

Volume 23, Summer 2003

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Promising New Alzheimer's Drug on the Horizon

The April 3 issue of the New England Journal of Medicine had an important report of a Phase III trial of a new Alzheimer's drug, Memantine. Phase III trials are large human trials intended to determine a treatment's safety and effectiveness. In December 2002, Forest Laboratories, Inc. submitted its new drug application (NDA) for Memantine to the U.S. Food and Drug Administration (FDA). The NDA, which is the formal request for approval in treating moderate to severe Alzheimer's disease, presents for the FDA's review all of the company's data gathered so far during the drug development process. According to Forest, the FDA "accepted the NDA for filing" on January 30, 2003. The FDA now has 10 months from January 30 to approve Memantine or issue a letter finding the drug "not approvable" or "approvable." A "not approvable" letter details defects in the data or the submission that are too serious to fix. An "approvable" determination finds that the drug can ultimately be approved, pending corrections to the submission.

Memantine is the first drug outside of the current class of already approved cholinesterase inhibitors to reach this point in testing. Memantine appears to protect the brain's nerve cells against excess amounts of glutamate, a messenger chemical released in large amounts by cells damaged by Alzheimer's disease or certain other neurological disorders. Because its mode of action is completely different from the currently approved

medications for AD, it's possible that Memantine will be used in combination with them.

Memantine appears to slow the mental and physical deterioration of patients with moderate to severe Alzheimer's disease, the stages when individuals develop problems with dressing, bathing, and other daily activities, and when behavioral symptoms that often complicate Alzheimer's tend to become significant. As a result, these are also the stages that cause the greatest caregiver burden and represent the points at which families tend to move relatives with Alzheimer's from their homes into residential facilities.

According to Barry Reisberg, M.D., Professor of Psychiatry and Clinical Director of the Silberstein Aging and Dementia Research and Treatment Center at NYU

School of Medicine, who led the study, "These patients seem to be declining much less, about half as much as ordinarily expected, over a six-month period. This medication will slow down the otherwise inexorable progress of this disease, and it is remarkably



**GOD'S LOVE
WE DELIVER®**

Let Us Help Put Food On Your Table

Food. It is so basic, so central to our well-being. We need it for sustenance, use it for socialization and celebration. Having a good meal and enjoying food together is a favorite activity for many of us. Indeed, many New Yorkers can be said to be obsessed with food; the latest restaurants, the hottest chef, the Food Network. We are constantly on the search for the best bagel or the perfect slice of pizza. Unfortunately for those who have Alzheimer's and their caregivers, getting food on the table is often a difficult chore. The person with Alzheimer's disease may no longer have the ability to create nutritious menus, shopping lists, or do the complex activity of cooking. For caregivers, many of whom are elderly and have their own medical illnesses, food preparation is also a burden.

Let us help you get nutritious food on the table. The New York City Chapter of the Alzheimer's Association is proud to announce a formal affiliation with

Join us at Riverside Park on Sunday, October 26th!

ALZHEIMER'S ASSOCIATION

Memory Walk 2003



Taking steps to end Alzheimer's

NEW

On-line Registration!

Visit our website to register or fill out the form on page 15 and fax or mail it to us.

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

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Related Disorders Association
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Director's Corner

Just A Few Highlights

After rereading my last two newsletter messages, I saw it was time to strike a brighter note. Yes, our Chapter's financial struggles continue and the ink at the bottom line is still deep red. We do need your support more than ever. Yet in spite of these hard times, we have continued to make a real difference in the lives of thousands of New Yorkers. The Chapter has accomplished many things these past months, and we have reason to be proud. Just a few highlights. . .

Stemming from our Nursing Home Training Initiative, a penetrating booklet entitled *Dementia Care in Nursing Homes: Leading the Way to Culture Change* has been published. It will be distributed to every nursing home in New York State. Describing the key role of the "culture change catalyst" in improving care, it reports on what was learned through the work supported by a multi-year grant from the NYS Department of Health. This important work was headed by William Senders, our Coordinator of Nursing Home and Residential Care Affairs and his colleagues. It will surely help improve the quality of life for demented residents and the paid caregivers on whom they rely while living in long term care facilities.

We eagerly anticipate the unique Volunteer Recognition Reception, planned by our Coordinator of Volunteers, Barbara Lepis, at the New York Design Center. This function will celebrate the extraordinary participation of the many wonderful volunteers who have contributed so much to our work for the past twenty-five years. News reporter Melissa Russo (WNBC-TV) will share her thoughts about Alzheimer's disease and on caregiving issues. Another function for which planning nears completion is the Chapter's Annual Gathering, scheduled for October 1st at the The Graduate Center (the old B. Altman's Building on Fifth Avenue). Best-selling author, Jonathan Franzen (*The Corrections*) will keynote this event. Call or check our website for more information.

Noting the impact of our Dementia Specialist Home Care Aides Training Program, the Board of Directors of the Isaac H. Tuttle Fund saw fit to renew support to sustain this critical work. Participating in the periodic graduation of yet another class of well trained Dementia Specialists is certainly a high point for me. The last such graduation took place on March 26th, (see page 5) and another class will be achieving this important milestone near the end of June. Special praise to Paulette Michaud, Coordinator of Education and Training, who teaches these intensive courses. And additional kudos, of course, to our graduates.

Our 24-Hour Telephone Helpline, under the leadership of Helpline Coordinator Reva Hoffman, has responded to a record number of calls, more than 650 calls each month for the last quarter. Our expanded website and the new on-line E-Newsletter described in my last column, and the extraordinary evolution of our dedicated Junior Committee are yet other examples of accomplishment that buoy the spirit during these difficult times. As I said, just a few highlights. . .

Speaking of our Junior Committee, several members played an effective role in the annual Public Policy Forum held in Washington, D.C. late in March. They also joined more veteran advocates in the hard work of advocating for AD-sensitive policies and funding at our statewide "Lobby Day" in Albany in April. We are grateful to Ann Berson for guiding our Chapter's participation in these events and for everyone who helps carry the message to officials at every level of government.

— John Jager
Executive Director



**Public Policy Forum,
Washington, D.C.,
March 29th-April 1st**
John Jager (center) with
members of the Chapter's
Junior Committee (l to r)
Juliana Garcia, Advocacy
Chair; Scott Coopersmith,
President; Craig Meisner,
Education Chair; Joel
Greenwald, Vice-
President.
Photo by r. langan,
Greater Wisconsin
Chapter



Albany Lobby Day, April 8th
John Jager with Assemblywoman Helene
E. Weinstein of Brooklyn, one of the most
ardent Alzheimer's supporters in the NYS
Legislature

Turn to page 9 for our complete Public Policy article.

A Safe Return Bracelet Might Have Spared Suffering

On January 21, 2003, Mr. G. left his apartment, as he does every day, and walked approximately one mile to a store where he works watching racks of clothing that are on the sidewalk. In exchange for his services, he receives a small salary and a hot lunch. He has been doing this for the past 5 years. Mr. G. is developmentally disabled and suffers from Alzheimer's disease. He is in the early to middle stages. He lives independently in an apartment building where his sisters also reside. They check on him twice a day. He is an insulin-dependent diabetic and requires 2 injections per day. His sisters prepare the injections and give them to him.

The morning of Tuesday, January 21st was very cold. Mr. G. was dressed appropriately and set off on his walk to work. HE NEVER ARRIVED! He was not carrying any identification. When Mr. G. becomes anxious he has difficulty remembering his name. He was not registered in the Alzheimer's Association Safe Return Program. The police department was called and Detective Daniels from the Missing Persons Squad was assigned to the case, as he is with all cases involving Alzheimer's disease.

Faxes were sent several times to all New York City hospitals, shelters, EMS, and morgues. Photos were handed out in the areas he was known to frequent – no results. We tried for television and newspaper coverage, but the war was beginning in Iraq and the media was not available to help.

Days became weeks, and the family was distraught. On April 16, 2003, three months after his disappearance, we received a call from a hospital in Manhattan. They had seen our fax broadcast and thought there was a possibility that a patient that had been admitted to the hospital was the gentleman we were looking for. The family was called, they went to the hospital, and yes, it was Mr. G. He was in good condition, but had suffered frostbite due to exposure to the cold.

IF ONLY HE WAS REGISTERED IN SAFE RETURN AND WAS WEARING HIS BRACELET! A hospital staff member would have noticed the bracelet and a call to the toll-free telephone number would have been made. In all probability we would have been able to reunite the family within a few hours.

Please remember that 6 out of 10 persons will wander at some time during the disease, and the Safe Return bracelet provides identification and a sense of security.

For further information on the Safe Return Program call 212-983-0700 ext. 205.

The Facts About Alzheimer's Disease and Wandering

As many as 60% of people with Alzheimer's disease will wander at some time during the progression of the disease. If he or she becomes lost or confused they may not be able to ask for help, leaving them vulnerable to traffic, weather and those who might take advantage of them.

