

Star Power Fuels 2002 Forget-Me-Not Ball



Nancy Barnett Morse, Gala Committee Chair with actor, David Hyde Pierce, special guest and Gala emcee.

If any organization knows that there's a place for will power, staying power (ask any veteran of the 36-hour day), and dollar power, it's the Alzheimer's Association. At this year's Forget-Me-Not Ball, held on June 6, 2002 at Cipriani on 42nd Street, we witnessed a demonstration of *star* power — and we're not talking box office.

Of course, David Hyde Pierce, the Emmy Award-winning actor best known for his portrayal of Dr. Niles Crane on NBC's "Frasier," is a fixture atop the Nielsen ratings. However, his most compelling television appearances have been outside of prime time, testifying on Capitol Hill as an advocate for increased funding to fight Alzheimer's disease.

Mr. Hyde Pierce brought all his eloquence to bear as the emcee at our gala. As when he addressed Congress, his appeal was anchored in the personal agony of seeing his own grandfather and father ravaged by Alzheimer's. As he recounted the serial coping mechanisms that caregivers adapt as the disease progresses, we were transfixed by a passion and wit far beyond the scope of sitcom scriptwriters.

In the Alzheimer's "community" we've grown accustomed to looking to each other for support. Most of us have been on both sides of the "Someone to Stand by You" equation. Even as the more than 300 attendees were inspired by Mr. Hyde Pierce's talk, our hearts went out to him: he struggles no more bravely than the rest of us, perhaps, but so much more publicly. Kudos to a celebrity who uses his visibility to achieve something more than a prime table at the "in-spot" of the moment. He is a treasure no less valuable than diamonds, a natural resource as indispensable as plutonium, and most important, he is willing to expend his personal currency on our behalf — here in New York City and around the country.



Elegant setting for the Forget-Me-Not Ball at Cipriani's on 42nd Street.

Cipriani, the elegant venue on 42nd Street, was an appropriate setting for the festivities. Richly yet tastefully appointed, it preserves many of the landmarked interior elements of the Bowery Savings Bank that occupied these premises for decades.

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New York City Chapter
Newsletter



In Memorium **Louis "Lou" Davis** (1909 - 2002)

What are the words that best describe *our* Lou? "Irrepressible" and "irreplaceable" come to mind. With his untimely passing at the beginning of August, the Alzheimer's community and the New York City Chapter of the Alzheimer's Association lost a dear and valued friend.

For more than seventeen years he encouraged us, he pushed us to do more and better, he put his money and his incredible energy where his heart was. He was the genuine article and we will miss him.

Lou played a major part in the growth and success of the New York City Chapter, as a member of the Board of Directors, on the Leadership Council, as an indispensable participant on countless gala committees, and as a good will ambassador without peer.

We all knew we could count on him, and he never failed us. He had a way with people, and his many friends supported him and his passion for the Alzheimer's Association because they liked him and they trusted him. Over the years Lou raised more than \$1 million for the cause. Who will fill his shoes?

He lived his life so well.

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Visit our website at: www.alzheimernyc.org

Director's Corner

BY THE NUMBERS

Here are some preliminary statistics representing the work accomplished and the challenges faced by your New York City Chapter of the Alzheimer's Association during the twelve months of Fiscal Year 2002 which ended on June 30, 2002.

During this period:

- 7,647 Callers contacted our 24-Hour Telephone Helpline seeking guidance and assistance. (more than 147 callers per week)
 - 2,000 Support Group members, participated in some 2,680 sessions of the 100 caregiver support groups sponsored by the NYC Chapter around our five borough service territory.
 - 7,086* Clients attended 364 meetings covering various aspects of Alzheimer's disease and service responses, as conducted by the NYC Chapter. These sessions included Education Meetings, Training Programs, Legal & Financial Seminars, Health Fairs and other presentations conducted by Chapter staff and volunteers.
- * This figure represents statistics gathered for the last six months of reporting year only.
- 20,805 Hours of volunteer service were offered by 410 volunteers across all elements of program service and chapter operations. Based on the hourly rate of \$16.06 per hour as the established per hour value of volunteer time according to the *Journal of Philanthropy*, this amounts to value added to the Chapter in the equivalent of \$333,920.
 - 598 Registrants were enrolled in the SAFE RETURN Program (our wanderers safety program), averaging 50 new participants per month.
 - 444 Cases of Missing/Found cases were handled by SAFE RETURN in New York City during this period. Of those registered in the program who were reported missing, we have a successful retrieval rate exceeding 95%
 - 32,804 Friends and "subscribers" received our Chapter newsletter free of charge each quarter.
 - 1,100 or more dedicated supporters participated in our 2001 Memory Walk "assembly" at the South Street Seaport, less than one month after the terror attacks of September 11th.

Income and Expense from July 2001 through June 2002:**

\$2,789,112 (Income)
\$3,190,214 (Expenses/Loss on Investment)
\$401,102 (Deficit)

** Since these numbers are unaudited, certain changes and variation resulting from accruals, allocations, and other adjustments are likely once the official audit is presented.

These numbers speak for themselves. Represented above is a snapshot of only some of the enormous amount of work that has taken place at the Chapter. All this in response to the still growing need.

The negative financial figures demonstrate clearly the adverse impact of "9/11," the drag of a sagging economy, and the Wall Street tumble, which has been evident during the reporting period.

Needless to say, we must do better during the year ahead. We count on your support to recover the ground we've lost, since clearly the need for our services is greater than ever. As always, we thank you all for your crucial and anticipated support.

- John A. Jager
Executive Director





It was so sad to learn that Ronald Reagan would have company at that last round-up. Charlton Heston, who has been playing larger than life figures (Moses, Michelangelo, Andrew Jackson) for so long that the mantle of heroism settled on the actor's own broad shoulders, announced the beginning of his own long ride into the sunset. No matter how quick on the draw, these "guys in the white hats" hadn't a chance against Alzheimer's. This insidious killer has a way of sneaking up on us that is tantamount to being shot in the back.

Heston's rugged individualism reflected well on the NRA; as their president he cloaked their militant philosophy in an aura of patriotism (did we say he played Andrew Jackson?). Yet Heston had a core integrity that made us respect him despite an ideology that shifted from the liberalism of the Civil Rights era (when he marched with Martin Luther King, Jr.) to embrace Reaganism. The man had depth; read his autobiography and you'll know he wrote his own sign-off.

Whatever we think of Heston's politics, he made a darn good spokesman for the NRA. Even as his farewell was bringing tears to our eyes, we dared to imagine what he might accomplish as a poster boy for Alzheimer's. Perhaps his eloquence will allow him to chronicle his experiences, as Thomas DeBaggio does in "Losing My Mind," reviewed on page 5. Heston's plight lends our Chapter's third annual conference on Early Stage Alzheimer's additional urgency. See page 14 for details.

—Chris MacLeod

Junior Committee

The Junior Committee is dedicated to raising awareness of individuals in the 21 to 40 age range through events, support and education to further the efforts of the chapter. In an effort to continue to grow and become an even greater contributor to the chapter the committee recently formed sub-committee's of Advocacy, Community Outreach, Education, Events, Fundraising/Development and Press/Publicity.

