



Published quarterly for our donors, volunteers, advocates and friends in the Alzheimer community

New Toll Free Helpline #: 800-272-3900

(see page 3)

Alzheimer's Association, New York City Chapter, Names President and CEO

Manhattan resident Lou-Ellen Barkan has been named president and chief executive officer of the Alzheimer's Association, New York City Chapter, effective March 1, 2004.

Ms. Barkan most recently held the position of Vice President for Administration at UJA-Federation of New York. Prior to joining UJA-Federation, she served in the Office of the Mayor during the Giuliani Administration in a number of high-level appointments, including director of finance and administration, chief of staff to Deputy Mayor Randy Mastro and special advisor to the School Construction Authority.

"This is a critical time in the Alzheimer's community," Ms. Barkan said. "The emerging scientific research has enormous promise to help those who have this devastating disease. In addition, as the baby boomers begin the aging process, the new research has potential to diagnose, protect and treat an entire generation. I am delighted to join the NYC Chapter as they embrace the new national Alzheimer's Association agenda, while continuing New York's 25-year history of providing essential programs and services to individuals and their families who are coping with the crisis of Alzheimer's. With the growing momentum in research, the increased knowledge and resources for people with the disease and their caregivers, these are exciting times. I am confident that we will have many opportunities to collaborate with our colleagues and to share our message of hope."

Bill Kaye, co-president, NYC Chapter board of directors, Alzheimer's



Association, said: "We are fortunate to have Lou-Ellen's sound leadership, innovative ideas, and warm, personal commitment to the needs of those impacted by Alzheimer's disease. Her extensive knowledge of New York City leadership and industry will lead our chapter to new levels in addressing the needs of our constituents at a most important time."

During her tenure at City Hall, Ms. Barkan was responsible for oversight of the Mayor's Office of Contracts and for a number of major citywide initiatives, including the City's Y2K Project; "Smart Schools," the Board of Education's school computer project; and the creation of the Administration for Children's Services (ACS).

Additionally, Ms. Barkan previously enjoyed a successful career on Wall Street, holding executive positions at major financial institutions including Lehman Brothers, Citicorp and Paine Webber. She received her BA from Hunter College and has a MA from Teachers College/Columbia University. Ms. Barkan is married to attorney Mel Barkan and has two grown children. ●

Early Stage Now— Challenges and Choices

There has been a remarkable change in the mood and energy of the annual early stage Alzheimer conferences since the first one in 2000. Judging by the number of speakers now willing to reveal their trials and triumphs as newly diagnosed members of the Alzheimer's community, the specter of shame and hopelessness has been replaced by a more productive response: *I will make the most of the present, focus on what I can do and even try things I never made time for before.*

We're talking about more than smelling the roses. Some of the pursuits essayed by those in attendance included taking piano lessons (Dr. William Deutsch, who attended with his piano teacher, Susan Fisher), writing (Ivan Herman), tutoring, art (Josephine Wechsler) and poetry. Thomas Hendricks speaks to groups about his situation. The wife of a member of a group in Connecticut read a letter her husband sent out to about 30 friends when he finally decided (two years after being diagnosed) that he was ready to explain changes in him that they might have noticed. Only two out of the 30 didn't respond.

(continued on page 5)

Also in this issue...

Director's Corner	2
Safe Return	3
Editor's Note	3
Public Policy Update	6
Legal Guidance/Guia Legal	8/9
Education Calendar	10
Support Groups	12
Book Shelf	14
Tributes	16
Bulletin Board	20
Genetics Initiative & Clinical Trials	insert

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Director's Corner

I received a call last week from David Cassaday telling me that his mother, Mary, had died after living with Alzheimer's disease for over eight years. Some of you may recall that Mary was a member of one of the first early stage support groups held at our chapter. She was one of the panelists who first told their story to a group of professionals on Feb. 2, 1996 at a ground-breaking forum we held called *In Our Own Voices*.

Mary first called me in the fall of 1995. She had been recently diagnosed at NYU and was told about our support group. I did a brief phone interview and then Rea Kahn, my co-leader, and I met with Mary. Mary was ready for the group. She leapt at the chance to meet others who were similarly diagnosed, and for several years used the group as a source of comfort, a safe place to share all her feelings about the changes in her life, and a place to make friends. Indeed, she became very close to Elizabeth, another woman in the group. They went to the movies and lunch together, laughing about how neither of them could figure out the tip!

When we discussed the opportunity to talk to professionals, to share the early stage experience, Mary was eager to participate. She was nervous about speaking in public, but felt strongly that it was important to tell her story. She was still living life, enjoying the richness of New York, and savoring the fact that she was no longer working at a job that had become very stressful. "Every day was a holiday!" she said at that forum.

When our National Association was looking for an early stage person to be photographed, Mary again volunteered. She spent a day with a photographer in NY. Her photo appeared on the brochure "If You Have Alzheimer's," written for the person in the early stage. Mary was becoming a celebrity, a spokesperson. Yet she was losing fluency and speaking was becoming more difficult. The Chapter helped her enroll in a special speech program for persons with early stage AD.

Still, it was stressful for her children. Some attended support groups, and some



Jed A. Levine,
Acting Executive Director
and Director of Programs
and Services

came to the education meetings on a regular basis. Mary was pleased that her family was being helped here. They, too, helped with public awareness. Her son, David, appeared in several interviews and spoke at our Early Stage Conference two years ago.

As the disease progressed, Mary needed more help. She was becoming more anxious living alone, yet resisted having a home care companion with her. She and her family turned to the Chapter. We knew about Grace, a home health care worker, who went through our comprehensive training program. After checking references and interviewing her, she was hired. It was a match that worked, not always smoothly at first, but Grace knew how to provide direction and support without being too pushy.

Private home care was costly, and the family could only afford so much. Mary had been a working woman, an Executive Assistant at a major life insurance company. She wasn't wealthy, she wasn't poor. She had worked hard all of her life, and now was facing financial hardship as a result of her long-term care needs — and she was one of the lucky ones; she had health insurance from her job which covered prescription drugs. Mary's children attended a Chapter Legal/Financial Seminar, saw an elder law attorney and made plans.

Mary had other medical issues, serious dizziness and tinnitus caused by Meuniere's disease, which incapacitated her at times. She fell, fractured a hip and was placed in a nursing home after a long hospitalization. This was a difficult adjustment for all. Finding the right home, close enough to visit, and providing excellent care was a priority.

Again, the Chapter was able to assist the family in sorting out the bewildering

(continued on page 4)

ALZHEIMER'S ASSOCIATION

Safe Return

Taking the First Step

I do not know how many of you watched *The Forgetting*, which aired on PBS in January. For those who are caregivers for a relative diagnosed with Alzheimer's disease, it was a painful moment of identification. But in addition to the sadness, there are also moments of laughter and warmth. An undeniable reality of AD is that it affects the whole family.

Some families shown in *The Forgetting* were conflicted and feeling the stress of caregiving. Most families ultimately became closer in the course of their struggle with this disease. Alzheimer's affects the entire family. Many people still are reluctant to seek help because of a perceived stigma associated with AD. Many feel isolated. But you don't have to go through it alone.

We at the New York City Chapter of the Alzheimer's Association are here to help and support you. Because of the demands of caregiving, caregivers often neglect themselves. In this situation, it is not unusual to feel anger and resentment. These were supposed to be the golden years after retirement. Alas, life didn't turn out that way.

So what are caregivers to do?

Sometimes taking the first step in getting help is the hardest. Let us help you take that first step. Call the Chapter 24-hour Helpline at 800-272-3900. Ask about Chapter Orientation Meetings and Support Groups. Register your relative in the Safe Return Program. Then, in the event your relative wanders and gets lost, he or she may be found and returned to you in a safe and timely manner. Keep the Helpline number handy for your own support. When you need to talk, you'll know someone who understands will be on the other end of the line. You are not alone.

