

ADVOCACY ALERT

Each year, the statewide Coalition of NYS Alzheimer's Chapters develops public policy priorities for advocacy at the state level. This year's agenda appears below.

Please participate in advocating for the Coalition's legislative priorities by joining with the New York City Chapter at the lobby day to be held on March 31 in Albany and/or by working with the chapter at the local level to effect needed change. (A coupon is included on p. 10 for your use.)

- In advocating for more than 400,000 New Yorkers with Alzheimer's disease and their families, the Coalition of New York State Alzheimer's Association Chapters seeks to address policy and program issues involving the structure, financing and delivery of public and private sector services for this most vulnerable population.
- In order to carry out its mission, the Coalition is guided by a set of principles which will help assure persons with Alzheimer's and their caregivers access to and availability of services designed to meet their primary, acute and long term care needs.
- An overriding principle is that persons with Alzheimer's disease should have the option of remaining in their own homes and communities. To this end, there is a need for an array of home and community-based services which includes personal care, adult care (adult day services), respite and hospice care.
- The Coalition will work to assure that existing

Continued on page 10.



Teen Takes on Alzheimer's
Svetlana Zampolskaya with her Westinghouse Science research project (see page 6).

FUNDING PRIORITIES FOR 1998

- ◆ Seek \$300,000 in state funds for the newly enacted Alzheimer's Community Assistance Program. (AlzCAP).
- ◆ Secure funding for Chapter 685 social model adult day services through the State Office for the Aging (SOFA) and secure Medicaid funding of all forms of adult day services under NYS/DOH.
- ◆ Maintain funding for Medicaid personal care/home care services to assure access to and availability of services for persons with Alzheimer's.
- ◆ Increase Medicaid reimbursement under RUGs for nursing home residents with Alzheimer's disease.
- ◆ Secure a one year commitment for funding Safe Return through the Aging Committee and SOFA.

Also in this Issue . . .

Film Festival	5
Calendar	8
Legal Issues	7

Alzheimer's Disease and
Related Disorders Association
New York City Chapter
420 Lexington Avenue
New York, NY 10170
212-983-0700

John A. Jager

Executive Director

Jean Marks

Associate Executive Director

Ann Berson

Public Policy Coordinator

Yvette Bynoe

Secretary

Graham Hancock

Bookkeeper/MIS Manager

Gladys Harburger

Field Instructor

Gail W. Hoffmann

Safe Return Coordinator

Adeena Horowitz

Social Worker Coordinator

Rea Kahn

Support Group Coordinator

Ellen Kameny

Development Assistant

Jed A. Levine

*Coordinator of Training &
Special Projects*

Barbara London

Telephone Receptionist

Ruth Rothbart Mayer

Coordinator, Consumer Directed

Personal Assistance Program

Juan Diego Molyneaux

Administrative Assistant

Lisa Ramirez

Development Associate

Lynn V.P. Raymond

Director of Development

Cynthia Emiry Roy

Coordinator of Volunteers

William Senders

*Coordinator of Nursing Home &
Residential Care Affairs*

Anne Thomas

*Coordinator of Home Care &
Nursing Home Training*

Newsletter Staff

This newsletter is
a voluntary effort of

Chris MacLeod

Editor

Jack Pollock

Staff Writer

David Eisner

Copy Editor

ADRDA -New York City does not
endorse products, manufacturers or
services. Such names appear here
solely because they are considered
valuable as information. The
Association assumes no liability for
the use or context of any product or
service mentioned.

Director's Corner

Potpourri

Heading into 1998, it was suggested that I repeat for everyone interested in our work, the Chapter's *MISSION STATEMENT* as adopted by the Board of Directors. These are the guiding principles of our Chapter.

While the ultimate aim of the New York City Chapter of the Alzheimer's Association is to eliminate Alzheimer's disease and related disorders, our immediate mission is to create and promote comprehensive and humane care and support for persons with the disease and their families. We realize this mission through -



- building public awareness
- providing education, creating and encouraging replication of model programs
- undertaking advocacy, and
- supporting a nationally managed research program to find ways to prevent, treat and cure dementing illnesses.

We also seek to build the capacity of other institutions and individuals to respond with compassion and competence to the needs of those affected by dementia.

We are a charter member of the National Alzheimer's Association, the preeminent national non-profit organization concerned with all aspects of Alzheimer's disease. Our service territory includes the Bronx, Brooklyn, Manhattan and Queens.

Your opinions and viewpoints regarding the content of the Mission Statement and our efforts to achieve these principles are welcomed.



Next, thanks to each and every one of you who helped to make our *1997 Year End Campaign* the most successful such effort in our history. We certainly appreciate and need all of the contributions and support we receive. Our ongoing pledge remains to direct every dollar entrusted to us by our contributors towards the maintenance and growth of the crucial programs and services offered by our dedicated staff, volunteers, and service partners, and to the research, training, and public awareness goals as outlined in our Mission Statement.

If you didn't participate in the Year End Campaign, there is no reason to wait until December 1998 for our next Year End Campaign. Contributions are *always* welcome and sorely needed. Throughout this newsletter you will find a variety of ways in which you can become involved right now, financially and otherwise. Your participation in our *Memory Walk* (October 18, 1998), and possible consideration of a planned gift are just some of these ways to help financially or as a volunteer.

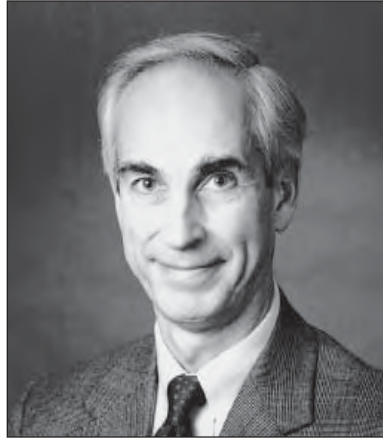


Finally, and with deep sadness, I must report the recent passing of our long-time Telephone Helpline and Support Group Volunteer, Marje Fields Karp. Marje, a talent agent of considerable renown, was an enormous talent and a committed caregiver in her own right. We will miss her enormously, and extend our heartfelt condolences to her family and all of her many friends.

– John A. Jager
Executive Director

IRVINE FLINN ELECTED TO BOARD

Irvine D. Flinn received an A.B. from Princeton in 1957. After serving in the United States Navy as a lieutenant from 1957-60, he received an M.A.T. from Harvard in 1961 and an LL.B. from Columbia Law School in 1964. He then joined the firm of



Sullivan & Cromwell, where he was made a partner in 1971. His area of legal expertise is real estate. He is the editor of *Securitization of*

Real Estate for the Practicing Law Institute and a member of the Institute's Real Estate Advisory Board. He is also a member of the Board of Visitors of Columbia Law School and a director of Search & Care, Inc. In March 1997, Mr. Flinn completed eight years of service as a director, secretary and a member of the executive committee of the national Alzheimer's Association. He and his wife, Elizabeth, have two sons.

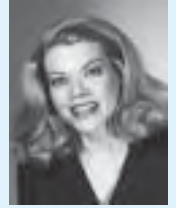
Real Estate for the Practicing Law Institute and a member of the Institute's Real Estate Advisory Board. He is also a member of the Board of Visitors of Columbia Law School and a director of Search & Care, Inc.

In March 1997, Mr. Flinn completed eight years of service as a

director, secretary and a member of the executive committee of the national Alzheimer's Association. He and his wife, Elizabeth, have two sons.

Editor's Note

This issue focuses on Advocacy. While we use the word to describe our efforts to



influence public policy regarding Alzheimer's, there is a need for a broader involvement by the AD community. Call it advocacy or activism, it takes many forms.

In these pages, you will see both individuals and groups tackling Alzheimer's by any means available to them. A high school girl pursued an original research project that won her national recognition. Our Junior Committee gives us another reason to believe that the next generation will join our fight. You'll also meet a group of women (including current and former caregivers) who started a social network that extends beyond support groups.