Effective June 1 the Junior Committee voted on officers and committee chairs for the upcoming 2002 - 2003 year.

Board: President - Scott Coopersmith, Vice-President - Joel Greenwald, Secretary - Jan Forster, Treasurer - Rob Wollin

Committee's: Advocacy - Juliana Garcia, Community Outreach - Karen Kadin, Education - Craig Meisner, Events - Kara Bauer, Fundraising/Development - Sam Martini, Press/Publicity - Mollie Maxwell

We would like to thank our previous Junior Committee chair Kathy White for her years of dedication and hard work. We are glad she will still be a part of the committee.

The Junior Committee will have a team in the upcoming Memory Walk on Sunday September 22nd. Please contact team captain Eileen Moore at eileenmoore@aol.com for more information and visit our team page.

The Events Committee is working hard to plan the next social fundraiser for mid-October. More information will follow as soon as it becomes available.

We are also always looking for new members to help further our efforts. If interested in becoming a member please contact our New Member Coordinator Sarah Marchand at sarahmarchand@yahoo.com.

Please visit our website, www.alzheimernycjuniorcommittee.org for more information or to join our mailing list.

Unforgettable Forget-Me-Not Ball continued from page 1.

As a highlight of the evening, the New York City Chapter honored William C. Weldon, Chairman & CEO of Johnson & Johnson with its 2002 Community Leadership Award for his family of companies' distinguished efforts to improve the lives of those affected by Alzheimer's disease and other devastating illnesses. Alex Gorsky, President of Janssen Pharmaceutica, chaired this festive event, which raised over \$500,000. A splendid time was had by all. The Chapter and its hardworking Benefit Committee extend their gratitude to all of the Gala leadership, and applaud the generosity of all our guests attending this signature event.

—Chris MacLeod



Gala honoree, William C. Weldon, Chairman & CEO of Johnson & Johnson, with Lou Davis, Gala Committee Chair and William Kaye, Co-President, Board of Directors.



William Kaye, David Hyde Pierce, Chapter Co-President Irvine Flinn with Jed Levine and Lynne P. Raymond, Chapter staff.



Gala guest enjoying our silent auction.



Caregiver Corner ~ El Rincón del Cuidador

COMBATIVENESS

When an Alzheimer patient becomes combative, angry or agitated, it may be because of frustration. The person may feel that he is being pushed to do something that simply can't be done.

Consider the following factors as possible sources of frustration:

Dressing – The person who can't get his arm through a sweater may grow increasingly upset and start to thrash around.

Bathing – The person who's frightened by running water in the bathtub may push away a caregiver who's trying to give him a bath.

Eating – The person who's doesn't like a certain type of food may refuse to eat it.

Keep in mind that combativeness takes many forms. Sometimes the person may simply try to push your hand away, while at other times the person may resist or strike you.

Deal with combativeness by trying to examine the underlying causes.

Consider the following issues:

Physical Causes – Is the person tired because of inadequate rest or sleep? Are medications such as sedatives and tranquilizers creating side effects? Is the person unable to express the fact that he's in pain?

Environmental Causes – Is the person over stimulated by loud noises, people or physical clutter? Is the environment unfamiliar? Does the person feel lost or abandoned by the caregiver?

Poor Communication – Are you asking too many questions or making too many statements at once? Are your instructions simple and easy to understand? Is the person picking up on your own stress and irritability? Are you making the person more frustrated by being overly negative or critical?

ACTION STEPS

Be on the lookout for frustration. – Look for early signs of frustration in such activities as bathing, dressing or eating, and respond in a calm and reassuring tone.

Don't take aggression and combativeness personally. – Keep in mind that the person isn't necessarily angry at you. Instead, he may misunderstand the situation or be frustrated with his own disabilities.

Avoid teaching. – Offer encouragement, but keep in mind the person's capabilities and don't expect more than he can do. Avoid elaborate explanations or arguments.

Use distraction. – Don't persist in making the person perform a particular task, especially if he has repeatedly been unsuccessful. If you see the person getting frustrated with buttoning a shirt, try to distract him with another activity such as putting on a pair of pants. After a time, you can return to the shirt or take the person to a quiet room, have a cup of tea, or go for a walk.

Communicate directly with the person. – Avoid expressing anger or impatience in your voice or physical actions. Instead use positive, accepting expressions such as "please", "thank you", and "Don't worry, everything's going to be fine". In addition, use touch to reassure and comfort the person. For example, you might want to put your arm around the person or give him a kiss. In addition, follow these tips:

- Speak slowly and clearly.
- Use short simple sentences.
- Approach the patient slowly and from the front.
- Use repetition and frequent reminders.

Decrease your level of danger. – Assess the level of danger for both yourself and for the person. In other words, if the person becomes combative, ask this question: "How much trouble am I in and what can I realistically do about it?" Often you can avoid harm by simply taking five steps back and standing away from the person for

AGRESION

Cuando un paciente de Alzheimer llega a ser agresivo, a estar enojado o alterado, podría ser a causa de sentir frustración. La persona podría sentir que está siendo presionada para hacer algo que simplemente no puede hacer.

Considere los siguientes factores como posibles fuentes de frustración:

Vestirse. – La persona que tiene dificultad para vestirse, podría sentirse disgustada y alterarse.

Bañarse. – La persona que se espanta al oír correr el agua en la tina del baño, podría empujar al cuidador quien está tratando de bañarlo.

Comer. – Cuando no le gusta cierto tipo de comida, podría rehusarse a comer.

La agresividad toma muchas formas. Algunas veces la persona podría simplemente tratar de empujarle la mano, mientras que en otras, podría resistirse o tratar de golpearle.

Causas Físicas. – La persona podría estar cansada por la falta de dormir o descanso. Es posible que los medicamentos, tales como sedantes y tranquilizantes estén creando una contrareacción. Probablemente, el paciente de Alzheimer no puede expresar el hecho de que algo le duele.

Causas del Medio Ambiente. – La persona podría estar molesta o cansada por los ruidos, la gente o el desorden. El medio ambiente podría ser desconocido para la persona. La persona se siente perdida o abandonada por el cuidador.

Falta de Comunicación. – La persona no puede entender si usted le hace muchas preguntas a la vez. Sus instrucciones deben ser simples y fáciles de entender. La persona puede observar si usted está tenso e irritable. Usted puede frustrar a la persona por ser demasiado negativo y crítico.

PASOS A SEGUIR

Trate De Entender Lo Que Origina La Frustración. – Observe los primeros síntomas de frustración en tales actividades como al bañarse, vestirse o comer. Responda con un tono calmado y brinde confianza.

No Tome La Agresividad Personalmente. – Recuerde que la persona no está necesariamente enojada con usted. En cambio, él/ella podría mal interpretar la situación o estar frustrado con su propia inhabilidad.

Enseñanza Y Motivación. – Ofrezca motivación. Pero recuerde la capacidad de la persona y no espere más de lo que puede hacer. Evite mayores explicaciones o desacuerdos.

Use La Distracción. – No insista en hacer que la persona lleve a cabo una tarea en particular, especialmente si se le hace difícil. Si usted ve que la persona llega a frustrarse al abrocharse la camisa, trate de distraerla con otra actividad, tal como ponerse un par de pantalones o calcetines. Después de un rato, usted puede volver a tratar de abrochar la camisa.