If you care for someone with Alzheimer's disease, don't be too hard on yourself; know you are doing the best you can under very difficult circumstances. Do something for yourself today. Call an old friend, take a walk, do something to exercise your mind or energize your spirit. For more information or for assistance in registering someone in the Safe Return program, please contact me at 212-983-6906 ext. 205 or by e-mail at Elizabeth.Santiago@alz.org. ●

—Elizabeth Santiago
SAFE RETURN COORDINATOR

NYC 24-Hour Helpline Adds Toll Free Number

After 16 years of offering 24-hour Helpline service in New York City, the Chapter is pleased to be adding a toll free number: **800-272-3900**. The first chapter in the network to offer 24-hour service, the New York City Chapter will be joining the National Alzheimer's Association Contact Center on March 15, 2004. The Contact Center will enhance our chapter's 24-hour Helpline coverage. Features of the Contact Center include language translation

services in 140 languages, the ability to transfer calls directly to other participating Contact Center chapters, and a toll free number. We will continue to provide the most current information about Alzheimer's disease, offer referral to chapter programs and community services as well as lend support to our callers whenever they turn to us. Contact us 24/7 at **800-272-3900**. ●

Editor's Note



Our recent Early Stage Conference was infused with a new optimism — confidence that lives can and will continue to be worthwhile as the early stage itself is extended. Medications now allow us to be proactive when faced with Alzheimer's.

Caring family and friends and peer support groups are also part of the safety net that allows those with early stage AD to bounce back from depression, anger and frustration. Instead, they are exploring their creativity, engaging with life and appreciating every moment of it.

At the same time as our perception of what AD is evolves and expands, the public in general is becoming more aware of its nuances — how differently AD affects each individual. Such broadcasts as PBS' *The Forgetting* show the toll that caregiving takes on families. While fictional presentations still tend to fade out before AD reaches its catastrophic end stage, documentaries don't flinch from depicting the devastation ahead.

In some ways, the Association's mission is more challenging than ever. Originally, our focus was primarily on the family members and caregivers. Chapters offered them guidance and support, but there wasn't much we were able to offer the person with Alzheimer's. Once, we referred to them as patients or victims, speaking about them rather than to them.

Now, we can encourage the newly diagnosed, and help them stay in charge of their lives to the fullest extent possible. Yet we're still committed to families, directing them to the specialized legal, financial and medical services as needed. We're helping the national organization identify and fund promising research that will prevent, treat or cure AD.

We're also in business to train professionals who care for people with AD. Our input has proven invaluable to hospitals, nursing homes and assisted living facilities as they learn to understand the disease and the people who suffer from it.

There's so much to our mission now, but the New York City Chapter has yet to regain its pre-9/11 level of contributions. With your help, we can make sure we're here when you, or someone you love, needs us. ●

—Chris MacLeod

Director's Corner

(continued from page 2)

array of choices. The last time I saw Mary was two years ago. I was so happy to see her. She still knew me, and was so pleased that I had come to visit. She looked great, her hair beautifully colored and coiffed as always. She and David showed me around the home. She liked some things and hated others about the place. Grace was still with her several hours a day.

Several months ago David called to talk. The situation had gotten worse. Mary seemed tortured by the endless assault of Alzheimer's. She cried so pitifully when her children left that they were debating whether it was less painful for her if they didn't visit at all. She wasn't walking any more, she wasn't eating very much, she seemed depressed and despondent. David sounded exhausted. He and his sisters had been through so much in caring for their mom.

Two weeks ago David called to talk about end of life care. We spoke about the options. The family was clear about what Mary would have wanted. She had essentially stopped eating, and slipped into a coma. She died peacefully on January 17, 2004 at the age of 70.

Mary and her family's valiant fight against this disease, her desire to stay independent and not to burden her family, her willingness to speak out, to demand to be noticed, and to put a face on Alzheimer's disease bring home all the compelling reasons we must do better in the future. We must find better treatment, prevention, and hopefully a cure. We must also continue to improve the way we care for persons with Alzheimer's disease and their families.

The Alzheimer's Association is entering a new era: we have a new look and are recommitted to our mission. I am pleased to announce that as of March 1st, the New York City Chapter has a new President and CEO, Lou-Ellen Barkan. Lou-Ellen is deeply committed to this cause. With her help we will fulfill our vision of creating and sustaining a comprehensive and humane system of patient care and family support which enhances the quality of life for persons affected by the disease until the time that the disease is eradicated. I look forward to working with Lou-Ellen and with all of you to help fight this debilitating disease, and to provide better care for all affected by it. People with Alzheimer's disease deserve it. Mary Cassaday will not be forgotten. ●

Combined Drug Study on Aricept and Namenda

Individuals with moderate to severe Alzheimer's disease who took memantine (Namenda™) while receiving donepezil (Aricept™) fared better on measures of cognition, daily activities and overall function than individuals who took a placebo with their donepezil.

Results of this multicenter clinical trial are reported in the Jan. 21 *JAMA*, the *Journal of the American Medical Association*. Forest Laboratories, the pharmaceutical company that markets memantine in the United States, funded the study.

Participants had started on donepezil at least six months before enrolling in the trial and had been taking the same dose for at least three months. On average, they had been taking donepezil for over two years before starting memantine.

Memantine earned approval by the U.S. Food and Drug Administration (FDA) in October 2003 as the first drug indicated for treatment of moderate to severe Alzheimer's disease. It appears to act by regulating the activity of glutamate, one of the brain's cell-to-cell messenger chemicals involved in learning and forming memories.

Donepezil is in another class of Alzheimer drugs currently approved for mild to moderate symptoms. These drugs support levels of acetylcholine, another cell-to-cell messenger chemical. The other two commonly prescribed drugs in this category are rivastigmine (Exelon™) and galantamine (Reminyl™). This trial did not investigate the effects of memantine in

addition to either of these drugs.

Because investigators studied participants in this trial for only 24 weeks, the trial does not provide data on the effects of long-term use of memantine when it is added to donepezil. Investigations of longer-term use are ongoing.

In June 2003, Forest reported preliminary data from a trial of memantine combined with any of the three acetylcholine-supporting drugs to treat symptoms of mild to moderate Alzheimer's. According to Forest's own analysis, which has not been peer reviewed or published, individuals taking memantine experienced no greater benefit than those taking a placebo in addition to any of those three drugs.

Although both memantine and drugs that support acetylcholine temporarily delay worsening of Alzheimer symptoms through different mechanisms, neither class of drugs is known to stop the underlying progression of the disease. Though the benefit of the memantine/donepezil combination was statistically significant in treating moderate to severe symptoms according to the detailed assessments of function used in this study, the effect may be modest in terms of everyday situations and will vary from person to person.

Side effects seen more frequently in participants taking memantine and donepezil included episodes of confusion and headache. In memantine recipients, confusion most commonly occurred an average of 32 days after beginning memantine and improved within two weeks. Headaches usually lasted one day. ●

New Comprehensive Web Site Launched January 15

Faced with the immediate need for a wide range of day-to-day, practical care giving information — as well as the need to address financial, legal and other planning issues — persons with Alzheimer's and their caregivers can become overwhelmed.

To address this problem, the Alzheimer's Association, NYC Chapter, launched a new, comprehensive web site on January 15, 2004, that gives persons with Alzheimer's, their caregivers and healthcare professionals, up-to-date information in a "user-friendly," easy-to-navigate format.

Located at www.alznyc.org, the site includes:

- Information about the programs of the

Chapter, including educational seminars and support groups;

- Advice on handling caregiving challenges, day-to-day activities and much more;
- A road map through myriad legal and financial issues affecting people with the disease;
- Information on the specific resources available to New York City residents, including information on adult day care programs, diagnostic centers and geriatric hospitals; and
- Links to other important sites, both throughout the web site's content and in our resource database.

(continued on page 15)

Early Stage Now—Challenges and Choices

(continued from page 1)

Every member of the panel (and his or her spouse) encouraged others to share the news of the diagnosis as soon as possible. This will begin to make people realize that Alzheimer's doesn't mean the end, that friendship and productivity can and should be maintained.

Through their courage, creativity and humor, these people have already succeeded in "Transforming the Early Alzheimer's Experience," the theme of the December 4 gathering. Hundreds of attendees reserved their places at our new venue, the Graduate Center of the City University of New York (in what was once the B. Altman flagship store).

