

Alzheimer's Research: To Delay, To Detect, To Destroy

Some twenty years ago, a significant milestone in Alzheimer's disease research was reached. It was the discovery by Dr. Peter Davies and other researchers of a chemical deficiency in the Alzheimer brain. The chemical, acetylcholine, is a neurotransmitter, carrying messages between brain cells. To remedy the deficiency, pharmaceutical companies designed various drugs to enhance the production of acetylcholine. A number of these drugs are in use today. But laboratories throughout the world are seeking newer and more effective treatments, and learning more about the causes and the possible prevention or cure of the disease.

On the cutting edge of this research is a laboratory at the Albert Einstein College of Medicine. The laboratory is directed by Dr. Peter Davies. During a wide-ranging interview in his office, Dr. Davies, a gracious and unpretentious man, discussed Alzheimer's research in general and the work of his laboratory in particular. Dr. Davies stresses the importance of early diagnosis of AD. At present, the only definitive diagnosis is examination of brain tissue, usually at autopsy. An early diagnosis would make early intervention possible. Dr. Davies, working with a small biotech company, Molecular Geriatric, has developed a spinal fluid test that is close to one hundred percent accurate for Alzheimer's disease. And since there is some reluctance to use spinal taps, they are currently working on a diagnostic blood test – a much simpler process. The obvious question is, if the test shows signs of Alzheimer's, what can be done?

According to Dr. Davies, several

pharmaceutical companies are developing drugs that can actually stop the formation of the telltale amyloid plaques in the Alzheimer brain. This could be a major advance; it would make early diagnosis crucial. Not all scientists think that the plaques are the cause of Alzheimer's, but many do. Dr. Davies himself has not joined the amyloid bandwagon. He believes that the other brain abnormality in Alzheimer's, the neurofibrillary tangles, also plays a still-undetermined role. And he is in search of a more fundamental causation. He wants to understand the mechanisms by which the plaques and tangles are created.

In Dr. Davies' laboratory are many so-called transgenic mice. These mice have been genetically engineered to develop signs of Alzheimer's in their brains. Until recently, these mice have developed only the amyloid plaques. But

Continued on page 7.

New Drug Approved

Galantamine hydrobromide (also known by the trade name Reminyl) is the fourth prescription drug approved by the U.S. Food and Drug Administration (FDA) specifically to treat symptoms of Alzheimer's disease. It is also approved as an Alzheimer treatment in the European Union and several other countries around the world.

In clinical trials comparing galantamine to placebo (inactive treatment), participants taking galantamine experienced better results than partici-

Continued on page 7.

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Director's Corner



Since No Chapter is an Island . . .

After nearly two decades of working together within the Alzheimer's Association, the New York City Chapter serving the boroughs of The Bronx, Brooklyn, Manhattan and Queens, and the Staten Island Chapter serving Richmond County — New York's fastest growing borough, located on the other side of the Verrazano Narrows Bridge — have come together as a single expanded chapter.

Staten Island found itself without the presence of the Alzheimer's Association when that chapter decided to withdraw from the Association at the end of last year. Given efforts to strengthen the performance of the Alzheimer's Association nationwide, enhanced performance standards were established for every chapter in the network. Staffing guidelines to achieve programmatic, management and fundraising base lines have resulted in a variety of new chapter configurations around the country.

On Staten Island, the former chapter's voluntary leadership decided to forge ahead on its own under a new corporate banner. Because the NYC Chapter remains convinced that no part of America, and certainly no part of our own city, should be left unserved by the Alzheimer's Association, we have agreed to assume programmatic and organizational responsibility for this additional borough of New York.

In the interest of the Alzheimer's community on the Island, we will seek to collaborate and sustain relationships with our colleagues from the former SI Chapter. In addition and effective immediately, our telephone Helpline, educational activities, the Safe Return program and other supportive services will now be formally available to SI residents. In time, the NYC Chapter's support group network, our educational programs and other community outreach activities will all be developed on Staten Island, just as they have been in each of the other boroughs. We expect to work closely with the Island's professional community, and with families throughout our expanded catchment area. Likewise, we look forward to the support of the Staten Island community we will serve.

And on Another Island . . .

Seeking to increase our presence and essential client access to Alzheimer's Association services in eastern Queens, and to better serve the residents of western Nassau County, the NYC and Long Island Chapters of the Alzheimer's Association, in partnership with the Parker Jewish Institute for Health Care & Rehabilitation, have joined together to establish an Alzheimer's Association Resource Center at the Institute's facility on the grounds of LIJ Hospital at 271-11 76th Avenue in New Hyde Park. This facility straddles the Queens/Nassau border.

The new collaboration was launched with a ribbon cutting ceremony attended by many guests and officials from all three organizations on February 13th. It was preceded by the first of a four-part, weekly educational series, *Living With Alzheimer's – A Seminar for Caregivers and Professionals*. Nearly 100 people attended this first symposium.

With staff and volunteers from both chapters assigned to develop this additional portal to the full array of chapter and other AD-related services (whether in NYC or on Long Island), we fully expect this new initiative will make a real difference to those needing the help of the Association. To reach the Alzheimer's Association Resource Center at Parker Jewish please call (718)289-2375. Look for more information about this new program in future newsletters as we develop and expand this collaboration in the coming months.

* * * * *

Finally, as I did in the last issue of our newsletter, I urge our readers to make an additional tax-deductible contribution towards the battle against Alzheimer's disease in New York State by utilizing the **check-off option on your NYS Income Tax form for 2000**. Funds designated in this fashion will be earmarked for patient and caregiver support in all parts of New York State. Please utilize, and share this important new option with family friends and neighbors.

John A. Jager
Executive Director

OPPORTUNITIES FOR MAXIMIZING YOUR GIVING...

HOW TO MAKE THE MOST OF YOUR RESEARCH GIFT

Many of our supporters who are concerned about ensuring continued breakthroughs in scientific research have made generous contributions designated for research to the New York City Chapter. As a result, over the years the Chapter **has contributed well over \$1,000,000 to research** efforts of the National Alzheimer's Association – the largest private funder of Alzheimer's research. One hundred percent of every dollar raised in the New York City area earmarked for research is directed to the National Alzheimer's Association research program. Absolutely no part of a gift designated as such remains on the New York City Chapter's accounts. Be assured that your charitable intents are honored.

However, **what if you want to contribute to research, but have received wonderful support from the New York City Chapter and also want to help sustain the Chapter's programs and services?** Many have asked this question. In response, the National Alzheimer's Association has developed a program that allows donors to do both. It is called the **Dues Offset Program**.

By telling us that you would like your research gift to qualify for the **Dues Offset Program**, 100% of your gift will still be channeled through the Chapter to the National Alzheimer's Association to directly support its research efforts. However, in return, the national office will issue an operational credit to the New York City Chapter equal to 40% of your gift amount.

To qualify your research gift for the **Dues Offset Program**, simply write on the correspondence accompanying your gift: **"I want my research gift to qualify for the Dues Offset Program I learned about from reading the New York City Chapter newsletter."** Send your gift to us along with this note.

Your extra effort to write that statement of intent will stretch your gift further and allow the Chapter to qualify for the 40% operational credit. **Please remember that the statement above must be on your correspondence in order for this to happen.**

An example: If you were making a \$5,000 gift to research, making note of the statement of intent above, the New York City Chapter would receive a \$2,000 credit from the National office. That translates into \$2,000 of support to continue our education and support programs and services in this area. Your investment in research, then, has now become an investment in the Chapter as well!