Comuníquese Directamente Con La Persona. – Evite la expresión de enojo o impaciencia en sus acciones físicas o en su voz. Use expresiones positivas de aceptación, tal como: "Por favor", "Gracias" y "No te preocupes, todo va a salir bien". Además, use el tacto para dar confianza y comodidad a la persona con la enfermedad de Alzheimer.

Por ejemplo: abrazar o besar a la persona. Además, le sugerimos seguir estos pasos:

- Hable lenta y claramente.
- Use oraciones cortas y simples.
- Acérquese al paciente de frente y lentamente.
- Use la repetición.

Disminuya El Nivel De Peligro. – Evalúe el nivel de peligro para usted y el paciente. En otras palabras, si la persona llega a ser agresiva,

continued on page 6.

Alzheimer's Exposed

By J. Hollie Fick

Rare among non-fiction works published on the neurological disorder Alzheimer's disease, is an account written by one who is actually affected. Even more exceptional is an account as revealing and as capable of tugging at the heart strings of those both familiar with the disease and not, as in Thomas DeBaggio's "Losing My Mind."

A tribute to a memory lost, at first this book's dizzying ping pong from one subject to another – bouncing from biographical accounts, to italicized journal entries and then to scientific research – seems erratic and difficult to follow. It is not until the reader recognizes the parallels between the disjointed feed of information and DeBaggio's own frame of mind, that difficulty in following the passages translates to new insight into the world of this awesome and mind-numbing disease.

A horticulturalist who specializes in herbs, DeBaggio contemplates whether or not he has worked too hard — not allowing himself time to stop and smell life's proverbial flowers because he was too busy growing them instead. Often working up to 90-hour weeks in his urban greenhouse, he describes the stressful environment as one often plagued with customers who "demanded horticulture surrender." DeBaggio so entangles himself in the business that it materializes in the physical attributes of his book. The spine is green and he chooses leafy-print separators to divide his thoughts. This possibly follows from the subject matter of his three previous works: "Growing Herbs from Seed, Cutting and Root," "Basil: An Herb Lover's Guide" and "The Big Book of Herbs."

DeBaggio has finally found a platform from which he can reach a deserving audience. Though during the course of its construction, this dais becomes increasingly difficult for him to mount. As the disease progresses, writing becomes so treacherous that DeBaggio admits that often neither his nor his computer's spell check function can decipher the original intent of the illegible language he writes. Sometimes he spends days just chasing after lost thoughts that evaporate faster than the tears he cries in his sleep.

But DeBaggio stays determined, citing the most important reason for his day-to-day struggle with sentences as a means of "breaking through the shame and silence Alzheimer's has engendered." He is boldly successful in his attempt to humanize the illness. What comes as a surprise is the late emergence of the subplot in which this descendent of Norwegian and Italian immigrants vividly recounts some of his colorful reporting-related endeavors. These demonstrate a possible explanation for the prowess of the literatus-cum-journalist.

DeBaggio and his wife Joyce were self-described "peaceniks." As a dedicated civil rights activist during the time before, during, and after the Vietnam War, DeBaggio went to great lengths to expose acts of civil and racial injustice. For a story, he went so far as attending a Ku Klux Klan rally in Maryland. In the state of Delaware, he was permanently barred from being placed in any of the state's prisons after a piece he wrote exposing the severe treatment of Delaware prison inmates.

In the sixties, DeBaggio created a paper he named *Underground*, while living in Arlington, Virginia. The publication was recognized by none other than the great Carl Bernstein, in an article for the Washington Post. The exposé focused on the impropriety of an American University official who tried to prevent DeBaggio and his wife, Joyce, from selling their paper on campus.

While it is no surprise that DeBaggio blames the descent of his career in journalism on patience lost on too many tunnel-visioned editors, the fact that neither his talent nor his passion has faded over time emanates from the pages of this book as brightly as the Mexican sun he recalled baking his skin to a golden brown when he was young.

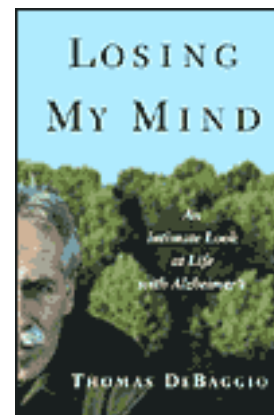
His efforts are perhaps summed up best by a letter DeBaggio received from a listener after he agreed to be a guest, along with his son, Francesco, and Joyce on National Public Radio. They discussed Alzheimer's and its effects on family. The response was from a fellow horticulturalist and part of it read: "...there are times when we must take root among rocks." And armed with only a pen and a keyboard to fight a silent killer head-on, DeBaggio has not only rooted among the rocks, he has *flourished* among them.

Of Spirits Tried

And so it goes in time of trouble; the moon beneath the sky
And hope and imagination lost among the lasting mortal cry;
I reach right out and touch her hand and feel her wrinkled brow,
And realize this all there is . . . she lives within the now.
The tears of memories so lovely for all the lives they meant,
Are gone . . . alas have disappeared, the moments finished and spent.
She reaches upon the air for answers infinitely tremendous – yet tiny and so small,
Unsteady and inconsistent as she wobbles down the hall.
I see not the ancient, tired bones of ages lived long ago,
I see not the fallen recollections she will never come to know.
I see not the hopes lost and the dreams gone awry,
I see not the afflicted soul . . . lest I would dare to cry.
The sun awakens our early morn and
peeks through the curtains still,

Yet day is night is day and she has had her fill.
The rains pour down from the sky and echo in the nature's song,
Here for the moment, but alas linger not for long.
My patience once sound and mighty is now a whisper as I pray,
For just a simple time – a miracle in a day.
And sometimes I see a glimmer of what once was our reality,
Of a time ago when her mind was extraordinarily free.
I love her as I love myself and may even love her more,
As slowly but surely, there is less and less of that mother I do adore.

Kelly Ilene Steier



*Losing My Mind:
An Intimate Look
at Life with Alzheimer's*
By Thomas DeBaggio
The Free Press, \$24.00

Education Series for New Early Stage Care Partners

With the help of a generous grant from the Achelis and Bodman Foundations, the New York City Chapter of the Alzheimer's Association is launching an effort to develop a new model of education and support for spouses of people with AD. The service, which will be called *Coping with a New Diagnosis: An Educational Series for Spouses* will have two primary goals according to Dr. Alan Dienstag, Coordinator of Psychological and Research Projects for the chapter: to provide earlier intervention than existing support group services provide, and to increase the utilization of support groups among spouses overall.

"Support groups save lives," said Dr. Dienstag, "their availability and acceptance as one of the tools we have to improve the quality of life of families and people with the disease is a great success story, and this chapter has been an integral part of that story."

Unfortunately, only a small percentage of caregivers avail themselves of support group services and of these, many do so when caregiving related pressures are approaching or are at the breaking point. "Many spouses of people in the early stages of Alzheimer's disease conclude that they do not need support group services *yet*, and associate support groups with the later stages of the illness," said Dienstag.