Greetings were extended by early stage person Margaret Henighan — who spoke of her newly discovered passion, quilting. Jed Levine, acting executive director of the Alzheimer's Association's NYC Chapter, introduced our keynote speaker, Joel Meyerowitz. A world-renowned photographer, Meyerowitz presented a *Nightline* broadcast that featured excerpts from the film he made about his father.

Pop follows three generations of Meyerowitz men on a trip to Disney World. Pop is 88, a former stand-in for Charlie Chaplin whose brio and sense of humor remain even as Alzheimer's closes in. He laughs at his own mistakes — such as when he rediscovers what a light switch does — kibitzes with African-Americans at the theme park (thinking he must be in Harlem, where he grew up). "His personality hasn't changed," commented the filmmaker. "Losing his inhibitions made pop more willing to reach out...he was living with Alzheimer's, not dying from it." He lived another four years.

The group then dispersed to their chosen workshops, which emphasized creative approaches to communication, coping and advocacy, humor and spirituality. I chose to sit in on "Spirituality: Exploring New Paths," facilitated by Maureen Matthews, RN, MSN. The openness of Anthony Laureano, who shared how he was affected by his diagnosis five years ago, was compelling. He said that while his faith hadn't been that strong before, he "went to church and meditated and felt the Holy Spirit entering my soul."

Since then, Laureano has been drawn to art museums, fascinated by "who these artists were and what they felt while creating" their works. "I thank God for the drugs that have allowed me to stabilize," he exclaimed. His advice: "Don't make yourself miserable by dwelling on your illness."

This message was seconded by Modesta Murphy, a caregiver whose husband, an artist, has AD. Metaphorically, the early stage is a bridge from the struggle (confusion, anger) to the light (acceptance, focus). There literally isn't any time to waste being depressed. It might indeed help anyone to imagine how he or she would live each day if they had Alzheimer's. ●

—Chris MacLeod



Keynote Speaker, Joel Meyerowitz and Acting Executive Director, Jed A. Levine



Three-Time Returning Early Stage Conference Volunteers, (l to r) Bernice Shirwindt, Genevive Constantino, and Lena Veechio, listening to the keynote speaker

CHOICES AND CHALLENGES: Confronting a Dual Diagnosis with Creativity and Determination



By Margaret Henighan,
Member, Planning Committee,
As told to Susan Goldfein,
Ed.D., Program Coordinator,
4th Annual Early Stage
Alzheimer's Conference

I have temporal lobe epilepsy that for many years went undiagnosed and untreated. I had become familiar with the effects of this disorder and had learned to live with them. However, in 1999, I went to my neurologist complaining of symptoms which were unusual even for me. He suspected early Alzheimer's disease and put me on the Alzheimer's medication regimen. I was not unfamiliar with Alzheimer's disease. My mother is in the last stage and my aunt died from it six years ago. So there is a clear family history. And unfortunately having one disorder does not provide immunity against other disorders. My early symptoms included speech problems — losing words, using wrong words and a lot of hesitation in conversations. I knew what I wanted to say but I couldn't come out with it. Also, I had trouble locating places I had to go to, places I was familiar with and had traveled to many times.

After going through the shock and fear of confronting Alzheimer's disease I realized I had choices to make. Was I going to let the situation defeat me or was I going to be resourceful and creative and live my life to the fullest for as long as I could? I chose the latter.

I am a single woman and a retired nurse. I reside in assisted living housing on the upper west side of Manhattan. One of the first things that I did was go to the New York City Alzheimer's Association where I received helpful information and enormous support. One of their suggestions was that I join an early stage support group at Mt. Sinai Hospital. Here was my first new choice. I am basically a shy person and had never done anything like this before. I decided to join and the group has become invaluable to me. I receive so much encouragement from the other group members and from the leader, Elizabeth Fine. In addition to meeting wonderful people in similar situations to mine, it has opened many doors and given me the courage to try new things. It was through the support group that I became involved with the Annual Early Stage Conference three years ago. All year I attend the planning committee meetings and feel my input really matters. Each year I participate in a workshop and one year even volunteered to be one of the plenary session speakers — I who had never addressed an audience before in my life!

In my struggle with my dual diagnosis, I have learned to reach out, accept help and embrace opportunities. The devoted

To see additional photos of the conference, please visit www.alznyc.org/Newsletter.htm and select Early Stage Now - Challenges and Choices.

(continued on page 15)

Public Policy Update

Federal & State Issues February 2004

Medicare Prescription Drug Coverage

The long-awaited Medicare prescription drug legislation was passed by Congress and signed into law by President Bush in early December. This \$534 billion legislation is extremely complicated and numbers of provisions will require clarification including those relating directly to different beneficiary groups. For example, low income persons not on Medicaid, those eligible for both Medicare and Medicaid (dual eligibles), and those with higher incomes who can afford a level of financial risk. Advocacy groups and health care experts are already actively analyzing and seeking to address issues of concern. Enrollment for prescription drug coverage will be voluntary. Also, beneficiaries will be able to remain in traditional Medicare as they know it and sign up for a stand-alone drug insurance policy. The bill, however, does encourage enrollment of beneficiaries in private plans. For those who choose a private plan, drug coverage will be included along with physician services and hospital care.

The following example has been widely circulated to provide a framework for understanding out of pocket costs for a Medicare prescription drug beneficiary. As things stand now under the new law, enrollees will pay a \$250 annual deductible, a premium of \$35 a month, and a 25% co payment on drug costs up to \$2,250 in a year, then there is a gap in coverage of all drug costs until a total of \$3,600 has been spent out of pocket (for the equivalent of \$5100 in prescription drugs). Medicare will pay 95% of the cost of prescriptions beyond that as catastrophic coverage. Dual eligibles will pay no premium or deductible and will not have a gap in coverage, but they will have co pays for drugs. Co-pays are waived for persons in nursing homes. Persons with low income not on Medicaid with income below \$13,000 (\$17,600 for couples) and assets of under \$6,000 (\$9,000 for couples) will pay no premium or deductible and

have no gap in coverage, though they will have co-payments for their drugs.

Obviously, none of this is simple. Each aspect of coverage raises issues, and it is beyond the scope of this article to provide any in depth information or analysis. The legislation, however, does not become effective until January 2006, and a great deal of analysis and information will be made available before then that will help to clarify beneficiary coverage and options in making their decisions.

Prescription Drug Discount Cards

Prescription drug discount cards are expected to be available in June. Medicare will be sponsoring these cards, expected to save 10% to 15% on brand name prescription drugs and bigger savings for generic drugs. While there are expectations of even higher savings, these will depend on prices card sponsors negotiate with drug companies. Seniors with low incomes earning less than \$12,123 a year (\$16,362 for a couple) will not have to pay a fee to purchase a card and will receive a \$600 allowance toward the cost of their drugs. The discount cards will vary in what drugs they cover, and seniors will have to make choices as to which card to purchase. You will be able to purchase only one card.

There is already considerable discussion about the benefit of having a card, and whether these cards will be better than having one of the already existing discount cards or purchasing drugs from Canada. Although Medicare is to provide information on the different cards available, once again the consumer will have to make the choice. But it can be expected that various advocacy groups and organizations concerned with consumer issues will be making information available.

State Issues Update

The State Senate Medicaid Reform Task Force and the Governor's Working Group on Health Care

At the end of December the NY State Senate Medicaid Task Force made its

recommendations. The report calls for substantially restricting spousal refusal and asset transfers and extending the look back periods for transfers. Implementation of these recommendations would have a tremendous impact on Alzheimer's families. Currently, the well spouse can refuse to make monies available for the support of the ill spouse in need of long term care. Similarly, there is no waiting period for the NYC home attendant/personal care program if assets are transferred to establish one's Medicaid eligibility.