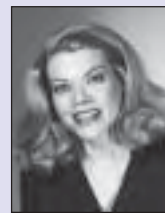
The same principle applies if you were to leave a gift of stock, a bequest in your will or trust, or by a designation through your life insurance or retirement plan. **If the New York City Chapter can document that it solicited the research gift through a brief statement given by you like the one above, we all benefit – Alzheimer's research, the efforts of the New York City Chapter and our loved ones.**

Other opportunities –

Your employer may have a **matching gift program**. If so, you can double, triple or quadruple your gift by including a completed matching gift form from your company!

NEW! You can make a donation by clicking on to the **New York City Chapter's www.alzheimernyc.org website.**

Editor's Note



As I write this I have just heard a radio report about an 87-year-old woman in Brooklyn who died searching for her husband. It seems he suffered from Alzheimer's, and had wandered away four days earlier. The 85-year-old man was eventually found, in good shape, in a bus station. The woman was found some 30 blocks away from their home, frozen to death.

When I first heard this broadcast, I thought to myself, is the problem with outreach? We (and many other agencies and institutions situated even closer to the neighborhoods they serve) do all we can to publicize the "Safe Return" program, which equips persons with Alzheimer's who are potential wanderers with an identification bracelet.

If they are found—either by police or by a good samaritan—the bracelet has a telephone number that will connect the caller with the "Safe Return" registry. Then, it takes only moments to locate the wanderer's caregiver.

Thinking about this tragedy, I was amazed that with all the senior services and health, religious and community centers where support and information would have been available, that this woman could have remained outside the loop, so to speak.

My next thought was to wonder how this couple, Italian, probably parents and grandparents to younger generations, of whom some would be living in the vicinity, could have been so neglected, or overlooked.

Just 22 minutes later, the radio broadcast was updated. It seems that the wife had Alzheimer's disease, too. Suddenly I understood how this tragedy could happen, but I still felt that it could have been prevented; that someone should have known or cared.

– Chris MacLeod

PUBLIC POLICY UPDATE: Federal and State Legislative Priorities

FEDERAL ACTIONS

With the passage in December of the final federal budget by Congress, funds were appropriated for initiatives of major importance to the Alzheimer's community.

The Labor/HHS Appropriations bill included a 14 percent increase in funding for Alzheimer's research. This brings federal spending on Alzheimer's research for FY2001 to more than \$500 million. (For the first time total federal funding for Alzheimer's research will exceed the Association's long-standing \$500 million goal.) In addition, \$9 million was included for Alzheimer's demonstration grants. These grants are provided to states to develop innovative services for persons with Alzheimer's.

The Family Caregiver Support Program received full funding of \$125 million. This new program was established under the reauthorized Older Americans Act and provides for federal grants to the states for support of family caregivers. These supports include information and assistance, counseling, organization of support groups, caregiver training, respite care and adult day care. The distribution of funds and determinations on specific services to be funded will be handled at the county level by the local Area Agencies on Aging. In New York City, the Department for the Aging (DFTA) will be the responsible agency. The state is projected to receive over \$7 million, approximately half of which will go to New York City. We will report further as information becomes available on the DFTA community-based funding decisions.

In addition, the budget included \$900,000 for the Alzheimer's Association's nationwide Safe Return Program identification of persons who wander or are lost.

Unfortunately, the \$3000 tax credit for families that care for a relative with Alzheimer's in the caregiver's home was not funded.

Lastly, the Medicare home health requirement that the patient be "homebound" was clarified to allow beneficiaries to attend adult day care and retain their home health care eligibility. Until this clarification, patients had to choose between receiving home health care for which they were eligible or going to adult day care.

ALZHEIMER'S ASSOCIATION FEDERAL LEGISLATIVE PRIORITIES FOR 2001

- Increase funding for Alzheimer research by \$100 million.
- Continue \$1 million in funding Safe Return.
- Target any tax incentives for long term care to provide financial support to family caregivers.
- Add prescription drug coverage to the Medicare benefit package.

NEW YORK STATE ACTIONS

Governor Pataki has proposed important protections to ensure that nursing home residents receive quality care. These protections are included in the Governor's proposed Nursing Home Quality Improvement Act. The Act includes criminal background checks on all health care employees who provide direct care to the elderly in nursing homes and home care. Increased fines are called for against nursing homes for deficiencies and higher fines for repeat violations. The Act would also give the State Health Commissioner authority to replace, without going through the courts, an operator of a nursing home who has not maintained the facility and insured a safe environment for residents. New auditors will be hired for a Medicaid Strike Force Unit. New nursing home inspectors are to be added. There will be a new centralized, toll free nursing home complaint hotline.

The New York City Chapter and our statewide coalition of chapters will follow this proposed legislation and provide information as the legislative session progresses. In addition, the chapter and coalition will continue to advocate for passage of "Safe Staffing in Nursing Homes" legislation. We will also continue to seek better staffing, competitive pay levels, and sufficient training in order to recruit and retain committed staff and help redress the very serious workforce shortage issues throughout the state.

Home and community-based services remain top priority concerns. As such, we will seek reinstatement of safety monitoring as a personal care task in the Medicaid home care/personal care program. Inclusion of hours of care for safety monitoring will prevent reduction in hours of care for persons in need of supervision and enable persons with Alzheimer's to remain at home. Funding will also be sought for social model adult day care to further expand this needed option.

Your participation in advocacy efforts is welcome and needed. We'll keep you posted as 2001 legislative activities proceed.

Ann Berson
Public Policy Coordinator

BARBADOS NURSES' ASSOC. OF AMERICA SUPPORTS ALZHEIMER'S COMMUNITY



From left to right: Albert E. Cummings of the Alzheimer's Association accepts generous contribution from Maureen V. Green, President and Eglantine Gollop, Business Manager of the Barbados Nurses' Association at their Millennium Extravaganza in Woodhaven, NY.

FREE Training Program for Dementia Care Workers



Early in December, a graduation ceremony was held in our Chapter office to honor the second group of home care workers who participated in an intensive training program on caring for people with dementia. The training, which was offered to home care workers who are not affiliated with agencies, was made possible by a grant from a foundation that has asked to remain anonymous.

We are extremely happy to announce that the Association has recently received additional funding from this donor to provide more trainings in 2001. How can the training help you? As one participant said, "I was grateful to be given the opportunity to learn more about Alzheimer's. I now feel much more comfortable and secure — it's wonderful to have tools to fall back on. I truly feel that I can be more successful in caring for Alzheimer's patients." If you are a home care worker who is privately employed (not working through an agency) and you would like to learn more about how to provide the best care for a person with Alzheimer's or another type of dementia, call Paulette Michaud, Coordinator of Education and Training, at 212-983-0700, ext. 206.

WOMEN'S AUXILIARY ~ NEWS ~

The Women's Auxiliary is planning a very special annual event for November 2001! More information and a Save The Date will be mailed shortly.

WEBSITE NEWS!

The New York City Chapter is pleased to announce that it's website: www.alzheimernyc.org has a new look.

The site, which is now designed and maintained by the chapter's MIS Manager Juan Diego Molyneaux, has new features, such as a message board, and calendar of events. There is information on everything you may need – contacts, meetings, daycare and diagnostic centers, support groups, research, events, our newsletter online, and much more. You can also make donations to the chapter, register for Safe Return, or visit our online store.