For many such spouses, the term caregiver may not quite fit or feel right. But our experience with these spouses has also taught us that adaptations to the incapacities of the spouse with AD predate the diagnosis by months if not years, as do the fears, anxieties and attendant stress. The foundations of the caregiving role are usually established long before the spouse with AD is diagnosed or functionally dependent.

"What we are trying to develop is a tool that we can use to address the needs of spouses at this stage of the process, one that will effectively lay the groundwork for a healthy adaptation to the demands of caregiving later on," said Dienstag.

The group will have an educational focus and consist of seven sessions in which information about the illness, the risks of caregiving, and coping strategies will be provided. Methods for managing the intense feelings that arise in spouses of people with Alzheimer's disease and aspects of the support group experience will be illustrated and emphasized.

Recruitment for the limited number of spaces available in this stage of the project will begin in September. Priority will be given to participants whose spouses have been diagnosed with AD within the last 12 months, and have a high degree of functional independence. Spouses who are currently participating in a caregiver support group will not be eligible for this program at the present time. Participants will be asked to participate in a telephone or face-to-face interview four times a year as part of this project. This program is free of charge.

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



Caregiver Corner continued from page 4.

a short period of time. On the other hand, if the person is headed out of the house and onto a busy street, you need to be more aggressive.

Keep the environment calm, quiet and clutter free.

Be conservative in using restraint or force. – Unless the situation is serious, try to avoid physically holding or restraining the person. By fighting with the individual, you'll probably make him even more frustrated and anxious.

Experiment with objects that have a soothing effect. – Some caregivers believe that stuffed animals have a soothing effect on the person, while others find that pets have a calming effect.

Learn from previous experiences. – Try to avoid situations or experiences that make the person combative. For example, if the individual tires easily when she visits with family members, you might want to limit the length of these visits. Try to identify early signs of agitation. For example, outbursts are sometimes preceded by restlessness, frustration, fidgeting, or blushing.

Restructure tasks and the person's environment.

- Simplify tasks or plan more difficult tasks for the time of the day when the person is at his best.
- Give the person adequate time to respond to your directions or requests.
- Allow the person to make some choices, but limit the total number of choices. Having too many decisions to make about what to eat or wear might be confusing or overwhelming.
- Break down each task into small steps and allow the person to complete one step at a time.

Keep the environment calm, quiet and clutter free.

hagase esta pregunta: ¿En qué problema me encuentro y qué es lo que realmente puedo hacer acerca de esto? Frecuentemente ud. puede evitarse daño, simplemente al estar cinco pasos alejado la persona y permanecer retirado por un momento.

Por otra parte, si la persona sale de casa y se dirige a la calle, ud. necesita hacer algo inmediatamente.

Adaptese A La Persona. – Si la persona tiene problemas en tomar las pastillas, ud. podría tratar de molerlas y mezclarlas con los alimentos. Algunos medicamentos podrían obtenerse en forma líquida.

Tome Precauciones De Seguridad. – Coloque un candado en el gabinete de las medicinas o guarde los medicamentos en un cajón cerrado. Si la persona escupe las pastillas, asegurese que esas pastillas no las levanten o las ingieran los niños o el animal doméstico.

Evite dejar a la persona sola en el cuarto con las botellas de medicamentos y asegurese de tirar todos los medicamentos viejos.

Esté Preparado En Caso De Emergencia. – Investigue los nombres y números telefónicos de farmacias o de servicios que pueden hacer entrega de los medicamentos.

También, investigue los nombres de las farmacias que estan abiertas los domingos, los fines de semana y/o las 24 horas del día.

En Caso De Envenenamiento O Emergencia. – Conserve a la mano la dirección y el número telefónico de las Clínicas de Salud en caso de emergencia o envenenamiento.

Si ud. sospecha de una sobredosis de medicamentos, llame al número telefónico antes de provocar el vomito o hacer otra cosa.

*Just the Facts, Alzheimer's Association
Chicago, Illinois*

SUPPORT GROUP OPENINGS

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

Openings are now available in the following support groups:

BRONX

Spouses' Group

Montefiore Medical Center

DAY AND TIME: 5:00 – 6:30 P.M. Tuesdays

CONTACT: Phyllis Antis 718-379-8180

Adult Children's Group

Albert Einstein College of Medicine

(Morris Park Ave./Eastchester Rd.)

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

CONTACT: Molly Schroeder 718-885-0609;

Pat Loscalzo 718-231-0985 or

Marilyn Paul 718-364-2156

BROOKLYN

Spouses' Group

Catholic Charities (Pierrepont St., Brooklyn Heights Area)

DAY AND TIME: 12:30 – 1:30 P.M. Wednesdays

CONTACT: Sharon Byrnes 718-852-3391 *(New Group)*

Mixed Groups

Fairview ADHC (Carnarsie area)

DAY AND TIME: 4:00 – 5:30 P.M. 1st & 3rd Tuesday

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

(New Group)

Methodist Hospital (Park Slope)

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

CONTACT: Lianna Dressner 718-780-5533

Kings Bay Y (Sheepshead Bay)

DAY AND TIME: 6:45 – 8:00 P.M. 2nd & 4th Tuesday

CONTACT: Sophie Finkelman 718-646-2973

MANHATTAN

Daughters' Group

West 56th Street & Broadway

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

CONTACT: Deborah Rubin 212-757-4202

Adult Children's Group

360 Lexington Avenue (40th & 41st Streets)

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

CONTACT: Marge Blaine 718-469-5308

Mixed Groups

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

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

CONTACT: David Currier 212-927-5600

Columbia Presbyterian Medical Center (168th Street)

DAY AND TIME: 1:00 – 2:30 PM 1st and 3rd Tuesday

CONTACT: Lynn Stiles 212-305-3785 *(New Group)*

360 Lexington Avenue (40th & 41st Streets)

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

CONTACT: Susan Hason 646-486-3840

Central Harlem

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

CONTACT: Carmen Becker 718-457-8099

Lower East Side (Grand St. area)

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

CONTACT: Kendall Hamid 212-358-8489, Ext. 310

Allen Pavilion's Health Outreach (Inwood)

DAY AND TIME: 6:00 – 7:130P.M. 1st and 3rd Friday

CONTACT: Rose Mary Cortez 212-932-5843 *(New Group)*

Spanish Language Groups

Columbia Presbyterian Family Medicine Clinic (Nagle Ave.)

DAY AND TIME: Call Oneida Brown for Day and Time

CONTACT: Oneida Brown 212-567-2291 *(New Group)*

360 Lexington Avenue (40th & 41st Streets)

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

CONTACT: Elizabeth Figueroa 718-433-0800

Licia Berlinck 718-805-9694

Lilia Nicoletti 718-526-5242

Spouses' Groups

360 Lexington Avenue (40th & 41st Sts)

DAY AND TIME: 12:00 Noon – 1:00 P.M. Mondays

CONTACT: Paulette Michaud 212-983-0700

(Appropriate for individuals caring for spouses in the middle & late stages.)