A transfer of assets waiting period for home care would result in delaying access to care at home under Medicaid and increasing caregiver burden. In addition, there are insufficient alternative services in the community that can provide the level of needed service. Similarly, a dire situation would face the spouse who wants to keep the ill spouse at home and exercise spousal refusal. The well spouse would have no financial protections. Must this spouse resort to placing the ill spouse in a nursing home, often prematurely, to secure a measure of asset and income protection? Indeed many spouses resorting to nursing home placement and exercising spousal refusal have assets and income that may barely exceed allowable resources. As such, they may well face twenty or more years of old age with drastically limited and depleted resources. Must there be a divorce after decades of marriage?

The Senate report also calls for single access points, referral, and assessment for long term care. While a more systematized approach to access to long term care is a worthwhile goal, our concern remains that implementation in the five boroughs would be of variable quality and accuracy. A high level of staff training and education would be required. Above all, appropriate and sufficient services must be available if persons throughout the city are to be diverted from Medicaid and remain in their own communities. At this time the needed services are not in place throughout the city, and non-Medicaid services cannot meet the demand for hours of personal care in the home. This situation will have

(continued on page 7)

(continued from page 6)

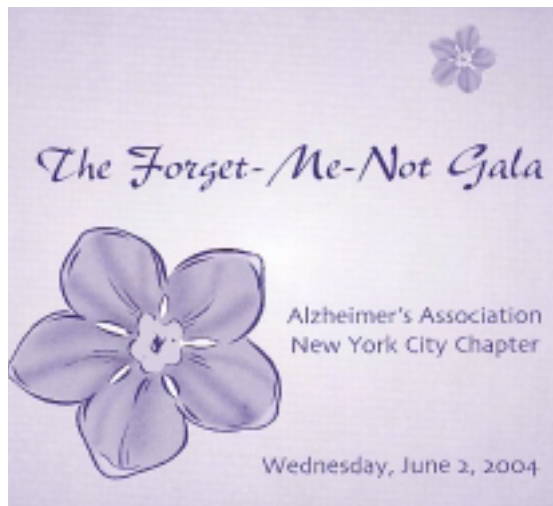
serious consequences and result in premature institutionalization for many people who otherwise could remain in their own communities throughout the duration of illness. The Senate Task Force does come out for expansion of the managed long term care program, caregiver support, and respite. However, for those who are employed or aging and caring for another aged person, personal care hours and sufficient immediately available options are important to avoid burnout as the disease progresses.

The recommendations of the Governor's Health Care Reform Working Group mirror many of the Senate Task Force proposals. The Governor's Working Group calls for applying the look back period for transfer of assets to home care, expanding the look back period from three to five years, and eliminating spousal refusal. The Working Group has proposed a sweeping redesign of the long term care system to create a home and community-based model called NY ANSWERS. This single point of entry model would be a consumer driven approach involving information, assessment, referral, and access to health and social service supports.

Our Coalition of New York State Alzheimer's Chapters recognizes in its 2004 Legislative Agenda the importance of Medicaid for the Alzheimer's population. The Legislative Agenda opposes restrictions with regard to transfers of assets and spousal refusal and also opposes extension of the look back period for establishing Medicaid eligibility. Our chapter will work with concerned organizations, advocacy groups and others to oppose these limitations and additional Medicaid cuts proposed in the governor's budget. We will also alert the Alzheimer's community to respond to specific legislative proposals as they are introduced in bill form by writing, calling, or emailing the governor, members of the legislature, and chairs of the relevant legislative committees. ●

—Ann Berson,
PUBLIC POLICY COORDINATOR

* Visit www.alznyc.org to take action against Medicaid cuts.



HONORING
Howard Solomon
Chairman and Chief Executive Officer
Forest Laboratories, Inc.

Wednesday, June 2, 2004
The Pierre

Please join us for an elegant, exciting evening of dancing, dining, and both silent and live auctions.

For more information,
please contact Meredith Sanandres
at 212 888-7003

Taking Combined Vitamin E and Vitamin C May Reduce Alzheimer Risk

Older adults who take supplements containing at least 400 international units of vitamin E and 500 milligrams of vitamin C may reduce their risk of Alzheimer's disease, researchers report in the January 2004 Archives of Neurology.

The conclusion is based on data from the Cache County Study on Memory, Health and Aging, a long-running investigation of the occurrence of Alzheimer's disease and factors that may influence its development in several thousand older residents of Cache County, Utah.

The current recommended daily allowance for vitamin E is 22 international units or 15 milligrams, and 75 to 90 milligrams of vitamin C, levels that are typically found in a general-purpose multivitamin. The higher doses most strongly associated with reduced Alzheimer risk in this study are more often found in individual supplements.

Researchers found no notable association between reduced occurrence of Alzheimer's and taking vitamin E or vitamin C alone or with use of B complex vitamins. The study did suggest, however, that there may be some protective effect of vitamin E in a dose of 400 international units combined with the lower amount of vitamin C typically found in a multi-vitamin.

Because this was an observational

investigation looking at existing behaviors in the study population, the data can suggest an association between vitamin E and C intake and reduced risk of dementia but cannot prove cause and effect. The investigators note that as a group, participants who took the high levels of vitamin E and C supplements tended to be younger, better educated, and in better general health than other study subgroups, all factors that may be associated with a reduced risk of dementia.

The authors suggest that the results are strong enough to justify a controlled clinical trial in which participants are randomly assigned to take the high-dose combination vitamin regimen or a placebo. Data from such a trial would provide stronger evidence that use of the vitamins directly affects dementia risk.

The theoretical basis for the interest in vitamins E and C is their antioxidant effect. Although oxygen is essential for life, normal cell processes produce certain highly reactive oxygen molecules that can damage cell structures. This damage may play a role in aging as well as in Alzheimer's disease, cancer and other disorders. Antioxidants may protect cells from the damaging effects of these highly reactive oxygen-containing molecules.

This study was supported by grants from the National Institutes of Health and the National Institute of Mental Health. ●

Legal Guidance



Medicaid Update 2004

The beginning of each year is an opportune time to review developments in the Medicaid program, which is so critical to individuals and families coping with Alzheimer's.

The devastating emotional loss to the family and the strain of providing care is all too frequently accompanied by the financial havoc long term home care and institutional care has on family finances. Planning for Medicaid eligibility is the only way that many families who have worked their entire lives will avoid destitution. Recently a Court again validated the planning process for Medicaid eligibility as both appropriate and legal. In the case a nursing home sued a resident's family claiming that by their receiving gifts from the resident they had violated the nursing home's right to have the resident spend all her money on nursing care. The resident had actually done Medicaid planning by transferring to her family part of her assets but retaining sufficient assets to pay for her care until she became eligible for Medicaid. This New York court held that transfers while retaining assets reasonably calculated to cover the cost of care until a person becomes eligible for Medicaid cannot be considered a fraudulent conveyance to defraud creditors.

Home care provided by Medicaid has been instrumental in making New York State a leader in supporting individuals and families dealing with Alzheimer's and related cognitive disorders. Home care allows the Alzheimer's patient to remain at home in familiar surroundings, which slows deterioration and can reduce the impact on the patient. Unfortunately the number of hours of personal needs care provided by Medicaid is determined by a system of "task based assessment" which adds up the hours for each task where assistance is needed. However, by recent regulation, the Department of Health has stated that task based assessment is not to be used where the person needs continuous 24 hour personal care. This rule applies even if some of the 24 hour continuous personal

care is provided by informal caregivers such as family members.

Among the tasks the State Department of Health does not recognize in "task based assessment" is safety monitoring for a cognitively impaired individual. However, in an Administrative Memorandum, the Department of Health recently reminded local social services officials around the state that safety monitoring while the cognitively impaired are transferring, toileting, walking or engaging in other activities of daily living is an appropriate consideration in determining the amount of home care that should be provided.

The Department of Health is eliminating the face-to-face interview requirement for Medicaid renewal, beginning April 1, 2004, and has developed a simplified renewal form for most Medicaid recipients. Medicaid recipients receiving home care in New York City already use mail-in recertifications, but now no recipient, even those in the early stages of cognitive disorder, will not have to travel to a face-to-face interview.