We hope you visit us soon and help us build a stronger Alzheimer's community online.

The New York City Chapter thanks Mary Ginsburg, volunteer web author, for her long-time service to the Alzheimer's community and to the chapter. She got the chapter online and kept the site current for many years. *Thank you Mary!*

USEFUL WEBSITES

General information on Alzheimer's research and current trials, see the website from ADEAR (Alzheimer's Disease Education and Referral Center of the National Institute on Aging): www.alzheimers.org

For information from the National Alzheimer's Association: www.alz.org

For information on Alzheimer's in a variety of languages from Arabic to Vietnamese: see www.alznsn.asn.au, the website of the Alzheimer's Association of New South Wales, Australia.

For information on agitation in Alzheimer's disease:

www.psychguides.com click on Agitation in Older Persons with Dementia

For information on Social Security: www.ssa.gov

For information on Medicare, including information on Nursing Homes: www.medicare.gov



What word best expresses the caregiving experience – loyalty? frustration? overwhelming? love? burden? nightmare? gift? loneliness?

“Always On Call”

Edited by Carol Levine

A new book edited for the United Hospital Fund and the experiences invoked by each of the above words found their way into the chapters contributed by various authors. The book is divided into two parts: the voices of caregivers themselves and the experiences and thoughts of professionals who work in the health or caregiving world. The result is a book that often captures the poignant and harrowing journey of a caregiver. As the book makes clear, the journey not only involves coping with profound and debilitating illness but also includes dealing with the severe shortcomings of America’s health care system.

After an introduction to the issues by Carol Levine, the first chapter, titled ‘*First My Mother, Then My Aunt*’, written by Carol Ann Young, is a poignant tale of the struggle she and her sister faced caring for her mother and her aunt, both of whom were diagnosed with Alzheimer’s disease. Carol Ann’s retelling of her experiences spans almost 20 years and depicts the challenges of caregiving while trying to make a living. Sadly, Carol Ann’s mother died on 1999. Yet even now Carol Ann continues to care for her aunt who is in a nursing home.

Other caregivers tell their stories as well. Rabbi Gerald I. Wolpe tells about the rugged transformation he made from his role as trusted religious leader to confused, exhausted, mystified caregiver after his wife suffered the rupture of two brain aneurysms.

Timothy J. Sweeny relates the agony of losing his brother Mark to AIDS and the caregiving crises he experienced wrestling with complicated health care system even as he was losing a beloved family member. Jane Bendetson shares the trials and relief that come with needing to continue to work to support her family after her husband in stricken with chronic heart disease. Gladys Gonzalez-Ramos eloquently describes the devastating indignity that Parkinson’s Disease bestows upon her mother and the enormous toll the disease took on her father. As a social work professor trained to work with those suffering great losses, she still found herself unprepared for how profoundly she experiences the “ambiguous loss” that comes with caring for a loved one that is no longer really the person she knew.

Finally, Carol Levine shares her own draining trip through the world of caregiving purgatory after her husband suffered traumatic brain injury due to an automobile accident. As a medical ethics and health policy expert, Carol pinpoints the essence of the struggle for caregivers by declaring she finally realized... “I am not doing anything wrong. It is the health care system that is out of order”.

In Part II, several experts discuss the caregiving experience as it relates to the emotional experience, the struggle to maintain caregiving while working, the enormous

financial cost to the worker who is also a caregiver, the cost of providing and paying for appropriate care, the attitudes of health care professionals as they interact with caregivers approaches and the “emotional, physical and financial tolls” endured by caregivers as the end of life approaches their ill relative. The book ends with a chapter that attempts to guide caregivers toward resources that may help lighten the load on the journey.

As a former caregiver and current social work professional I found I was often moved by what I read. However, the greatest impact for me was the ‘me too’ syndrome as in “that happened to me too!” The facts and figures cited in the book go a long way toward helping people like me realize that Carol Levine is right: we are often doing the best that we can. It’s the health care system that needs work – a lot of work. Indeed, one of the powerful points made is when Raymond L. Rigoglioso reported on the United Hospital Fund Study that quantified the price on the open market of the caregiver labor donated in the U.S. It is conservatively estimated at \$196 billion!

Former First Lady Rosalynn Carter said “ there are only four kinds of people in the world: those who have been caregivers, those who are current caregivers, those who will be caregivers, and those who will need caregivers”. Rabbi Wolpe aptly states, “ This makes caregiving a universal problem”. **Always On Call** is an easy-to-read but powerful witness to the caregiving drama faced by millions of us.

Available for \$20 plus \$3.50 for shipping & handling by calling 1-888-291-4161. Prepayment by credit card or check is required.

— Sue K. Humphries

“I Remain in Darkness”

By Annie Ernaux

(Seven Stories Press; \$18.95)

If one needed more convincing that Alzheimer’s is not only a universal problem, but one that the rest of the Western world is no more prepared to handle than we are in the U.S., you would find the evidence in Annie Ernaux’s “I Remain in Darkness.”

Ms. Ernaux is prized in France because of her pared down—yet painfully honest—accounts of love, loss, shame and regret. Although her earlier work coyly blurs the line between fiction and fact, here, there is little let-up from the downward spiral she, her mother and her sons are sucked into once Alzheimers is the diagnosis.

Ernaux’s diary records a dossier of incidents marking her mother’s inexorable decline; the lack of analysis makes us trust her to relate what she sees without excessive mediation or literary polish. The mother-daughter bond remains strong even as mother’s moorings loosen and cast her adrift into the raw terror that surfaces when the Alzheimer’s haze lifts to allow lucid moments. Ernaux’s

Bookself *continued*

mother continues to recognize her, to miss her when she can't visit—in short, she can still make Annie feel guilt.

With her two teen sons, Ernaux tries for six months to care for her mother at home. Then she is moved to a hospital's geriatric wing. Once there, Ernaux notes, "She mislays all her personal possessions, but has quit looking for them. She has given up. I think of the frantic efforts she would make to find her toiletry bag at my place; she still had a hold over the real world through her belongings. I am dismayed by such indifference."

Soon, her mother's watch, cologne, eyeglasses and even her dentures vanish. "Here, the things that get lost are never found. No one cares: they're going to die anyway." Yet mother still has her voice and familiar fragments of her personality surface unexpectedly, as when she remarks to a visitor, "She's not nearly as nice as the other one," meaning Annie's sister, who died before she was even born."

We know where this journey will end, but the horrors along the way have their own fascination. We can't help wondering what we might do, or whether we did enough. If Alzheimer's must be so cruel, we can at least be vigilant in advocating for the institutionalized friend or relative—as we muster all the support we can for ourselves.

— Chris MacLeod

Research *Continued from page 1.*

now his laboratory, in collaboration with several others, has produced a strain of mice that develop tangles as well. And because these mice are so valuable for research, they are treated like royal guests in the laboratory. Dr. Davies displayed one of these mice tenderly, holding it gently while it nibbled his hand.

Asked about the reports of a vaccine that prevents or reduces amyloid deposits in transgenic mice, Dr. Davies urged caution. In humans, he fears, such a vaccine might in time promote an auto-immune response similar to multiple sclerosis. Discussing other recent research studies, Dr. Davies cited several that might be helpful against Alzheimer's. A Duke University study of identical twins suggests that ibuprofen may delay Alzheimer's. In another research project, the anticholesterol drug Lipitor and other drugs classified as statins are thought to reduce amyloid deposits. Tests under way of vitamin E and C and their possible deterrent effect on Alzheimer's. Clearly, research throughout the world is going on at a feverish pace. Our own Federal Drug Administration recognizes the urgency of Alzheimer's Disease and has given it the same priority as research on AIDS.