360 Lexington Avenue (40th & 41st Streets)

DAY AND TIME: 12:30 – 1:30 P.M. Thursdays

CONTACT: Sharon B. Shaw 212-222-8924

Lenox Hill Neighborhood House

GENERIC *(Any caregiver involved in the care of persons 60 & older)*

DAY AND TIME: 1:00- 2:30 PM Mondays

CONTACT: Mathew Brumbaugh 212-744-5022, Ext. 1210

St. Vincent's Manhattan

DAY AND TIME: 2:00–3:30, 2nd & 4th Tuesday

CONTACT: Rosemarie Greene 212-604-7332

Mt. Sinai Medical Center (Fifth Ave & 98th St.)

DAY AND TIME: 4:00 – 5:30 P.M. 1st & 3rd Thursday

CONTACT: Joan Dickson 212-628-5045

Wives of Persons with Early Onset AD

360 Lexington Ave (40th & 41st Streets)

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

CONTACT: Sheila Crandles 212-983-0700

Sharon Shaw 212-222-8924

QUEENS

Adult Children's Group

Atria Kew Gardens (117-01 84th Ave)

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

CONTACT: Nettie Harper 718-441-0300

Joanne Loughlin 212-263-8395

Mixed Group

Samuel Field YM-YWHA (Little Neck Parkway)

2 Groups at this location

DAY AND TIME: 12:45-1:45 P.M. Tuesdays;

12:00-1:15 P.M. Wednesdays

CONTACT: Alissa Pizzutiello 718-225-6750 Ext. 331

(A personal interview is required.)

Flushing Hospital (Parsons Blvd.)

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

CONTACT: Trudy Chaiken 718-428-4278

Sunnyside (39th Street.)

DAY AND TIME: 10:30-12:00 P.M. Saturdays

CONTACT: Janet Bauman 718-784-6173, x 150

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

(Little Neck Parkway) **2 Groups at this location**

DAY AND TIME: 7:00-8:30 P.M. Every Other Wednesday

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

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

WEDNESDAY October 2

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

THURSDAY October 3

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

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

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

MONDAY October 7

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

Educational Meeting
Time: 6:00 – 7:30 p.m.
Place: Chapter Office
Topic: The Grieving Process: Understanding and Living With Feelings of Loss and Grief As a Caregiver
Speaker: Benyamin Cirlin, C.S.W., Director, Center for Loss and Renewal; Bereavement Coordinator, Jacob Perlow Hospice, Beth Israel Medical Center

WEDNESDAY October 9

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

FRIDAY October 11

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

WEDNESDAY October 16

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

ALL EDUCATIONAL MEETINGS ARE FREE OF CHARGE

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

We wish to thank the following for their generous donations of space for the Orientation Meetings: CAPE at the Samuel Field YM-YWHA, CNR, Fort Washington Houses, The Park Slope Geriatric Day Center, Inc., and RAIN Parkchester Senior Center.

THURSDAY October 17

Introducción da la enfermedad de Alzheimer
Hora: 5:30 – 7:00 p.m.
Lugar: The Park Slope Geriatric Day Center
1 Prospect Park West, Brooklyn

MONDAY October 21

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

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

TUESDAY October 22

Eighteenth Mayoral Conference on Alzheimer's Disease
Call 212-442-3086 for more information
Place: Marriott Hotel, Brooklyn

THURSDAY October 24

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

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

MONDAY November 4

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

WEDNESDAY November 6

Queens Educational Meeting
Time: 10:00 a.m. – 12 Noon
Place: TBA
Topic: Alzheimer's Disease: An Overview and Research & Treatment Update
Speaker: TBA

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

THURSDAY November 7

3rd Annual Early Stage Conference
See page 14 for more information
Place: Crowne Plaza Hotel, New York, NY

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

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

FRIDAY November 8

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

MONDAY November 11

Educational Meeting
Time: 6:00 – 7:30 p.m.
Place: Chapter Office
Topic: Getting Through: How to Communicate Effectively With the Person Who Has AD
Speaker: Kassie Witte, M.S., Coordinator of Speech Pathology/Audiology, Hebrew Home for the Aged in Riverdale

TUESDAY November 12

Orientation Meeting for Professionals
Time: 9:30 – 11:00 a.m.
Place: Chapter Office

WEDNESDAY November 13

Brooklyn Educational Meeting
Time: 10:00 a.m. – 12 Noon
Place: TBA
Topic: Alzheimer's Disease: An Overview and Research & Treatment Update
Speaker: TBA

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

continued on page 9.

MONDAY November 18

Medicaid Home Care Seminar:
A Practical Guide to the System
Time: Noon – 1:30 p.m.
Place: Chapter Office

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

TUESDAY November 19

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

WEDNESDAY November 20

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

THURSDAY November 21

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

TUESDAY November 26

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

MONDAY December 2

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

WEDNESDAY December 4

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

THURSDAY December 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, N.Y.

Medicaid Home Care Seminar:
A Practical Guide to the System
Time: 5:30 – 7:00 p.m.
Place: Chapter Office

MONDAY December 9

Educational Meeting
Time: 6:00 – 7:30 p.m.
Place: Chapter Office
Topic: Community Services Available to
Caregivers: Adult Day Care, Home
Care, and Residential Care Facilities
Speakers: To be announced

TUESDAY December 10

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

WEDNESDAY December 11

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

FRIDAY December 13

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

MONDAY December 16

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

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

WEDNESDAY December 18

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

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

BULLETIN BOARD

New PBS Special on Caregiving!

On October 9, 2002, be sure to watch "And Thou Shalt Honor" at 9 pm on channel 13. This PBS special hopes to increase awareness of the needs of family caregivers across America. Several Alzheimer's families were interviewed for the show. The Alzheimer's Association is proud to be a National Outreach Partner for the project.

Need help?
Stressed out, exhausted?
Looking for services in
your area?

We can help!

Visit our website at
[www.alzheimernyc.org/
helpline.html](http://www.alzheimernyc.org/helpline.html), email us at
helpline@alz.org or call 212-
983-0700 and ask for the
Helpline - 24 hours a day.

Visit us on the web at www.alzheimernyc.org
for news, events in your area, and information on
programs and services offered by the New York City
Chapter. You can also buy books and obtain free
informational material at our online store.

PUBLIC POLICY UPDATE:

Federal and State Alzheimer's Advocacy

State Advocacy

The New York State budget for fiscal year 2003 passed at the end of May. Although state tax revenues fell short of projections, the \$89.6 billion budget passed with the expectation that next year's revenues will be better. In this difficult fiscal time our Alzheimer's needs did not go unrecognized.

The Assembly restored \$102,000 to the budget to advance the work of the Coalition of New York State Alzheimer's Chapters and the Alzheimer's Disease Assistance Centers (ADACs) in providing education, training, counseling, support services, and diagnostic services. The Senate provided for an additional \$200 million for Alzheimer's to be divided among a number of different organizations and entities. Our chapters will receive a portion of the \$200 million. In addition, the Senate and Assembly passed important legislation before the close of the session at the end of June that provides a legislative match of the voluntary State Income Tax Check-off for Alzheimer's. This legislation has been approved by the Governor. All monies generated through the check-off for the 2002 tax year (to be contributed in April 2003) will be matched by an equal sum from the legislature and paid in the fall of 2003. The above were all priority advocacy issues for our Coalition of New York State Alzheimer's chapters.