In "Outrage," you will hear from people who spoke out and fought back when hospitals or nursing homes did not provide an appropriate level of care — or respect — to those entrusted to them.

And in our cover story, Ann Berson (our Public Policy Coordinator) lays out what our organization stands for in seeking home and community-based services for New York's 400,000 AD patients and their families. We want our state representatives to know who WE represent. Let them know that AD matters to you. If you can write to your local legislator (or write us a check) — that's advocacy, too.

— Chris MacLeod

KEY ELEMENTS OF DEMENTIA CARE FOR HOME CARE WORKERS

When: On consecutive Tuesdays - 9:00 a.m. to 1:00 p.m.
May 5, 12, 19, 26, and June 2, 9, 1998

Where: The Alzheimer's Association - New York City Chapter
420 Lexington Avenue (between 43rd & 44th Streets), Suite 610
New York, NY 10170

Topics to be discussed:

- Overview of the disease and description
- Differences between normal aging & dementia
- Stages and progression of the disease
- Understanding the emotional world of the person with dementia
- Impact of the illness on families
- Coping with stress
- Personal care and emergencies
- Practical issues of caregiving including: communication, creating meaningful activities and understanding difficult behavior

Cost: \$250.00 for the six week course.

Registration:

- Interested home care workers must be willing and able to attend all six sessions
- Have experience caring for someone with dementia
- Speak, read and write basic English
- Have a desire to obtain a more indepth understanding of dementia care

Space is limited and enrollment is on a first come, first served basis.

**For more information please contact
Anne Thomas at (212) 983-0700 ext. 211**

OUTRAGE



Readers: Thank you for your generous response for second copies of submission to *Outrage*. We are alternating between stories of experiences in nursing homes and in hospitals.

Highlights from Hell

My husband had been an attorney, a word-master, an intellectual, a music lover and a gifted sculptor whose life and mind were destroyed during 10 harrowing years by Alzheimer's disease.

The last 9 months of that life were suffered as a full paying patient in a renowned nursing home. From the day he entered until his demise, I had to be his vocal and persistent advocate.

Unfortunately, in nursing homes, the ultimate care and hands-on responsibility for the day-to-day condition of a patient is delegated to the least trained and educated. Realizing this, I prepared a health and psychological profile of my husband in the hope of assuring the highest level of care for him. The head of social services took it along with my urgent request that enough copies be made so that anyone caring for my husband could consult it. It was several weeks before it reached his chart where it was buried for good. I made additional copies and taped one on the mirror in his room. To judge by the questions posed to me about my husband and the care he received, no aide ever read it.

The nurse in charge apparently also did not caution the aides (who changed assignments every 3 months) about grave physical debilities of my husband which had to be monitored especially carefully. Thus, my husband's left ankle, susceptible to ulceration, if certain creams and care were not provided, became ulcerated. I had to bring it to the attention of the nurse in charge for a referral to the doctor. A few weeks following this, the ankle having healed somewhat, my husband was seen walking near an elevator. An anti-wandering anklet was instantly ordered and put on the infirm ankle, against the ulcer-prone skin under a heavy elastic stocking. When I arrived that day and protested, no one took responsibility.

My husband's appetite diminished constantly during his stay in the home, so it was obviously very important that he be able to masticate the food he did consent to eat. A capped tooth broke on which a bridge hinged; the bridge disappeared and I became aware that it was missing only when the aide showed me the fragment of tooth. I found the bridge under the bed. Once his upper plate disappeared for 2 days and then mysteriously reappeared after I raised a row. It took a 28 pound weight loss appearing on the reams of paper to which nurses *do* pay attention, before an appropriate plan of care was made.

The nadir of my husband's care was reached during the New Year's Eve period. When I saw my husband on 12/31 he was dressed, but seemed to have difficulty sitting on his bed or chair. His body seemed flaccid and his aide complained about the difficulty of getting him dressed. The head nurse ordered a doctor (not the usual

one in charge of the floor) who came but appeared to be very young.

He examined my husband very cursorily and muttered, "He's an accident waiting to happen," and left. Did he leave an order for the railings to be put up on the bed? Evidently not, because at 11:30 p.m. that night I got a call that my husband had fallen out of bed, but was OK. The nurse in charge that night and the aide were substitutes from an agency, but I was never able to learn their identities. The reasons for their anonymity were ludicrous, i.e., "the name is illegible." "The roster is lost." When I saw my husband on New Year's Day he was in pain and his leg was at an odd angle. The second doctor who was summoned because I insisted examined him in bed. The diagnosis: probable broken hip. He was promptly hospitalized, had a successful operation, but never walked again. The trauma of the injury and the hospitalization accelerated his decline and four months later he was dead.

For months after his death, I received notices from Medicare covering visits of doctors of many specialties who saw or treated my husband. I was never informed about these non-routine examinations. Dermatologists, urologists, and psychiatrists - all were paid but their findings/visits were never disclosed to me. In placing a spouse with the institution, one loses control. That is one of the most hurtful parts of the nursing home experience. I, who had monitored every facet of my husband's existence at home, could not prevail against the institutional culture.

My experience led me to conclude also that psychological needs are hardly ever considered where Alzheimer's patients are concerned. They are written off as hopeless and helpless. I came to understand that the avoidance of individual responsibility was the best organized part of the institution. Trying to counter the neglect and inefficiency constantly eroded this loving spouse's remaining strengths.

Editor's note: During the business career of this writer, she negotiated multi-million dollar international loans, dealing with heads of commercial and central banks across the globe; she and her husband were among 1% of Americans, who could afford any cost in purchasing appropriate care for their family members. This confirms what we have been realizing for some time: "You cannot buy what the culture does not produce." If you would like to join the New York City Chapter in advocating for change in the responses to people with Alzheimer's disease or related disorders, please call Ann Berson, Juan Molyneaux or me at 212-983-0700.

— Jean Marks

Three New Tax Benefits for Long Term Care Services and Insurance

In an effort to “reward” those individuals who are paying privately for their long term care services, i.e., nursing home care, home care, or medical day care, or long term care insurance premiums, the Health Insurance Portability and Accountability Act of 1996 offers some tax benefits.

For Federal and State tax purposes, beginning January 1, 1997, long term care services are generally treated in the same way as medical care. Thus, for individuals who itemize medical care expenses, the unreimbursed expenses for long term care services may be deductible. The long term care services deductions must be for care of the taxpayer, his or her spouse, and dependents to the extent that the expenses exceed 7.5 percent of the taxpayer adjusted gross income. The tax definition of “medical care” now includes (1) premiums paid for any qualified long term care insurance contract (up to limits allowed by law), and (2) amounts paid for qualified long term care services. You don’t **have** to have long term care insurance to deduct expenses for qualified long term care services.

To summarize, if you are paying privately for “formal” home care or nursing home care, or in some instances, medical adult day care, and you file a “long form” and itemize, you can deduct those expenses as allowed by the IRS code. Informal long term care services or services provided by unlicensed providers are not eligible for deductions. If you are paying for long term care insurance premiums, those, too are allowed as deductions as medical expenses, (to the extent that the expenses exceed 7.5% of the taxpayer adjusted gross income) but are limited by the law, according to the age of the policy holder. The 1997 limits are for those age 51-60: \$750, age 61-70: \$2,000, age 71 and older: \$2,500.

As with all financial and tax matters, the consumer is encouraged to consult a qualified tax advisor for specific advice or information about his or her situation.

The New York City Department for the Aging’s Health Insurance Information Counseling Assistance Program (HIICAP) is a good resource for information and guidance. You can reach them at 212-333-5511.

– Jed. A. Levine

In part the information in this article was taken from “Federal and New York State Tax Benefits for Long Term Care Services and Insurance,” NYS Health Insurance Information, Counseling and Assistance Program, Dec. 1997.