If a wanderer with AD is not found within the first 24 hours, there is nearly a 50% chance they will be at risk for serious injury and even death. Wandering may be caused by anxiety, agitation, restlessness, fear, disorientation, confusion related to time, medication side effects or a desire to fulfill former obligations, such as going to work.

The tendency to wander may be reduced by involving the person with AD in such daily tasks as folding laundry or helping with meal preparation. Regular exercise tends to lower agitation and restlessness. If he or she seems disoriented, reassure the person that he or she is in the right place, and safe.

Putting deadbolt locks on exterior doors will prevent the person from leaving the house while you are busy in another room or asleep. Inform your neighbors about the person's condition and exchange telephone numbers. Also make sure you have the contact numbers and addresses for your local police and fire departments, hospitals and poison control centers. Smoke alarms and fire extinguishers should be maintained in working order.

Help protect the person with dementia from the dangers of wandering by enrolling him or her in the Alzheimer's Association Safe Return Program, a nationwide identification system designed to assist in the safe return of people who become lost. Enrollment in the program will ensure that these resources will be there for you should you ever need them.

Editor's Note

We have heartening news to report on at least two fronts. They're both front page headlines. The efficacy of a new drug called Memantine in moderate to severe cases of AD has been proven in a recent large multi-center trial. Although this drug has been taken safely in Germany for more than a decade, our FDA has not yet given its approval. This may come in a matter of months, but as we all know, even one month can make a huge difference.



Persons with Alzheimer's living in the five boroughs of New York City may now be eligible for healthy, nourishing meals brought to their door courtesy of God's Love We Deliver. This non-sectarian, non-profit organization began in the 1980s by feeding people with AIDS in their own homes.

Through the generosity of such patrons as mogul David Geffen and socialite Blaine Trump, the charity is now extending its mission for persons with AD and other serious illnesses and also to caregivers who are themselves too weak or sick to shop or prepare meals.

Truly, we could use a few angels with deep pockets ourselves. Our budget has been tightened because fewer contributions have been forthcoming since 9-11. One possible money-saving proposal explored limiting the distribution of this newsletter.

We don't want to cut off anyone who values our publication. Right now, we are asking our "subscribers" to do one of two things:

PLEASE make a contribution to defray our costs—which run nearly \$10 annually for each of you.

OR, sign up to receive our newsletter electronically. It has even more information than you find between these covers—PLUS, IT WILL BE AVAILABLE TO YOU AS MUCH AS TWO WEEKS before the printed version. Please sign up by visiting our website: www.alzheimernyc.org.

Another event where we ask EVERYONE to give at least a little is our 15th Annual Memory Walk. See page 15 for all the fun that's in store for us.

—Chris MacLeod

Legal Guidance



Planning and Paying for Long-Term Care

Many of our clients have been diagnosed with Alzheimer's disease or a related dementia. They require home care services (\$100 per day for round-the-clock care); adult day care services (\$150 per day); or nursing home services (\$250 per day). These clients are realistically concerned that in paying for long-term care they will become destitute and unable to provide for themselves, their spouses or their families.

If individuals are unable to pay privately and do not have long-term care insurance, their options are limited to two insurance programs — Medicare and Medicaid. Medicare is an acute care health insurance program providing hospital and medical services to eligible elderly and disabled beneficiaries. Medicare provides very limited long-term health care coverage and only when skilled nursing or rehabilitation is needed. The majority of our clients require custodial but not acute care. They need assistance with the basic activities of daily living – feeding, dressing, toileting, walking, bathing etc. Medicare does not provide for their custodial needs.

New York, unlike most states, has a Medicaid program that comprehensively addresses the critical need for custodial care. It provides 24-hour home care, nursing home care, adult day care programs, prescription drug coverage, and other services, substantially without charge, to eligible elderly and disabled. Originally intended to serve only persons of very limited means, Medicaid has evolved into the long-term health care provider for the middle class as well.

Although they have to be virtually impoverished to be eligible, middle-class applicants in need of Medicaid's long-term care services do *not* have to spend down all of their savings. There are specific provisions under the law that permit Medicaid applicants to qualify for Medicaid while preserving their savings and their homes and, often, even their incomes.

Eligibility for Non-Institutional Medicaid

To be eligible for Medicaid while living in the community (as opposed to living in a nursing home) a Medicaid applicant in 2003 may not have more than \$3,850 in resources, and a \$1,500 burial account or irrevocable, prepaid, funeral contract of any amount. In New York City, Medicaid permits the funding of the burial account

and the purchase of a funeral contract.

An individual may not have more than \$662 per month in income. If the individual's income exceeds \$662, he or she is required to contribute the excess income, except health insurance premiums and out-of-pocket medical charges, to the cost of care. In some instances, all income may be exempt.

There is no penalty period for transferring resources of any amount to receive Medicaid home care, adult day care services or prescription drug coverage. Applicants with resources above \$3,850 may become eligible for those Medicaid services on the first day of the month after they transfer their excess resources to a trust or to an individual.

Eligibility for Institutional (Nursing Home) Care

To be eligible for Medicaid in a nursing home, the same resource limits as above apply. However, all of the individual's income except health insurance premiums and a \$50 per month personal needs allowance must be paid to Medicaid to help cover the cost of care.

If the applicant is married, the resource and income rules are enhanced to protect the spouse at home. The "community spouse" is permitted to retain in 2003 a maximum of \$90,660 in resources. Not included in that figure is the value of the couple's residence. The community spouse is also permitted a monthly income of \$2,267. If that spouse's monthly income is less than \$2,267, he or she may draw upon the income of the nursing home spouse to reach that limit.

Transferring Assets and Medicaid Nursing Home Eligibility

Generally, when unmarried applicants for Medicaid transfer resources to trusts or to individuals, they incur penalty periods during which time they are ineligible for Medicaid nursing home services. **There is an exception for applicants who are disabled and under 65 years of age: they may transfer their resources, including inheritances and personal-injury settlements, to supplemental-needs trusts without a penalty period.**

Married individuals may transfer resources to spouses without a penalty period being imposed. Once impoverished, they become eligible for, and will receive, Medicaid. The assets owned by the community spouse, however, may later be subject to recovery by Medicaid. If assets are transferred to persons other than a spouse or certain specified individuals, a

penalty period is incurred during which the applicant is not eligible for Medicaid nursing home services.

It is never too late to transfer assets. An individual who has resources in excess of the Medicaid limits and faces immediate placement in a nursing home or is already a resident there, may protect approximately 50% of his or her resources and still qualify for Medicaid.

Determining the Penalty Period

After a Medicaid application for nursing home is filed, Medicaid reviews all the financial records of the applicant (and, if married, the spouse) for the previous 36 or 60 months, the look back periods.

If any assets were transferred to individuals or trusts, a penalty period will be imposed. All transfers are added together, and the total is then divided by the average monthly cost of the nursing home (currently \$8,157 in New York City). The result is the number of months the applicant is ineligible for Medicaid in the nursing home.

For example, if Ms. X, a New York City resident, transfers \$81,570 to a trust or to a non-exempt individual, she incurs a penalty period of 10 months during which time Medicaid will not cover her nursing-home costs: $\$81,570 \div \$8,157 = 10$ months.

Transferring the Home: A Vital Issue

An individual's home — a house, cooperative or condominium apartment — is an "exempt" resource for purposes of determining initial Medicaid eligibility. Ultimately, however, Medicaid may place a lien on the sale proceeds of the home and take back from the sale the amount it spent on behalf of the Medicaid recipient. For this reason, the home must be considered an asset, and appropriate steps must be taken to transfer it. The transfer must be undertaken with caution, and no transfers should be made without advice from an elder law attorney.

For an expanded version of this article, please visit our on-line newsletter at www.alzheimernyc.org/newsletter.htm and click on "Legal Guidance."



Martin Petroff is a partner with Lamson & Petroff, a law firm concentrating in the rights of the elderly and disabled, estate planning, trusts, public benefits, probate and guardianships.

Cabrini Medical Center Announces The Alzheimer's Care Program

Recruiting Families and Volunteers

The Cabrini Alzheimer's Care Program offers compassionate respite care with the goal of providing excellent patient services and respite for the caregivers. This program is made up of a diverse group of volunteers, trained by the NYC Chapter of the Alzheimer's Association, to engage people with Alzheimer's on a one-to-one basis in their homes, and the hospital. It includes creative arts services to people with Alzheimer's disease, as well as instruction, advocacy, and respite care to family caregivers. The program also offers home visits from a nurse practitioner specializing in geriatrics. The nurse practitioner conducts health assessments and provides medical treatment for people with Alzheimer's, related dementias and elder care needs.

