

advANCES

PROGRESS IN ALZHEIMER RESEARCH AND CARE

Alzheimer's Disease Costs Businesses Billions

Alzheimer's disease costs American businesses \$33 billion a year, according to a recent study commissioned by the Alzheimer's Association.

The study found businesses lose \$26 billion due to absenteeism by caregivers—employees caring for people with Alzheimer's disease, including spouses and parents. Businesses pay another \$7 billion toward the total cost of care.

"It's been assumed that businesses don't have to be concerned about Alzheimer's because most people get the disease after age 65. This report shatters that assumption," says Edward F. Truschke, Alzheimer's Association president and CEO.

Businesses not only lose productivity due to caregiver absences but spend billions replacing caregivers who leave the workforce or take a leave of absence, utilizing temporary employment agencies and continuing health care coverage for those on leave.

IBM/Tivoli vice president Lynn Wilczak says the study is very conservative based on her experience.



Caregiver absenteeism costs businesses \$26 billion each year.

"Employees are affected when they try to cover for a distracted or interrupted employee who has caregiving responsibilities."

On average, a full-time employee with caregiving responsibilities is absent 12 full or partial days per year, is interrupted an average of 50 hours per year, and has other time losses totaling 23 days per year.

The cost to businesses and society is probably far greater than projected because many factors, such as the amount of money spent on employees with the disease, could not be measured in the study.

"The actual cost might be two to three times higher," said Ross Koppel, PhD, professor of sociology at the University of Pennsylvania, who conducted the study.

As baby boomers age, the costs to businesses and society will grow dramatically.

"The nation needs to invest more in Alzheimer research in order to stop this rising epidemic," said Truschke.

The Alzheimer's Association has already pledged to triple its own research investment to \$30 million a year in the next three years. And as a result of the efforts from hundreds of Association advocates, Congress approved a \$50 million increase in federal funding for Alzheimer research. 

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Bad Reaction to Medication

Your article, "Is Your Medication Helping or Hurting?" alerted me. My husband has been to three doctors, and each prescribed a different medication. I immediately called my pharmacist to ask about any side effects since I noticed that he has not felt good since the drugs were prescribed. The pharmacist told me that my husband may be taking too many drugs. The doctor now wants to see my husband again. Thanks.

*Frances Barnhart
French Camp, Calif.*

Alzheimer's Is Nothing to Joke About

The "political incorrectness" of joking about Alzheimer's disease by the general public needs to be addressed. Every time I hear an Alzheimer's joke it is like putting a knife through my heart.

I would appreciate suggestions on how I can best respond when these situations arise.

*Nancy Judson
East Greenbush, N.Y.*

WE WANT TO HEAR FROM YOU!

Please share with us your experiences related to issues covered in *Advances* or suggest topics you'd like to read more about.

Memory Walk Raises Record \$12 Million

More than 120,000 walkers in over 300 communities nationwide participated in the Alzheimer's Association's *Memory Walk* held in October. The walk raised more than \$12 million for programs and services for people with Alzheimer's and their families. An all-star cast of celebrities, including David Hyde Pierce of *Frasier*, Shelly Fabares of *Coach*, Sharon Lawrence of *NYPD Blue*, and Nancy O'Dell of *Access Hollywood*, participated in the *Talk the Walk*, a lighthearted competition among celebrities to recruit friends for the walk.



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For more information on Alzheimer's disease and the Association or to be placed on the *Advances* mailing list, call (800) 272-3900. Information is also available via the Internet at <http://www.alz.org>

Send letters to Michele Pellissier, Editor; faxes to (312) 335-1110; and e-mail to michele.pellissier@alz.org. *Advances* does not publish unsolicited poems or short stories or accept advertisements.

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Coping with Loss

Alzheimer's disease is commonly called the "long good-bye." This is an appropriate designation for a disease that can span from 2 to 20 years. Throughout its unpredictable course and long after, caregivers experience varying degrees of loss.

First, caregivers mourn the loss of the relationship and companionship once shared with the person who has dementia. Second, they must cope with the fact that their plans for the future have changed dramatically. Finally, they must grapple with a loss of self and change in identity after assuming various caregiving responsibilities.

"Caregivers are so preoccupied with caregiving responsibilities that they often don't pay attention to their feelings," says Naomi Naierman, president and chief executive officer of American Hospice Foundation.