Social adult day care has been another of our coalition's continuing legislative priorities. While the legislature did not provide for funding at the needed level to make this option more widely available, \$1 million was restored to the budget to continue providing assistance to the 19 programs awarded monies in FY2001. In addition, \$462,000 was restored to the budget for respite.

As noted in the last newsletter, in mid-January prior to presentation of his budget message Governor Pataki proposed and the legislature passed a health care reform package focused on workforce recruitment and retention. This major effort is to be funded by a \$1.8 billion gross amount over three years. Workforce issues are of paramount importance if there is to be quality care in home care services and in residential settings, and these issues have been a top priority of our Coalition and the national Alzheimer's Association and chapters throughout the country.

On another note of importance to the Alzheimer's community, legislation sponsored by Assemblyman Cahill and Senator Maziarz passed (now awaiting the Governor's signature) which creates the Most Integrated Setting Coordinating Council to develop and implement statewide plans to comply with the U.S. Supreme Court's Olmstead decision. The Olmstead decision provides a legal framework to enable individuals with disabilities to live in the most

integrated setting appropriate to their needs. In keeping with the decision, the New York State legislation is designed to increase opportunities for persons of all ages with disabilities to live at home and participate in their communities rather than reside in residential settings. Working with the advocacy groups concerned with the state's planning process for the implementation of Olmstead, our statewide coalition of chapters will stress the need for services to be in place in sufficient amount to enable persons with Alzheimer's (included as a group under the Americans with Disabilities Act definition of disability) to remain in their own homes and communities.

The proposed increase in the minimum wage from \$5.15 an hour to \$6.00 in 2003 and to \$6.75 in 2004 was not passed. Also, despite its long awaited and expected passage, legislation to define and regulate assisted living was not passed. At this point in time, the Senate and Assembly have each passed an assisted living bill, and the Governor has proposed a third version. It is expected that both the minimum wage and assisted living will be addressed in the coming session of the legislature.

Federal Advocacy

A nationwide poll of likely voters released by the Alzheimer's Association indicates that 95% of Americans view Alzheimer's disease as a serious problem, 57% indicate they are personally concerned about getting Alzheimer's, and 64% of those age 35 to 49, the baby boomers, are concerned about getting the disease. The poll indicated very strong support (74%) for increasing federal funding for Alzheimer's research to \$1 billion dollars a year, and federal advocacy continues to focus on securing this increase. The need to increase research funding is further supported by a new study that sets costs to business of \$61 billion a year in caregiver time, productivity loss, and medical expenses.

In late June, the Senate Health, Education, Labor and Pensions Committee passed S. 2059, the Alzheimer's Research, Prevention & Care Act of 2002. The bill increases the federal commitment to Alzheimer's research. It now goes to the Senate floor. As of this writing, it is uncertain when the full Senate will act, and the bill does not guarantee funding as only the Appropriations Committee can do that. A companion bill (H.R. 4606) is pending in the House of Representatives.

With regard to the ongoing and perhaps unending debate on a prescription drug benefit under Medicare, the Republicans and Democrats continue to debate the extent of out-of-pocket costs to consumers and the overall costs of the benefit calculated at hundreds of billions of dollars over a ten year period.

— Ann Berson
Public Policy Coordinator



Dementia Home Care Graduations 2002

On July 2nd, a graduation ceremony was held at the Association for 14 home care workers who successfully completed our 43-hour Dementia Care Training Program. The participants chosen for the training are employees of The First Chinese Presbyterian Community Affairs Home Attendant Corporation, a Manhattan based agency. Certificates of Achievement were awarded to the proud graduates as agency staff, family members and friends looked on. Following the ceremony, a reception was held where guests and graduates celebrated this special occasion together and words of congratulations filled the air. This training was made possible by a grant from The Isaac H. Tuttle Fund.

— Paulette Michaud
Coordinator of Education and Training

Legal Guidance



IRAs & Medicaid Eligibility

In *re the Matter of the Appeal of Arnold S.*, a recent fair hearing, confirmed the unavailability of a Medicaid applicant/recipient's individual retirement accounts (IRAs), as long as they are in periodic payment status. This decision makes clear that an applicant's IRA will *not* be considered an available asset for Medicaid eligibility purposes, provided that the applicant is receiving periodic payments. The periodic payments (likely the minimum required distributions) will, however, be deemed to be available monthly income.

Approximately a year ago, we consulted with the family of an individual with dementia who needed nursing home care immediately. The individual had IRA's of approximately \$400,000 and very minimal additional assets. If we attempted to do traditional "rule of halves" planning, transferring part of the IRA and using the remainder to pay for nursing home care, a tremendous tax liability would have resulted. Traditional IRA's (non-Roth) are funded with pre-tax dollars and therefore taxes must be paid upon withdrawal of the funds.

At the time of our meeting, the common consensus among elder law practitioners was that the local Medicaid agencies would view IRA assets as an available resource. Inclusion of IRA's as available resources was significant – an applicant may retain no more than \$3,800 (for 2002) in order to qualify for Medicaid benefits.

In representing this particular family, we reviewed relevant statutes and regulations as well as New York's Medicaid Reference Guide and Medicaid's internal memorandums. We found that in 1998, Medicaid issued an internal memorandum (GIS 98 MA/024), which stated that, in part, "... once an individual is in receipt of or has applied for periodic payments, the principal in the retirement fund is not a countable resource. ... Once an individual is receiving periodic payments, the payments are counted as unearned income on a monthly basis, regardless of the actual frequency of the payment." In addition, the Medical Reference Guide had similar language regarding IRA's and other qualified retirement accounts.

Medicaid's actual policy seemed to be in direct conflict with its written policy. However, at the New York State Bar Association's annual Elder Law meeting in January of this year, Howard Gibbs, Esq. of New York City's Office of Revenue and Investigation stated that he believed that an IRA of an applicant is exempt. Shortly thereafter, a key individual in the Nassau County Department of Social Services also agreed.

Last fall, I presented these ideas to Rene Reixach, Esq. of Woods, Oviatt, and Gilman, a Monroe County elder law attorney who has had much success litigating elder law issues. Mr. Reixach was retained by Arnold S., a Medicaid applicant who held an IRA. Monroe County Department of Social Services ("DSS") did not agree that IRA's were exempt and Rene argued this issue on Mr. S' behalf.

On January 11, 2002 Arnold S. submitted a Medicaid application to the Monroe County DSS. The application was denied on March 29, 2002 due to excess resources. On the application, Arnold S.'s spouse had \$45,098.86 in individually held accounts. She also had an IRA of \$44,760.40 and the

Applicant had an IRA of \$55,791.04. The couple had a joint account of \$1,685.86. Both the applicant and spouse had been taking periodic payments from their IRAs.

DSS computed the total assets at \$147,336.16 and assets held by the spouse at \$89,859.26. Resources attributed to the applicant were \$57,516.16, calculated by subtracting the community spouse resources allowance ("CSRA" of \$89,820) from the total assets (\$147,336.16). Hence, the application was denied due to excess resources.