Teen Takes on Alzheimer's



Svetlana Zampolskaya

Svetlana Zampolskaya, a 17-year-old senior at Brooklyn's Midwood High School, is one of thirteen 1998 Westinghouse Semi-Finalists at the school (a national record). The research papers submitted by these students show an incredible level of sophistication. But Svetlana's paper, in addition to its sophistication, is of special interest to the Alzheimer's community.

Her project is entitled "Bimodal Distribution of Errors in the Assessment of Navigation Estimation: A Novel Test for Diagnosing Alzheimer's Disease and Navigational Abilities in Humans." As the title implies, the study deals with the ability, or lack of it, of people to find their way around. One of the characteristics of Alzheimer's disease is that its victims tend to get lost. And so, Svetlana reasoned, perhaps the inability to navigate (read "find one's way") might be a sign of Alzheimer's.

Svetlana became interested in Alzheimer's disease as a volunteer at the nursing home where her mother is a staff member. In the course of her weekly visits to the nursing home, Svetlana has frequent opportunities to work with patients in various stages of AD. She participates with these elderly residents in arts and crafts, dancing and bingo. With youthful pride and a touch of poignancy, Svetlana relates how she pairs a mentally disabled with a physically disabled patient so that they can help each other in the bingo game. She offers prizes of fruit or coins to the winner. From her mother, Svetlana has learned about the distinguished former lives of some of her hopelessly demented friends. In some small way, Svetlana hopes her Westinghouse project might contribute to the solution of the Alzheimer's enigma.

Svetlana's study was based on prior research on the navigational ability of animals. This research demonstrated that animals orient themselves by means of an area of the brain called the *entorhinal cortex*. The entorhinal cortex happens to be where the pathology of Alzheimer's disease in humans occurs early and heavily. Working under a mentor at the SUNY Health Science Center at Brooklyn, Svetlana was advised to see whether she could develop a means of testing the navigational ability of humans. Perhaps, Svetlana speculated, a valid test might be used in early diagnosis.

Through a series of carefully controlled experiments, Svetlana demonstrated that it is possible to test the navigational ability of humans. In her own words:

"The objective for this study was to assess how humans navigate through space. The motivation for this work was to develop a test that would diagnose the loss of one's navigational functions at the onset of Alzheimer's disease. Subjects performed a series of directional tasks on the given apparatus. The results illustrated two distinct groups of people whose behavior can be classified as that of field dependent and field independent personalities. The test developed can possibly be used in the future to diagnose the loss of navigational ability in Alzheimer's disease."

Svetlana's achievement is all the more remarkable since she has been in this country for only six years. Born in the Ukraine, she moved with her parents to Latvia after the nuclear disaster in Chernobyl. In Latvia, her father was an engineer at a Diesel company, and her mother a music teacher. Anti-Semitism impelled the family to leave the Soviet Union.

When Svetlana arrived in the U.S., she was in the middle of the sixth grade. Her mother, determined to have her daughter master English rapidly, insisted she learn twenty new words each day. It worked. Today Svetlana is at least as fluent as any native born American, and an outstanding scholar.

Asked about her career plans, Svetlana responds that she hopes to become a physical therapist. Why not a scientist? Her experience in the nursing home, she replies, has shown her the value of working with individuals. And, Svetlana adds, her grandmother, who recently died of cancer, had taught her that helping one person is equivalent to helping the world.

– Jack M. Pollock

A CHECKLIST FOR MEDICAID PLANNING

IS MEDICAID PLANNING A CRIME?

Q: I have read that a new federal law applies criminal penalties to anyone who counsels another to dispose of assets to become eligible for Medicaid. Is this true?

A: The previous so-called “Granny Goes to Jail Law,” which exposed the elderly to criminal penalties for Medicaid transfers, has been repealed. The present law, dubbed “Lawyer Goes to Jail,” shifts the threat of criminal liability to attorneys and others who counsel clients, thereby denying the elderly the advice to make entirely legal transfers. Along with the New York State Bar Association, we believe the law is unconstitutional and a violation of traditional American notions of basic justice and fair play. Today, as before, we as legal practitioners are ethically bound to provide quality Medicaid advice when questioned by our clients and to insure that they avail themselves of asset conservation strategies available under the civil laws, both state and federal. Our firm supports the Bar Association in its suit against the federal government to overturn this law because it is a dangerous precedent for other potential restrictions on the freedom of speech, the right to counsel, and the attorney-client relationship.

Q: My mother transferred all her money to me six months ago. She needs home care. I understand that because of this transfer she will be ineligible for Medicaid home-care services for 36 months. Is this true?

A: **No! There is no penalty period for transfer of assets when applying for community or non-nursing home Medicaid coverage in New York State.** However, for Medicaid nursing-home services

the rule is quite different. If assets are transferred to persons other than a spouse and/or certain specified individuals, a penalty period is incurred and during that period an individual is ineligible for Medicaid nursing-home coverage. For further discussion of the Medicaid penalty period, see discussion below.

INCURRING A PENALTY PERIOD

Q: My father recently transferred \$65,210 to his grandchildren. I understand that for purposes of applying for Medicaid nursing-home service, my father created a penalty period during which he is ineligible for that benefit. Would you please explain how the penalty period is determined.

A: When a Medicaid application for nursing-home coverage is made, Medicaid reviews all financial records of the applicant and spouse for 36 months (60 months for trusts) before the month of application to determine whether there were any uncompensated transfers that would incur the imposition of a penalty period. All uncompensated transfers are added together and the total is divided by a number representing the average monthly cost of a nursing home in the area where the patient resides. The current figure for New York City is \$6,521. The result of the calculation is the number of months the applicant is ineligible for Medicaid coverage in the nursing home. For example, when your father transferred \$65,210 to his grandchildren, he incurred a penalty period of 10 months during which Medicaid will not cover his costs in a nursing home. The penalty period starts running on the month following the transfer.

About the Author

Carole C. Lamson, Esq. is at LAMSON & PETROFF, (212) 297-3318, a firm concentrating in the area of Elder Law. She is a member of the NYS Bar Association Section on Elder Law; the Committee on Legal Problems of the Aging at the NYC Bar Association; and the National Academy of Elder Law Attorneys.



WEDNESDAY March 4

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

THURSDAY March 5

Brooklyn Education Meeting
Time: 1:30 - 3:30 p.m.
Place: Midwood Alzheimer's Center
1215 Avenue O
Brooklyn, NY 11230
Topic: Understanding and Managing Caregiver Stress
Speakers: Tobi Abramson, Ph.D.,
Mary Hume, CSW

MONDAY March 9

Education Meeting
Time: 6:00 - 7:30 p.m.
Place: Empire Blue Cross Blue Shield
622 Third Avenue
Topic: Getting Through: Effective Communication with the Alzheimer's Person, a Practical Approach
Speakers: Susan Goldfein, Ph.D.,
Jed Levine, M.A.

THURSDAY March 12

Bronx Education Meeting
Time: 1:30 p.m. - 3:30 p.m.
Place: Providence Rest Nursing Home
3304 Waterbury Avenue
Bronx, NY 10465
Topic: Understanding and Managing Caregiver Stress
Speakers: Phyllis Antis, R.N.

MONDAY March 16

Legal/Financial Seminar
Time: 5:30 - 7:00 p.m.
Place: Chapter Office
Speaker: Dan G. Fish, Atty.

THURSDAY March 19

Legal/Financial Seminar
Time: 1:30 p.m. - 3:30 p.m.
Place: Samuel Field YM-YWHA
58-20 Little Neck Parkway
Little Neck, NY 11362
Topic: Understanding and Managing Caregiver Stress
Speakers: Joan Baraf, ACSW
Isabel Guzman, R.N.

WEDNESDAY April 1

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

MONDAY April 6

Legal/Financial Seminar
Time: 12:00 noon - 1:30 p.m.
Place: Chapter Office
Speaker: Peter Strauss, Atty.