Feelings of loss may first express themselves as denial and anger. Caregivers often disbelieve that the person with Alzheimer's is really ill and may feel frustrated with the person and with demanding caregiving tasks. Physical symptoms, such as weeping, sighing, changes in appetite and sleep, and exhaustion, are also common among caregivers, especially right after the disease is diagnosed.

Throughout the grieving process, many caregivers are overwhelmed with guilt. Guilt may stem from feelings of failure or a sense that something different could have been done after the person was diagnosed, especially if the person with Alzheimer's must be placed in a care facility. In many cases, guilt is linked to unrealistic expectations that caregivers place on themselves or to thoughts that "I must be perfect" or "I must do everything." Caregivers may also experience burnout and depression as a result of not being able to ask for or accept help from others.



Because people with Alzheimer's disease may appear to be physically well, family and friends may not understand or recognize a caregiver's grief.

"Caregivers feel tremendous guilt when they grieve for a loved one who has not yet died but is otherwise gone," adds Naierman.

Because the person with Alzheimer's may appear to be physically well, family and friends may not understand or recognize a caregiver's grief. As the disease progresses, many feelings of loss may be overlooked or not validated by others.

"When feelings of loss can't be shared, caregivers may feel very isolated and emotionally neglected," says Naierman. "They may defer grief, bury it, and carry the emotional burden."

Every person has his or her own way of dealing with loss. Because each family member may perceive loss in different ways or be at different stages in the mourning process, conflict often arises. Taking the time to allow each family member to share feelings about loss in a nonjudgmental setting may help strengthen family unity.

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Today Show Series Sparks Questions from Families

A three-part series on Alzheimer's disease, recently aired by NBC's *Today* show, left many people wanting more in-depth information about research and treatments.

A featured expert in the series, Jeffrey Cummings, MD, of the Alzheimer's Disease Center at UCLA, discussed the status of Alzheimer research and the many potential treatments that have appeared in the news over the past year.

Following the series, the Alzheimer's Association received thousands of calls. We asked Cummings the most popular questions posed by callers.



Jeffrey Cummings, MD, talks with *Today* show host Ann Curry about treatments for Alzheimer's disease.

Q: Is there anything a person can do or take to prevent Alzheimer's disease?

A: Currently, no medications exist to prevent Alzheimer's disease. Some potential risk factors being studied are low levels of education, head injury, and high blood pressure. Recent studies show that higher education levels and a reduced risk of head injury may make Alzheimer's less likely. Also, because there may be an interaction between blood vessel problems in the brain and Alzheimer's disease, controlling high blood pressure may help reduce the risk of blood clots that may destroy nerve cell function.

Q: Can ginkgo biloba help with the memory loss associated with Alzheimer's?

A: Ginkgo biloba produced a very mild improvement in cognitive function in individuals with Alzheimer's disease in a study published in the October 22/29, 1997, issue of the *Journal of the*

American Medical Association. The findings were small and indicated that the group on the drug could not be distinguished easily from the group receiving a placebo (sugar pill). According to this study, if ginkgo biloba has a positive effect, the benefit appears to be modest.

Q: Does vitamin E help? If so, what is the recommended dosage?

A: Vitamin E was shown to slow the progression of Alzheimer's disease by 25 percent, according to a study published in the April 24, 1997, issue of the *New England Journal of Medicine*. In the study 2,000 International Units (IUs) of vitamin E taken for two years

delayed the clinical signs and symptoms of the disease for people with moderate Alzheimer's disease. The U.S. Government Recommended Dietary Allowance for vitamin E is 30 IUs per day. Because vitamin E may be associated with increased bleeding in individuals with risk factors for these problems, all decisions regarding medications or vitamin supplements should be discussed with a physician.

Q: What drugs should *not* be taken with donepezil (Aricept)?

A: Donepezil has been shown to interact with very few other drugs. It should not be given with other cholinesterase inhibitors such as tacrine (Cognex) or with anticholinergic drugs, such as trihexyphenidyl HCl (Artane) and benztropine mesylate (Cogentin), that fight the effects of donepezil. Interactions with other drugs that have many anticholinergic side effects, such as amitriptyline or thorazine, should also be avoided.

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Q: Would donepezil help the average person who experiences occasional forgetfulness but has not been diagnosed with Alzheimer's?