"With volunteer assistance, Alzheimer's patients will experience an increased sense of well-being, satisfaction and connection to others. There is no better way to offer assistance to the community than to train and match volunteers from the same community," Jeffrey M. Nichols, M.D., Medical Director and Chief of Geriatrics, a renowned specialist in geriatric care, says.

The program is a joint project of Cabrini Division of Geriatrics and Cabrini Hospice. For more information about volunteering or to refer patients, contact the Cabrini Alzheimer's Care Program at 212-995-6572.



Staff Transitions

A Fond Farewell

It is with great regret that we say goodbye to Sheila Crandles, Support Group Coordinator since July 2000. Sheila relocated to Oregon in March to join her husband and pursue a new career. Under her quiet competent leadership the support group network grew to well over a hundred groups, including the partnership with DOROT's Caregivers' Connections. With Sharon Shaw, Sheila expanded the support group leaders' bi-annual seminars. Her superb clinical and group skills were well utilized in orientation meetings, individual and family counseling sessions with caregivers, as well as family caregiver and early stage support groups.

We will miss her gentle, serious and thoughtful approach to this work, and the lightness and humor she brought to the office. We wish her well.

Welcome Wendy Panken

We are delighted to welcome Wendy Panken, CSW, who has joined the staff as Support Group Coordinator. With over 20 years of group and clinical experience, Wendy is well grounded in group therapy and practice. She has many years of developing and supervising groups and clinical services to varied populations. She has led support groups for performing artists, HIV+ adults and adolescents, recovering alcohol and drug addicts, custodial and non-custodial parents, homeless mentally ill, and parents of mentally ill adults. She has a special interest in bereavement work. Wendy hopes to help the support group network expand. She is eager to meet all of the support group leaders, and to help family members find the right group for their needs. Wendy can be reached at 212-983-0700 ext. 214.

Dementia Home Care Graduation 2003

On March 26th, 17 home care attendants who are privately employed received Certificates of Achievement for having successfully completed a 43-hour Dementia Home Care Training Program, made possible by a grant from a foundation that asked to remain anonymous. The participants marked this special day with a graduation ceremony and



reception that was held here in the Chapter's Training Center. Family, friends, employers and Association staff all joined together to honor this dedicated group of women who worked very hard to master the fine points of providing their clients with quality dementia care. Congratulations again to all of the graduates!

— Paulette Michaud
Coordinator of Education & Training

Poems

Sheila

This poem is a reflection of Sheila's work at the Chapter.

Good-bye to Sheila we'll all miss you
Gentle and kind, helpful and encouraging
May your next step through life bring happiness
Bring challenges that keep you young
And help you to find much love and peace
Just take care to have rain gear
And patience for the rain to stop.
Remember — the frequent rains
Help to clear the air and
Make the fields of Oregon bountiful
Enjoy the next phase of your life
And thank you for helping us
To get on with the challenges of our lives
We wish you health and joy.

—Richard Bornstein
early stage support group member



Losing Me

Each day is a personal challenge
because of this disease.
Once simple tasks are frustrating,
and difficult for me.

I strived hard for perfection,
Worked hard all my life.
A once successful doctor,
A mother, and a wife.

Healing was my profession
And I did it well for years.
Now going to the doctor
Is one of my biggest fears.

I know that friendly face
But I cannot find the name.
People understand
But inside I feel the pain.

I have a loving husband
In him I can confide.
I know that I will persevere
With him by my side.

I am not afraid of death
Or the things I cannot see.
The biggest fear I have of all
Is the fear of losing me.

— Nicola McLaughlin & Una Hume
(Graduates of the Dementia Home Care Training Program)

WEDNESDAY July 2

Easing the Transition from Home to a Residential Care Facility
Time: 6:00 – 8:00 p.m.
Place: Chapter Office

THURSDAY July 3

Orientation Meeting for Caregivers
Time: 8:30 – 10:00 a.m.
Place: Chapter Office

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

MONDAY July 7

Legal/Financial Seminar
Time: Noon – 1:30 p.m.
Place: Chapter Office

FRIDAY July 11

Orientation Meeting for Caregivers
Time: Noon – 1:30 p.m.
Place: Chapter Office

MONDAY July 14

Educational Meeting
Time: 6:00 – 7:30 p.m.
Place: Chapter Office
Topic: The Grieving Process: Understanding and Living with Feelings of Loss and Grief as a Caregiver
Speaker: Benyamin Cirlin, C.S.W., Director, Center for Loss and Renewal

TUESDAY July 15

Introduccion a la enfermedad de Alzheimer
Hora: 5:30 – 7:00 p.m.
Lugar: Fort Washington Houses
99 Ft. Washington Ave., Manhattan

WEDNESDAY July 16

Orientation Meeting for Caregivers
Time: 5:30 – 7:00 p.m.
Place: Chapter Office

MONDAY July 21

Medicaid Home Care Seminar: A Practical Guide to the System
Time: Noon – 1:30 p.m.
Place: Chapter Office
NOTE: Prior attendance at a Legal/Financial Seminar required.

Legal/Financial Seminar
Time: 5:30 – 7:00 p.m.
Place: Chapter Office

ALL EDUCATIONAL MEETINGS ARE FREE OF CHARGE

The NYC Chapter Office is located at 360 Lexington Avenue (between 40th and 41st Streets), 5th floor, New York, N.Y. 10017
We wish to thank the following for their generous donation of space for the Orientation Meetings: CAPE at the Samuel Field YM-YWHA, CNR, Fort Washington Houses, The Park Slope Geriatric Day Center, Inc., and RAIN Parkchester Senior Center.

TUESDAY July 22

Orientation Meeting for Caregivers
Time: Noon – 1:30 p.m.
Place: Chapter Office

MONDAY August 4

Legal/Financial Seminar
Time: Noon – 1:30 p.m.
Place: Chapter Office

WEDNESDAY August 6

Easing the Transition from Home to a Residential Care Facility
Time: 6:00 – 8:00 p.m.
Place: Chapter Office

THURSDAY August 7

Orientation Meeting for Caregivers
Time: 8:30 – 10:00 a.m.
Place: Chapter Office

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

Medicaid Home Care Seminar: A Practical Guide to the System
Time: 5:30 – 7:00 p.m.
Place: Chapter Office
NOTE: Prior attendance at a Legal/Financial Seminar required.

FRIDAY August 8

Orientation Meeting for Caregivers
Time: Noon – 1:30 p.m.
Place: Chapter Office

MONDAY August 11

Educational Meeting
Time: 6:00 – 7:30 p.m.
Place: Chapter Office
Topic: Coping With Alzheimer's Disease: Three Workshops on the Early, Middle and Late Stages
Facilitators: New York City Chapter Staff

TUESDAY August 12

Introduccion a la enfermedad de Alzheimer
Hora: 10:00 – 11:30 a.m.
Lugar: RAIN Parkchester Senior Center
1380 Metropolitan Avenue

WEDNESDAY August 13

Orientation Meeting for Caregivers
Time: 5:30 – 7:00 p.m.
Place: Chapter Office

MONDAY August 18

Medicaid Home Care Seminar: A Practical Guide to the System
Time: Noon – 1:30 p.m.
Place: Chapter Office
NOTE: Prior attendance at a Legal/Financial Seminar required.

Legal/Financial Seminar
Time: 5:30 – 7:00 p.m.
Place: Chapter Office

WEDNESDAY August 20

Orientation Meeting for Caregivers
Time: 5:30 – 7:00 p.m.
Place: Chapter Office

TUESDAY August 26

Orientation Meeting for Caregivers
Time: Noon – 1:30 p.m.
Place: Chapter Office

WEDNESDAY September 3

Easing the Transition from Home to a Residential Care Facility
Time: 6:00 – 8:00 p.m.
Place: Chapter Office

THURSDAY September 4

Orientation Meeting for Caregivers
Time: 8:30 – 10:00 a.m.
Place: Chapter Office

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

Medicaid Home Care Seminar: A Practical Guide to the System
Time: 5:30 – 7:00 p.m.
Place: Chapter Office
NOTE: Prior attendance at a Legal/Financial Seminar required.

MONDAY September 8

Educational Meeting

Time: 6:00 – 7:30 p.m.

Place: Chapter Office

Topic: Understanding the Role of Genetics in Alzheimer's Disease

Speaker: Jennifer Williamson, MS, CGC
Columbia University Taub Institute

TUESDAY September 9

Orientation Meeting for Professionals

Time: 9:30 – 11:00 a.m.

Place: Chapter Office

WEDNESDAY September 10

Orientation Meeting for Caregivers

Time: 5:30 – 7:00 p.m.

Place: Chapter Office

FRIDAY September 12

Orientation Meeting for Caregivers

Time: Noon – 1:30 p.m.

Place: Chapter Office

MONDAY September 15

Medicaid Home Care Seminar: A Practical Guide to the System

Time: Noon – 1:30 p.m.

Place: Chapter Office

NOTE: Prior attendance at a Legal/Financial Seminar required.