A recent and recurring problem around the state regards the implementation of the privacy provisions of the federal Health Insurance Portability and Accountability Act (HIPAA) by local social service agencies. The agencies have interpreted HIPAA as barring the discussion of specifics of Medicaid applications with family members or advocates on the grounds that to do so would violate HIPAA's privacy provisions. Advocates and family members will be able to view or discuss the Medicaid records with the local agency of an applicant or recipient if they obtain, complete, and submit to the local agency its authorization form (in New York City, use MAP-751D "Authorization for Disclosure of Individual Health Information").

Medicaid eligibility income and resource amounts have been updated for 2004. Individual Medicaid recipients in the community may receive monthly income of \$679 without adversely affecting

Medicaid coverage. The resource allowance for an individual is \$3,950. For the community spouse of an institutionalized individual the maximum Community Spouse Resource Allowance is \$92,760. The community spouse's Minimum Monthly Needs Allowance is \$2,319. The state has also updated the "transfer penalty rates." The transfer rate for New York City is one month for each \$8,695. For information on how any of these income, resource or other rates affect Medicaid eligibility you can attend one of the Legal/Financial Seminars held three times a month at the chapter office or you can consult a knowledgeable Elder Law attorney. ●

Jeffrey G. Abrandt is a partner at Goldfarb Abrandt Salzman & Kutzin, LLP with offices in New York City and White Plains, New York. The firm is in the general practice of law concentrating in litigation, trusts and estates, health law and the rights of the elderly and disabled. Mr. Abrandt is a fellow of the Brookdale Center of Aging and has served as chair of the Senior Section of the National Legal Aid and Defenders Association.



Guía Legal



Medicaid Al Día 2004

El principio de cada año es oportuno para revisar desarrollos en el programa de Medicaid, el cual es crítico para personas y familiares que enfrentan la enfermedad de Alzheimer.

La devastadora pérdida emocional que la familia siente y el gran esfuerzo de proveer cuidado es todo muy frecuentemente acompañado por los estragos financieros de cuidados en la casa a largo plazo y el cuidado institucional que recae en las finanzas familiares. Planear para la elegibilidad de Medicaid es la única manera en que familias que han trabajado toda su vida pueden evitar la indigencia. Recientemente una Corte volvió a validar el proceso de planificación para la elegibilidad de Medicaid tanto legal como apropiado. En caso que un asilo de ancianos demande a la familia de un residente reclamando que al recibir regalos del residente ellos habían violado el derecho del asilo de ancianos en recibir todo el dinero de el residente como paga por el cuidado. En realidad el residente había hecho planificación para Medicaid al transferir parte de sus bienes a su familia pero reteniendo suficiente bienes para pagar por su cuidado hasta ser elegible para Medicaid. Esta corte de Nueva York sostuvo que transferencias mientras se retengan bienes razonablemente calculados para cubrir el costo de cuidado para la persona hasta que esta persona sea elegible para Medicaid no puede ser considerada una transmisión fraudulenta para defraudar acreedores.

El cuidado en la casa proveído por Medicaid ha sido instrumental en hacer a el estado de Nueva York un líder en apoyar a personas y familias que lidian con la enfermedad de Alzheimer y otros desordenes cognoscitivos. El cuidado en la casa permite al paciente permanecer en casa rodeado de recuerdos familiares, el cual reduce el deterioro y puede reducir el impacto negativo en el paciente. Desafortunadamente el numero de horas para el cuidado personal previsto por Medicaid es decidido por un sistema de

“valoración basado en tareas” el cual suma las horas para cada tarea donde se necesita ayuda. Sin embargo, reciente regulación, por el Departamento de Salud ha indicado que la valoración basado en tareas no se ha de utilizar cuando la persona necesita continua ayuda personal las 24 horas al día. Esta regla aplica aún si algunas horas de cuidado personal son proveídas por familiares.

Dentro de las tareas el Departamento de Salud no reconoce en la “valoración basado en tareas” el control de seguridad para una persona con deterioro mental. Sin embargo, recientemente en un Memorandum Administrativo, el Departamento de Salud recordo a los oficiales estatales de los servicios sociales locales que el control de seguridad mientras la persona con deterioro mental este siendo trasladada, aseada, caminando o envuelto en otras actividades del diario vivir es una consideración apropiada en determinar la cantidad de cuidado en el hogar que debería ser proveído.

Empezando el 1 de abril el Departamento de Salud eliminará la entrevista de cara-a-cara que se necesita para renovar el Medicaid, y ha desarrollado una forma de renovación más simple para la mayoría de receptores de Medicaid. Receptores de Medicaid que reciben cuidado en el hogar en la ciudad de Nueva York ya utilizan la recertificación por correo, pero ahora ningún receptor, aún aquellos en la primera etapa de desordenes cognoscitivos, no tendran que ir a una entrevista.

En el estado existe el reciente y recurrente problema de la ejecución de provisión privadas federales llamado Health Insurance Portability and Accountability Act (HIPAA siglas en ingles) por las agencias de servicio social locales. Las agencias han interpretado HIPAA como impidiendo conversación sobre los temas específicos de la solicitud de Medicaid con familiares o representantes basados en que eso violaría las provisiones de privacidad de HIPAA. Representantes y familiares podrán ver o dialogar sobre los archivos

de Medicaid con la agencia local del que aplica o receptor si ellos obtienen, completan, y someten a la agencia local una forma de autorización (en la ciudad de Nueva York, utilizar MAP- 751D “Authorization for Disclosure of Individual Health Information”).

Las cantidades de ingreso y recursos para la elegibilidad de Medicaid han sido puestas al día para el 2004. Receptores individuales de Medicaid en la comunidad pueden recibir un ingreso mensual de \$679 sin que afecte desfavorablemente el cubrimiento de Medicaid. Los recursos individuales permitidos son de \$3,950. Para la pareja de una persona que vive en una institución la cantidad maxima como recurso permitido es de \$92,760. Para quien vive en la comunidad mientras su pareja vive en una institución se le permite una Pensión para sus Necesidades de un Mínimo Mensual de \$2,319. El estado tambien ha puesto al día los “índice de penalidad por transferir”. El índice por transferir en la ciudad de Nueva York es un mes por cada \$8,695. Para información de cómo algunos de estos ingresos, recursos u otros índices afecta su elegibilidad de Medicaid usted puede asistir a uno de los seminarios de asuntos legales y financieros que se llevan acabo tres veces al mes, en ingles en nuestras oficinas o puede consultar un abogado que tenga experiencia en Leyes para Personas Mayores. ●

Jeffrey G. Abrandt es un socio en la firma de Goldfarb Abrandt Salzman & Kutzin, LLP con oficinas en la ciudad de Nueva York y White Plains, Nueva York. La firma es en práctica general de leyes con enfoque en litigio, fideicomiso y propiedades, leyes de salud y los derechos de los envejecientes y personas con incapacidades. El Sr. Abrandt es ún becado del Brookdale Center of Aging y ha servido como presidente de el Senior Section del National Legal Aid y Defenders Association.

Education Calendar • Spring 2004

THURSDAY April 1

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 is required.

MONDAY April 5

LEGAL/FINANCIAL SEMINAR

Time: Noon – 1:30 p.m.
Place: Chapter Office

WEDNESDAY April 7

EASING THE TRANSITION FROM HOME TO A RESIDENTIAL CARE FACILITY

Time: 6:00 – 8:00 p.m.
Place: Chapter Office

FRIDAY April 9

ORIENTATION MEETING FOR CAREGIVERS

Time: Noon – 1:30 p.m.
Place: Chapter Office

MONDAY April 12

EDUCATIONAL MEETING

Time: 6:00 – 7:30 p.m.
Place: Chapter Office

Topic: A Frank Discussion About End of Life Issues For People with Advanced AD

Speaker: Judith Ahronheim, M.D., former Chief of Geriatrics, St. Vincent's Medical Center

TUESDAY April 13

ORIENTATION MEETING FOR CAREGIVERS

Time: 5:30 – 7:00 p.m.
Place: Chapter Office

THURSDAY April 15

BROOKLYN LEGAL/FINANCIAL PLANNING & MEDICAID HOME CARE MEETING

Time: 2:00 – 4:00 p.m.
Place: St. Brendan's Senior Houses
1215 Avenue O

MONDAY April 19

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 April 21

ORIENTATION MEETING FOR CAREGIVERS

Time: 5:30 – 7:00 p.m.
Place: Chapter Office

THURSDAY April 22

LEGAL/FINANCIAL SEMINAR

Time: 5:30 – 7:00 p.m.
Place: Chapter Office

TUESDAY April 27

ORIENTATION MEETING FOR CAREGIVERS

Time: Noon – 1:30 p.m.
Place: Chapter Office

MONDAY May 3

LEGAL/FINANCIAL SEMINAR

Time: Noon – 1:30 p.m.
Place: Chapter Office

WEDNESDAY May 5

EASING THE TRANSITION FROM HOME TO A RESIDENTIAL CARE FACILITY

Time: 6:00 – 8:00 p.m.
Place: Chapter Office

THURSDAY May 6

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.