A: Occasional forgetfulness — not remembering the name of an acquaintance or losing your car keys — is common in the course of normal aging and does not indicate the presence of Alzheimer's disease. Donepezil has been studied *only* in individuals who have been diagnosed with mild to moderate Alzheimer's disease and is not recommended for memory loss observed in the course of normal aging.

Q: What are some of the "new" antidepressants and "novel" antipsychotics, and how are they more helpful to individuals with Alzheimer's disease than "older," more conventional drugs?

A: The "new" antidepressants belong to a class of drugs known as selective serotonin reuptake inhibitors (SSRIs). This class includes sertraline (Zoloft), paroxetine (Paxil), fluoxetine (Prozac), fluvoxamine (Luvox), and citalopram (Celexa). These

drugs have fewer side effects than more traditional antidepressants. Fluvoxamine and citalopram have been studied in individuals with dementia and have been shown to relieve depressive symptoms.

"Novel" antipsychotics include risperidone (Risperdal), olanzapine (Zyprexa), and quetiapine (Seroquel). These agents are less likely to induce adverse side effects such as Parkinsonism and abnormal muscle movements than traditional antipsychotic drugs like haloperidol (Haldol).

Q: You mentioned that proteins were involved in the disease process. What proteins were you referring to? Should people with Alzheimer's lower their protein intake or avoid protein altogether?

A: One of the proteins that accumulate in the brains of individuals with Alzheimer's disease is amyloid protein. Amyloid is a product of abnormal brain function in Alzheimer's disease and does not appear to be affected or induced by proteins in the diet. No changes in diet are recommended at this time. 

This article is not intended to be medical advice. Always consult your physician before taking any treatments.

R_x CORNER



Metrifonate Study on Hold

Bayer Corporation, in consultation with the Food and Drug Administration (FDA), has temporarily postponed all clinical studies of its drug metrifonate (ProMem). Metrifonate was pulled from studies after serious muscle weakness was reported in 20 cases out of more than 3,000 people treated with the drug. Bayer is now collecting all relevant data and performing an in-depth analysis of its studies, with plans to resume clinical trials within the next few months. Bayer had submitted metrifonate to the FDA in late 1997 for approval for the treatment of mild to moderate Alzheimer's disease.

Clinical drug studies currently recruiting patients with Alzheimer's disease include:

- Donepezil HCl (Aricept)
- ENA 713 (Exelon)
- Estrogen
- Idebenone
- Lazabemide
- Melatonin
- Women's Health Initiative Memory Study of Estrogen

For information about these studies, call your local chapter or (800) 272-3900 and ask for the drug fact sheets.

The Struggle to Pay for Alzheimer Care

While the future of Medicare is being debated in Washington, most Alzheimer families are depleting all of their resources to pay for care.

The costs of caring for a person with Alzheimer's are high, averaging close to \$175,000 throughout the span of the disease. For that reason, it is important to find out what financial resources and programs exist as soon as a diagnosis of Alzheimer's has been made.

Make a Plan

If you are a caregiver for someone with Alzheimer's, advance planning can help you meet some of the financial expenses you will face. You may be responsible for financial duties, including paying bills, arranging for benefit claims, making investments, and preparing tax returns. The following suggestions can help you begin to understand your financial picture:

Assess your needs

Discuss immediate and future financial needs while the person with Alzheimer's still has the capacity to understand, express his or her opinion, and take part in decision making.

You may want to involve other family members in the discussion, particularly when it comes to sharing caregiver duties and expenses. Meet initially to identify the needs and wishes of the person with Alzheimer's and to explore different resources and options available.

Then define roles and agree to specific actions. For example, name who will keep track of medical expenses or drive Mom to the doctor. Keep in mind that the needs and abilities of the person will change over time, so caregiving responsibilities and plans may need to be renegotiated.

Locate legal and financial documents

Gather legal documents such as wills, living wills, and medical powers of attorney. Also, you may want to find financial documents, including bond certificates, bank and brokerage account statements, Social Security payments, retirement benefits summaries, and insurance policies.

Review your financial picture

The person with Alzheimer's may not have all the financial resources he or she will need to pay for care. You may need to review your own sources of income to see if your insurance plan will meet future financial needs. If the person is financially dependent on you, consider what plans should be in place in case something were to happen to you, such as naming a second caregiver.