Legal/Financial Seminar

Time: 5:30 – 7:00 p.m.

Place: Chapter Office

WEDNESDAY September 17

Orientation Meeting for Caregivers

Time: 5:30 – 7:00 p.m.

Place: Chapter Office

TUESDAY September 23

Orientation for Caregivers

Time: Noon – 1:30 p.m.

Place: Chapter Office

THURSDAY September 25

Legal/Financial Seminar

Time: 5:30 - 7:00 p.m.

Place: Chapter Office

WEDNESDAY October 1

Chapter Annual Gathering

Time: 5:00 - 7:30 p.m.

Place: The Graduate Center

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



Do You Shop Online?

The NYC Chapter has teamed up with iGive.com, a website representing over 400 brand name specialty stores for online shopping. iGive.com will donate up to 26% of every purchase to the NYC Chapter. Enrollment is easy, secure and FREE.

For more information or to sign up, visit www.alzheimernyc.org.

EDUCATIONAL MEETING VIDEOTAPES NOW AVAILABLE

Once again, videotapes of our monthly Educational Meetings are available for your use. If you are unable to attend one of our sessions and would like to view a VHS cassette of the meeting, please contact Yvette Bynoe (ext. 217). A \$20.00 deposit fee is required for each video rented. For videotapes that are mailed, you will be reimbursed \$15.00 for each video when returned to the office (there is a \$5.00 shipping and handling fee). For in-person pick-up and return to our office, you will be reimbursed the full deposit.

COPING WITH A NEW DIAGNOSIS Education for Spouses of People With Early Alzheimer's Disease

A new 7-week course designed to give partners and spouses of people in the early stages of Alzheimer's disease the information and tools they need to cope with the illness is accepting new members. The course is run by Dr. Alan Dienstag, a clinical psychologist and the Coordinator for Psychological Projects and Research for the Alzheimer's Association, New York City Chapter.

The course will be run as a learning group of up to eight people. All participants will be spouses or partners of people in the early stages of Alzheimer's disease.

Major topics covered will include:

- Early Alzheimer's disease; its progression and impact on the person with the illness and family members.
- The risks associated with the caregiving role and ways of protecting yourself from these risks.
- How to make constructive use of feelings that arise in the process of living with someone with Alzheimer's disease.
- How to manage typical problems and challenges in early Alzheimer's (i.e. driving, disclosing the diagnosis to friends and family, etc.).

There is no charge for the course but space is limited. Priority will be given to participants whose spouses have been diagnosed within the last 12 months and have a high degree of functional independence. Spouses who are currently participating in a support group will **not** be eligible for this program at the present time.

If you or someone you know is interested in participating in this new program, call the chapter at 212-983-0700, ext. 214 and ask about **COPING WITH A NEW DIAGNOSIS FOR SPOUSES**.

Promising New Alzheimer's Drug on the Horizon

continued from page 1

free of side effects. These are very impressive results. It looks like this drug really will have an impact on this disease.”

Memantine proved to be significantly superior to a placebo on three independent levels: clinical global impression, cognitive performance, and activities of daily living. At the same time, Memantine reduces caregiver time by more than 45 hours a month.

Neil Buckholtz, Ph.D., Chief, Dementias of Aging Branch at the National Institute on Aging says: “This study shows that treatment in the very late stages of Alzheimer's disease can be beneficial in a number of ways, for both patients and caregivers.”

“It isn't yet known if Memantine can slow the disease for more than six months,” says Dr. Reisberg. “It may slow the progression for a longer period of time, and we have some evidence that it does, but that remains to be definitively determined. The drug also may be effective in milder forms of the disease, and in combination with other medicines, and studies are underway to assess its other potential uses.”

In his presentation on understanding and managing the progressive stages of AD at the April education meeting at the Chapter, Dr. Reisberg reiterated that the drug is not a cure for the disease, and that although it appears to slow the progression of symptoms, we don't know its effect on the underlying disease process. A videotape of Dr. Reisberg's lecture *Alzheimer's: Life's Mirror* is available for loan by calling Yvette Bynoe, Office Manager, at 212-983-0700 ext. 217.

Memantine is the first drug to seek approval for treatment of people with moderate to severe AD. The cholinesterase inhibitors were tested and approved for use in people with mild to moderate AD. Memantine is currently approved for use and available in Europe, and is under development for marketing in the United States. For more information you can contact Forest Laboratories, Inc., at 1-800-678-1605 ext. 7301. The Alzheimer's Association is excited to see more research that may lead to effective medications.

Although not approved by the FDA, Memantine has been in use in Germany for many years for the treatment of Parkinson's and neuropathy. It was approved last year by the 15 nations in the European Union for the treatment of Alzheimer's disease, where it is known as Axura and Exiba.

It is available in the United States and Canada through “buyer's clubs” and international pharmacies. One source is DAAIR (Direct Access Alternative Information Resources) a members-only, not-for-profit buyer's club formed to promote self-empowered healing to help manage HIV and other chronic illnesses. For more information contact www.daair.org or call 212-255-9280.

You can also inquire through international pharmacies such as www.globalrx.com, or www.pharmacy-international.com among others.

In most instances, you will need a physician's prescription to purchase the medication. As this medication is not FDA approved, you will need to assess your level of comfort in taking a non-approved medication. It is a good idea to discuss this medication with your health care provider. You can reference the NYCARE article “The Caregiver's Dilemma” in our Winter 2002 Newsletter, available on-line, for further information.

Let Us Help Put Food On Your Table *continued from page 1*

God's Love We Deliver (GLWD). GLWD's mission is to alleviate hunger and malnutrition among men, women and children living with HIV/AIDS and other serious medical illnesses such as Alzheimer's disease, Multiple Sclerosis, cancer, or Parkinson's disease. Together we hope to assist persons with Alzheimer's to get nutritious home-delivered meals, and to relieve many caregivers of the burden of food shopping, preparation, and clean up. There is no fee for this service. This is a natural partnership between two leading agencies in the city.

In the initial phase of this partnership the person with Alzheimer's disease must live with a family caregiver or a paid caregiver to ensure that the meal will be properly received, stored, or eaten immediately. (GLWD does not use preservatives in its food.)

In addition to providing meals for the person with Alzheimer's disease, GLWD can provide service to caregivers who have a serious illness themselves. Many family caregivers are older and suffer from the chronic illnesses associated with age: hypertension, heart disease, diabetes, osteoporosis, and arthritis. If you are a caregiver and have a serious illness that prevents you from shopping or cooking for yourself, you may be eligible for home delivered meals. Call the Helpline at 212-983-0700, or GLWD at 212-294-8102, or toll-free at 1-800-747-2023 for more information. Meals are delivered in the five boroughs of NYC and in Hudson County, NJ.

When you call GLWD you will be interviewed about your medical needs, dietary needs, and other information. The only eligibility requirement for the program is a letter from a physi-

cian, physician's assistant, or certified nurse practitioner stating the diagnosis, and that the applicant is either fully or temporarily restricted in the activities of daily living, and/or the ability to shop and cook for him or herself. The forms are available beforehand on their website www.glwd.org.

God's Love We Deliver meals are prepared daily from fresh ingredients, in a spotless kitchen at their headquarters in SoHo. The kitchen is staffed by a superb professional team, as well as by hundreds of New Yorkers who generously donate their time to chop vegetables, prepare foods, and stir soups.

The result is delicious, and fresh non-institutional tasting food.

A nutritionist is available to review all dietary needs and answer questions and all callers are entitled to free, unlimited nutritional counseling. Unfortunately kosher food is not available at this time.

To find out more about this exciting initiative, please call the New York City Chapter Helpline at 212-983-0700, or call GLWD at 212-294-8102, or toll-free at 1-800-747-2023. Their website is www.glwd.org.

Note: If you are presently receiving Meals on Wheels or are otherwise eligible for Meals on Wheels in your neighborhood, this should be your first phone call before calling God's Love We Deliver. You can call The New York City Department for the Aging at 212-442-1000 or visit their website at www.ci.nyc.ny.us/aging for eligibility information or the meal center nearest you. Click on DFTA's on-line services.

PUBLIC POLICY UPDATE:

Federal and State Alzheimer's Advocacy

Federal Advocacy Update

The 15th Annual Alzheimer's Association Public Policy Forum was held in Washington D.C., March 29-April 1. The forum enabled the Alzheimer's chapters public policy staff and family caregivers from all over the country to speak with their representatives in Congress. The nation is at a critical juncture in domestic public policy. Congress will be turning its attention in the coming months to Medicare and Medicaid in an effort to reduce the federal costs of these programs. High on the Congressional agenda is the need to address the prescription drug issue and create a Medicare prescription drug benefit.