MONDAY April 6

Time: 6:00 - 7:30 p.m.
Place: Chapter Office
Topic: Recruiting, Hiring and Training a Personal Assistant for the RWJ Consumer Directed Home Care Program.
Speaker: Ruth Rothbart Mayer, CSW

MONDAY April 13

Education Meeting
Time: 6:00 - 7:30 p.m.
Place: Empire Blue Cross Blue Shield
622 Third Avenue
Topic: Understanding Issues of Loss and Anticipatory Grief in Alzheimer's Disease
Speakers: Benyamin Cirlin, CSW

MONDAY April 20

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

THURSDAY April 30

Time: 2:00 p.m. - 3:00 p.m.
Place: ICD
340 East 24 Street
New York, NY 10010
Topic: Legal and Financial Planning for Seniors
Speakers: Daniel G. Fish, Atty.
Jed A. Levine, M.A.
(Please call James Simon at 212-585-6082 to register)

MONDAY May 4

Legal/Financial Seminar
Time: 12:00 - 1:30 p.m.
Place: Chapter Office
Speaker: Richard Anderson, Atty.

WEDNESDAY May 6

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

MONDAY May 11

Education Meeting
Time: 6:00 - 7:00 p.m.
Place: Empire Blue Cross Blue Shield
622 Third Avenue
Topic: End of Life Issues: A discussion of treatment options and hospice care in advanced Alzheimer's disease.
Speakers: To be announced

MONDAY May 18

Legal/Financial Seminar
Time: 12:00 - 1:30 p.m.
Place: Chapter Office
Speaker: Michael Long, Atty.

MONDAY June 1

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

WEDNESDAY June 3

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

THURSDAY June 4

Brooklyn Education Meeting
Time: 1:30 - 3:30 p.m.
Place: To be announced
Topic: Legal/Financial Seminar

MONDAY June 8

Education Meeting
Time: 6:00 - 7:30 p.m.
Place: Empire Blue Cross Blue Shield
622 Third Avenue
Topic: Understanding the Role of Genetics in AD
Speakers: Norman Relkin, M.D.

THURSDAY June 11

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

MONDAY June 15

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

WEDNESDAY June 17

Time: 2:00 p.m. - 3:00 p.m.
Place: ICD
340 East 24 Street
New York, NY 10010
Topic: Caring for a Loved One with a Chronic Illness
Speakers: Rea Kahn
Jed A. Levine
(Please call James Simon at 212-585-6082 to register)

THURSDAY June 18

Queens Education Meeting
Time: 1:30 p.m. - 3:30 p.m.
Place: To be announced
Topic: Legal/Financial Seminar

ALL MEETINGS ARE FREE OF CHARGE

The NYC Chapter Office is located in the GRAYBAR Building, 420 Lexington Avenue, (between 43 and 44 Streets), Suite 610, New York, NY 10170

For our monthly Manhattan Education meetings we wish to thank Empire Blue Cross Blue Shield for generously donating space.

We also wish to thank CAPE at the Samuel Field YM-YWCA for the generous donation of space for the Queens Orientation meetings.



~ ORIENTATION PROGRAM EXPANDED ~

The New York City Chapter of the Alzheimer's Association is pleased to announce that due to increased demand, we are adding one more Orientation Meeting a month in Manhattan. **Orientation Meetings** for families new to Alzheimer's disease are now held **five times a month** in the Chapter office at the following times:

The First Thursday from 8:30 - 10:00 a.m.
The Second Wednesday from 5:30 - 7:00 p.m.

The Second Friday from 12 noon - 1:30 p.m.
The Fourth Tuesday from 12 noon - 1:30 p.m.

The Third Thursday from 5:30 - 7:00 p.m.

We are also very pleased to announce that beginning April 2, 1998 we will be holding an Orientation meeting in Queens, once a month at the **Samuel Field YM-YWCA, CAPE Conference Room, 59-28 Little Neck Parkway, Little Neck, NY.** The meeting will be held in the CAPE (Community Advisory Program for the Elderly) offices, in the building on the corner of 60th Avenue, adjacent to the "Y." The entrance is through the parking lot. The meeting will be held in the CAPE conference room on the **First Thursday of the month from 12:30 - 2:00 P.M.** Please call the chapter office to register. For travel information, please call CAPE at the Samuel Field Y at 718-224-0566.

The Orientation meetings are a safe, comfortable place to get information about Alzheimer's disease. Topics covered include the importance of assessment and diagnosis. AD vs. normal age-related memory changes, understanding dementia, understanding the disease process and physiological characteristics, symptoms, stages, treatment and research options. We also discuss what families need to know when planning for care, both for the identified patient, and for the caregiver. Resources, services and literature are shared with the participants. The Orientation meetings are an important first step in getting your bearings in the new role of caregiving for a relative with dementia. The meetings are limited to 15 participants. All Orientation meetings are led by staff or social work interns of the Alzheimer's Association, New York City Chapter. We are planning to add Orientation meetings in Brooklyn and the Bronx in the near future.

To reserve a place at the Orientation meetings, or for more information, please call 212-983-0700. Seating is limited, and reservations are mandatory.

WHAT IS A PLANNED GIFT?

HOW CAN I MAKE A PLANNED GIFT TO THIS CHAPTER?

Just what *is* a Planned Gift?

How can it help my *family's* well being?

A planned gift is a way to gain a personal benefit for you **and** your family while planning for your favorite charity. There are several ways to plan your gift.

Your benefits can be to:

- ◆ **Reduce your federal income taxes**
- ◆ **Transfer assets to your children** so that tax-advantaged earnings may be used for college expenses
- ◆ **Provide retirement income** needed to maintain your standard of living
- ◆ **Avoid capital gains tax, and enhance current income**
- ◆ **Avoid estate and inheritance taxes** at your death
- ◆ **Avoid depletion of your assets in case of a long-term nursing home stay**
- ◆ **Provide for your care in the event of your disability or incapacity**
- ◆ **Shelter your assets** from creditors

How can I accomplish any of the above?

Here's a brief overview, and some additional questions to ask yourself. **Do you own an asset – such as real estate or stocks and bonds – that...**

- ◆ produces too little income
- ◆ takes too much time and effort to manage
- ◆ is too concentrated, and you would like to diversify your portfolio without paying income taxes?

Would you like to be able to use this asset to create...

- ◆ An ongoing stream of income for yourself and any one else you name
- ◆ Significant current and future tax savings
- ◆ An endowment for a favorite charity?

If so... Let us help you.

Come to one of our spring seminars.

You could consider creating a tax-exempt *lifetime income* arrangement. How? Briefly, there are several ways through which you might do so. You could create a **Charitable Remainder Trust**. This trust provides an income to the donor or the donor's beneficiary with **the remainder distributed to the charity, at the donor's/beneficiary's death, or, after a certain number of years,** (specified by the donor). There are *two* main types of charitable remainder trusts:

1. The **Charitable Remainder UNITRUST** pays a percentage of your planned gift's value every year as income to the donor or donor's beneficiary. The donor selects the percentage at the outset of the plan, (no less than 5% of the fair market value of the planned gift). The income for each year is based on the trust principal as of December 31 of the prior year. Your income can rise if the principal grows—or fall if the principal shrinks. The remainder of this planned gift, goes to the charity at the donor or beneficiary's death, *or,* after the number of years specified by the donor. The donor may make multiple contributions to this gift, and gets charitable income tax deductions each time.
2. The **Charitable Remainder ANNUITY TRUST** provides a fixed dollar amount each year to the donor or beneficiary. The annual payment must be 5% or more, (such as 7% or 8% or perhaps even higher) of the initial value of the gift. It continues for the life of all income recipients, or for a specific number of years. The charitable remainder annuity trust allows only one contribution.

