle and Late Stage Issues
 Facilitators: To be announced

WEDNESDAY August 11

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

FRIDAY August 13

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

MONDAY August 16

Medicaid Home Care Seminar:
 A Practical Guide to the System
 Time: 12 Noon - 1:30 p.m.
 Place: Chapter office 360 Lexington Ave.
 Speaker: Adeena Horowitz, CSW, NYC Chapter staff
 Joanne Spellane, Attorney
 Prior attendance at a Legal and Financial Planning Seminar required.

MONDAY August 16

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

WEDNESDAY August 18

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

TUESDAY August 24

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

WEDNESDAY Sept. 1

Time: 6:00 - 8:00 p.m.
 Place: Chapter office
 Topic: Easing The Transition From Home to Nursing Home

THURSDAY Sept. 2

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

THURSDAY Sept. 2

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.

WEDNESDAY Sept. 8

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

MONDAY Sept. 13

Legal/Financial Seminar
 Time: 12:00 Noon - 1:30 p.m.
 Place: Chapter office
 Speaker: To be announced

MONDAY Sept. 13

NEW YORK CITY CHAPTER ANNUAL MEETING
 Time: 6:15 p.m. - 7:45 p.m.
 Place: To Be Announced
 For more information please call
 Yvette Bynoe 212-983-0700

VOLUNTEER POSITIONS AVAILABLE

The 24 hour Helpline (212) 983-0700

POSITION AVAILABLE:

Daytime Helpline Counselor

"Stands-by New York's Alzheimer's community" round the clock, 365 days a year, at no charge to callers.

To provide caregivers with direct, immediate access to a team of dedicated volunteers and concerned professionals who are familiar with Alzheimer's disease.

Duties: Answering helpline call's, provide a supportive and listening ear, help define callers questions and concerns, provide informational materials to help caller, refer caller to community resources as appropriate, refer caller to professional staff as required.

Hours. 4-6 hours: the following shifts are available: (9am-1pm) (1pm-5pm) or (11am-3pm) Psychology/Social Work College students and retirees are encouraged to apply.

FOR ALL OF THESE POSITIONS-PLEASE CALL JENNIFER GREENE SUSSER, COORDINATOR OF VOLUNTEERS 212/983-0700



ASK ELLICE

by Ellice Fatoullah, Esq.*

QUESTION: Mother, a widow with early Alzheimer's, fell last month, and was rushed to a New York City hospital. The x-rays showed a broken hip. After two weeks in the hospital, the social worker advised my brother and I that "Mother's DRG days were up," and that she, a widow previously living alone, would have to leave the hospital within the next couple of days. If she remained, the hospital would have no choice but to start billing her directly for the per diem cost of her hospital stay.

Mother is extremely frail and considerably more disoriented after her fall. My brother and I believe that Mother could come home, but only with 24 hours of home care in place. Unfortunately, the hospital social worker advised us that Mother is eligible to receive only 8 hours a day of home care for three weeks after her discharge; and that if we believed more was necessary, we could pay for it ourselves, or place Mother in a nursing home. As to nursing homes, the social worker recommended a nursing home we never heard of.

We're frantic, we don't think Mother needs to go into a nursing home now, but we can't afford to pay for around the clock home care indefinitely. Do we have to accept the 8 hours of home care or the nursing home the hospital recommended? What exactly *are* our rights in this situation?

ANSWER: Basically, upon receipt of the hospital's notice that in their view hospital care is no longer medically necessary, both federal and state law provide that the patient is entitled to a host of fundamental due process rights. Many of the details surrounding the patient's discharge planning and appeal rights are, however, still unsettled, and will remain so during the next few years of ensuing litigation. Unfortunately, to compound the problem, at both the federal and state levels, agencies are writing corollary regulations on the subject, sometimes differing, sometimes stating the same rules in different ways, or using different nomenclature — and often, at both of these governmental levels, *each* agency is writing *three* sets of rules, depending on whether the patient is on Medicare, Medicaid, or private insurance — and *then* each of these sets of regulations may make distinctions, depending on whether the patient is a fee for service patient, or on managed care. However, after wading through each of the above regulatory permutations, there are some core principles which, I believe, may be stated succinctly.