These issues are of paramount concern to persons with Alzheimer's. Their heavy utilization of Medicare and Medicaid results in high costs to these programs. There are really no alternatives. Those with costly chronic medical needs are dependent on access to and availability of Medicare for their treatment and care. For those who cannot meet the very high costs of long term care in the home and in residential care settings, maintenance of Medicaid is essential. As prescription drug costs continue to escalate, large numbers of persons with Alzheimer's simply cannot meet the costs of their drugs and have funds left for other important costs of living.

While cognizant of the difficult fiscal environment and the large cuts current federal programs face, our advocates called on their representatives in Congress to address the urgent needs of those with Alzheimer's. Advocates stressed the following federal legislative priorities developed by the national public policy office.

INCREASE FUNDING FOR ALZHEIMER'S RE-SEARCH at the National Institutes of Health by \$200 million in Fiscal Year 2004 to keep Congress on track toward the goal of \$1 BILLION for research and to:

- protect up to 14 million babyboomers from the disabling impact of Alzheimer's
- stop Alzheimer's from destroying Medicare and Medicaid
- prevent Alzheimer's from bankrupting family, state, and federal budgets

MODERNIZE MEDICARE to meet the health care needs of all beneficiaries with Alzheimer's disease by:

- adding a chronic care benefit to Medicare, including payment for geriatric assessment and targeted chronic care management
- providing meaningful prescription drug coverage to assure that all beneficiaries have access to affordable and necessary medications

Preserve the MEDICAID LONG TERM CARE SAFETY NET by:

- providing additional financial assistance to the states to maintain current benefits
- preserving federal guarantees regarding eligibility and quality

Continue the successful collaboration between the Alzheimer's Association and the Federal Government by:

- appropriating \$25 million for the **ALZHEIMER'S MATCHING GRANT PROGRAM** to extend family support services to the underserved minority populations and rural communities

- continuing \$900,000 for **SAFE RETURN**, a nationwide system to help law enforcement and public safety personnel locate and protect persons with Alzheimer's who wander from home

State Advocacy Update

Governor Pataki's proposed budget called for major cuts in health care funding and aging services as part of the effort to address the \$11 billion plus state deficit. Seeking Medicaid cost savings of \$1.2 billion, the governor called for cuts that affected hospitals, nursing homes, and home health care agencies. There was vigorous opposition to these cuts that would result in reduced services, staffing, and quality of care. Of importance to persons on Medicaid home care in New York City who receive home attendant services, the governor's budget did not propose cuts in services, hours of care for clients, or eligibility for the Medicaid home care program. However, there may be hard times ahead and many thousands of persons with Alzheimer's depend on this program for hours of personal care to help with bathing, feeding, dressing, and other activities of daily living.

The Legislature restored most of the cuts proposed by the governor. Subsequently, the governor vetoed the legislative actions. The Legislature, however, for the first time in two decades overrode a governor's veto and restored spending on schools and health care. It remains to be seen what further action the governor will take.

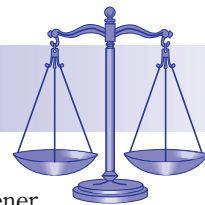
Costs of pharmaceuticals continue to be a major issue for both the state and patients. The governor has proposed prior authorization for Medicaid prescription drugs and a preferred drug list. He may propose higher co-payments for EPIC, the elderly pharmaceutical program, as well as limits on its growth. Our Coalition of NYS Alzheimer's Association Chapters is opposing limits on EPIC and prior authorization. If there is to be a preferred drug list, we are advocating for assurance that all Alzheimer's drugs are on the list and readily accessible to patients.

On April 8, our Coalition of chapters held its annual lobby day in Albany. Despite the bad weather, a busload of advocates made the trip from New York City. The priority issues for the Coalition included support for the maintenance of Medicaid funding, the need for funding and support for the Coalition's Alzheimer 2000 initiative to enable the chapters to provide needed support services, and implementation by New York State of the Supreme Court Olmstead decision to enable individuals with disabilities, including those with Alzheimer's, and seniors to remain in their own homes and communities with sufficient services. Our New York City advocates stressed as well the need for Medicaid home care/personal care hours for supervision of persons with Alzheimer's to assure their health and safety.

Our Coalition also stressed its opposition to the governor's proposal to eliminate the legislative match of funds generated by the Alzheimer's tax check off on the state income tax form. The check off would remain, but the governor is seeking elimination of the legislative match.

Despite the fiscal crisis the state faces, the legislators we visited understand and remain committed to our issues.

—Ann Berson
Public Policy Coordinator



Planificar y pagar por el cuidado de larga duración

La mayoría de nuestros clientes se están enfrentando una crisis. Son personas discapacitadas de varias edades o ancianos débiles que necesitan atención médica de larga duración. Necesitan servicios de cuidado doméstico (aproximadamente \$100 por día para el cuidado de veinticuatro horas); servicios de cuidado diurno para adultos (aproximadamente \$150 por día); o servicios de asilo de ancianos (aproximadamente es de \$250 por día).

Si no pueden pagar por el cuidado de forma privada y no disponen de seguro de cuidado de larga duración, entonces sus opciones se limitan a dos programas de seguro —Medicare y Medicaid. Medicare es un programa de seguro de cuidados intensivos que proporciona servicios hospitalarios y médicos a los beneficiarios ancianos o discapacitados que cumplan con los requisitos. Proporciona cobertura muy limitada de atención médica de larga duración y solamente cuando se precisa cuidado especializado de enfermería o rehabilitación. La mayoría de nuestros clientes necesitan atención custodial pero no cuidados intensivos. Necesitan ayuda con actividades básicas de la vida cotidiana —comer, vestirse, asearse, caminar, bañarse, etc. Medicare no proporciona servicios para sus necesidades de atención custodial.

A diferencia de la mayoría de los estados, Nueva York tiene un programa de Medicaid que trata necesidad de obtener atención custodial. Proporciona cuidado doméstico las 24 horas, cuidado en asilo de ancianos, programas diurnos para adultos, cobertura de medicamentos con receta y otros servicios generalmente sin recargos personas que cumplan con los requisitos. Aunque al principio tenía el objetivo de servir solamente a personas con medios muy limitados, Medicaid se ha convertido también en el programa proveedor de atención médica de larga duración para la clase media.

Aunque tienen que ser prácticamente pobres para recibir los servicios, los solicitantes de la clase media que necesitan los servicios de atención médica de larga duración de Medicaid *no* tienen que gastarse todos sus recursos. Existen disposiciones específicas bajo la legislación de Nueva York que permiten que los solicitantes califiquen para recibir Medicaid a la vez que puedan conservar o guardar sus ahorros, sus casas y, en algunos casos, incluso sus ingresos.

Elegibilidad para Medicaid no institucional

Para recibir Medicaid mientras reside en la comunidad (a diferencia de vivir en un asilo de ancianos) el solicitante de Medicaid en el 2003 no puede tener más de \$3,850 en recursos, y una cuenta de entierro de \$1,500 o un contrato funerario prepagado irrevocable. En la ciudad de Nueva York, Medicaid permite la financiación de una cuenta de entierro y la compra de un contrato funerario.

Un individuo no puede tener unos ingresos mensuales de más de \$662. Si el individuo tiene unos ingresos mensuales superiores a \$662, él o ella tiene la obligación de contribuir el exceso de ingresos hacia el costo del cuidado. A menudo, todos los ingresos están exentos.

No se aplica ningún período punitivo por transferir recursos de cualquier cantidad para recibir servicios de Medicaid de cuidado a domicilio, de cuidado diurno de adultos o de cobertura de medicamentos con receta. Un solicitante con recursos que excedan \$3,800 puede ser elegible para servicios no institucionales de Medicaid el primer día del mes después de que transfiera esos recursos en exceso a un fondo fiduciario o a otro individuo.

Elegibilidad para cuidado institucional (asilo de ancianos)

Para ser elegible para recibir Medicaid en un asilo de ancianos, se aplican los mismos límites de recursos que se mencionan más arriba. Sin embargo, se deben pagar al programa todos los ingresos del individuo salvo las primas de los seguros médicos, los gastos médicos de bolsillo y \$50 para necesidades personales.

Si el solicitante está casado, las reglas de recursos y de ingresos proveen protecciones para el cónyuge que permanece en la casa. El “cónyuge que vive en la comunidad” puede retener en 2003 un máximo de \$90,660 en recursos. A esta cifra no se le incluye el valor de la vivienda del matrimonio. Al cónyuge en la comunidad también se le permite recibir unos ingresos mensuales de \$2,267. Si los ingresos mensuales del cónyuge en la comunidad son menores a \$2,267, él o ella podrá retirar dinero del cónyuge que vive en el asilo de ancianos hasta alcanzar dicho límite.

