

## Alzheimer's Disease Centers An infrastructure for research, caregiver assistance

Marsel Mesulam, MD, had his goal clearly in sight from the start. Back in 1996, the National Institute on Aging awarded a \$4 million grant to Northwestern University to open an Alzheimer's Disease Center (ADC). At the time, Mesulam, named to head the Northwestern site, sent a newsletter to his university colleagues outlining the new program.

The center, he stressed, would forge a firm "commitment to excellence in all areas of research, education, and patient care ... [with the ultimate beneficiaries being] patients and their families."

Four years later, on a late winter afternoon, Mesulam sits in his 11th floor office at Northwestern University, talking about the accomplishments of Northwestern's center and, more generally, of the federal government's ADC program.



Neuropsychologist Nancy Johnson, PhD (right), of Northwestern University's ADC, educates family caregivers about the disease and provides strategies for reducing stress.

"Our center here is a full-service facility," says Mesulam. "We engage in basic science research and, through our clinic, we provide patient care, psychosocial outreach, and support for caregivers."

During the past four years, researchers from Northwestern have, among other accomplishments, identified new neurotoxins that may spur nerve cell malfunction, developed new methods of studying neurofibrillary tangles, and established a brain bank with more than 100 specimens available to scientists nationwide.

Discussing his center's growth, Mesulam is quick to identify the federal government's role. "What the National Institute of Aging provides with its ADC program," he says, "is an infrastructure for research and patient care. It primes the pump for further accomplishments."

Established in 1984, the NIA's Alzheimer's Disease Centers program represents the U.S. government's response to the growing threat posed by Alzheimer's. Federal officials aimed to build a national network of research projects focused on finding a cure and helping those afflicted.

Prior to the early '80s, Alzheimer studies were few, recalls Zaven Khachaturian, PhD, former director the NIA's office of Alzheimer's research who was a key mover behind the establishment of the ADCs.

"There had been no systematic studies on Alzheimer's," he says. What's more, "some people in the scientific community didn't recognize the need for the centers program," continues Khachaturian, who currently serves as senior science adviser to the Alzheimer's Association. "There was a substantial amount of misgiving. They thought funding individual projects would be a much better idea because putting together a large program would entail a major commitment of money."

But Khachaturian and others pressed for the centers, an effort that involved educating key members of congress and



Marsel Mesulam, MD, heads Northwestern University's ADC.

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others. When congress eventually passed legislation for the centers, opposition disintegrated and the program began to take shape.

Aside from supporting basic research, the centers today also “provide a mechanism for enrolling patients in studies in order to learn how to provide more effective diagnosis and care,” says Creighton Phelps, PhD, current director of the NIA’s Alzheimer’s Disease Centers program. “Centers also are very involved in training and education, technology transfer, and cooperative studies of diagnosis, treatment, and [brain pathology] correlations.”

During its 16-year history, the ADC program has helped spur a number of advances. These include identification of four genes (on chromosomes 21, 19, 14, and 1) linked to Alzheimer’s. The ADCs also provide research resources such as patient data, brain and other tissue samples, and molecular probes.

A recent priority has been to encourage collaboration among the centers. “Last year,” says Phelps, “we set up what we call the National Alzheimer’s Coordinating Center in Seattle. This is a very large operation where data from all the centers are now being collected in one place. Now we can do studies based on pooled data. This is a big, big step forward.”

Starting with five centers in 1984, the ADC program today numbers 29 participating medical institutions. Some of these centers “have elected to specialize in certain areas,” says Phelps.

Caregiving studies, for instance, have been a priority at the New York University ADC. “Our work has been based on the realization that an important part of the Alzheimer’s issue is dealing with families—that is, develop-

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**Says DeKosky: “Speaking not as a director of an ADC but as a scientist and clinical researcher, I can say that without the center’s program—its support for basic research and clinical studies—we wouldn’t have gotten this far.”**

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ing support and intervention strategies,” says Steven Ferris, PhD, director of the center. In the late 1980s, researchers at the center designed a program for caregivers that consists of quality care strategies, support groups, and counseling sessions.

“Families were then randomized either to receive the formal program or be

assigned to what might be called a quasi-control group, which consisted of families that had access to assistance, but only if they requested it,” continues Ferris.

Scientists evaluated the families every six months.

“The results have been dramatic,” says Ferris. “For example, over an eight-year course (the study is ongoing), we were able to delay nursing home placement by almost a year, and the project has been effective in reducing depression. So the efficacy of providing support and education to caregivers has been well documented, and many other groups across the country have now adopted it.”