Dr. Davies does not design drugs. His interest is rather in designing systems for use by the drug companies. Although his diagnostic tests for Alzheimer's offer great promise, Dr. Davies has not sought to publicize them. If publicity comes, well and good. What he is seeking, he says softly, is bright young minds. A number of such bright minds are already at work in his laboratory. It is from minds like these, he believes, that answers to the riddle of Alzheimer's will come.

— Jack M. Pollock

New Drug *Continued from page 1.*

pants in the placebo group in measures of thinking and reasoning, day-to-day functioning, and behavior. Although galantamine recipients performed better as a group, the drug did not help every individual who took it. It is not a cure for Alzheimer's, and it does not appear to stop disease progression.

How does galantamine work?

In Alzheimer's disease, nerve cells in brain regions important for memory, thought, and judgment degenerate and die for unknown reasons. Some of the most severely affected nerves communicate by means of the neurotransmitter acetylcholine. Normally, acetylcholine is produced by these cells, released to carry signals to other nerves, then broken down for reuse. By damaging and killing nerves in the acetylcholine system, Alzheimer's disease disrupts the brain's communication network and decreases the amount of acetylcholine available to carry messages among surviving nerves.

Galantamine inhibits the action of cholinesterase, one of the enzymes that breaks down acetylcholine. This inhibition increases the amount of the chemical available for cell-to-cell communication, which may relieve some of the memory impairment and other symptoms associated with Alzheimer's. In addition, galantamine appears to stimulate release of acetylcholine and to strengthen the way that certain receptors on message-receiving nerve cells respond to it.

Is it effective in all individuals with Alzheimer's disease? Like the three previously approved Alzheimer drugs—tacrine, donepezil, and rivastigmine—galantamine is approved for treatment of mild to moderate Alzheimer's disease. All of these drugs are designed primarily to inhibit breakdown of acetylcholine. There is no known way to predict who may benefit more from taking one drug rather than one of the others; however, patients who do not benefit from one may respond favorably to another.

Where can I get it and how is it supplied?

Galantamine is available only with a physician's prescription. Janssen Pharmaceutica, the manufacturer, anticipates that the drug will be available in pharmacies in May 2001. It is supplied in the form of tablets in strengths of four, eight and 12 milligrams. Consult your physician to discuss whether you should consider the drug and the best dose for you.

What are the side effects?

The most frequent side effects of galantamine include nausea, diarrhea, and other gastrointestinal symptoms. They are usually mild and temporary, improving with ongoing treatment. People with Alzheimer's who are considering taking a new medication should meet with their doctors and family members to discuss potential side effects and how the new treatment may interact with other prescription or over-the-counter drugs they are taking.

This article is provided for your information only and does not represent an endorsement of galantamine by the Alzheimer's Association.

MONDAY April 2

Legal/Financial Seminar
Time: 12 Noon – 1:30 p.m.
Place: Chapter office

WEDNESDAY April 4

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

THURSDAY April 5

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

Queens Orientation Meeting for Caregivers

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

MONDAY April 9

Educational Meeting
Time: 6:00 – 7:30 p.m.
Place: Chapter office
Topic: Alzheimer's Disease: Research and Treatment Update
Speaker: Peter Davies, Ph.D

WEDNESDAY April 11

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

FRIDAY April 13

Orientation Meeting for Caregivers
Time: 12 Noon – 1:30 p.m.
Place: Chapter Office

MONDAY April 16

Medicaid Home Care Seminar: A Practical Guide to the System
Time: 12 Noon – 1:30 p.m.
Place: Chapter office
Prior attendance at a Legal/Financial Seminar required.

Legal/Financial Seminar

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

WEDNESDAY APRIL 18

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

THURSDAY April 19

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

TUESDAY April 24

Orientation Meeting for Caregivers
Time: 12 Noon – 1:30 p.m.
Place: Chapter office

THURSDAY April 26

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

WEDNESDAY May 2

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

THURSDAY May 3

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

Queens Orientation Meeting for Caregivers

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

MONDAY May 7

Legal/Financial Seminar
Time: 12 Noon – 1:30 p.m.
Place: Chapter office

ALL MEETINGS ARE FREE OF CHARGE

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

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

WEDNESDAY May 9

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

FRIDAY May 11

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

MONDAY May 14

Educational Meeting
Time: 6:00 – 7:30 p.m.
Place: Chapter Office
Topic: Anticipatory Grief: Understanding and Living With Your Grief Throughout The Caregiving Process
Speaker: Benyamin Cirlin, C.S.W.

WEDNESDAY May 16

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

THURSDAY May 17

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

MONDAY May 21

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

Legal/Financial Seminar

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

TUESDAY May 22

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

THURSDAY May 24

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

MONDAY June 4

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

WEDNESDAY June 6

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

THURSDAY June 7

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

Queens Orientation Meeting for Caregivers

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

FRIDAY June 8

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

MONDAY June 11

Educational Meeting
Time: 6:00 – 7:30 p.m.
Place: Chapter office
Topic: End of Life Issues: Hospice Care and Whether or Not to Autopsy
Speakers: Mary Cooke, R.N., MA
Mary Sano, Ph.D

WEDNESDAY June 13

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

THURSDAY June 14

Brooklyn Educational Meeting
Time: 10:00 a.m. - 12:00 p.m.
Place: TBA
Topic: Coping With Alzheimer's Disease: Early, Middle and Late Stages

MONDAY June 18

Medicaid Home Care Seminar: A Practical Guide to the System
Time: 12 Noon – 1:30 p.m.
Place: Chapter office
Prior attendance at a Legal/Financial Seminar required.

Legal/Financial Seminar

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

WEDNESDAY June 20

Orientation Meeting for Caregivers
Time: 5:30 – 7:00 pm.
Place: Chapter office

THURSDAY June 21

Bronx Educational Meeting
Time: 10:00 a.m. - 12:00 p.m.
Place: TBA
Topic: Coping With Alzheimer's Disease: Early, Middle and Late Stages

Medicaid Home Care Seminar: A Practical Guide to the System

Time: 5:30 – 7:00 p.m.
Place: Chapter office
Prior attendance at a Legal/Financial Seminar required.

TUESDAY June 26

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

THURSDAY June 28

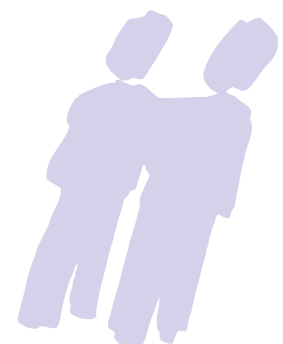
Queens Educational Meeting
Time: 10:00 a.m. - 12:00 p.m.
Place: TBA
Topic: Coping With Alzheimer's Disease: Early, Middle and Late Stages

Legal/Financial Seminar

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

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

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



This article is a collaborative effort of the New York City Alzheimer's Disease Centers:
Mt. Sinai School of Medicine, NYU Silberstein Aging & Dementia Research Center & Taub Institute at Columbia University

THE ROLE OF GENETICS IN ALZHEIMER'S DISEASE

Elizabeth Fine, M.S.W., Deborah Marin, M.D., Mary Mittelman, Dr. P.H.,
Mary Sano, Ph.D., Christine Weber, Ph.D. and Jennifer Williamson, M.S.