DSS asserted that because the Applicant could withdraw the funds in the IRA, the IRA assets are a countable resource, superseding the election to receive monthly payments. However, the hearing was decided in Arnold S.' favor. As the decision pointed out, DSS relied upon 88 ADM 30, which referenced the *old* Medical Assistance Resource Guide (MARG) at pages 247-249, which did not address retirement funds that are in periodic payment status. The correct reference is the Medical Reference Guide (MRG) at pages 257-258 and GIS 98 MA 024, which sets forth that once an individual is receiving or has applied for periodic payments, the retirement fund is not a countable resource.

Of course, the periodic payments received from the IRAs will be counted as unearned income on a monthly basis. A Medicaid applicant must apply for the maximum periodic income payments as a condition of eligibility. However, the decision provided that once an individual is receiving or has already applied for such payments, even if the payment amount is less than the maximum, the principal is not a countable resource.

The Arnold S. decision is certainly good news for Medicaid applicants who have assets held in retirement accounts.

–Ronald A. Fatoullah, Esq.



Ronald A. Fatoullah, Esq. is the managing attorney of Ronald Fatoullah & Associates. The firm concentrates on elder law, estate planning, Medicaid planning, guardianships, estate administration, trusts and wills. The firm has offices in Forest Hills, Great Neck, and Brooklyn. Mr. Fatoullah has been named a "fellow" of the National Academy of Elder Law Attorneys and has been a member of its board of directors for four years. He also serves

on the Executive Committee of the Elder Law Section of the New York State Bar Association, where he chairs its Legislation Committee. Mr. Fatoullah has been Certified as an Elder Law Attorney by the National Elder Law Foundation. This article was written with the assistance of Stacey Meshnick, Esq., an associate attorney at the firm.

Tributes - In Memory of...

05/01/02 - 07/31/02

Mr. Hyman Lawrence Aaron
Mr. & Mrs. Eric Waxman
Mrs. Margaret Abate
Frank Gerardi, M.D.
Mrs. Mother of Pat Acetta
Ms. Sandra Booklan
Ms. Jean Agnese
The Force Family
Ray Catena Lexus of Monmouth
Mrs. Carla A. Anderson Rota
Ms. Louise Alaimo
Mr. Joseph Gerry
Henrietta Albert
Mrs. Leah Richmond
Mr. Carmelo Alessi
Mr. Paul Guth & Maddy Dempster
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Walter, Marylou & Lucy Costanzo
Mrs. Constance Allocca
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Ms. Anita Meyerhoff
Ms. Enza Amato
Ms. Josephine Gulloto
Ms. Lucy Pavone
Mr. Edward Anderson
Joan & Earl Garrison
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Angelina Torrents, Miriam Rosin &
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Elliot & Adrienne Katz
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Ms. Rose Marie A. Savino
Ms. Connie Ann Velez
Phyllis A. Weltz & Family
Mr. Father of Steve Cooper
Ciciley & Abram Margolies
Mother of Bruce & Virginia Cornell
Mr. Arnold H. Kossoff
Mother of Dr. Steven Corwin
Sandra & Paul Izenman, Ellen & Nat
Savlowitz & Dondi & Alan Izenman
Mrs. Anna De Losa
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Ms. Theresa DeFrancis
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Mother of Louise Dembeck
Fraya I. Karsh, D.M.D.
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THE NEXT STEP: FROM AWARENESS TO ACTION

On November 7th, 2002, at the Crowne Plaza Hotel in Manhattan, the voices of people with Alzheimer's disease will once again be heard at the Third Annual Early Stage Alzheimer's Conference. Following on the heels of last year's highly successful event, a planning committee has been meeting since January to develop this year's conference. This committee consists of people with the diagnosis, caregivers and professionals from the tri-state (New York, New Jersey and Connecticut) area. The driving force behind the conference continues to be the person diagnosed with early stage Alzheimer's disease.

This year's conference theme is "The Next Step: From Awareness to Action." While the goals of the first two conferences were to challenge the stereotypes of people with Alzheimer's disease, raise public awareness, and influence public policy, this year's Conference advocates for more opportunities for people in the early stage to continue to contribute to society. It urges professionals in the field to develop programs which encourage early stage people to use their talents and abilities in a meaningful way.

This conference features nine new workshops, including one in Spanish, which will be offered during the morning, and again in the afternoon, enabling participants to attend two different workshops. There will be a medical update and a keynote address by Dana Tyler, news anchor, WCBS News. During the morning panel session, early stage people will discuss specific enriching activities in which they are involved. The audience will have the opportunity to dialogue with them, as well as with the professionals who facilitate the activities.

The following is an interview between the author of this article and Dr. William Deutsch, a person with early-stage Alzheimer's disease who has been active on the planning committee for two years and who participated in last year's conference. He discusses the importance of the current conference's mission.

Interviewer: Bill, you had a full-time podiatry practice with two offices. Your diagnosis forced you to give them up. What was the effect of that?

Dr. Deutsch: It was terrible! I had had a lot of responsibility, including performing surgery. When I began forgetting things and found I lost my concentration it became necessary to dispose of my practice and place my license on inactive status.. I had been working six days a week from eight a.m. to six p.m. and desperately missed the personal contact. But I was afraid of making mistakes that would harm my patients. It left a big hole in my life.

Interviewer: What about the effect on your family?

Dr. Deutsch: Having me around all the time created stress on my wife and some friction. I definitely withdrew and had difficulty adjusting to my new life.

Interviewer: What helped you adjust to your "new life?"

Dr. Deutsch: Activity! Having activity to turn to gets you through rough times. It gives direction and structure and stops you from dwelling on yourself.

Interviewer: How did you locate activities?

Dr. Deutsch: I got on a web site and looked up Alzheimer's, but there was not a lot out there. I was lucky – I had a lot of interests, like music for example. I started taking piano lessons. I'm slower than a five-year-old, but I'm still at it.

Interviewer: Do you think that the Alzheimer's professional community has a role in responding to the needs of early stage people?

Dr. Deutsch: Definitely. You can't just depend on your family. Some people can find things on their own, but many can't. A diagnosis of Alzheimer's disease freezes you into passivity. You don't have the courage to venture out on your own. People need a push so they won't become withdrawn. If the professional community offered more programs, they can help people realize that there are many pleasurable things they can do.

Interviewer: What types of programs would you like to see?

Dr. Deutsch: I would like to see programs that are creative and enjoyable and also facilitate memory and concentration. There is not a lot you **can't** do in the early stage. You may not become a chess master, but perhaps you can still play some chess. You can paint, write, travel, make music. You can use your skills in volunteering. And some of us can still learn new things.

Interviewer: What do you hope that this will Conference accomplish?

Dr. Deutsch: It is my hope that this Conference will spearhead many new programs and opportunities for early stage people. The professionals can help people with the diagnosis retain dignity and a positive self-image so that we can use our remaining abilities to feel useful, be creative and make contributions.

– Susan Goldfein, Ed.D.
Conference Coordinator

FOR MORE INFORMATION ABOUT THE THIRD ANNUAL EARLY STAGE CONFERENCE CALL (212) 983-0700, ext. 230, OR LOG ON TO THE NYC CHAPTER WEBSITE AT www.alzheimernyc.org.