Work with a professional

Qualified professional advisers such as financial planners, estate planning attorneys, and accountants can help coordinate financial strategies, locate potential financial resources, identify tax deductions, and make sound investment decisions. Also consider working with professionals who specialize in elder

care issues such as laws affecting the elderly, health care and aging, and money management. Your local Alzheimer's Association chapter can refer you to professionals in your community. In addition, many banks have programs to assist elderly people in paying bills and conducting financial transactions.

Identify Expenses You May Encounter

Because different levels of care may be needed as the disease advances, it is important to start planning a long-term budget as soon as possible. Start by writing down potential expenses, including costs for

ongoing medical treatment, prescription drugs, care services, and consumable supplies such as incontinence products, nutrition supplements, and skin care items.

The costs for caring for a person with Alzheimer's are high, averaging close to \$175,000 throughout the span of the disease

"Caregivers tend to save their money for the more expensive care at the later stages," says Tim Millar, certified financial planner. "Using resources for early-stage services such as respite care can increase quality of life for the caregiver and the person with Alzheimer's."

Seek Out Resources

A long list of expenses may be overwhelming at first; however, there are many financial resources available, including:

- **Health Care Insurance:** Health care insurance may include private and retiree insurance and Medicare.
- **Medicare:** Medicare is a federal health insurance program generally for people age 65 or older who are receiving Social Security retirement benefits. Medicare covers inpatient hospital care and a portion of the doctor's fees and other medical expenses. There are specific eligibility requirements for this program. Medicare covers some, but not all, services a person with Alzheimer's disease may

require. Applications for Medicare can be sent to a local Social Security office.

- **Medigap:** Medicare coverage can be supplemented with Medigap, a private insurance that covers copayments and deductibles required by Medicare. The more expensive policies may cover prescription drugs.
- **Medicare HMO (Medicare Managed Care):** Medicare HMO offers some additional benefits and less paperwork in exchange for restrictions on choices of hospitals, doctors, and other professionals. Medicare HMO plans vary by location, the type and amount of service provided, government reimbursement, and choice of providers. Most Medicare HMOs cover nursing home and home health care for limited periods only under special circumstances.
- **Medicaid:** Because Medicaid is a federal program typically administered by each state's welfare agency, eligibility and benefits vary from state to state. Medicaid covers all or a portion of nursing home costs. A person with Alzheimer's can qualify for long-term care only if he has minimal income and cash assets. Most Medicaid dollars go toward nursing home care expenses, but states are developing home and community care options under "waivers" for some people who qualify for nursing home care.

The person with Alzheimer's should be very careful about giving assets away to family members in order to qualify for Medicaid. There are strict laws governing this area. Families should have a thorough understanding of the legal and financial implications respecting transfers and seek proper advice before proceeding.

- **Retirement Benefits:** Retirement benefits that provide critical financial resources include retirement

SEE PAYING FOR CARE, PAGE 11

New Guide Offers Tips on Selecting a Nursing Home

Placing a loved one in a nursing home is one of the most agonizing decisions that families must make. Finding the right facility to meet the needs of the person with dementia can be challenging and time consuming. The new Alzheimer's Association

publication, *Residential Care: A Guide for Choosing a New Home*, offers ideas about what questions to ask and what look for in order to find a place that provides quality Alzheimer care.

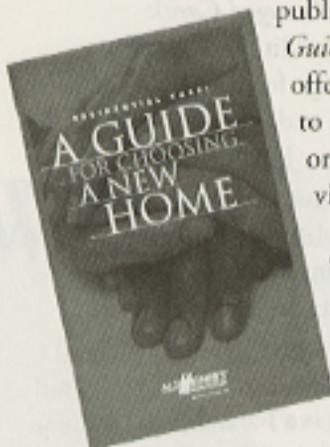
The guide offers questions to help you determine

- the facility's approach to caring for Alzheimer residents

- the facility's process for developing a care plan
- what assistance is provided specifically for persons with dementia
- the types of activities offered
- staffing levels and the staff's qualifications
- how the environment supports the person with dementia.

Additionally, tips for preparing caregivers and the person with Alzheimer's for the transition from home to nursing home are included. Caregivers can also learn ways to stay involved in caregiving after their loved one has been admitted to a facility.

To request a copy of *Residential Care: A Guide for Choosing A New Home*, contact your local chapter of the Alzheimer's Association or call (800) 272-3900. 