The causes of Alzheimer's disease (AD) are not currently known, however researchers are actively examining the role of heredity in the disease process by identifying individuals with a family history of memory problems. Through investigating families with memory problems, genetics links and modes of inheritance can be discovered that may offer hope in treating or preventing AD.

Do genes play a role in determining who will get AD?

Researchers are yielding data which suggest that genes do play a role in developing AD. The overall lifetime risk of developing AD is estimated to be 10-12% in the general population, in comparison to 15-30% for a first-degree relative (parent, child or sibling) of a person with the disease. Geneticists attribute this difference to an individual's genetic predisposition. AD can be defined as either (sporadic) or (familial) in nature. Individuals with sporadic AD have a negative family history (no other family members known to have AD). The more common form of AD is sporadic AD, which generally occurs later in life (over the age of 65). Familial AD, which refers to AD in families with multiple affected members, may be further divided into two different categories; early-onset familial and late-onset familial. Early-onset familial Alzheimer's disease, onset less than 60 years of age, accounts for less than 5% of all AD cases. The inheritance of early onset, familial AD is autosomal dominant, meaning families with many affected individuals in multiple generations. In some of these families, a mutation (or change) in one of the three known genes associated with early onset AD, *APP*, *PS1*, or *PS2* genes, can be detected. Late onset, familial AD has been associated with the APOE gene.

Genes have an effect on factors involved in the formation of plaques and neurofibrillary tangles, or other AD-related pathologies in the brain. Plaques and neurofibrillary tangles are the hallmark of AD and interfere or block communication between neurons in the brain.

What is the APOE gene, and its relationship to AD?

The APOE gene encodes a protein, Apolipoprotein E, and this protein plays a role in the distribution of cholesterol in the blood. All individuals have 2 copies of the APOE gene, one copy inherited from their mother and another copy inherited from their father. The APOE gene occurs in three different forms called alleles APOE-e2, APOE-e3 (the most common), and APOE-e4 (e is pronounced epsilon). Gene combinations are based according to the APOE allele an individual inherits from each parent. The APOE-e4 allele is associated with an increased risk of AD.

The APOE-e4 allele is a risk factor but not a definitive predictor of AD. Individuals who have one copy of e4 have a moderately increased risk for AD and those with 2 copies have a high risk for AD. However, APOE-e4 is neither necessary nor sufficient as a cause of AD. An individual with two copies of the APOE-e4 allele may never develop AD, and an individual without any APOE-e4 alleles may still develop AD. Approximately 42% of people with AD do not have an e4 allele. There is also data to suggest that APOE-e4 may not be associated with the same increased risk of AD in certain ethnic groups. This demonstrates that the actual role of APOE-e4 in the development and course of AD is unclear. Many researchers believe that it affects the ability of neuron's in the brain to communicate with other neurons by shortening the dendrites—the branchlike extensions that receive messages from other neurons. Others argue an association between APOE-e4 and the formation of the plaques and neurofibrillary tangles found in the brains of AD patients.

Research continues to identify other genes and environmental factors that may play a role in the risk of AD. Should someone be tested to determine his or her APOE genotype?

Presymptomatic genetic tests are available that can determine whether a person carries the very rare genetic mutations that cause early-onset familial AD. Presymptomatic genetic tests for APOE-e4 are currently not recommended, and this type of genetic testing is only available through research studies. Genetic counseling is recommended for individuals who are concerned about their risk for AD or who are interested in genetic testing for AD.

While genetic testing for APOE will not predict whether an individual will develop AD, such testing may add confidence to the clinical diagnosis of the disease when dementia symptoms are already present. In Alzheimer's Disease Centers, clinical diagnosis is correct over 90 % of the time without APOE testing. When APOE genotyping is performed in combination with the clinical criteria for the disease, the specificity of the diagnosis is improved to about 97%. In the future, genetic testing may have an increased role for predicting the response to medication or as an aid in early diagnosis.

If you would like information on genetics studies at one of the National Institute of Aging Alzheimer's Centers in NYC please call:

Mt. Sinai School of Medicine
Alzheimer's Disease Research Center
Elizabeth Fine, M.S.W.
(212) 241-5673
www.mssm.edu/psychiatry/adrc.shtml

NYU Silberstein Aging and Dementia Research Center
Maria Vlassopoulos
Clinical Coordinator
12-263-8088
www.aging.med.nyu.edu

**Taub Institute for Research on Alzheimer's Disease
and the Aging Brain at Columbia University**
Jennifer Williamson, M.S.
212-305-4655
www.alzheimercenter.org

CURRENT CLINICAL TRIALS AT THE NYC ALZHEIMER'S DISEASE CENTERS

Taub Institute ~ Columbia University

Alzheimer's Disease Vitamin Study: A study for people with Alzheimer's disease to determine whether vitamins B12, B6 and folate can reduce levels of homocysteine. Reducing levels of homocysteine may be beneficial in slowing disease progression. To learn more, call Gina Garcia at 212-305-5805.

Dementia Prevention Study: Researchers at Columbia University are seeking healthy women 65 years of age and older who have a family history of AD or memory problems for a four-year, placebo controlled study to determine whether estrogen can prevent memory loss. Participants will be paid. To learn more, call Evelyn Dominguez-Rivera at 212-305-5805.

Memory Study: Researchers at Columbia Presbyterian Medical Center are seeking men and women aged 55 and older, with and without memory problems, to participate in a study examining memory and other thinking processes. Participants will be paid for a one-time visit to our medical center. To learn more, call Effie Mitsis at 212-305-1927.

Silberstein Aging and Dementia Center ~ New York University

Clinical trial of Galantamine for mild cognitive impairment (MCI): Galantamine is a new cholinesterase inhibitor that will soon be marketed for the treatment of AD. This study will test its effectiveness in delaying AD in individuals with mild cognitive impairment. Participants will receive either galantamine or a placebo for up to two years, with visits to the Center every three months.

Clinical trial of CP-457, 920 for AD: This study will test the effectiveness of an interesting, novel drug treatment in patients with mild to moderate Alzheimer's disease. Subjects will receive either this new compound, or marketed drug Aricept, or a placebo for a period of three months. Patients will be required to make visits to the Center every two weeks.

Clinical trial of Neotrofin for AD: This interesting compound has neuroprotective effects and may slow the progression of AD. The current study will test higher doses than previously examined. Patients with mild to moderate AD will receive either this compound or placebo, but all participants will eventually receive Neotrofin. The total period of the study is 6 months.

Current Clinical Trials at the NYC Alzheimer's Disease Centers

Mount Sinai School of Medicine

Guanfacine/Aricept Study: We are currently conducting a study which combines Guanfacine, or a matching placebo (sugar pill), with Aricept to test improvements in cognition and behavior associated with Alzheimer's Disease. All patients are eligible for 1 additional year of treatment upon completion of the study - at no cost. For more information please contact Stacey Kleinbaum at 212-241-1514. GCO #84-119. MSSM IRB approved from 8/1/00 to 3/31/01.