Another life income arrangement possibility is the **Gift Annuity . . .** a fund made up of federal government securities and other audited investments. Annuity payments are paid to donors monthly, quarterly or semiannually from insurance rate tables approved by the New York State Department of Insurance. A portion is federally taxable, but the balance of payments are tax-free for the life expectancy of the donor(s).

Or perhaps you might like to “pool” your resources in a **Pooled Income Fund**. This is done by making a gift to your favorite charity that provides you with a quarterly stream of income at or around retirement. The Charity administers your gift and invests it for growth in its bank. The bank has multi-million dollar common investing funds used for its many thousands of trust clients. These common investing funds contain high grade common and preferred stocks, government and corporate bonds and cash equivalent money market instruments. (They do not include tax exempt securities.)

When you invest in this pool of common income, you are assigned a number of shares. These shares represent your portion of interest in the total Fund. **Your charity's Pooled Income Fund has an investment goal of earning high income while guarding your principle investment. Earnings from the Fund are paid to you quarterly on the basis of your number of shares.** The year your gift is made, you may claim a federal income tax deduction an amount equal to the remainder interest in the gift. This remainder interest, (or your contribution deduction), is computed from Treasury Department tables.

Other planned gifts you might want to consider are these. An **IRA or Pension Fund left in an estate is often taxed at rates that can exceed 70%**. A bequest of an IRA to your charity may mean that beneficiaries lose very little, and assure that the *US Treasury makes a substantial contribution*. Also, you could remember us as a beneficiary in your **Will** with a bequest, or take out a **Life Insurance** policy with the Chapter as a beneficiary.

The Alzheimer's Association, New York City Chapter, can help you understand how to make any of these kinds of “planned gifts.” We invite you to attend one or more of our quarterly “Planned Gifts” seminars. These are facilitated by a panel of legal, bank, accountant and insurance experts. **Sessions are designed to explain which planned gift is appropriate for you, given your age, financial circumstances and wishes. Please sign and return this form in the enclosed envelope so that we can plan for your attendance.**

Two thoughts we leave you to ponder until our next newsletter:

“We make a living by what we get, but we make a life by what we give.” . . .

“Give us the tools and we will finish the job!” – Sir Winston Churchill



ALERT!

LETTERS/CALLS NEEDED
March, April and May, 1998

TIME IS RUNNING OUT FOR ALZHEIMER RESEARCH FUNDING

The Alzheimer's Association is mounting an all-out campaign to convince Congress to add **\$100 million** to the research budget at the National Institutes on Health THIS YEAR to **find a way to prevent Alzheimer's disease.**

There are many competing demands on available funds and we cannot win unless every Member of Congress hears from his or her constituents about the importance of Alzheimer research back home.

Write your Senators and Representatives today.

TELL THEM TO SUPPORT A \$100 MILLION INCREASE IN
FUNDING FOR ALZHEIMER RESEARCH AT NIH – THIS YEAR!
TELL THEM – **TIME IS RUNNING OUT!**

Here are key points you can make:

- **Congress cannot save Medicare** unless science finds a way to prevent Alzheimer's disease.
- By the time the **baby boomers** reach the age of greatest risk, **14 million Americans will have Alzheimer's.** They will cost Medicare 70% more than beneficiaries who are not cognitively impaired.
- The disease process starts as much as **20 years before disease symptoms appear.** By the time a person knows he or she has Alzheimer's, **it is too late to cure the disease.**
- **Scientists know what they need to do. But there is not enough money to do it.**

The Address for your members of Congress is:

For Senators: The Honorable _____
United States Senate
Washington, DC 20510

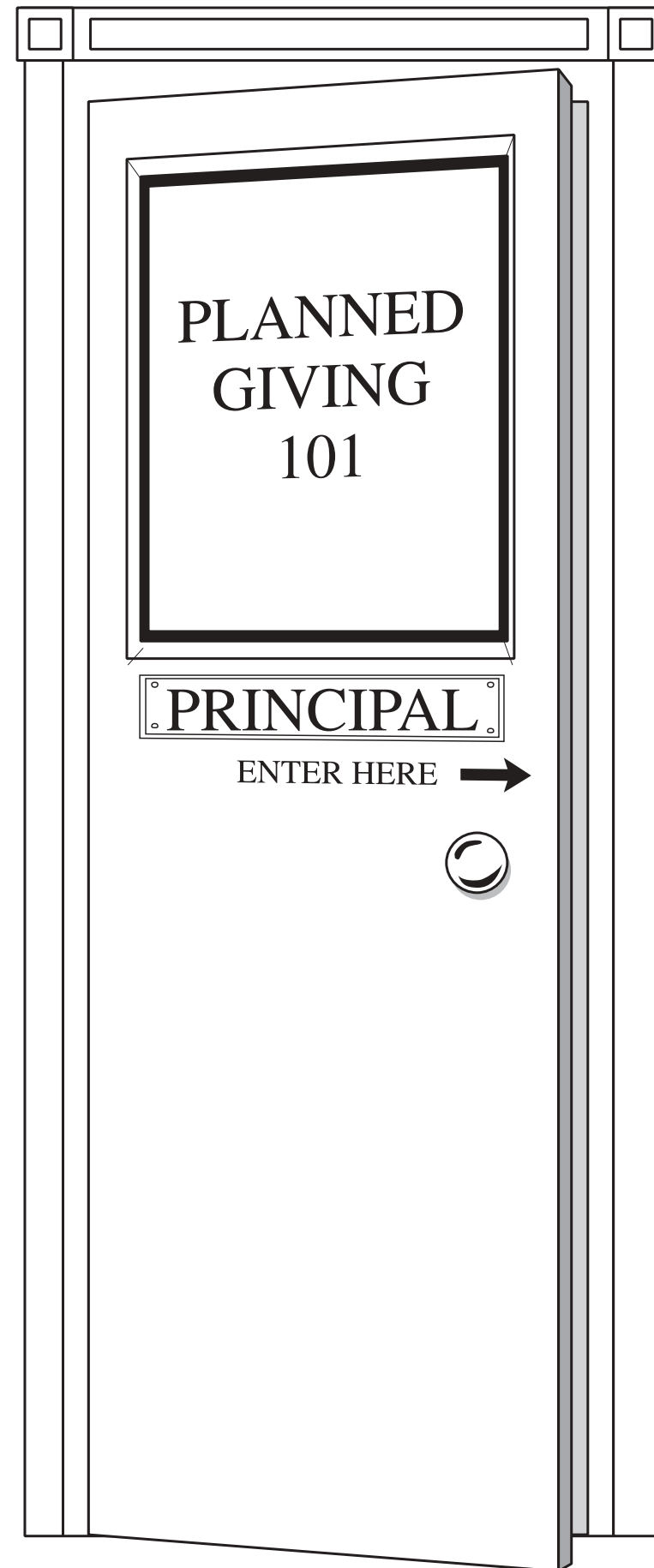
For Representatives: The Honorable _____
US House of Representatives
Washington, DC 20515

*For more information on who in Congress you should contact, call your local library
Or call the Alzheimer's Association at 02-393-7737 (e-mail: michael.splaine@alz.org)*



ALZHEIMER' DISEASE AND RELATED DISORDERS ASSOC. INC.

Washington Office: • 1319 F St., NW Suite 710 • Washington, DC 20004 • Phone: (202) 393-7737



Advocacy Alert *Continued from page 1.*

in-home personal care services are maintained for persons with Alzheimer's disease and related illnesses.

- The Coalition will work with the appropriate governmental agencies to assure the development and funding of social model adult day care (adult day services) throughout New York State.

- Given the extremely high cost of private care which makes private pay prohibitive for all but the wealthiest, Medicaid-funded services, whether home or community-based or in an institutional setting, must be maintained and made available to persons with Alzheimer's disease.