First, before a hospital can discharge a patient, it must have prepared an "adequate" discharge plan. By law, the plan *must* be in writing, and *must be given to the patient, or the patient's family*. Although rarely received by the patient or family, this important patient right needs to be pursued more aggressively. Further, the plan must be "individualized" and "comprehensive" in order to meet the patient's identified post-hospital care needs. The plan must be determined in conjunction with the patient and the patient's family. And the patient and family are entitled to receive written as well as verbal information regarding the range of services available in the community to meet the patient's needs. An adequate discharge plan may not consist of only placement to a nursing home, even for persons assessed to need that level of care, but must include also consideration of non-nursing home services, such as home care, hospice services, day care and respite care. Finally, virtually all New York City hospitals have Medicaid "Bridge" programs in place.

Under the Bridge program, the hospital will send a patient home with home care provided by the hospital's own home health care agency, in essence, advancing the cost of the patient's home care until an application for presumptive Medicaid eligibility is approved.¹ Further, under *Medicaid* home care, as opposed to *Medicare* home care, the patient may receive a full 24-hour, around the clock level of service. Unfortunately, many hospital discharge planners do not routinely volunteer advice about the Bridge program to their patients. Often, you have to ask the hospital specifically for Bridge home care services in order to receive them.

If a nursing home is appropriate, the patient and family must be afforded the opportunity to participate in the selection of the nursing home, and the patient does not have to accept a bed more than 50 miles from the patient's house. Second, no one may be discharged until the services required by the discharge plan are secured, or determined to be "reasonably available." However, if the patient no longer needs hospital care, discharge cannot be delayed indefinitely. As just mentioned, you must accept a bed within a 50 mile radius from the patient's home. For Medicaid patients, the hospital will ask that you select five nursing homes within that radius. The hospital will then prepare a patient assessment form, and send it to each of the nursing homes you have selected. You are then required to take the first available bed from that list of five.² How to negotiate extending your hospital stay until

Continued on page 12.

¹In order to qualify for this benefit, the patient must appear to be financially eligible for Medicaid home care. Since there is no transfer of assets penalty period applicable in the Medicaid home care context; the Bridge program should be of benefit to most patients.

²If you are coming from a nursing home and are already on Medicaid, the nursing home from which you came must reserve your bed for 15 days, if the recipient is expected to return to the facility. One extension of 5 days is permitted.

TAKING CARE

The first thing Geri Gagliardo did when her mother was diagnosed with Alzheimer's was gain power of attorney and become her mother's health care proxy, so that she could handle all financial and health care decisions.

Then she applied for Medicaid and had to take whatever home-care assistant was provided (Gagliardo wasn't happy with several of them).

Finally, she found out about the Consumer-Directed Personal Assistance Program, a Medicaid-financed program that allows you to hire, train and fire your own home-care workers. Now, Patricia Liverani is her mother's main "personal assistant" and stays with her from 7 a.m. to 7 p.m. every day. Gagliardo's daughter and niece also have been trained and help take care of the patient after 7 p.m.



Daily News L.P. Photo

For more information about CDPAP, call the Alzheimer's Association at 212-983-0700, ext. 218.

"The Battle Against Alzheimer's Disease" by Amanda Gardner
Staff Writer, New York Daily News – Monday, April 26, 1999

Special SUMMER Session

The New York City Chapter of the Alzheimer's Association and Mt. Sinai Medical Center are pleased to offer "The Caregiver's Program." The Caregiver's Program is an eight-week program for individuals with memory loss and their caregivers. It provides information, education and techniques to help families or paid caregivers understand and deal with the changes associated with dementia.

The memory-impaired persons meet with an occupational therapist who provides activities and socialization during the time their caregivers are in the education program. Participants will also receive an occupational therapy assessment at their last session.

Both programs will be held from 10 am – 12 noon on Tuesday mornings beginning June 29, concluding August 17.

A total contribution of \$60.00 for the two programs is suggested.

Families interested in participating in the program please call Feroza Marker, OTR, 212-241-9250 or Ruth Rothbart Mayer, CSW, 212-983-0700 for more information.

Enrollment is limited to 12 participants.

the facility of your choice has a bed available will be addressed below.