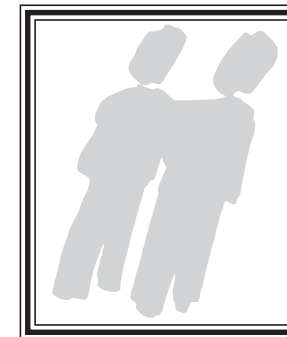
Capacity to Discuss Advance Directives: This is an interview study for those who have been diagnosed with Alzheimer's disease (AD) and their caregivers. The interview will give the AD individual a chance to learn about advance directives (documents that allow you to give directions for your future medical care). This discussion will offer the opportunity to ask questions, and talk about these issues with a doctor and family members. To find out more about the study, please call Dr. Margaret Sewell at 212-241-0438. GCO #00-0266. MSSM IRB approved from 9/11/00 to 5/14/01.

The Caregivers Program is designed for Alzheimer's individuals and their caregivers (family or paid). The program provides education and support to caregivers, and maximizes functional ability of individuals with memory problems. The program is offered once a week for 7 weeks, and is offered in Spanish and English. To find out more about the program contact Feroza Marker, OTR at 212-241-9250.

*For more information about these or other clinical trials at NYU,
call the Clinical Trials Coordinator, at (212) 263-5708.*

HEALTHY Adults 60 +

People over the age of 60, in good health, without memory problems who wish to participate in a research study on understanding normal aging and memory, may earn \$10/hr at Columbia-Presbyterian Medical Center (Res. Found. for Mental Hygiene). - No medications prescribed. Call Yesenia Camacho at (212- 543-5956 for more information. Spanish-speaking participants welcomed.



(actual size 2" x 1½")

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care about Alzheimer's and
can help make
others aware . . .*



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PLEASE MAKE CHECKS PAYABLE TO:

ALZHEIMER'S ASSOCIATION
NEW YORK CITY CHAPTER
360 LEXINGTON AVENUE, FIFTH FLOOR
NEW YORK, NY 10017

- ALLOW 3 WEEKS FOR DELIVERY.
- CUT OUT COUPON AND RETURN WITH YOUR PAYMENT

IT PAYS TO PLAN AHEAD (Part 2)

In the last issue of our newsletter, we began to investigate how a little planning on your part now could save your family and your heirs a lot of money in estate taxes later. Having an “estate plan” in place means that you have considered all the assets you have accumulated over your lifetime, decided how you want them distributed after your death, and used appropriate strategies for making sure Uncle Sam takes as small a share of them as possible.

Assuming you have followed the advise given in Part 1 of this article and made a list of everything you own, assigned a dollar value to each item, decided upon a plan to take care of yourself financially, and chosen your beneficiaries, you now must go about

FINDING THE RIGHT ESTATE PLANNING STRATEGIES FOR YOU!

Once you’ve chosen your beneficiaries, the next step is to select the best estate planning arrangements to implement your wishes. Keep in mind the needs of your beneficiaries, the protection of your money, and the impact of estate taxes. Here are some (not all) components of an estate plan.

- **Your will.** This disposes of your assets that will not pass by other means, such as those about to be described. Also, your will can name a personal representative (executor) to settle your estate. When it comes to good estate planning, this document makes certain nothing is overlooked.
- **Trusts.** You can create a trust in your will or by an agreement. You can put assets in a “living trust” during your lifetime, perhaps for your own benefit; the disposition of the trust principal and income will be governed by the terms of the trust agreement.
- **Title arrangements.** These can supersede the terms of your will. For example, you may hold bank accounts, securities, or your home in a form of joint tenancy with someone else—perhaps your spouse—which entitles the survivor to full and outright ownership of that asset.
- **Retirement plans.** Benefits from your employer, a rollover IRA, or other retirement plan may comprise a substantial part of your estate. After your lifetime, these benefits will be paid to the beneficiaries you have designated in the plan.
- **Life insurance.** The proceeds are payable to the beneficiaries you have named under the options you selected in your policies or subsequent endorsements. If planned properly, there need be no estate tax on the insurance proceeds.
- **Buy-sell agreement.** This governs the sale of a closely held business, with the proceeds payable to a beneficiary named by the deceased owner. The agreement specifies who may buy the interest at the person’s death, the terms of sale, and the method of payment.
- **Life income plans.** In return for a gift to the Chapter or another charitable organization, you can arrange a life income for yourself and even a survivor from a charitable remainder trust or other plan. Upon your death and that of your survivor beneficiary (if you choose one), the remainder will be distributed to the Alzheimer’s Association of New York City or the other charitable organization you have named in the plan.

GETTING HELP

Remember our advise from the first part of this article. If you feel that you will need help in order to come up with the ideal plan and maximize your estate tax saving, YOU ARE RIGHT! Do not be tempted by the do-it-yourself approach. You may expose your estate to even greater expense!

If you have access to them, seek the assistance of legal and tax professionals who specialize in estate planning. Or, call our Development Director, Lynne Raymond, (at 212-983-0700) to guide you to planned giving specialists who can explain the wide range of gift opportunities that can satisfy your wishes, save taxes, and support the Alzheimer’s Association of New York City’s mission at the same time.

Clients often ask us about important issues regarding the rights of the elderly. This time, we focus on questions that deal with the rights of nursing home patients with regard to certain aspects of their care.

Keep in mind that the answers in this column may not consider your particular circumstances. You need to speak to a professional advisor to get the answer that will best fit your circumstances.

Question: *Under what circumstances is the nursing home staff permitted to restrain a resident against his/her will?*

Answer: Federal law gives nursing home residents the right to be free from any physical or chemical restraints not imposed for the treatment of their medical symptoms. New York State law goes even further. It stipulates that physical and/or chemical restraints must be authorized in writing by a physician for a specified and limited period of time.

In case of an emergency, restraints may only be applied by a qualified licensed nurse. The nurse must then write a report detailing the circumstances requiring the use of the restraint. If a chemical restraint is used, a physician must be consulted within twenty-four hours. Restraints may not be used for staff convenience or disciplinary purposes.

Question: *Is a nursing home resident entitled to receive notice from the nursing home before the nursing home adjusts or alters a resident's plan of care? What about the health care agent? Is she/he entitled to receive notice?*

Answer: Under New York law, all nursing home residents are entitled to receive appropriate medical care and must be fully informed of their medical condition and the corresponding proposed medical treatment. Residents also may refuse medication and treatment provided they understand the consequences of their action. In addition, residents have the right to be fully informed in advance about the care and treatment that may affect their well-being.

Although the law does not specifically address whether health care agents are entitled to this information,

it does entitle them to receive medical information and clinical records necessary to make informed decisions regarding the resident's health care.

We suggest that health care agents who wish to be advised of any adjustments and/or alterations to a patient's plan of care write a letter to the nursing home advising the facility that they have been appointed as health care agents and that they wish to be advised of any changes to the resident's plan of care. This letter should be prominently placed in the resident's medical file.

Question: *Can a nursing home staff transfer a resident to a hospital or psychiatric without obtaining permission from either the resident or his/her appointed health care agent?*

Answer: Such a transfer may only be made if the nursing home's interdisciplinary medical care team, *in consultation with the resident or the resident's designated representative(s)*, determines that (1) the transfer is necessary for the resident's welfare, (2) skilled nursing care is no longer needed, or (3) the transfer is necessary for the welfare of others in the facility, and (4) all reasonable alternatives to transfer or discharge have been explored.

Except in cases of emergency transfer, notice must be given to the resident and to the designated representative in writing and "in a language and manner they understand" 30 days before the resident is transferred. In the event of an emergency transfer or an appeal, the resident's bed must be held until a hearing is held.