Disclosing the Diagnosis: Should the Truth Be Told?

Families and professionals often struggle with the decision about whether or not to tell an individual that he or she has Alzheimer's disease.

The Alzheimer's Association recommends that professionals disclose the diagnosis to the individual with Alzheimer's disease. The diagnosis may need to be disclosed to families first though in cases where the individual with the disease may not have the capacity to understand what's happening. Telling the individual with Alzheimer's early in the disease process allows him or her to play an active role in planning for the future.

What are your thoughts on this difficult issue?

- Should the person with Alzheimer's be told of the diagnosis?
- Is it always best to tell the truth even if the person is severely impaired when diagnosed?
- Who should disclose the diagnosis – physicians or family members? 

Send your opinions to:

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LOSS...CONTINUED FROM PAGE 3

In order to cope with feelings of loss, caregivers should try to:

- **Accept and acknowledge feelings whenever they arise.** Know that they are a normal part of the grieving process.
- **Talk to others.** Share feelings with family, friends, and with other Alzheimer caregivers. If necessary, seek therapy from a professional who specializes in grief counseling. Support groups sponsored by the

When feelings of loss can't be shared, caregivers may feel very isolated and emotionally neglected.

Alzheimer's Association offer the opportunity for caregivers to express feelings and receive validation from other caregivers.

- **Monitor health and well-being.** Physical and emotional stress from caregiving can take its toll if caregivers are not careful. It is very important to visit a physician regularly. If grief is so prolonged or severe that physical and mental health deteriorate, caregivers should consider being tested for depression.
- **Do things you once enjoyed.** Caregivers often give up enjoyable activities and companionship. Try to incorporate these into your daily routine. Reconnecting with friends, relatives, and the community may relieve stress and strengthen the support network.
- **Locate support services.** The local chapter of the Alzheimer's Association can refer you to services such as support groups and respite care in your area. Also, local hospice programs offer grief programs and support groups that may help caregivers through this difficult time. 

People with Alzheimer's Also Suffer Loss



Caregivers and family members should also acknowledge the feelings of loss that the person with Alzheimer's disease may be experiencing including:

- Loss of independence
- Inability to make decisions
- Decline in cognitive and physical abilities
- Difficulty communicating
- Inability to drive a car
- Trouble performing routine tasks
- Inability to continue working
- Changes in personal relationships

As the disease progresses, communication can become challenging. Sensitive, ongoing communication is important, no matter how difficult it may become or how confused the person may appear.

People with Alzheimer's often feel isolated and lonely because friends and family can't fully understand what they are going through. Many of the Association's chapters operate support groups specifically for individuals with Alzheimer's disease. To locate the chapter nearest you, call (800) 272-3900.

Q & A presents answers to your research or caregiving questions from leading professionals in the field of Alzheimer's disease. Debbie Greiner responds to the following question about visiting a person with Alzheimer's.

Q: *My mother has Alzheimer's disease and lives with my family. With the holiday season approaching, we will have a number of visitors in our home. How can I educate visitors about what to expect when visiting someone with Alzheimer's, and how should I prepare my mother?*

A: When someone you love has Alzheimer's disease, it can add a lot of stress to your daily life. Combine that with the ordinary stresses of the holidays, and you have a recipe for potential disaster.

Visiting an individual with Alzheimer's, whether it is at someone's home or in a care facility, is exceptionally difficult for many people. It is also difficult for the person who has Alzheimer's since visiting may disturb the person's routine.

If you have family and friends coming in to your home or visiting a facility, consider explaining how the individual with Alzheimer's may have changed. Let them know that the affected person may wander, fidget, or display other strange behaviors. Offer tips for communicating with the person who has Alzheimer's. For example, ask visitors to:

- **Introduce themselves** every time they come. "Hi, Mom, it's Sue. I came to visit."
- **Be flexible.** Don't have too many expectations of the visit.
- **Involve the person with Alzheimer's** whenever possible. Give the person the ability to feel useful.

Looking at old photos with a person who has Alzheimer's is a useful way to help them reminisce.



Bring pictures that you can put into an album together, help the person decorate a card for someone, or go for a walk together.