La transferencia de bienes y la elegibilidad para

Medicaid en un asilo de ancianos. Generalmente, cuando los solicitantes de Medicaid transfieren recursos a fondos fiduciarios o a otros individuos, se incurre en períodos punitivos durante los cuales no son elegibles para los servicios de Medicaid de asilo de ancianos. **Existe una excepción para los solicitantes discapacitados menores de 65 años de edad: pueden transferir sus recursos, incluyendo herencias e indemnizaciones por daños personales, a fondos fiduciarios para necesidades adicionales sin incurrir en un período punitivo.**

Los individuos casados pueden transferir sus recursos a los cónyuges sin que se les imponga un período punitivo. Una vez que éstos empobrezcan, serán inmediatamente elegibles para Medicaid. Sin embargo, los bienes que son propiedad del cónyuge que vive en la comunidad pueden luego ser objeto de recobro por parte de Medicaid. Si se transfieren bienes a una persona que no es el cónyuge o a ciertas personas específicas, se incurrirá en un período

punitivo. Durante este período punitivo la persona no podrá tener derecho a la cobertura de Medicaid para el asilo de ancianos.

Nunca es demasiado tarde para transferir bienes. Una persona que tenga ingresos superiores a los límites de Medicaid y está a punto de ser internada a un asilo de ancianos, o ya reside en un asilo, puede proteger aproximadamente 50% de sus recursos y finalmente poder calificar para recibir Medicaid.

Cómo determinar el período punitivo

Una vez que se haya presentado una solicitud a Medicaid para el asilo de ancianos, Medicaid revisa todos los datos económicos del solicitante (y, en el caso de estar casado, los del cónyuge) de los 36 ó 60 meses previos, período de revisión de datos pasados. Si se transfirieron bienes a individuos o a fondos fiduciarios, se impondrá un período punitivo. Se suman todas las transferencias y se divide el total por el número representativo del promedio mensual de costo de un asilo de ancianos (actualmente es de \$8,157 en la ciudad de Nueva York). El resultado es el número de meses en los que el solicitante no podrá tener derecho a la cobertura de Medicaid para el asilo de ancianos.

Por ejemplo, si la Sra. X, residente de la ciudad de Nueva York, transfiere \$81,570 a un fondo fiduciario o a un individuo no exento, incurrirá en un período punitivo de 10 meses durante el cual Medicaid no cubrirá el costo del asilo de ancianos: $\$81,570 \div \$8,150 = 10$ meses.

La transferencia de la vivienda: un tema vital

La vivienda del individuo —una casa, un apartamento en una cooperativa o un condominio —es un recurso “exento” para determinar la elegibilidad inicial a los beneficios de Medicaid. En última instancia, sin embargo, Medicaid podría tener derecho a retener la recaudación de la venta de la vivienda y tomar de la venta la cantidad que se gastó en nombre del beneficiario de Medicaid. Por esta razón, se debe considerar la casa como un bien y se deben tomar los pasos apropiados para transferirla. La transferencia de la vivienda debe realizarse con precaución y no se deberían hacer transferencias sin el asesoramiento de un abogado de derecho para la tercera edad.

Para una versión más detallada de este artículo visite www.alzheimernyc.org/newsletter.htm y haga click en “Guía Legal.”



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JUNIOR COMMITTEE HOSTS BRAZILIAN CARNIVAL GALA



The Alzheimer's Association Junior Committee, New York City Chapter hosted its annual Gala fundraiser on March 1st at the Union Square Ballroom in Manhattan.

Over 250 people attended the Gala, which netted more than \$10,000. DJ Johnny Danger kept the music hot while live Brazilian dancers cavorted around the ballroom.

Prizes were raffled off through the night; including a Club Med vacation, a Site 59 Getaway gift certificate, New York Knicks tickets, tickets to Late Night with Conan O'Brien, a J. Sisters Salon gift certificate, and dinner for four at Casa Restaurant in the West Village. The Junior Committee would like to thank all of their prize donors and Grey Goose Vodka for sponsoring the event.



For additional event photographs, and information about the Junior Committee, please visit www.alznycjuniorcommittee.org.



A Daughter's Nightmare

"Elder Rage or Take My Father...Please!" How to Survive Caring for Aging Parents

Even before you plunge into the tempest that sweeps away Jacqueline Marcell, her parents, and any semblance of a normal life, you get a sense of "Elder Rage" from the six pages of endorsements that open the book.

Everyone from Regis Philbin to Leeza Gibbons (an Alzheimer's activist as well as a television personality) to Jacqueline Bisset (who says her mother's dementia lasted 35 years) to Senator Tom Hayden to half a dozen Alzheimer's specialists concur on the book's value.



Jacqueline Marcell
author

One reason why the book is so gripping is its lack of either literary pretensions or scientific jargon (a 70-page appendix supplies those details as well as specific strategies for dealing with behavior patterns of dementia, an extensive list of resources and a reading list).

We share a journey with Ms. Marcell, who starts out with no idea of how to cope with her father's increasingly erratic ways. She is a television producer in Los Angeles, recovering from back surgery when she is forced to step in. She puts her own life and career on hold, uprooting herself to be on the scene several hundred miles away to attempt to stabilize the situation.

It is ironic that for more than a decade, Marcell's father, Jake, has been caring for her mother after a major heart attack. Now the caregiver needs care—but he won't relinquish control. He is in denial about his own condition. A series of narrow escapes due to dad's insistence on driving, housekeeping (Ms. Marcell finds that her parents have been living amid innumerable health and safety hazards) and leaving the stove unattended are not enough to convince dad that he needs help.

He has already banished his son, and barred his wife from even trying to keep in touch by phone. Their daughter's presence

threatens his autonomy. It isn't long before she becomes aware that he has beaten his invalid wife. Then, in a harrowing scene, he—possessing amazing strength even at age 85—assaults and attempts to strangle Ms. Marcell. When she fights back, she learns that she is now vulnerable to charges of elder abuse!

It gets worse before it gets better. Time after time, Dad is able to charm the hospital psychologists and convince them that he poses no danger to himself or others. He resists taking his medications. Removing blockage from his carotid artery does not halt his decline. Diagnosed with multi-infarct vascular dementia, he is the embodiment of the proverbial "36-hour day" that frustrates and exhausts those who try to help. (Later, Marcell's mother, Mariel, will be diagnosed with Alzheimer's disease.)

It's as if the three of them are in a lifeboat poised on the edge of a whirlpool. Finally, with the help of an inexperienced but effective home health aide, behavior modification techniques and Aricept—the local chapter of the Alzheimer's Association was another lifeline—the sinking ship is righted. The results are hardly immediate. Since every "case" is different, the trial and error methodology applies.

"Elder Rage" is surely a page-turner, as suspenseful as any novel. There is one minor irritant: Ms. Marcell's conversational style leads her to continually use names as metaphors or shorthand for lengthier descriptions. In the course of a mere two pages, James Cagney, Mary Richards, Marty Feldman, Shirley MacLaine, Vincent Van Gogh, Stevie Nicks and Hannibal Lecter are employed in this capacity. However, one ongoing comparison couldn't be more relevant—Ms. Marcell's father is, by turns, Dr. Jekyll and Mr. Hyde.

—Chris MacLeod

Additional information and resources are posted at Ms. Marcell's website, www.ElderRage.com. "Elder Rage" may be ordered by phone (949) 975-1012 or fax (949) 975-1013 with a credit card. Or you may send a check for \$19.95 (plus \$4.00 for shipping) to Impressive Press, 25 Via Lucca (Suite J-333), Irvine, California 92612-0604.

Tributes - In Memory of...

01/01/03 - 03/31/03

Ms. Lucille C. Abbatiello

Ms. Lucille C. Abbatiello
Jacqueline G. Chard & Family

Mrs. Gladys Abraham

Mrs. Gladys Abraham
Bernard & Doris Solomon

Ms. Eva Abrams

Ms. Eva Abrams
Ms. Linda Zletz

Ms. Anna Allmaier

Ms. Anna Allmaier
Mr. & Mrs. Thomas E. Cairns

Persa & readis

Persa & readis
Ms. Lori Cottone

Mr. Murray Ansis

Mr. Murray Ansis
Mrs. Judy Lee & Family

Ms. Esther List, Ms. Ida Oginsky & Ms. Libby Lefkin

Ms. Esther List, Ms. Ida Oginsky & Ms. Libby Lefkin
Ms. Rhea Lipitz

Ms. Mariann G. Perseo, Esq.