Third, if the patient disagrees with the plan, or believes the services are not reasonably available, under New York law, the patient has the right to an appeal; and this is true whether you are on a fee for service traditional plan, in an HMO, on Medicare or on Medicaid. In fact, under New York law, despite the hospital's verbal statements to you, you can not be billed until you receive a formal, written notice, advising you that you will be responsible for your hospital care because the hospital believes you no longer need that level of care, and an appropriate discharge plan has been found for you and you have refused it. If you appeal by noon of the first working day after receipt of the hospital notice, you may not be billed for hospital services until noon of the day after you receive notice by a reviewing entity sustaining the hospital's decision.

Under all programs, the patient's attending physician must agree with the determination, or the hospital can appeal to the reviewing entity. Under Medicare, the entity is called the "PRO," or "Professional Review Organization," under Medicaid and for private insurance, it is called the "IPRO," or "Independent Professional Review Organization." Thus, it is useful to have a physician you know well admit you, and be your designated attending, because you may need him or her to advocate on your behalf sometime in the future.

How you appeal depends on which program is paying for the care. The Medicare appeal process can be tricky. Under Medicare, if you are on fee for service, the hospital will make the decision that hospital care is no longer needed. The hospital will then consult with your physician. If the physician agrees with the hospital, you will get a written notice from the hospital that the hospital and physician believe you no longer require hospital care, and an appropriate discharge plan has been prepared for you, presented to you and refused by you. An oral notice is not sufficient. You are entitled to receive this notice in writing, which must also include a description of your rights on appeal. It is from this *hospital* notice that you must request an immediate review to *Medicare* by noon of the business day following receipt of the hospital's notice, in

order to avoid being charged for hospital services until noon after the day you receive an adverse response from Medicare.

Thus, your appeal steps are: (1) you receive the hospital's notice of non-coverage; (2) you request immediate review of the hospital's determination to Medicare; and (3) Medicare then makes its Initial Determination. Don't be too confused. The second notice you actually get is called *Medicare's* Initial Determination because it's *Medicare's* initial notice to you. Remember the rule stated above about your right to receive a written discharge plan? You should have received that written discharge plan no later than the time the hospital informs you in writing of their decision regarding non-coverage, which is step (1) above.

Next is step (4). Here, you have the right to a formal "re-consideration" of Medicare's Initial Determination. It is at this stage that you should be receiving a real and fair, albeit speedy hearing. If you request re-consideration and an expedited review within three business days of Medicare's Initial Determination, you must receive a decision from the Medicare PRO within three business days of the date of your request. However, if you lose your appeal, you may *still* be charged as of noon of the first business day following Medicare's Initial Determination of Non-Coverage, step (2) above.

In the Medicare HMO situation, also known as "Medicare+ Choice," the first notice you receive is Medicare's Initial Determination, thereby truncating steps (1) and (2) above. After that, the same rights to a formal "re-consideration" apply.³

All this boils down to the fact that indeed you do have rights; they are substantial, and you should be willing to exercise them. But when care really is no longer medically necessary, you should not delay indefinitely. As a practical matter, the standard of conduct best employed by both sides is one of reasonableness. Usually, a hospital discharge planner is willing to look the other way, when a nursing home bed not closest to your house becomes available, so long as it's reasonable to assume that the home you are holding out for will be available within a reasonably short period of time, and you will take that bed when it comes through.

³In *Grivalva*, a 1996 federal court case, the Court commented that most people would look at Medicare's Initial Notice of Non-Coverage and assume it is a bureaucratic form notice, from which any appeal would be a hopeless endeavor. Therefore, the Court stated that a patient was entitled to notice of the factual basis of the reasons acute care was no longer needed; conclusions alone were insufficient; and to know the standard for which hospital care would be allowed. Without this kind of meaningful notice, the Court went on to note, Medicare "hides the ball" from the patient because "a claimant can not begin to fathom what additional evidence to present to rebut the denial."

Although *Grivalva* was remanded recently for further consideration by the Supreme Court, this fundamental principle of meaningful notice still applies to the review of Medicare's Initial Determinations.

* * * * *

We invite your inquiries. Please send them to the Alzheimer's Association, New York City Chapter's office.