- As New York State moves to encourage and mandate Medicaid managed care, it is imperative that the needs of Alzheimer's patients for diagnosis and evaluation be addressed, and the availability of physicians knowledgeable about the care needs of Alzheimer patients, support services and long term care be assured.

- If New York State undertakes to include Medicaid-only Alzheimer patients and those with both Medicare and Medicaid (the dually eligible) in Medicaid managed care, the Coalition will work to assure that the responsible governmental entities confront, understand and address the special needs of persons with Alzheimer's.

- New York State is encouraging the development of managed long term care program models which integrate primary, acute and long term care services. The Coalition will work to assure that persons with Alzheimer's have access to and are included in these program models.

- New York State is encouraging the development of consumer-directed care options under Medicaid, including its statewide Consumer-Directed Personal Assistance Program (CDPAP) and a Cash and Counseling demonstration funded by the Robert Wood Johnson Foundation. The Coalition will work to assure participation of persons with Alzheimer's and their families in these programmatic efforts.

- The Coalition seeks \$300,000 in funding from New York State for the Alzheimer's Community Assistance Program (AlzCAP) as enacted by the Legislature in the last session and signed by the Governor.

AlzCAP will assist all thirteen Coalition chapters in New York State to carry out and strengthen their telephone helplines, counseling services, and their training and public education efforts. These programs have been proven to delay institutionalization of people who have Alzheimer's disease. The Coalition continues to strongly support essential funding for the existing Alzheimer's Disease Assistance Centers (ADACs) and the Alzheimer's Community Services Program (ASCP).

- The Coalition seeks state funding support for the Safe Return Program, a wanderers' safety program organized nationally by the Alzheimer's Association and operated in New York State by all thirteen chapters. Safe Return offers a measure of security to persons with Alzheimer's disease. It furnishes a statewide mechanism to register persons with dementia, provides identifiers and maintains a registry which expedites identification when a registrant is lost. Support from New York State will help increase public awareness and participation, spur training of public safety personnel and support one-time registration fees.

- The Coalition opposes efforts to reduce or eliminate financial protections currently afforded persons with Alzheimer's and their families. These include existing support for the community spouse of an institutionalized Alzheimer patient, the right of spousal refusal and the permissible transfer of assets to secure Medicaid-funded home care without a waiting period.

- The Coalition will oppose any efforts on the part of the state to eliminate or weaken regulations that would result in reducing the quality of care in nursing homes or restrict Alzheimer patient access to nursing homes. As sub-acute care develops in nursing homes, the Coalition opposes any efforts to exclude Alzheimer's patients who require long term care from admission to nursing homes. Therefore, the Coalition strongly supports increased reimbursement under the Resource Utilization Groups (RUGs) system for nursing home residents with Alzheimer's disease and related dementing illnesses.

Join us in advocating!

Call Alzheimer's Association, 212-983-0700 and ask for Ann Berson. Or, fill in this coupon and mail to Alzheimer's Association, 420 Lexington Avenue, Suite 610, New York, New York 10170, Att: Advocacy Alert.

THERE IS STRENGTH IN NUMBERS 

Name _____

Address _____ Apt. _____

City _____ State _____ Zip _____

Phone (day) _____ (evening) _____

____ I will come to Albany on March 31.

SAFE RETURN: What a Difference a bracelet makes

Did you know that:

59% of people diagnosed with AD wander and become lost at some point in the disease?

People with AD do not usually seek help when they're lost?

October 1, 1997, Police Officer S was called to the scene by a neighbor of Ms. T's. Ms. T was alone, locked in her apartment and could not get out. The Officer called the patient's daughter; he would not leave Ms. T. in a locked apartment. The daughter arrived; the patient was very agitated and was transported to Columbia Presbyterian Medical Center's Emergency Room. She was discharged the next morning. The chapter worked with the daughter on obtaining 24 hour home care and exploring nursing home placement.

October 3 Mr. N was found unconscious on a downtown Manhattan street. He was taken to NY Downtown Hospital. The police saw his Safe Return bracelet, called Safe Return, and contacted the family. Mr. N was returned home. The family is working with the Bensonhurst Senior Assistance Center, there is some home care in place.

October 4 This is the fourth wandering incident for Ms. H. A good Samaritan discovered Ms. H outside her home. She noticed she wasn't dressed appropriately. She then noticed her Safe Return bracelet; the good Samaritan took her into her home and called Safe Return. Safe Return was able to contact the second caregiver (the first caregiver was not available), who picked up Ms. H. Medicaid was approved for 24 hour care which will start in 3 weeks. In the meantime an intercom plus an alarm on the door were suggested.

October 9 Ms. R lives with her son. He checked on her at 1:00 a.m.; she was asleep; when he checked

again at 7:00 a.m., she was missing. Safe Return was called, and faxes were sent. The police discovered her at Kings County Hospital, she had her Safe Return bracelet on. Her son picked her up. The son has a social worker who is assisting him in obtaining Medicaid for home care and day care.

October 13 Ms. R was found wandering and was transported to the ER at Harlem Hospital. The physician noticed her Safe Return bracelet and called Safe Return. We gave him the names of the caregivers and she was reunited with her family. We spoke with her son, who stated the home attendant went to the bathroom and Ms. R wandered out.

October 21 Ms. C wandered away from an Adult Day Care Center in Brooklyn. The police were notified, along with Safe Return and all the employees of the Day Center. Ms. C was found the next day at Brookdale Hospital listed as a Jane Doe.

Her family picked her up. She was in good condition. All the day care participants are now wearing Safe Return bracelets.

October 29 Mr. R was eating in a restaurant and became agitated. He said he did not know how to get home. The restaurant manager called the police. Police Officer P responded, saw the Safe Return bracelet and called Safe Return. The Police Officer was given Mr. R's home address and took him home. The Chapter is working with the son on medical, legal and financial issues.



For more information on how to register your person with Alzheimer's disease, please contact Gail Hoffmann, Safe Return Coordinator, 212-983-0700 ext. 201.

EMPOWERING HOME CARE CONSUMERS

The Robert Wood Johnson Foundation grant the Alzheimer's Association received this past year has given the organization a great deal of information about the kinds of home care services people need, want, and can handle. The grant offers families the opportunity to hire, through Medicaid financing, their own home care staff.

For those who have signed on to consumer-directed home care, the project has been a blessing. One man caring for his aunt said, "She's able to maintain a good quality of life because the people I hired are interested in her. They like her, and we wouldn't have it any other way. How do I do it? I want to. She was always good to me and since I know how to run a business, getting the right people in to care for my aunt is just extending what I have already been doing for many years."

Some people are afraid to "go it alone" because the home care agencies promise to always provide back-up help when needed. "Well," said a daughter caring for her mother, "we made sure to have a few people we could rely on in the event our main person couldn't come. It took a little time to find reliable people, but it was less stressful in the end because my mother knows them. There are fewer surprises now that we are in charge of our own staff. Now I can concentrate on getting my mother out to participate in programs and not wondering if anyone will show up that day."

Taking care of a family member at home and being an employer is not easy. "At first it didn't seem natural," the wife of an ill husband said. "I worked over the

years, but I wasn't a boss. This took getting used to. I tried not to get angry with her when she was late, but it did make me angry. At the same time, I knew it was important to make her comfortable in our home. At first it was hard but now we've developed an understanding of each other. I feel good about being able to keep my husband at home."

One role of the RWJ project staff is to help people negotiate their way through the Medicaid process. As acceptance by Medicaid Home Care comes closer, staff informs families how to apply to Concepts, the fiscal intermediary, which handles payroll for the personal assistants. Additionally, a home visit helps the RWJ staff understand each family's circumstance. An assessment is

done with families to help them think about services they might need or ways to recruit and work with the personal assistant they have hired.

The RWJ staff continues to look for ways to support families who become involved in the consumer-directed model as a way to keep their family member at home.