Ms. Mariann G. Perseo, Esq.
Bernice Rosenthal & Lynn Henry

Jerry Saliman & Ray Vallejo

Jerry Saliman & Ray Vallejo
Mr. Peter A. Sepe

Ms. Madeline Siegal

Ms. Madeline Siegal
Ms. Mildred Weiss

Ms. Zeldia Wiener

Ms. Zeldia Wiener
Mr. Saul L. Zalkin

Ms. Christine Anzalone

Ms. Christine Anzalone
Dr. Saul W. Katz

Mrs. Dorothy Applebaum

Mrs. Dorothy Applebaum
Dr. Carla Dixon

Ms. Stella Arem

Ms. Stella Arem
District 22 Guidance Counselors

Fern Eisgrub & Ed Peckoff

Fern Eisgrub & Ed Peckoff
Mike, Rob, Carol, Effie & Nora

P.S. 277

Ms. Loretta Asselta

Ms. Loretta Asselta
Mr. & Mrs. Angelo J. Giancola

Mr. Lou Baird

Mr. Lou Baird
Rhoda & Sy Porcelan

Mrs. Dorothy Ballan

Mrs. Dorothy Ballan
Mr. & Mrs. Leonard Sitzer

Mr. Marty Balmuth

Mr. Marty Balmuth
Mr. & Mrs. Daniel H. Matofsky

Mr. Joseph D. Banks

Mr. Joseph D. Banks
National Consulting Services, Inc.

State of New York Insurance Department Liquidation Bureau

Ms. Rose Barilla

Ms. Rose Barilla
Lindsay Rich & Family

Ms. Susan Shupnik

Ms. Susan Shupnik
Father of Debra Barnett

Ms. Barbara C. Paris

Ms. Barbara C. Paris
Florence Bartolo

Ms. Tommasina Tibaldi

Ms. Tommasina Tibaldi
Father of Karen Beals

Beals Associates Boston & New Hampshire

Mr. Albert Behar

Mr. Albert Behar
Herman & Ruth Darnell

Mrs. Pauline Belaief

Mrs. Pauline Belaief
Ms. Estelle Weber

Mrs. Vera L. Bergman

Mrs. Vera L. Bergman
Ms. Lucille Bergman

Mr. Jules Berkow

Mr. Jules Berkow
Ms. Christy Brechner

Father of Tamara Berman

Father of Tamara Berman
Ms. Tamara Berman

Mr. Leon Berman

Mr. Leon Berman
Ms. Geraldine Telchin

Mrs. Lois Berman

Mrs. Lois Berman
Mr. & Mrs. Mathias Berman

Jane Brite

Jane Brite
Mrs. Francis Gebet

Mrs. Francis Gebet

Mrs. Francis Gebet
Mary Ellen Kenny

Anatole & Rosaria Konstantin

Anatole & Rosaria Konstantin
Ms. Rita Loeb

Mr. Edward Ney

Mr. Edward Ney
Ms. Sharon Shniper

Mr. Mark E. Stroock

Mr. Mark E. Stroock
Mr. & Mrs. Bernard Zvirman

Mrs. Annette Bernstein

Mrs. Annette Bernstein
The Schwartzberg & Schlossberg Families

Mr. Joseph Bernstein

Mr. Joseph Bernstein
Mrs. Jean Feldman

Mrs. Edna Bily

Mrs. Edna Bily
Ms. Doris E. Mula

Mrs. Ethel Birenbaum

Mrs. Ethel Birenbaum
Mrs. Emily Epstein

Charles & Susan Tribbitt

Charles & Susan Tribbitt
Ms. Cynthia Bitter

Michael & Barbara Goldstein & Family

Michael & Barbara Goldstein & Family
Mrs. Wendy Blauner

Mrs. Wendy Blauner
Ed Goldman & Judith Roven

Mrs. Ruth Block
Kathy Hillman & Dom Palmo

Mr. & Mrs. Paul D. Petrino

Mr. & Mrs. Paul D. Petrino
Mr. & Mrs. David A. Twersky

Dr. Walter Bobushkin

Dr. Walter Bobushkin
Dr. & Mrs. Harold H. Kalman

Mr. George Bohn, Sr.

Mr. George Bohn, Sr.
Douglas Weitz

Mr. Maurice Bois

Mr. Maurice Bois
Mr. & Mrs. John Mattera

Ms. Rita Boland

Ms. Rita Boland
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SUPPORT GROUP OPENINGS

The New York City Chapter currently sponsors over 100 Family Support Groups for spouses, adult children, siblings, etc. Some support groups are composed of only spouses or adult children, while others are mixed, that is, made up of all different caregivers. Before attending a group you first need to call the group leader to schedule a personal interview. If you have any questions about our support groups, please contact our Support Group Coordinator, Wendy Panken at 212-983-0700, Ext. 214. **Openings are now available in the following support groups:**

BRONX

Adult Children's Group

City Island Area

DAY & TIME: 6:30 – 8:00 P.M. 1st & 3rd Wednesday

CONTACT: Molly Schroeder 718-885-0609;
Pat Loscalzo 718-231-0985 or Marilyn Paul 718-364-2156

Spanish Language Groups

*Montefiore Medical Center

DAY & TIME: 1:00 – 2:30 P.M. 1st & 3rd Friday

CONTACT: Karina Aquilar 212-983-0700

Spouses' Group

Montefiore Medical Center

DAY & TIME: 5:00 – 6:30 P.M. Tuesdays

CONTACT: Phyllis Antis 718-379-8180

BROOKLYN

Adult Children's Group

Heights & Hill Community Council (Montague Street) GENERIC

DAY & TIME: 6:30 – 8:00 P.M. 2nd & 4th Tuesday

CONTACT: Susan Hason or Judy Willig 718-596-8789

Mixed Groups

Fairview ADHC (Carnarsie area)

DAY & TIME: 4:00 – 5:30 P.M. 2nd & 4th Tuesday

CONTACT: Laura Schlatter 718-251-5600, Ext. 204

Neptune Avenue (425 Neptune, Community Room of Bldg 2)

DAY & TIME: 3:00 – 4:30 P.M. 1st & 3rd Thursday

CONTACT: Jack Pollock 212-721-3537 or Pearl Goldfarb 718-377-0737

Methodist Hospital (Park Slope)

DAY & TIME: 5:30 – 7:00 P.M. Every Other Wednesday

CONTACT: Lianna Dressner 718-780-5533

Spouses' Group

Young Israel of Bedford Bay (Sheepshead Bay)

DAY & TIME: 10:00 – 11:30 A.M. Tuesdays

CONTACT: Tobi Abramson 516-484-3188

(Although there is no out-of-pocket expenses, if you have insurance your company will be billed)

MANHATTAN

Adult Children's Group

360 Lexington Avenue (40th & 41st Streets)

DAY & TIME: 12:45 – 2:00 P.M. Every Other Wednesday

CONTACT: Lorraine Ruggieri 212-362-6500

360 Lexington Avenue (40th & 41st Streets)

DAY & TIME: 12:30 – 1:30 P.M. Every Other Friday

CONTACT: Wendy Panken 212-983-0700

Atria (West 86th Street)

DAY & TIME: 6:00 – 7:30 P.M. 1st & 3rd Tuesday

CONTACT: Helene Bergman 212-724-3170, or
by e-mail: EldCareAlt@aol.com

SPOP (West 88th Street)

DAY & TIME: 6:00 – 7:30 P.M. 1st & 3rd Wednesday

CONTACT: Ginny Abrams 212-787-7120, Ext. 116

Daughters' Group

West 56th Street & Broadway

DAY & TIME: 12:15 – 1:30 P.M. Thursdays

CONTACT: Deborah Rubin 212-757-4202

360 Lexington Avenue (40th & 41st Streets)

DAY & TIME: 6:45 – 8:15 P.M. 1st & 3rd Wednesday

CONTACT: Jeanne Lieb 212-496-1198

Gay & Lesbian Caregivers

Lesbian & Gay Community Center (West 13rd Street)

DAY & TIME: 6:45 – 8:15 P.M. 1st & 3rd Thursday

CONTACT: Carolyn Altman 212-741-2247

Mixed Groups

Ft Washington Houses Services for the Elderly (163rd Street)

DAY & TIME: 11:00 – 12:00 Noon Every Other Thursday

CONTACT: David Currier 212-927-5600

Columbia Presbyterian Medical Center (168th Street)

DAY & TIME: 1:00 – 2:30 P.M. 1st & 3rd Tuesday

CONTACT: Lynn Stiles 212-305-3785

360 Lexington Avenue (40th & 41st Streets)

DAY & TIME: 1:00 – 2:00 P.M. Thursdays

CONTACT: Susan Hason 646-486-3840

360 Lexington Avenue (40th & 41st Streets)

DAY & TIME: 6:00 – 7:30 P.M. 2nd & 4th Thursday

CONTACT: Susan Caccappolo 212-481-5403 or
Beatrice Maloney 212-420-5659

Central Harlem

DAY & TIME: 2:00 – 3:30 P.M. 2nd & 4th Sunday

CONTACT: Carmen Becker 718-457-8099

Lower East Side (Grand St. area)

DAY & TIME: 1:30 – 2:30 P.M. Wednesdays

CONTACT: Francine Shore 212-358-8489, Ext. 313

Lower East Side (Grand St. area)

DAY & TIME: 6:00 – 7:15 P.M. Every Other Monday

CONTACT: Kendall Hamid 212-358-8489, Ext. 303
Bonnie Errico 212-358-8489, Ext. 303

Allen Pavilion's Health Outreach (Inwood)

DAY & TIME: 6:00 – 7:30 P.M. 2nd & 4th Wednesday

CONTACT: Rose Mary Cortez 212-932-5843

Spanish Language Groups

Columbia Presbyterian Family Medicine Clinic (Nagle Ave.)