Littman Krooks Roth & Ball P.C. is pleased to announce that Bernard A. Krooks has become Chair of the Elder Law Section of the New York State Bar

Association and Vice President of the National Academy of Elder Law Attorneys. In addition, Howard S. Krooks has become Chair of the Medicaid Committee of the Elder Law Section of the New York State Bar Association and has become certified as an Elder Law Attorney by the National Elder Law Foundation.

ALZHEIMER'S ASSOCIATION NAMES NEW PRESIDENT AND CEO

Chicago – The Alzheimer's Association has appointed Alan J. Stone as president and chief executive officer effective February 19, 2001. Stone was most recently president of Alma College in Michigan, from 1988 to 2000. With more than two decades of experience heading higher education institutions, Stone has had a long and distinguished career in academia.

Stone, 58, will succeed Edward F. Truschke, who announced last May that he would retire in the spring of 2001. Truschke led the Association for the past 14 years.

Selected from among an extraordinary group of applicants, Stone says he hopes to help the Alzheimer's Association expand its outreach and support to the millions of families who face Alzheimer's disease and accelerate the pace of research to find a prevention and cure for the disease, which currently affects more than four million Americans.

Alzheimer's Association board chair, Orien Reid, says Stone has an impressive record in organizational growth, management and fundraising. "We are excited and pleased that Alan has accepted the challenge of leading the Alzheimer's Association in the new century," says Reid. "His background and experience show that he is a good decision maker, who is insightful, supportive and compassionate."

The New York City Chapter welcomes Alan Stone to the Alzheimer's Association.

SUPPORT GROUP OPENINGS

The New York City Chapter currently sponsors some 80 Family Support Groups for spouses, adult children, siblings, etc. Some support groups are composed of only spouses (S) or adult children (C), while others are mixed (M), that is, made up of all different caregivers. Before attending a group you first need to call the group leader to schedule a personal interview. If you have any questions, please contact our Support Group Coordinator, Sheila Crandles, at 212-983-0700, Ext. 214. *Openings are now available in the following support groups:*

BRONX

Spouses' Group

Hebrew Home for the Aged at Riverdale

DAY: Tuesdays

TIME: 11:30 A.M. – 1:30 P.M. Tuesdays

CONTACT: Cidalia Luis 718-581-1615

Mixed Group

Hebrew Hospital Home (Co-Op City)

DAY: Tuesdays

TIME: 6:00 – 7:30 P.M.

CONTACT: Lauri Wasserman 718-379-5020, Ext. 6695

Adult Children

Hebrew Home at Riverdale

DAY: Tuesdays

TIME: 6:30 – 8:00 P.M. Tuesdays

CONTACT: Rina Ginat 718-581-1628

BROOKLYN

Mixed Groups

Catholic Charities

(Flatbush & Flatlands Ave)

DAY: Mondays

TIME: 11:00 A.M.–12:30 P.M.

CONTACT: Robin Stopeck 718-677-9848

Jewish Community House (Mixed Group)

Bay Parkway & 78th Street

DAY: 1st & 3rd Thursdays

TIME: 10:30 A.M. – 12:00 P.M.

CONTACT: Janie Eisenberg 212-243-5135

Carol Landau 516-764-2277

Neptune Avenue

DAY: 1st & 3rd Thursday

TIME: 3:00 – 4:30 P.M.

CONTACT: Jack Pollock 212-721-3537

Pearl Goldfarb 718-377-0737

MANHATTAN

Mixed Groups

Council Senior Center West 72nd Street

DAY: Fridays

TIME: 12:00 Noon – 1:30 P.M.

CONTACT: Ruth Rothbart Mayer 212-799-7205

NYU Medical Center

DAY: Thursdays

TIME: 1:00 – 2:30

CONTACT: Emma Shulman

Gertrude Steinberg 212-263-5756

Penn South Program for Seniors

DAY: 2nd & 4th Thursday

TIME: 1:30 – 2:30 P.M.

CONTACT: Adeena Horowitz 212-243-3670

Spouses' Group

Mt. Sinai Medical Center

DAY: 1st & 3rd Thursday

TIME: 4:00 – 5:30 P.M.

CONTACT: Joan Dickson 212-628-5045

Dorothy Calvani 212-889-4310

There are openings in the following daytime and evening groups held at the Chapter Office: - 360 Lexington Avenue, between 40th & 41st Streets.

Adult Children

DAY: Every other Wednesday

TIME: 12:45 – 2:00 P.M.

CONTACT: Lorraine Ruggieri 212-362-6500

Daughters' Group

DAY: 1st & 3rd Wednesday

TIME: 6:45 – 8:15 P.M.

CONTACT: Jeanne Lieb 212-496-1198

Mixed Groups

DAY: Thursdays

TIME: 2:00 – 3:30 P.M.

CONTACT: Susan Hason 646-486-3840

Eleanore Rothenberg 212-831-5586

Day: 1ST & 3RD Monday

TIME: 6:00 – 7:15 P.M.

CONTACT: Margery Elson 212-860-4145 Ext. 305/

Carolyn Koch 212- 628-2800 Ext. 20

QUEENS

Mixed Groups

Flushing Hospital (Parsons Blvd.)

DAY: 2nd & 4th Wednesday

TIME: 2:00 – 3:30 P.M.

CONTACT: Trudy Chaiken 718-428-4278

Peter J. Dellamonica Center for Seniors

Astoria Area

DAY: Thursdays

TIME: 1:30 – 3:00 P.M.

CONTACT: Jennifer Chillemi 718-626-1500

C.A.P.E. /Samuel Field YM-YWHA

2 Groups Available on Wednesday Evenings

TIME: 7:00 – 8:30 P.M.

CONTACT: The Support Group

Coordinator at the Chapter Office/212-983-0700

Flushing (Kissena Blvd.)

DAY: 2nd & 4th Thursday

TIME: 7:00 – 8:30 P.M.

CONTACT: Lorraine Greenberg 516-942-8954

Adult Children

Kew Gardens

DAY: 2nd & 4th Wednesday

TIME: 6:00 – 7:30 P.M.

CONTACT: Julie Rosenberg 718-286-6562 /

Joanne Loughlin 718-470-7396

Contributions Gratefully Acknowledged in Memory Of:

January 1, 2001 ~ February 28, 2001

Mary Abbene
Mr. & Mrs. Salvatore Mazziotta
Mr. Samuel Abrams
Ms. Karen Sloan & Family
Mrs. Jacob Finkelman
Mr. Harold Abramson
Dr. Stanley H. Sahn & Mrs. Esther L. Sahn
Ms. Ramona Acevedo
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Mr. Anthony Autilia
Mr. & Mrs. Albert Milone, Sr.
Mr. Zachary Awer
Mr. Greg Stankiewicz & Ms. Julia Rubin
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Mother of Claudia DiSalvo
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Reader's Digest Foundation
Ms. Ina Ebenholtz
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Ms. Ruby Louisa S. Forte
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Early Stage Group at the Chapter Office – Openings for the Early Stage Group are currently available. This group is aimed at helping individuals who have been told they have a diagnosis of early stage Alzheimer's Disease. Members need to be able to acknowledge their memory loss and communicate their feelings and experiences. Information & support are offered by professional leaders. A personal interview is required. Call the group leader for an appointment before attending the group.

Early Stage Group at the Alzheimer's Association
360 Lexington Avenue (40th & 41st Streets)
TIME: 11:30 A.M. – 1:00 P.M. Fridays
CONTACT: Sheila Crandles 212-983-0700

Telephone Support Group for Spouses

For spouses who are unable to attend a group, we plan on starting a weekly telephone support group. If you are interested please call Sheila Crandles at the Chapter Office 212-983-0700.