MONDAY May 10

EDUCATIONAL MEETING

Time: 6:00 – 7:30 p.m.
Place: Chapter Office

Topic: Music Has Power: How Music Can Help People With Alzheimer's Disease

Speaker: Concetta Tomaino, D.A., MT-BC
Vice President, Music Therapy
Beth Abraham Family of
Health Services

TUESDAY May 11

ORIENTATION MEETING FOR CAREGIVERS

Time: 5:30 – 7:00 p.m.
Place: Chapter Office

FRIDAY May 14

ORIENTATION MEETING FOR CAREGIVERS

Time: Noon – 1:30 p.m.
Place: Chapter Office

MONDAY May 17

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 is required.

Education Calendar • Spring 2004

LEGAL/FINANCIAL SEMINAR

Time: 5:30 – 7:00 p.m.
Place: Chapter Office

WEDNESDAY May 19

ORIENTATION MEETING FOR CAREGIVERS

Time: 5:30 – 7:00 p.m.
Place: Chapter Office

THURSDAY May 20

BROOKLYN LEGAL/FINANCIAL PLANNING & MEDICAID HOME CARE MEETING

Time: 2:00 – 4:00 p.m.
Place: St. Brendan's Senior Houses
1215 Avenue O

TUESDAY May 25

ORIENTATION MEETING FOR CAREGIVERS

Time: Noon – 1:30 p.m.
Place: Chapter Office

THURSDAY MAY 27

LEGAL/FINANCIAL SEMINAR

Time: 5:30 – 7:00 p.m.
Place: Chapter Office

WEDNESDAY June 2

EASING THE TRANSITION FROM HOME TO A RESIDENTIAL CARE FACILITY

Time: 6:00 – 8:00 p.m.
Place: Chapter Office

THURSDAY June 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

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 June 7

LEGAL/FINANCIAL SEMINAR

Time: Noon – 1:30 p.m.
Place: Chapter Office

TUESDAY June 8

ORIENTATION MEETING FOR PROFESSIONALS

Time: 9:30 – 11:00 a.m.
Place: Chapter Office

ORIENTATION MEETING FOR CAREGIVERS

Time: 5:30 – 7:00 p.m.
Place: Chapter Office

FRIDAY June 11

ORIENTATION MEETING FOR CAREGIVERS

Time: Noon – 1:30 p.m.
Place: Chapter Office

MONDAY June 14

EDUCATIONAL MEETING

Time: 6:00 – 7:30 p.m.
Place: Chapter Office
Topic: Understanding and Coping With the Stresses Of Caregiving: A Workshop for Caregivers
Speaker: Tobi Abramson, Ph.D., Psychologist in Private Practice and Support Group Leader

WEDNESDAY June 16

ORIENTATION MEETING FOR CAREGIVERS

Time: 5:30 – 7:00 p.m.
Place: Chapter Office

THURSDAY June 17

INTRODUCCION A LA ENFERMEDAD DE ALZHEIMER

Hora: 10:30 a.m. – 12:00 p.m.
Lugar: Park Slope Geriatric Adult Day Center
1 Prospect Park West
Brooklyn

BROOKLYN LEGAL/FINANCIAL PLANNING & MEDICAID HOME CARE MEETING

Time: 2:00 – 4:00 p.m.
Place: St. Brendan's Senior Houses
1215 Avenue O

MONDAY June 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

TUESDAY June 22

ORIENTATION MEETING FOR CAREGIVERS

Time: Noon – 1:30 p.m.
Place: Chapter Office

THURSDAY June 24

ORIENTATION MEETING FOR CAREGIVERS

Time: 4:00 – 5:30 p.m.
Place: CNR, 596 Prospect Place
Brooklyn

LEGAL/FINANCIAL SEMINAR

Time: 5:30 – 7:00 p.m.
Place: Chapter Office

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. ALL MEETINGS ARE FREE OF CHARGE.

The NYC Chapter Office is located at 360 Lexington Avenue — 5th floor New York, NY 10017 (between 40th and 41st Streets)

We wish to thank the following for their generous donation of space for the meetings: CAPE at the Samuel Field YM-YWHA, The Park Slope Geriatric Day Center, CNR, Fort Washington Houses, RAIN Parkchester Senior Center, and St. Brendan's Senior Houses.

Support Groups

The New York City Chapter sponsors over 100 caregiver support groups throughout the Bronx, Brooklyn, Manhattan, Queens and Staten Island. We offer support groups for spouses, partners, adult children, etc. Some groups are composed of only spouses or adult children, while others are mixed, that is composed of many types of caregivers. There are also support groups for people of all ages who have been diagnosed with Alzheimer's disease and are in the early stages of the illness. Before attending a support group we recommend you attend a Chapter Orientation Meeting. Call 800-272-3900 and ask for the Helpline to reserve a seat.

You will also need to call the support group leader and schedule a brief personal interview before attending a group. Wendy Panken, Support Group Coordinator, is available to discuss your questions and concerns about joining a support group at 212-983-6906 x214. For a complete list of our support groups, visit our website at www.alznyc.org or call the Helpline at 800-272-3900.

All support groups are open for new members, however, the following are groups actively seeking new members:

BRONX

BI-LINGUAL GROUP (SPANISH/ENGLISH):

Montefiore Medical Center (210th St.)
Day & Time: 1:00 – 2:30 PM, 1st & 3rd Fridays
Contact: Karina Aquilar 212-983-0700

MIXED GROUPS:

Riverdale Senior Services (Netherland Ave.)
Day & Time: 6:00 – 7:30 PM, 1st & 3rd Mondays
Contact: Wendy Bolton 718-884-5900 x19
Allison Hartman 718-432-2448

Beth Abraham Health Services (Allerton Ave.)
Day & Time: 6:00 – 7:15 PM 1st & 3rd Wednesdays
Contact: Hilary Horvat 718-519-4068

BROOKLYN

ADULT CHILDREN'S GROUP:

Bensonhurst Senior Assistance Center (Benson Ave.)
Day & Time: 6:30 – 8:00 PM every other Tuesday
Contact: Mary Hume 718-236-3205

MIXED GROUPS:

Palm Gardens ADHC (Kensington)
Day & Time: 5:30 – 6:30 PM 1st & 3rd Mondays
Contact: David Yanovsky 718-633-3300
Sunrise Assisted Living (Sheepshead Bay)
Day & Time: 6:45 – 8:00 PM 2nd & 4th Tuesdays
Contact: Sophie Finkelman 718-834-0731

SPOUSES' GROUP:

Sheepshead Bay Services for the Elderly (Ave. O)
Day & Time: 1:00 – 2:30 PM every other Friday
Contact: Robin Berkman 718-375-3377

MANHATTAN

ADULT CHILDREN'S GROUP:

Beth Israel Hospital (17th St. & 1st Ave.)
Day & Time: 6:15 – 7:30 PM 1st & 3rd Thursdays
Contact: Ellen Cox 212-420-2558

EARLY STAGE GROUP:

360 Lexington Ave. (40th & 41st Streets)
Day & Time: 11:00 AM – 12:30 PM Fridays
Contact: Paulette Michaud 212-983-0700

GENERIC ADULT CHILDREN'S GROUP:

Lenox Hill Neighborhood House (E. 70th St.)
Day & Time: 6:30 – 8:00 PM Tuesdays
Contact: Christopher Chin 212-744-5022 x1266

GENERIC GROUP FOR LONG DISTANCE CAREGIVERS:

Lenox Hill Neighborhood House (E. 71st St.)
Day & Time: 6:30 – 8:00 PM Mondays
Contact: Christopher Chin 212-744-5022 x1266

GENERIC SPOUSES' GROUP:

Lenox Hill Neighborhood House (E. 71st St.)
Day & Time: 11:00 AM - 12:00 PM Thursdays
Contact: Christopher Chin 212-744-5022 x1266

MIXED GROUPS:

The Riverside Church (Claremont Ave. & W. 120th St.)
Day & Time: 12:30 – 1:45 PM every other Friday
Contact: Lorraine Ruggieri 212-362-6500

The Hallmark (Battery Park/Tribeca)
Day & Time: 6:30 – 8:15 PM 2nd & 4th Monday
Contact: Katherine Berger 212-791-2500

The Jewish Community Center (Amsterdam Ave./76th St.)
Day & Time: 6:30 – 8:15 PM 1st & 3rd Thursdays
Contact: Sunny Kenowsky 212-371-6039
Rita Golub 212-316-7724

Columbia Presbyterian Medical Center (W. 168th St.)
Day & Time: 12:00 – 1:15 PM 1st & 3rd Tuesdays
Contact: Lynn Stiles 212-305-3785

SAGE (Lesbian & Gay Community Service Center)
Day & Time: 6:45 – 8:15 PM 1st & 3rd Thursdays
Contact: Jan Gibeau 212-741-2247

SPOUSES' GROUPS:

360 Lexington Ave. (40th & 41st Streets)
Day & Time: 10:30 – 11:45 AM 1st & 3rd Mondays
Contact: Wendy Panken 212-983-0700

360 Lexington Ave. (40th & 41st Streets)
Day & Time: noon – 1:15 PM Mondays
Contact: Paulette Michaud 212-983-0700

Mt. Sinai Medical Center (5th Ave./98th St.)
 Day & Time: 4:00 – 5:30 PM 1st & 3rd Thursdays
 Contact: Joan Dickson 212-628-5045
 Dorothy Calvani 212-241-5561

WIVES' GROUP:

360 Lexington Ave. (40th & 41st Streets)
 Day & Time: 5:00 – 6:15 PM 1st & 3rd Tuesdays
 Contact: Sharon Shaw 212-983-0700

QUEENS

MIXED GROUPS:

Forest Hills Community House (62nd Dr.)
 Day & Time: 12:30 – 2:00 PM 2nd & 4th Tuesdays
 Contact: Laurie Avery 718-592-5757 x 237
 (A respite program is available for the family member with dementia)

Hillside Manor (Jamaica)

Day & Time: 11:00 – 12:30 PM 2nd & 4th Wednesdays
 Contact: Casey Graham 718-264-6868

SPOUSES' GROUP:

Granat Alzheimer Center/ Parker Jewish Institute (Little Neck)
 Day & Time: 11:00 AM– 12:00 PM 1st & 4th Wednesdays
 Contact: Martha Wolf 718-289-2105

TELEPHONE SUPPORT GROUPS:

DOROT's Caregivers Connections
 Contact: Lori Friedman 212-769-2851

Estos grupos de apoyo estan disponibles para aquellas personas que cuidan a un ser querido con problemas de memoria. Venga a compartir sus experiencias y obtenga apoyo emocional y ayuda para desarrollar nuevas técnicas de cuidado.

GRUPO BILINGUE — ESPAÑOL/INGLES

JUEVES – 6:00 – 7:30 pm
 360 Lexington Avenue, New York, NY

GRUPO EN ESPAÑOL

VIERNES – 1:00 – 2:30 pm
 Montefiore Medical Center, 210th Street, Bronx, NY

GRUPO EN ESPAÑOL

MIERCOLES – 10 – 11:30 am
 Park Slope Geriatric, One Prospect Park West, Brooklyn, NY

Para más información sobre como asistir a un grupo de apoyo o para inscribirse en un grupo por favor llame a Karina Aguilar al 212-983-6906 ext. 241.

Training is available for professionals and former caregivers interested in leading support groups. For information, call Sharon B. Shaw at 212-983-6906 ext. 221.



Dementia Home Care Graduation 2003

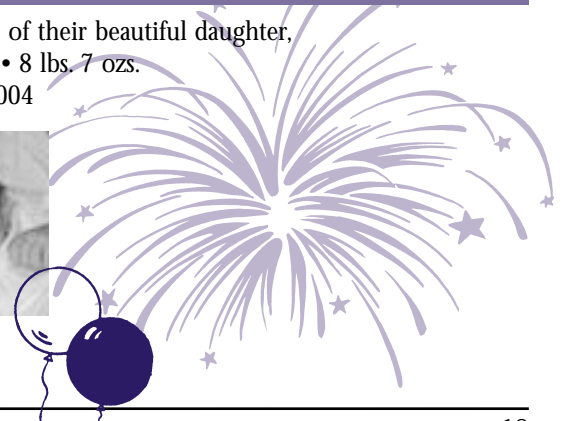
Sixteen home care workers from United Jewish Council of the East Side Home Attendants Service Corporation graduated from our Dementia Care Training Program on December 11, 2003. This training was funded by a grant from the Isaac H. Tuttle Fund. One of the graduates, Gisele Baptiste, opened the ceremony with a prayer that was followed by speeches from several staff members. Dorette Burton, another graduate, shared her feelings about the value of the training and Gerta Brunache read a poem about Alzheimer's that she had written for the occasion. Many of the graduates then treated the audience to a group song, "My Life Is In Your Hands." The ceremony was closed by Marie Alexis who shared special comments about what the training program meant to her and the group. A joyous reception followed bringing graduates, family, friends and agency staff together to offer their warm congratulations. ●

Paulette Michaud
 COORDINATOR OF EDUCATION AND TRAINING

Congratulations

*to Development Associate Director
 Wendy Washo and husband Mark*

on the arrival of their beautiful daughter,
 Sophie Anne • 8 lbs. 7 ozs.
 January 15, 2004

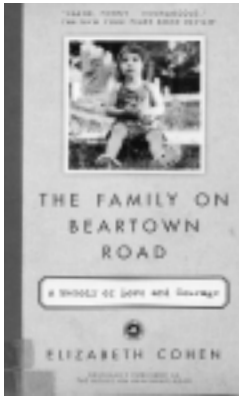


Book Shelf



The Family on Beartown Road A Memoir of Love and Courage By Elizabeth Cohen

270 pp., Random House, 2003; \$12.95



Elizabeth Cohen's *Family on Beartown Road* is a beautifully written memoir of learning and forgetting. Identifying herself as part of the "sandwich" generation, she recounts the year when she

was caregiver for both her infant daughter, Ava, and her elderly father, Sanford, who has been diagnosed with mid to late stage Alzheimer's disease. Life on Beartown Road is unpredictable. It is filled with joy, laughter, anger, tears, and the unconditional love that binds them together as a family.

Through her memoir, Elizabeth gives a unique perspective of the mind in all stages: beginning, middle and end. Ava's thirst for knowledge and insatiable curiosity is juxtaposed against Sanford's jumbled words and escaping memories in his struggle to maintain his identity. Elizabeth, in the middle of both learning and forgetting, endeavors to maintain a sense of normalcy, whatever that may be.

Elizabeth's memoir is an intensely moving glimpse into the life of a caregiver. Through her personal experience she raises awareness of the disease to those unfamiliar with its impact on the family. Readers of all backgrounds will be touched in some way by the story of *The Family on Beartown Road*.

—Letitia O'Toole

Memory By Margaret Mahy

278 pp. Aladdin Paperbacks/
Simon & Schuster Children's Publishing Division
\$8.00

Memory itself is evasive and oftentimes mysterious, and that is just what is conveyed in the young adult novel, *Memory* by Margaret Mahy. Mahy tells the story of Jonny Dart, a teenager who is still suffering from immense guilt after a fatal accident that killed his sister, Janine, five years ago. His memory of the exact details of the event are imperfect, and as such, haunt him, as he has managed to convince himself that his sister's fatal fall was his fault.