- **Help the person reminisce.** Sing favorite holiday songs or look through photos from past holidays.
- **Look at the person's behavior as a communication tool.** When words are no longer available, body language often tells the story loud and clear.
- **Limit the number of people** visiting at one time. Too many people may be overwhelming for the person with Alzheimer's.
- **Avoid disagreeing** with the individual.

People with dementia are very astute and can read discomfort, fear, and anxiousness very well. So, be sure that visitors are comfortable and want to be there. Also, more is not always better. A "short and sweet" visit can often end with more positive results.

Preparing the individual with Alzheimer's for the visit may not be quite as easy as preparing visitors. You may find that the best way to handle it is to prepare yourself. A good rule of thumb is to establish a focus for the visit. It should be something that the person with Alzheimer's has appreciated in the long-term past. Long-term memories remain intact for a longer period of time, so while last year's holiday may be lost, a Christmas from many years ago may still be a treasured memory.

While preparing yourself for the visit, try not to plan too much. Take on only as much as both of you can easily handle. It may also help to maintain your

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Q & A...CONTINUED FROM PAGE 10

loved one's routine as much as possible. Try blending seasonal rituals with regular activities, like taking walks.

Above all else, remember that it is difficult to visit someone who may no longer resemble the person you once knew. Make the most of each moment that you have with your loved one, and encourage visitors to do the same. 

Debbie Greiner is the director of Alzheimer Services at Whitehall North in Deerfield, Illinois.

Send us your questions...

If you have a question you'd like to ask about Alzheimer research or care, please mail it to: Alzheimer's Association, 919 North Michigan Avenue, Suite 1000, Chicago, Illinois 60611-1676, Attn: Sara Dusenbery, or send e-mail to: sara.dusenbery@alz.org.

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plans, individual retirement accounts (IRAs), annuities, and Social Security.

- **Personal Savings, Investments, and Property:** Investment assets (stocks and bonds, savings accounts, real estate, etc.) and personal property (jewelry, artwork, etc.) can be sources of income. Money from the sale of a home can be invested, or a reverse mortgage can be taken out on a home. This type of home equity loan allows a person age 62 or older to convert home equity into cash while retaining ownership. The person's eligibility to borrow generally is based on age, the home's equity, and the interest rate the lender is charging. Since home equity is an older person's most valuable asset, be sure to consult with your loved one, an attorney, and a financial adviser before applying.
- **Tax credit:** If the person is a dependent under federal tax regulations, you may be eligible for medical expense deductions and dependent care credits. You may also be entitled to a tax credit if you are deemed a "qualifying person," that is you live with a spouse or dependent who is physically or mentally incapable of self care and you incur expenses for his or her care so that you can continue to work.

Your local Alzheimer's Association chapter or religious and community organizations may provide or

help you locate low-cost or free services, including respite care and support groups. Your local Area Agency on Aging or Department of Health and Human Services can often help you, too.

These are just some of the many resources available to caregivers. Before taking any action, however, be sure you have involved your loved one and your family whenever possible in decision making and planning. 

Alzheimer's Association Resources

The Alzheimer's Association can help you locate financial resources in your area. To find the chapter nearest you or to request the following Association publications, call (800) 272-3900.

- *Taxes and Alzheimer's Disease*
- *Understanding Medicaid Long-Term Care*
- *Medicare HMOs: Tips for Consumers*

The information included in this article is not intended as financial advice. Consult a trusted financial professional to help you prepare financially for the cost of care.

Association Awards Its First \$1 Million Research Grant

The Pioneer Award for Alzheimer Research, the largest grant ever given by the Alzheimer's Association, was recently awarded to two scientists researching new methods for early diagnosis of Alzheimer's disease. This award is one of the largest research grants in the field of Alzheimer research.

The recipients, John Q. Trojanowski, MD, PhD, and Virginia M.-Y. Lee, PhD, study neurodegenerative diseases, including Alzheimer's and Parkinson's, for which both have received numerous awards. The two scientists are also husband and wife.

"Alzheimer's is a debilitating disease that robs victims of the very core of their being," says Trojanowski. "Dr. Lee and I are committed to continuing our research in the hopes of realizing a cure in the near future."



Lee and Trojanowski are working to improve Alzheimer diagnostics.

Trojanowski served as chair of the Alzheimer's Association's Reagan & Nancy Reagan Research Institute working group on diagnostic criteria for the neuropathological assessment of Alzheimer's disease. In 1991 Lee received the Association's Zenith Award for research.

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