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***Ellice Fatoullah, Esq.,** served on the Board of the Alzheimer's Association, New York City Chapter, and as Chair of its Public Policy Committee for seven years. She is the principal of Fatoullah Associates, a law firm specializing in protecting the rights of the elderly and disabled. Her offices are located in Manhattan, and New Canaan, Connecticut.

Women's Auxiliary Milestone

The Women's Auxiliary mission has been to run fun, affordable events, which family members and caregivers could attend, and which would raise money for a program or programs directly benefiting people with Alzheimer's disease, and/or their caregivers. We have now raised enough money to make our first contribution to the Chapter's programs. On with our mission! By the time you read this, our Third Annual Luncheon will be over. Baseball Great, Keith Hernandez, will have been our guest speaker. His mother died from Alzheimer's disease, and he has been a long-time supporter of the Association. We are proud of his contributions. As a special feature at the luncheon, he signed sports memorabilia.

Our "Amy's View" theater party was another winner. Judi Densch, Academy Award Winner, was touching in a role with which many of us could identify. The seats were great, and so are our supporters. Thank you. What's next? On Wednesday, June 23, 1999, we'll be visiting the French Culinary Institute on Broadway and Grand Streets, on the edge of SOHO, where we'll have a tour and a four-course lunch prepared by student chefs under the supervision of famous chefs from the best restaurants. Afterwards, you can visit the Downtown Guggenheim Museum, or wander around the galleries and trendy stores of SOHO.

After the summer hiatus, our first fall event will be a docent-led tour at the N.Y. Botanical Garden in the Bronx, with a box-lunch prepared by well-known caterer, Abigail Kirsch.

On Wednesday, October 27, 1999, we'll go back to medieval times with a trip to the beautiful Cloisters. And on Tuesday, December 14, 1999 we've reserved tickets for the Spectacular Holiday Show at Radio City Music Hall. Tickets are already at a premium.

As always, the committee welcomes your suggestions, your participation, and your help. Our deepest thanks to the many who have supported our efforts, not only by attending events, but also by donations.

If you need help, if you wish to join us, or if you have any questions, the telephone number is 212-983-0700 ext. 232.

Olivia McManus-Gross
Sandy Kalison
Co-Chairs

Include the Alzheimer's Association - New York City Chapter in your retirement plans

For people who would like to remember the Alzheimer's Association in their estate plan but have hesitated because they also feel a family obligation, there is an answer to the problem. You can enjoy the fruits of your labors during your lifetime and direct the U.S. Internal Revenue Service to make a contribution for you, by naming the Alzheimer's Association of New York as the beneficiary of your retirement funds.

Retirement funds include IRA accounts, 401K accounts and pension plans that make payments after death. Those funds, which we labor to accumulate during our lifetimes, are subject to post mortem income taxes that can reach 39.6% and estate taxes that can reach 60%. While planning can alleviate these taxes, eventually the income taxes must be paid and all estates over \$650,000 this year (rising to \$1,000,000 in 2002) must pay estate taxes.

Therefore, if you were to pay federal and state income taxes together with New York State's mandatory estate taxes, you would

have very little left from your retirement estate for your beneficiaries - and nothing for your charity of choice.

However, since the Alzheimer's Association of New York City is a fully recognized non profit organization and is not required by law to pay federal, state, or estate taxes, by naming it as beneficiary of your IRA or 401 K-type accounts, you will have donated Uncle Sam's tax gains to a very worthy cause.

Think about it, then phone Lynne Raymond, Director of Development, at 212-983-0700 for more information. She can direct you to capable certified public accountants, legal advisors or other estate professionals.

Milton Miller, CPA
Board Member
Planned Giving Committee

BULLETIN BOARD

Annual Conference

The New York State Adult Day Services Association, Inc. will be holding its 1999 annual conference: "Common Needs: Diverse Solutions" on Thursday, October 14 and Friday, October 15, 1999 at the Hilton Tarrytown, New York. This year's conference will focus on creative solutions to the rapidly changing environment of adult day services. For more information or to request a conference brochure, call (212) 986-4766.