New York Citizens' Committee

The New York Citizens' Committee on Aging is holding a conference entitled, "Women and Aging: Issues for Life," on Wednesday, November 13th from 9:00 AM to 1:00 PM at the Cherkasky/Davis Conference Center of 1199 National Pension and Benefit Fund, located at 330 West 42nd Street, NYC. The Alzheimer's Association, NYC Chapter is a co-sponsor of the conference which will focus on the economics of aging as it impacts women. Issues to be addressed include access to health and health care, multi-generational family responsibilities, income security and inequalities, and the needs of women in the workforce. Breakfast and registration start at 8AM. There will be a small charge.

Contact Paulette Geanacopoulos at (212) 353-3950 for further information.

14th Annual Luncheon Honors Volunteers

The Fourteenth Annual Volunteer Celebration was held on May 21, 2002 at the United Nations. Over 100 volunteers were welcomed by Board Co-President, Bill Kaye. Special Guest, Commissioner Marjorie B. Tiven, New York City Commission for the United Nations Consular Corps and Protocol, brought greetings from Mayor Bloomberg. The theme of the event was an International Buffet featuring a selection of foods from many different countries. Thanks to the generosity of various Home Care Agencies, the luncheon concluded with a spirited raffle of gift certificates for volunteers.



"Women's Auxiliary Members smile for the camera" Left to right – Mimi Wajsbort, Mickey Rosenberg, Jean London, Antonieta Castro, Hannah Bernstein, Sandy Kalison.



Left to right – Reva Hoffman, Helpline Coordinator and Alissa Pizzutiello, Support Group Leader



Left to Right – Laurie Wasserman, Support Group Leader; Lore Wallach and Joan Zimmerman, Helpline Volunteers



Commissioner Marjorie Tiven, New York City Commissioner to the United Nations "Brings greetings from Mayor Bloomberg"



Barbara Lepis, Coordinator of Volunteers "welcoming guests"



Left to right – Edith Rappy, Angie Memisha, June Schofield



Roberta Goodman, Past President Board of the NYC Chapter and Bill Kaye, current Co-President of Board "attend event to personally meet and thank volunteers"

ALZHEIMER'S RESEARCH SYMPOSIUM

For those of us beginning to lose hope in the battle against Alzheimer's, some degree of consolation is afforded by the ever-accelerating pace of research. All over the world, in laboratories, on web sites, in journals, and in conferences, reports are pouring in of studies, discoveries, and sometimes of possible therapies. Often we are disappointed, as in the recent suspension of tests of the vaccine (AN 1792) that offered promise of a weapon against AD. But science is undaunted. When researchers meet to share ideas to push the boundaries of our knowledge a bit further, we think we may be drawing closer to defeating Alzheimer's. One such meeting (co-sponsored by the NYC chapter of the Alzheimer's Association and funded by the Capital Institute for the Study of Aging) was recently held in our own city at the New York Academy of Science.

On May 2, 2002, before an audience of professionals and laymen, three distinguished researchers presented their findings at the Third New York Alzheimer's Research Symposium. Aided by graphic images projected on a large screen, Peter St. George Hyslop, M.D. of the University of Toronto; Huaxi Xu, Ph.D. of Rockefeller University; and Nocole Schupf, Ph.D. of Columbia University reported on what is surely the cutting edge of Alzheimer research.

Although there is disagreement about the cause of Alzheimer's, most current thinking tends to place the blame on the so-called amyloid plaques, clumps in the brain of a protein called beta amyloid. The three speakers at the symposium discussed the nature and generation of these plaques. While their research is too technical for the average person, it is clear that science is taking aim at these plaques. This effort has been considerably aided in the past several years by the development of "transgenic" mice, creatures who have been bred to develop amyloid plaques in their brains.

In his study, Dr. St. George Hyslop found that early-onset familial Alzheimer's disease may be caused by mutations in certain genes called presenilin 1 or presenilin 2. These mutations increase production of a highly toxic form of the amyloid protein. There are other biochemical factors in the brain, still being studied, that contribute to the amyloid build-up. The implication of these findings is that development of specific inhibitors of beta amyloid production might be an effective therapy for Alzheimer's Disease.

Dr. Huaxi Xu examined the action of the presenilin 1 gene in a "cell-free" system, noting that it leads to an increase in beta amyloid production. Dr. Nicole Schupf studied the effect of beta amyloid in the brains of Down Syndrome individuals, who develop dementia 10 to 30 years earlier than non-Down individuals. Both Dr. Huaxi Xu and Dr. Nicole Schupf lent support to the theory that better understanding of the process by which beta amyloid is generated and the ability to regulate or reverse this process might be effective against AD.

And so we in the Alzheimer's Association and affected individuals the world over continue to applaud the efforts of these and other researchers, awaiting the day when we can say for sure that beta amyloid is the villain and that we have found a way to control it.

—Jack M. Pollock

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Nursing home family caregivers needed!

If you are the primary caregiver for a family member/friend living in a nursing home, you are eligible for the Nursing Home Family Study, funded by the National Institutes of Health. Help us understand what you are going through and earn \$25 for a one-hour interview (in-person or by phone at your convenience). You may be eligible to complete a brief second interview and receive an additional \$25.

To learn more, contact Dr. Deborah Majerovitz, York College, City University of New York, 718-262-2498 or majerovitz@york.cuny.edu

Mood and Memory

Individuals who are experiencing some depression and mild memory problems may show improvement in memory with effective treatment of their depression. Researchers at New York Presbyterian Hospital are currently examining the effectiveness of FDA approved medications in this area. All treatment is provided free of charge. For more information, please contact Nicole Juszcak at (212) 543-5067.

Stress and Memory

Recent advances in functional brain imaging procedures have allowed us to evaluate the blood flow changes within the brain under various conditions. The goal of this study is to evaluate the role stress plays on the immediate blood flow within the brain. We are currently recruiting young health men, age 20 to 40, to participate in two days of Positron Emission Tomography (PET Scanning). Participants will receive considerable financial compensation. For more information, please contact Maggie Padilla at New York Presbyterian Hospital (212) 543-6651.

Help Prevent Hip Fractures

There is a new product that helps prevent hip fractures in persons at risk for falls. It's called **HipSavers**. This product has been tested and proven effective. It's worn as an undergarment and has padding over both hips. One of the reported benefits of this product over like products is the pads are a permanent part of the garment. Thus, when laundered, there is no risk of losing the pads (which is a predictable problem - particularly in large facilities where laundry is part of a mass production effort). They cost between \$29 and \$39 a pair and can be purchase on the internet at www.hipsavers.com.

Another source of hip pads is the online Alzheimer's store at www.alzstore.com. They have a product named SafeHip, but the pads in this product are removed before laundering.

Hormones and Memory

This study is designed to help understand the relationship between immune and hormonal systems and their effect on memory and emotion. In this study we evaluate the effects of small amount of adrenaline (a naturally occurring substance released by one's body during stress) on different biological systems. Three groups of subjects are currently being recruit, healthy elderly subjects, elderly subjects with depression, and elderly subjects with mild cognitive impairment. Participants will receive financial compensation. For more information, please contact Maggie Padilla at New York Presbyterian Hospital (212) 543-6651.



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