Continued on page 14.

Contributions *continued from page 13.*

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Reactions to AD Diagnosis

How has your life changed since you learned that you have Alzheimer's disease? This is the question that forms the basis for a doctoral dissertation proposed by Maureen Matthews, R.N., doctoral candidate at New York University.

Traditionally, research in AD has focused on the underlying pathology as well as the experience of caregivers. Only recently has the research community looked to the person with the diagnosis as a source of important information about the life altering experience of living with Alzheimer's disease.

If you would like to participate in Maureen's research study by sharing your personal experience, please call 203-324-7137.

Assessing Genetic Indicators

New York Presbyterian Hospital-Weill Medical College of Cornell University is conducting a study called "Genetic Risk Assessment and Counseling for Alzheimer's Disease." The study explores the impact of providing individuals with a genetic risk assessment of developing Alzheimer's disease. Participants must have a parent who is/was affected with Alzheimer's disease and cannot show signs of a cognitive impairment or depression. If you are interested in participating in this study or want more information, please contact:

Susan LaRusse, M.S.

Genetic Counselor

New York Presbyterian Hospital-Weill

Cornell Medical College

Department of Neurology and Neuroscience

525 E. 68th St. Box 117, New York, NY 10021

TEL 212-746-6580

FAX 212-746-8389

sal2012@med.cornell.edu

St. Vincent's Center Opens

The St. Vincent's Manhattan Family Caregiver Center has recently opened its doors. Located on the ground floor of the Hospital, the Center's goal is to help caregivers navigate the often-complex medical world during and after a patient's hospitalization via information, referrals, and supportive counseling. The Center, a joint venture of the Hospital's Section of Geriatric Support group in the Spring. For further information, please contact the Center's Director, Rosemarie G. Greene, CSW, at (212) 604-7332. St. Vincent's Manhattan is at the corner of 7th Avenue and 12th Street.

The following letter was sent to Sue Humphries, Coordinator of Social Work. Ms. Rockowitz discusses her experience with Cabrini Medical Center's sub-unit for persons with dementia, which was highlighted in the Summer 2000 issue of this newsletter.

Dear Sue:

There are no words that could adequately express my gratitude for referring me in my greatest time of need as a caregiver to Dr. Jeffrey Nichols and "Windows to the Heart".

Unfortunately, my mother succumbed to A.D. and congestive heart failure on 10/2/00 while in Hospice Care at Cabrini Hospital.

While I can't say enough about the excellent care she received under the supervision of Dr. Nichols, I find myself anguishing and ruminating still over my inability at having been able to protect her from the many months of pain and humiliation she sustained as a result of the indecencies imposed upon her time and time again, by the atrocious behaviors of medical professionals in a system that is ill prepared to meet the needs and challenges of the elderly and all those afflicted with dementia.

Although I know that over time strength and fortitude will diminish my anguished thoughts and carry me through my grief to where I am able to one day experience the joys of remembering those times past and gone that are but cherished memories. I don't know that I have the ability to forgive the atrocities that robbed my mother of her pride, dignity and self respect far more than the progression of her disease.

For now my greatest consolation comes from knowing how well she was cared for in her final days of life under the watchful eye of Dr. Nichols and his entire staff. For that, I will be eternally grateful.

Warmest regards, Roz Rockowitz

We have made every effort to acknowledge contributions and spell names correctly. If we have inadvertently omitted or misspelled your name, please let us know. We depend upon our friends to keep us going financially through donations, tributes and bequests.

HELP WANTED: VOLUNTEERS

Opportunity available to work with congenial colleagues, in pleasant, centrally located, office environment to support the programs and activities of the New York City Chapter of the Association. Orientation, training and supervision provided. Openings include

- Helpline Counselor: Duties consist of answering callers' questions, providing information, referrals and assistance. Ideal candidate will be understanding and resourceful. Comprehensive training provided.
- Development Assistant: Assist Director of Development with acknowledgements, data entry and filing
- Training/Education Program Aide: Greet and register seminar attendees; prepare packets and informational materials
- Clerical Support: Assist with special projects, i.e. Safe Return Program activities, mailings, copying, assembling informational packets

You'll like it here.

The Chapter not only appreciates the commitment of our volunteerswe appreciate our volunteers!

For information Call: Barbara Lepis
(212) 983-0700

Are You a Widow/Widower of an Alzheimer's Patient? Or Do You Know Someone Who Is?

You can help others learn more about your unique experiences with loss. A graduate student doing a thesis wants to contact widowed caregivers of spouses with Alzheimer's disease, in order to learn from your experiences in order to help others. If you are at least 60 years of age and widowed at least a year, or if you know someone who is, please make contact to be mailed the short questionnaire. All results will be kept completely confidential, and your name will not be used. Karen Gleeson, 560 Dean Street, Apt. 3L, Brooklyn, NY 11217 or you may call (718) 783-4196 or email <kgteach@aol.com>

Adult Day Program in Español

The Park Slope Geriatric Day Center is pleased to announce that *Creaciones de Hispanos'* Adult Day Services (in Spanish) will be open on Monday and Wednesday from 9:00 am to 3:00 pm at 199 14th Street, Brooklyn, NY.

In March 2001, the Spanish day program will expand its days of operation at 14th Street, and will be offered three days a week at One Prospect Park West. For more information, please call Evelyn Vasquez at 718-499-7701.

The NYC Latino Disease Taskforce Second Annual Conference

On January 25, 2001 the NYC Alzheimer's Disease Taskforce convened its second annual conference, "Alzheimer's Disease: Cultural Considerations." We take great pride in reporting the successful outcome. One hundred twenty participants heard presentations from expert physicians and psychologists from California, Florida, Puerto Rico, New York and Washington, DC. Papers were presented on issues concerning the elderly in Latin America. Several reported findings on a pilot study, a research study, a work in progress on culture and other relevant data. This was a historic event.

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Time Slips Project Offers Free Educational Presentations

In conjunction with the Time Slips Project, project director Anne Basting is now offering free, educational presentations throughout the spring. Time Slips is a public arts project whose aim is to encourage creative expression among people with Alzheimer's disease and related dementias.

What's amazing about the Time Slips Project is that it touches the fields of health sciences and the arts and humanities, says Basting. I have done presentations for everyone from nurses to acting students. Basting's presentations feature slides chronicling the project and address issues of memory and identity, the value of creative self-expression, structures of autobiography, and innovative, hands-on storytelling techniques.

In the first year two years of the project, Basting tested a storytelling technique and translated the stories told by people with dementia into a series of public arts events in Milwaukee, Wisconsin.

Now in the third year of the project, Time Slips will produce the arts and educational events here in New York, including a website (www.timeslips.org), a play production, an art installation, and a roundtable discussion entitled: *Is There an Art to Dementia Care?* The arts events will begin in October and run through November, 2001.

To book an educational presentation, or to find out more about Time Slips Project events, call Dr. Basting at the Brookdale Center on Aging at 212-481-4426. Or visit their website: www.timeslips.org.



"Forget-Me-Not Ball" 2001

Thursday, June 7, 2001

Cipriani at 42nd Street, New York City

For more details, please contact Alyson Raifman, Special Events Coordinator at (212) 983-0700

Memory Walk 2001

Sunday, October 7, 2001

South Street Seaport, New York City



Someone to Stand by You

New York City Chapter

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