Family Resource and Adult Day Services Opens in Brooklyn

The Center operates six (6) days a week, Monday through Saturday, twelve (12) hours a day. According to Executive Director Marianne Nicolosi, this center plans to live up to its name as a true "family resource." By offering extended service hours, working caregivers are relieved of the stress of having to constantly modify their schedules to ensure that elderly loved ones are properly cared for.

For additional information, please contact Marianne Nicolosi at: (718) 499-7701

Lifelines: Writing Group

The Lifelines Writing Group combines the benefits of a regular support group experience with in-group writing to preserve and communicate memories. No previous writing experience is necessary. An interview is required before admission to group. At 360 Lexington Avenue (40-41 Sts.) from 11:30 AM to 1:00 PM. For further information, contact Jed Levine at (212) 983-0700.

Columbia Presbyterian Medical Center/ Gertrude H. Sergievsky Center

Did someone in your family have memory loss or Alzheimer's disease?

Are you worried about protecting your own memory?

If so, you may be eligible for an Alzheimer's Disease Prevention Study with estrogens at Columbia Presbyterian Medical Center if you are:

A Woman

65 years of age and older

Not currently taking estrogen

Eligible women will be reimbursed for participation

For more information call (212) 305-5805

NYC Marathon for Alzheimer's

A team of runners for the 1999 New York City Marathon, to be held on November 7, 1999, is currently being organized. Team members will run in this premier event to benefit the Alzheimer's Association.

If you are planning to participate in the Marathon and have a number, and if you are interested in making your run a special effort to honor a loved one or to assist the Alzheimer's community, please call our Development Department at (212) 983-0700 (extension 203 or 204) to obtain preliminary information and to register your interest. A member of the Marathon Committee will then contact you with a follow-up call.

Volunteer Position Available

Support group leaders needed for Gay and Lesbian Caregivers' Group sponsored by the Alzheimer's Association in collaboration with SAGE.

The group meets at the "Center" in the Village every other Tuesday from 7:00-8:30 p.m. Training and supervision available.

A personal interview is required. For more information call Carolyn Altman at SAGE (212) 741-2247 or Jed Levine at the Alzheimer's Association (212) 983-0700.

JAZZ CONCERT AT THE BARGE

Mark your calendar for December 1, 1999! On that date the NYC Chapter of the Alzheimer's Association will sponsor an evening of jazz music featuring the famous Onyx Club Sextet. The event will be held at the Barge, a unique concert hall in a converted tobacco barge, moored at the foot of the Brooklyn Bridge.

The Onyx Club Sextet performs weekly at Manhattan's well-known Firebird Café on Restaurant Row on West 46th Street. Their cabaret-style music consists of jazz and swing arrangements of classical pieces from composers like Beethoven, Schubert, Dvorak, and Chopin. The New York Times, on March 12 1999, called their music an "amusing form of jazz, that having your head right in the middle of it, helps greatly in appreciating its charms."

Because seating at the Barge is limited to 130, you will be "right in the middle of it." Tickets will be priced reasonably at \$55, and will include refreshments. Parking is free. We expect a huge demand for this event, so "first come, first served." Call Jack Pollock or Bernie Saper - 212-983-0700, ext. 235 for an invitation.



MEMORY WALK 1999

**This October 17 Sunday Morning "Walk"
Promises to be Packed with Fun and Excitement!**

REMEMBERING OUR 1998 "WALK" . . .

October 18, 1998, dawned clear and bright on the beautiful Battery Park where over 1,500 participants were registering and entertained before the start of Memory Walk '98. WABC anchor Bill Ritter led the way along the sun-filled route, which included Battery Park City's Promenade, City Hall and Broadway. It concluded with a blue-sky-covered ferry ride to Ellis Island for an endpoint picnic. The NYC Chapter placed its first Memory Wall on the green for participants to place photos, mementos or messages in honor and remembrance of loved ones lost to Alzheimer's. The Wall and tributes collected on it grow as it became part of the tradition of the "Walk" that day.

BECOMING A TEAM BUILDER FOR OUR 1999 "WALK" . . .

We are encouraging as many companies, organizations and individuals as possible to build teams of ten or more walkers. We also are asking that your company send us the names of community outreach or human resources representatives so that we can contact them to increase walker turnout in 1999. Prizes will be awarded for largest team, fastest team, best team t-shirt and hat team and more!