DAY & TIME: 11:00 – 12:30 P.M. Mondays

CONTACT: Oneida Brown 212-567-2291

360 Lexington Avenue (40th & 41st Streets)

DAY & TIME: 6:00 – 7:30 P.M. 1st & 3rd Thursday

CONTACT: Providencia Calderon 212-867-1717 or
Virginia Cordero 212-860-1189

Settlement House (East 106th Street)

DAY & TIME: 11:00 – 12:30 P.M. Mondays

CONTACT: Mari Umpierre 212-241-6197

Spouses' Groups

***360 Lexington Avenue** (40th & 41st Streets)

Short-Term Educational Group for Caregivers of Newly Diagnosed Spouses

DAY & TIME: 11:30 – 1:30 P.M. Mondays

CONTACT: Wendy Panken 212-983-0700

***360 Lexington Avenue** (40th & 41st Streets)

DAY & TIME: 10:30 – 11:45 A.M. 1st & 3rd Mondays

CONTACT: Wendy Panken 212-983-0700

Wives of Persons with Early Onset AD

360 Lexington Ave (40th & 41st Streets)

DAY & TIME: 5:00 – 6:15 P.M. 1st & 3rd Tuesday

CONTACT: Sharon Shaw 212-222-8924 or Wendy Panken 212-983-0700

QUEENS

Mixed Group

C.A.P.E. /Samuel Field YM-YWHA (Little Neck Parkway) 2 Groups at this location

DAY & TIME: 7:00 – 8:30 P.M. Every Other Wednesday

CONTACT: Joan Baraf or Bonnie Tarlowe 718-224-0566

(A screening interview is required. Although there is no charge for the services, your insurance company will be billed. Contributions are appreciated.)

DOROT's Caregivers' Connections

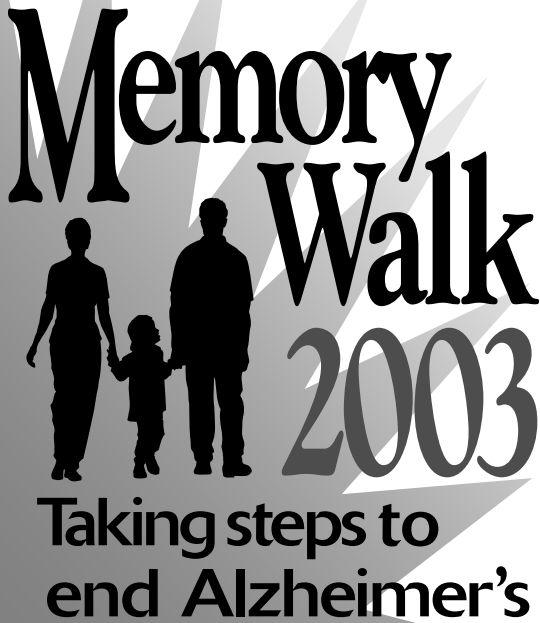
Telephone Support Groups

CONTACT: Faye Radding Liban or Lori Friedman
at 212-769-2850

***NEW SUPPORT GROUP**

15th Annual New York City Chapter

ALZHEIMER'S ASSOCIATION



Please fax completed form to Alzheimer's Association, Memory Walk 2003 at 212-697-6158 or mail to Alzheimer's Association, Memory Walk, 360 Lexington Ave., 5th Floor, New York, NY 10017

My goal is to raise _____ to help end Alzheimer's!

Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: (day) _____ (night) _____

Email: _____ @ _____

Company: _____

My employer has a matching gift program: YES NO

I will be walking as a
 Team Captain Team Member Individual

If you are a member of an Official Team, complete the following:

Team Name: _____

Team Captain's Name: _____

Want to form an Official Memory Walk Team? Call 212-983-6906 Ext. 242

How many years have you participated in the Memory Walk? _____

I am walking in honor/memory of _____

I am unable to walk, but:

Enclosed is my donation of: \$200 \$100 \$50 other \$ _____

Check payable to the Alzheimer's Association, NYC Chapter

Charge the following: Visa MasterCard American Express

Credit Card Number: _____ Exp. Date: _____

Signature: _____ Date: _____

Please send me additional materials:

Brochures (indicate quantity): _____ Posters (indicate quantity): _____

Information on volunteer opportunities

Information on the Alzheimer's Association

Waiver and Release of Liability

I hereby waive all claims against the Alzheimer's Association, sponsors, or any personnel for any injury I might suffer in this event. I attest that I am physically fit and prepared for this event. I grant full permission for organizers to use photographs of me and quotations from me in legitimate accounts and promotions of this event.

Signature: _____ Date: _____

(parent or guardian's signature if walker is under 18 years of age)

Join Bill Ritter, WABC-TV News Anchor
and Come WALK with Us

Sunday, October 26, 2003

Riverside Park, 83rd St. Entrance

Check-In & Breakfast 9:00 am

Opening Ceremonies 10:00 am

Walk Begins 10:30 am

Closing Ceremonies,
Raffle Prizes &
Special Awards 12:00 pm

Daylight Savings Ends Sunday, October 26

You have an extra hour of sleep before
Walking the Walk!



Register for the walk on-line at

www.alzheimernyc.org

and click on



- You'll receive your own Memory Walk web page that you can personalize with photos and messages.
- Build a team and get others to sponsor you by sending e-mails to family, friends and co-workers.
- It's easy and fun and you can help us spread the word.

Memory Walk Hotline 212-983-6906 Ext. 242

BULLETIN BOARD

Chinatown, ADCP

Hamilton-Madison House, located in lower Manhattan, is pleased to announce a new Adult Day Program for persons of all ethnicities with dementia and memory loss. The program goal is to improve the quality of life for participants while providing support and education to caregivers and family members. Staff members are bilingual and bi-cultural.

Services include: door-to-door transportation, meals, social and recreational activities, assistance with personal care and medication reminders.

The program runs Monday to Friday, 8:30 am – 6:00 pm. For more information, contact An Hoang, Program Supervisor, at 212-788-5757.

Coordinated Care Project

The Jewish Home and Hospital seeks to enroll Bronx and Manhattan residents over 65 in a four-year study to test whether Lifecare Plus, a Medicare funded Coordinated Care service, can help Medicare beneficiaries by arranging services and improving communication among the multiple health care providers caring for the individual.

There are no risks or costs to participants, and no need to change doctors or any other care providers. Transportation to activities and groups held at Lifecare Plus are provided free of charge. To enroll, patients must suffer from at least one high-cost chronic care condition (such as dementia, cancer, CHF, COPD, Parkinson's, depression or anxiety disorder). For details, call Patricia Mulvey, CSW, at 212-870-4667.

SAVE THE DATE!

New York City Chapter's 25th Anniversary Annual Gathering Wednesday, October 1st

The Graduate Center

Jonathan Franzen, Keynote Speaker and Prize-Winning Author
RSVP is necessary.

Please contact Albert Cummings at 212-983-0700, Ext. 245

NYC Marathon Alzheimer's Team Forming

Will you be running in the NYC Marathon?
Are you already registered and have you got a number?

Would you want to run for Alzheimer's
and raise funds to combat the disease?
Call (212)983-0700 ext. 215 to learn more.

New Adult Day Program in Chelsea

The Chelsea Adult Day Health Center believes the capacity to enjoy life does not end with a diagnosis of Alzheimer's disease or memory impairment. We strongly advocate that everyone has unique strengths, interests and needs regardless of their diagnosis.

We are pleased to announce that our adult day health program has opened a new dementia specific program. We already have a beautiful physical environment but have complemented this new program with staff trained by Anne Thomas, Program Director, and former NYC Chapter staff member. Additionally, our focus is organizing groups by the special needs of each person. The importance of the whole person – mind, body and spirit – is incorporated into all aspects of care.

Please call us at 212-337-9260 to schedule a visit.

Free Drug Benefit Eligibility Report

BenefitsCheckUpRx is a fast, free and confidential service providing seniors with a personalized eligibility report for over 240 prescription drug savings programs covering nearly 800 medications.

This new service expands the National Council on the Aging's BenefitsCheckUp website. Visiting www.benefitscheckup.org enables seniors (and their families and caregivers) to easily screen various state and federal programs. After filling out a brief questionnaire, seniors will get a list of the benefits they qualify for and detailed instructions on how to enroll.



Someone to Stand by You

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

Address Service Requested

NONPROFIT ORG.
U.S. POSTAGE
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PITTSBURGH, PA
PERMIT NO. 251