Over the next few months, several meetings will be scheduled to address questions about consumer-directed home care which consumers, their caregivers and professionals have. Call Ruth Rothbart Mayer at 212-983-0700 ext. 204 for time and place.

CONSEJOS PARA EL CUIDADOR Por Isabel Guzman, RN

Es necesario que la persona que se encarga de un paciente que padece de la enfermedad de Alzheimer considere ciertos reajustes que son muy importantes. La planificación es sumamente importante para sostener la calidad de vida del paciente y cuidador.

- 1 - Conocer bien la enfermedad para formular un plan realista para el futuro.
- 2 - Formule un plan para darle a la persona que se ha hecho cargo del paciente oportunidades de descanso, para que ésta persona no tenga que afrontar constantemente las dificultades de atender al paciente.
- 3 - Brindar supervisión. Estar atentos a los peligros en el hogar.
- 4 - Asegurar el bienestar médico del paciente. No existe cura y no hay tratamientos pero si hay algunos medicamentos disponibles que pueden ayudar a aliviar algunos de los síntomas, tales como la agitación, depresión y el insomnio.
- 5 - Ayudar con el cuidado personal. Ayudar con las actividades diarias, como bañarse, vestirse y comer.
- 6 - Para comunicarse más exitosamente el cuidador puede tomar a su favor el lenguaje de gestos y señales porque el paciente probablemente tenga problemas para comunicarse.
- 7 - Planee actividades que relajen al paciente como: bailar, hacer ejercicio, escuchar música, cantar canciones familiares, tocar instrumentos musicales o actividades en el jardín como plantar flores.
- 8 - Obtenga ayuda de los servicios disponibles, como los que ofrecen los centros de cuidado y las agencias que ofrecen ayuda y cuidados en el hogar.
- 9 - Mantenga su propio bienestar porque podría cansarse. Tal vez, turnarse con otra persona para atender al paciente o asistir a un grupo de apoyo y siempre mantenga la fe.
- 10 - Trate de obtener información con la gente de su comunidad. Para obtener más información sobre la enfermedad de Alzheimer se puede comunicar con La Clínica de la Memoria de el Hospital de Elmhurst (718-334-5374), en Manhattan la Asociación de Alzheimer's (212-983-0700).

A Bittersweet Birthday Celebration



Harry Rimm (left) and John Jager (right) present Elena Suhir with the historic White House photograph.

Our New York City Chapter was recently the beneficiary of some of the proceeds from a fundraiser organized by the Gramercy Park Young Republicans (with the assistance of members of our Junior Committee).

The occasion was the eighty-seventh birthday of Ronald Reagan, the fortieth

President of the United States. Whether or not one supported his policies, it cannot be denied that Mr. & Mrs. Reagan's choice to go public about his condition (in November 1994) drew unprecedented attention to Alzheimer's disease. Since then, Nancy Reagan has recorded public service announcements on behalf of the Alzheimer's Association, and lent her presence to several of our organization's benefits.

Although Mrs. Reagan did not attend the February 6 gathering at the Gramercy Park Hotel, she sent a touching letter. It was read by Elena Suhir (co-chair of the GPYR). Mrs. Reagan said she regretted missing this "fine and memorable evening," which, "as Ronnie would say, marks the forty-eighth anniversary of his thirty-ninth birthday." She thanked everyone for "a meaningful birthday gift" that would "raise awareness" of Alzheimer's.

Throughout the evening, people inscribed their best wishes on two giant birthday cards which would be sent to the Reagans in California. Among the other festive touches were balloons and a birthday cake large enough to insure that each of the 200 in attendance had a slice.

Ms. Suhir, 27, wanted to dedicate this party to the Alzheimer's "cause," because her grandmother is the same age as Ronald Reagan and also suffers from AD. As she observed, "Alzheimer's is a bipartisan disease."

Harry Rimm, representing our Junior Committee, emphasized the grim figures showing that at least 150,000 people in New York City have AD — while hundreds of thousands more are touched by its devastation.

John Jager, our chapter's executive director, presented the GPYR with a framed photograph taken in the Oval Office back in 1985, depicting President Reagan signing the first proclamation of Alzheimer's Awareness Month.

NOTE: The New York City Chapter's Junior Committee's next fundraising cocktail party is set for late March or early April. Over the last decade, these informal, inexpensive events — aimed at the under-35 set — have attracted thousands to various "in-spots" all around town.

The Junior Committee meets once a month. Please contact Kathy White at 212-526-2363 for additional information. New members are welcome!

— Chris MacLeod

VOLUNTEER Positions

**VOLUNTEERS ARE
NEEDED FOR
MEMORY WALK,
SCHEDULED FOR
OCTOBER 18, 1998**

**If you are interested in
volunteering for The Walk
or other items listed here,
please call
Cynthia Emiry Roy
212/983-0700 ext. 213**

**VOLUNTEER
POSITIONS AVAILABLE:
Daytime Helpline Counselor**

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

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

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

Hours: 4-6 hours: the following shifts are available on some days: (9am - 1pm), (1pm - 5pm) or (11am - 3pm)

College students and retirees are encouraged to apply.

Your father, who is in his seventies, starts to show signs of the early stages of dementia. He is experiencing some short term memory loss, and he gets a little disoriented following his afternoon nap. You start to take a more active role in caring for your father, calming his nerves when he is confused about his surroundings, and watching for any further memory changes.

Another very important thing you can do to in your caregiving role is to ask your father to fill out a **health care proxy**. A health care proxy is a form which allows your father to designate a "health care agent"—someone to make medical decisions for him if he's not able to make them himself.

Most people assume that doctors automatically consult with a patient's family before making a medical decision, whether it relates to medication changes or general treatment choices. But New York is one of two states where doctors are not required to get input from the relatives or caregiving friends of a mentally incapacitated patient, unless these caregivers are health care agents. Many people mistakenly believe that having Power of Attorney allows you to get involved in medical decisions. In actuality, a Power of Attorney is only concerned with financial and property decisions.

Depending on the type of decision a patient has to make, a certain level of capacity or competency is required. If your relative is mostly confused but has some moments of lucidity, he can fill out the proxy during a lucid time. Two witnesses are needed to sign the form, to acknowledge that the patient understands the health care proxy agreement. No signature from an attorney or notary public is required.

The need for a health care proxy is not well publicized, so many families only learn about its purpose after it's too late, when their relative's dementia is too advanced for decision-making. While some doctors continue to involve caregivers who are not designated as health care agents, the health care proxy **guarantees** an agent the right to remain active in a patient's care. The proxy also guarantees a caregiver's access to the patient's medical records.

Blank health care proxy forms are available at legal stationery stores, as well as hospitals and nursing homes. Don't forget to make multiple copies of the proxy once it has been filled out. Keep a few copies for yourself and other family members, and make sure that you bring a copy to any medical facility or doctor where your relative gets medical care.



Courtesy of Jennifer Weiss, program director for FRIA—Friends and Relatives of Institutionalized Aged, Inc. — a non-profit consumer organization, 212-832-4455.

Milestone for Women's Auxiliary

Thanks to the drive and dedication of Hannah Bernstein, the Chapter's Women's Auxiliary marked its first anniversary this month. The group's membership now numbers nearly 100. But anyone can support their efforts by attending the events being planned for the spring.

First up is a tour of the new Museum of Jewish Heritage at Battery Park (March 24). An anniversary luncheon (special guest to be Frank Field) will take place on April 29 at The Town Club. And if you want to be sure of getting tickets to "Art," the season's most highly anticipated Broadway play, why not plan to attend June 3rd's Wednesday matinee with our friendly group.

Proceeds from each of these moderately-priced events go to support the programs of our NYC Chapter. For information (or to make reservations) please call Hannah at 212-983-0700.



Enjoying the Holiday Party at the Harmonie Club are (l. to r.) Frances Decker, June Schofield, Carol Diamond, Mitchell Diamond, Bernard Rosenberg and Muriel Rosenberg.