***THE MONEY YOU RAISE WILL SUPPORT
PROGRAMS AND SERVICES OF THE NEW YORK
CITY CHAPTER-TO MEET THE NEEDS OF OUR
NEW YORK ALZHEIMER'S COMMUNITY.***

**MARK YOUR CALENDARS FOR OCTOBER 17! AND SET YOUR PERSONAL AND TEAM GOALS
AT \$100, \$500, \$1000 OR MORE!**

Memory Walk

Sunday, October 17, 1999 ~ Battery Park and Ellis Island

Name _____			Title _____		
Company _____					
Street _____					
City _____		State _____		Zip _____	
Phone (with area code) _____		Fax (with area code) _____		e-mail address _____	

I would like to build a team and/or help the Alzheimer's Association reach out to more companies.

Please contact me at the above number or email.

I am enclosing a contribution of \$_____ to support Memory Walk '99.

Please fax or mail this response form to: Memory Walk '99; 2801 M. Street, NW; Washington, DC 20007

Telephone: 1-800-308-2341 Fax: (202) 338-8182

NEW SUPPORT GROUPS

MANHATTAN

GROUP FOR NEWLY DIAGNOSED EARLY STAGE PERSONS

This group is for individuals who have been told they have a diagnosis of probable Alzheimer's Disease in the last six months. They need to acknowledge their memory loss and be able to communicate their feelings and experience. The group will offer the opportunity for support, information about the disease, sharing resources, and talking with other individuals who have the same diagnosis. A personal interview is required before admission to the group.

The group will meet on Tuesdays from 10:30 a.m. to 12:00 Noon. It will begin in the Fall '99 and meet at the NYC Chapter Office. Contact Rea Kahn or Jed Levine at 212-986-0700.

QUEENS

EARLY STAGE ALZHEIMER'S GROUP

Samuel Field YM-YWHA (Little Neck Parkway)
Tuesday & Thursday (will include lunch)
Eileen Friedman 718-225-6750 Ext. 331

A personal interview is required. There is a small charge for this group.
(To start Fall 1999)

BRONX

FAMILY SUPPORT GROUPS

Morningside House (Pelham Parkway)
2:00-3:00 p.m. 1st & 3rd Tuesday
Diane Chavez 718-824-4004 Ext. 531

BROOKLYN

Kings Bay Y
6:45-8:00 p.m. 2nd & 4th Tuesday
Sophie Finkelman 718-646-2973

Lutheran Medical Center (Bay Ridge) 9:30-11:00 a.m.
Every Other Thursday
6:00-7:30 p.m. Mondays
Ellen Garvey 718-921-5949

BROOKLYN (continued)

Metropolitan Jewish Health System
Adult Day Health Center (Boro Park)
300-4:00 p.m. 1st & 3rd Wednesday
Barbara Krinsky 718-621-3600

Palm Gardens Adult Day Health Center
5:30-6:30 p.m. Wednesdays
David Yanofsky/Carol Storms 718-438-5300

MANHATTAN

DOROT (West 80's)
11:00 a.m.-12:30 p.m. 2nd & 4th Tuesday
Reeva Mager 212-769-9285

Gay & Lesbian Caregivers Group
(In collaboration with SAGE)
7:00-8:30 p.m. Every Other Tuesday
Carolyn Altman 212-741-2247

Grief & Bereavement Group
360 Lexington Avenue (40th & 41st Streets)
6:30-8:00 p.m. 2nd & 4th Wednesday
Glenda Feinsmith 212-683-7225 (Evenings)

Morningside Heights (West 123rd Street) 7:00-8:00 p.m.
Every Other Wednesday
Jessica Shapley 212-666-4000

QUEENS

Kew Gardens
6:00-7:00 p.m. every other Wednesday
Jo Anne Louglin 718-470-7396
Julie Rosenberg 718-286-6562

Samuel Field YM/YWHA (Little Neck Parkway)
12:30-2:00 p.m. Tuesdays
Eileen Friedman 718-225-6750 X331
(A personal interview is required)



Someone to Stand by You

New York City Chapter
360 Lexington Avenue
5th Floor
New York, NY 10017

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