In order to try and understand what has happened, and to attempt to find some inner peace, Jonny goes in search of the only other witness to the accident. Just as he is about to locate the house in which this witness (a girl his age named Bonny Benedicta who was a close friend of Janine's) lives, Jonny encounters Sophie, an old woman who when she first meets him asks, "Are you the one?" Jonny comprehends that something is wrong with Sophie. Though he doesn't learn the name of Sophie's condition — Alzheimer's disease — until the end of the novel, Jonny does recognize that Sophie needs his help, as she has no one to take care of her. Jonny's kindness and good-natured personality assist him as he unofficially moves in with Sophie and becomes her companion.

Jonny never becomes frustrated or annoyed with Sophie. He takes her forgetfulness and confusion in stride, even protecting Sophie from a man who poses as her landlord, taking "rent" money from her every day. As the soft-spoken Jonny quickly learns, his standing up to such a thief not only helps Sophie, but it also strengthens his character, enabling him to stand up to bullies from his past. And this isn't the only way Sophie helps Jonny. She also assists Jonny in freeing himself from what haunts him most — the memories of his sister's tragic death. Sophie and Jonny form a close bond, and even after he peels away the false and fabricated memories of guilt and responsibility, he chooses to stay with Sophie. For in understanding the complexities of his own memories, he is able to conceive how memories can be lost and changed, confused and cluttered. It is this understanding that draws him to Sophie. Although he acknowledges that he may have at some point uncovered the truth on his own, Sophie's difficulty with her memory is the catalyst in helping Jonny to get to the bottom of his own.

Memory, a Boston Globe/Horn Book Award-winner, is truly poetic. Now, after being out of print for several years, it is available once again. This is a blessing, as this novel is for both young readers and adults alike. Its complexity and richness make it a worthy and compelling contribution to the growing body of literature of Alzheimer's disease.

—Anne R. Miller

Mark Your Calendars!



Sunday, October 17th • Riverside Park

The Cornell Memory Disorders Program at the New York Presbyterian Hospital-Weill Cornell Medical College

- Is conducting a research study entitled “Multi-Institutional Research in Alzheimer’s Genetic Epidemiology (MIRAGE).” The purpose of the MIRAGE study is to search for genes that may affect the course of Alzheimer’s Disease, such as genes that increase the likelihood that a patient with Alzheimer’s disease would also develop strokes.

You or your family members may be eligible to participate if you have a **living** family member diagnosed with Alzheimer’s disease **AND** your family member with Alzheimer’s disease has at least one **living** sibling (brother or sister) over the age of 50 without Alzheimer’s disease or memory problems. Siblings of Alzheimer patients participating in this study receive an MRI and memory testing free of charge. Participants do not have to travel to New York Presbyterian Hospital –Weill Cornell Medical College to participate in the study.

If you are interested in participating in this study or would like more information, please contact Beth Chisholm, Genetic Counselor and Co-Project Manager, at 212-746-6580 or Basia Adamiak, Co-Project Manager, at 212-746-6581.

- Is conducting a study entitled “Risk Evaluation and Education for Alzheimer’s Disease (REVEAL-2).” The purpose of the REVEAL-2 study is to explore the impact of providing individuals with information about their risk of developing Alzheimer’s disease. Volunteers accepted into the study will

undergo Alzheimer–related genetic testing and receive genetic counseling free of charge. Participants must travel to New York Presbyterian Hospital-Weill Cornell Medical College in Manhattan to participate in the study.

You may be eligible for REVEAL-2 if you have a living or deceased parent or sibling with Alzheimer’s disease and you are not currently suffering from memory loss or depression.

If you are interested in participating in this study or want more information, please contact Beth Chisholm, genetic counselor and project manager, at 212-746-6580.

- Is conducting a new clinical research study to evaluate whether an investigational drug that is not yet approved by the FDA may slow the symptoms and progression of Alzheimer’s disease.

Doctors are seeking people aged 50 and older with mild to moderate Alzheimer’s disease to participate in this 15-month trial. Participants and their caregivers must travel to the New York Presbyterian Hospital - Weill Cornell Medical College in Manhattan to participate in the study. Participants may continue to take other medication for the treatment of Alzheimer’s as long as they have been on a stable dose of the medication for at least 2 months before entering the study.

For more information, please contact Basia Adamiak at the Cornell Memory Disorders Program at 212-746-6581. ●

New Web Site (continued from page 4)

Unlike similar informational web sites on Alzheimer’s the New York City Chapter’s site offers very specific information about resources. “We don’t just publish a name and address of a resource,” says Jed Levine, Acting Executive Director. “We feature specifics on what is offered, who is eligible to participate and more.”

Key features of the web site include Search for Services, where users can type in the type of service they are seeking and desired location. The site will then direct them to one or more choices; In the News, which features articles on new developments in Alzheimer’s research and medications; and Events, which is a calendar listing of important events sponsored by the Alzheimer’s Association, such as Memory Walk and the Forget-Me-Not Gala. There is also information about the Chapter’s Safe Return program and volunteer opportunities.

Please visit us at www.alznyc.org. ●

Choices and Challenges (continued from page 5)

and generous staff at my assisted living residence helps me keep up with my insurance and medical paperwork. I’m in a work program here and I make breakfast twice a week for other tenants. I am also in a stress management group and a quilting group. My first quilt was exhibited at last year’s show and I’m now working on my second. Besides the early stage support group, I am in a women’s group at New York Presbyterian Hospital, and have just started a cognitive rehabilitation training program there. Also, I’ve been volunteering at the Metropolitan Museum of Art for three years.

My latest medical testing has concluded that I have Mild Cognitive Impairment (MCI). What blurs the test results is my temporal lobe epilepsy, which affects the same area of the brain. But mostly I remain hopeful and determined to fight back. I pray and read and act on all the good information that is out there on how to save your brain. I am particularly excited about this year’s conference theme, which focuses on creativity and transforming the early Alzheimer’s experience. We need to let people know that the diagnosis does not have to put an end to a productive and fulfilling life. We all have choices to make. ●

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NYC Chapter Junior Committee Gala "Return to Carnival" Twenty Four Fifth

Saturday, April 17th • 9:00 pm – 1:00 am
For more information and to purchase tickets, please visit:
www.alznycjuniorcommittee.org

A Support Group Leader Training Seminar...

is scheduled for four consecutive Fridays beginning April 23, April 30, May 7 and May 14, 2004. Anyone who is interested in the training, including those who are already leading a support group or those who wish to begin a new group, should contact Sharon B. Shaw, CSW at 212-983-6906, ext. 221. This training is available to professionals and former caregivers who wish to work with early stage or caregiver groups.

Chapter Volunteer Opportunities

- Seeking volunteers for our Speakers Bureau who are experienced in public speaking, knowledgeable about Alzheimer's, and would like to be part of our community education efforts.
 - Seeking bi-lingual (Spanish/English) volunteers who are available during daytime hours for our new Safe Return Outreach and Registration Program.
- For more information and a volunteer application, please call Barbara Lepis, Volunteer Coordinator at 212-983-6906 ext. 247.

Partnering With Your Doctor

In response to a nationwide survey, the Alzheimer's Association set out to develop an initiative to narrow the communication gap that separates physicians and caregivers. The result is a free 2-hour workshop entitled: *Partnering with Your Doctor*.

The workshop will address how to:

- Improve communication with one's doctor
- Improve how the person with the disease and care partner work together
- Help the caregiver get organized and prepare for doctor visits
- Help reduce stress
- Help ensure the best care possible

Our next scheduled workshop will be:
DATE: Thursday, April 29, 2004
TIME: 3:00 P.M. - 5:00 P.M.

LOCATION: NYU Medical Center
Coop Care Building, 15th Floor, Conference Room A
550 First Avenue, New York, NY 10016

Registration is required as each workshop will be limited to a maximum of 25 participants. To register, please call our Helpline at 800-272-3900. Visit our website at www.alznyc.org for additional workshop information.

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