Bulletin BOARD

Family Caregivers and the Health Care System

On April 2, a conference focusing on family caregivers will bring together researchers, social service and health care administrators and providers to explore how stronger partnerships can create more integrated systems of care that will benefit patients and their families. Sponsored by the United Hospital Fund, the conference will confront how current trends in the delivery of services have forced families to assume the many of costs and responsibilities of out-of-hospital care.

Health professionals, policymakers, and family caregivers are invited to attend the conference, to be held from 9:00 a.m. to 4:15 p.m. at the New York Academy of Medicine (Fifth Avenue at 103 Street). Attendance fees range from \$50-90. Please contact conference coordinator Brenda Lamb at 212-494-0761 for more information.

Ginkgo and Dementia

Headlines and advertisements have been premature in touting the benefits of ginkgo biloba as a memory booster. Although a recent study by Dr. Pierre Le Bars of the New York Institute for Medical Research (published in the "Journal of the American Medical Association") found that 120 mg. of ginkgo daily had a slightly positive effect on individuals with Alzheimer's, there was no measurable difference noted in their overall impairment.

"Because Alzheimer's is such a devastating disease, those affected are often desperate for any glimmer of hope that research can provide," said Zaven Khachaturian, Ph.D., director of the Alzheimer's Association's Ronald & Nancy Reagan Research Institute. While he conceded that "this study provides such hope," Khachaturian believes it "should be approached with caution."

Steve DeKosky, M.D., chair of our Association's Medical and Scientific Advisory Council, said that Le Bars's study indicates ginkgo is promising enough to warrant additional research. Among other "alternative" treatments currently under investigation are DHEA, a steroid hormone, and NADH, a human enzyme which may be involved in producing energy for cells. In addition, preliminary research suggests that Vitamin E, estrogen supplements, and such NSAIDs (non-steroidal anti-inflammatory drugs) as ibuprofen and aspirin may be able to delay the onset of Alzheimer's.

Memory Walk 1998

On your mark, get set, go!

on your

Mark your calendars for
Sunday, October 18, 1998!

get

Set your goal to raise \$100, \$500 \$1,000 or more!

Go build your team and meet us at the starting line!

Plans are underway for **Memory Walk 1998**. This year's walk will have a new look, new locations, new entertainment, and the same commitment to raise dollars and public interest in our fight against Alzheimer's disease.

Put Memory Walk on your calendar and **start building your team** now. Set a goal of 25 walkers and ask every team member to raise contributions in support of their participation. *The money you raise supports the programs of this Chapter — right here in New York.*

In the past two years, Memory Walk has more than tripled in size. We can do better — if we set goals and start early. Watch this newsletter and your mail for details and a registration brochure.

See you on October 18!

Two New Research Studies: Nimesulide and Guanfacine

The Alzheimer's Disease Research Center at Mt. Sinai recently started recruiting for two new drug studies: one investigating the effect of the non-steroidal anti-inflammatory medication (NSAID) nimesulide on patients with Alzheimer's disease (AD) and another administering the drug guanfacine to AD patients.

If you are interested in participating in these studies, please contact Jennifer Northop at 212-241-0438.

THESE SUPPORT GROUPS NOW HAVE OPENINGS

The Alzheimer's Association - New York City Chapter offers many Support Groups at a variety of times in different community settings at no charge to the participant. The groups listed below still have openings for new members. Since changes in scheduling may occur, it is essential to call the group leader before you attend the first time. Orientation meetings are encouraged as a first step before joining a group. Please call the Chapter HELPLINE at 212-983-0700 to schedule an orientation meeting.

COMPOSITION OF GROUPS: M=MIXED, S=SPOUSES, C=ADULT CHILDREN, S&S=SPOUSES & SIBLINGS, D=DAUGHTERS, W&D=WIVES & DAUGHTERS, W=WIVES.

BRONX

Location: Jewish Home & Hospital (M)*
(W. Kingsbridge Rd)
Time: 12:00 noon - 1:30 p.m. Thursdays
Contacts: Shirley Bernstock 718-579-0531, Linda Graves 718-579-0588

Location: Kings Harbor Care Center - North Bronx * (M)
Time: 2:00 p.m. - 3:00 p.m. 1st & 3rd Tuesday
6:00 p.m. - 7:00 p.m. 1st & 3rd Wednesday
Contact: Lillian Kliffeld 718-320-0400 Ext. 571

BROOKLYN

Location: Brookdale Medical Center * (S)
Kings Plaza Campus (Flatbush Avenue/AveT&U)
Time: 10:00 a.m. - 11:00 a.m.
Contact: Tobi Abramson 718-240-5455

Location: Metropolitan Jewish Geriatric Nursing Home (M)
(A participating agency of Metropolitan Jewish Health System* (Boro Park)
Time: 2:45 p.m. - 3:45 p.m. 1st & 3rd Wednesday
Contact: Barbara Krinsky 718-851-5924

Location: Palm Gardens Adult Day Health Center* (M)
Time: 10:00 a.m. - 11:00 a.m. Every Other Tuesday
Contact: David Yanofsky 718-438-5300

MANHATTAN

Location: Community Group Center (West 13th Street) (M)
GAY AND LESBIAN CAREGIVERS' GROUP *
(In Collaboration with SAGE)
Time: 7:00 p.m. - 8:30 p.m. Every Other Tuesday
Contact: Carolyn Altman 212-741-2247
Note: A small contribution to SAGE will be welcomed

Location: West 60's * (S)
Time: 2:00 p.m. - 3:30 p.m. Every Other Tuesday
Contact: Amanda Leis 212-273-5217

Location: DOROT * (M) (West 85th Street)
Time: 11:00 a.m. - 12:30 p.m. Every Other Tuesday
Contact: Reeva Mager 212-769-2850

Location: Crisis Center (Cathedral St. John The Divine) (M)
Time: 2:00 p.m. - 3:00 p.m. 1st & 3rd Wednesday
Contact: Julie Kelm 212-280-7363

QUEENS

Location: Elmhurst Hospital Center* (M)
Time: 1:00 p.m. - 2:00 p.m. Mondays
Contact: Isabel Guzman 718-334-5374

Location: Hanac (Astoria) * (M)
Time: 2:00 p.m. - 3:30 p.m. Thursday
Contact: Stav Joannidis 718-777-5505

GRIEF & BEREAVEMENT GROUP (TIME LIMITED)

Location: 420 Lexington Avenue (43rd Street)
Time: 6:00 p.m. - 7:30 p.m. Wednesdays
Contact: Glenda Feinsmith 212-683-7225 Evenings

TEENS GROUP (TIME LIMITED: 12 WEEKS)

Location: 420 Lexington Avenue (43rd Street)
Time: 6:00 p.m. - 7:30 p.m. Thursdays
Offered in January & September
Contact: Rea Kahn 212-983-0700

GROUPS FOR NEWLY DIAGNOSED EARLY STAGE ALZHEIMER'S PERSONS

These are groups of individuals who have been told they have a diagnosis of probable Alzheimer's Disease. They acknowledge their memory loss, and can communicate their feelings and experiences. Information and support will be offered by professional leaders.

**Call the group leader for an appointment and
information before attending a group.**

BROOKLYN

Location: Brookdale Medical Center*
Kings Plaza Campus (Flatbush Avenue/Ave. T&U)
Time: 11:00 a.m. - 12:00 noon Tuesdays
Contact: Tobi Abramson 718-240-5455

QUEENS

Location: Elmhurst Hospital*
Time: 11:00 a.m. - 12:00 noon Wednesdays
Contact: Isabel Guzman 718-334-5374

**Support groups co-sponsored with other organizations or institutions*



New York City Chapter
420 Lexington Ave., Suite 610
New York, NY 10170

Address Correction Requested

NONPROFIT ORG.
U.S. POSTAGE
P A I D
PITTSTON, PA
PERMIT NO. 251