At the University of Pittsburgh Medical Center’s ADC, the emphasis has been on neuropsychiatric symptoms of Alzheimer’s and the natural history of the disease’s progression. Steven DeKosky, MD, director of the center, says, “We did some of the first work correlating changes in the brain with behavioral changes in people with Alzheimer’s. And we did some of the seminal studies that have looked at assessing changes in people with Alzheimer’s over time.”

Ethical issues are among the most challenging aspects of studying people with

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# World Alzheimer Congress 2000

*Sharing ideas, finding solutions*

**N**ext month, families, researchers, physicians, professional care providers, and staff and volunteers from Alzheimer organizations worldwide will join in Washington, D.C., to share their experiences at the 10-day World Alzheimer Congress 2000 (Alzheimer 2000).

Alzheimer 2000 is presented jointly by the Alzheimer's Association (U.S.A.), Alzheimer's Disease International, and Alzheimer Society of Canada. "Alzheimer 2000 will offer a unique opportunity to share knowledge and identify strategies for eliminating the threat of Alzheimer's disease to today's citizens and future generations," says Bill Thies, vice president of medical and scientific affairs for the Alzheimer's Association. "Participants will focus on a vast array of topics and challenges related to the disease, from genetics, biomarkers, and treatments to diagnosis, ethical issues in dementia care, support to caregivers and families, and standards of care."

Expected to attract 5,000 attendees, the 10-day congress consists of three programs:



## **Pivotal Research**

(July 9-13)

A five-day program for scientists and clinicians interested in the causes, mechanisms, and treatment of Alzheimer's disease.



## **Bridging Research and Care**

(July 13-14)

A two-day program designed for physicians and advanced practitioners interested in the diagnosis, care, and treatment of Alzheimer patients.



## **Creative Care**

(July 15-18)

A four-day program that brings together family caregivers, professional care providers, and staff and volunteers from Alzheimer associations worldwide to share ideas about dementia care.

*Creative Care* combines the 16th Alzheimer's Disease International, 9th National Alzheimer's Disease Education, and 22nd Alzheimer Society of Canada Conferences. Program themes include recognizing the global impact of dementia, translating research to practice, addressing early needs of individuals with Alzheimer's and their families, understanding systems of care, supporting

the workforce, and reaching diverse and underserved populations.

Designed to address the diverse interests of hands-on professional care providers, public policymakers, researchers, and staff from Alzheimer organizations worldwide, workshops will focus on the key elements of dementia care, including:

- Environmental issues
- Family support and assistance
- Managed care
- Related dementias and disabilities
- Therapies

Selected sessions will be tailored to family caregivers. "Family caregivers will have the opportunity to benefit from this event by attending sessions created specifically for them," says Sam Fazio, director of education and training for the Alzheimer's Association.

*Pivotal Research* incorporates the 7th International Conference on Alzheimer's Disease and Related Disorders, the leading forum for Alzheimer researchers. For five days, the world's pioneers in Alzheimer research will share their theories related to basic and clinical research as well as learn about and debate findings that may provide clues to stopping this devastating disease.

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# Clinical Trials

## World War II to the World Wide Web

The process of developing and evaluating drugs has changed dramatically since penicillin was first tested in Britain in 1941 on 43-year-old policeman Albert Alexander in Oxford's Radcliffe Infirmary. Alexander had scraped his face on a rose bush, and the scratch had festered into a raging infection that destroyed an eye and threatened his life. The penicillin used to treat him was derived from a mold cultured in a stack of clean bedpans.

Alexander improved immediately, but the supply of purified penicillin ran out after a week. Desperate, his doctors recycled the drug from Alexander's own urine. Unfortunately, the amount was insufficient to sustain Alexander's recovery, and he died.

Some 60 years later, the search for potential wonder drugs follows a much more stringent path. Clinical trials proceed according to strict rules designed to protect participants. Before the U.S. Food and Drug Administration (FDA) will authorize a clinical trial, a drug's sponsor must submit preclinical data from animal or test-tube studies that provide convincing preliminary evidence of safety and effectiveness. Preclinical submissions include an explanation of the chemistry of a drug—how it appears to work, how it is absorbed and broken down in the body, and its toxicity.

For drugs that successfully meet

preclinical requirements, clinical testing in human subjects proceeds in three phases. Treatments must perform well enough in each phase to justify progression to the next:

- Phase I trials focus on safety. Researchers enroll a small group of 20 to 80 people to determine a safe dosage range, identify side effects, and learn more about how the body processes a drug.
- Phase II trials, which generally enroll a few hundred people, focus on demonstrating a drug's effectiveness and further evaluating its safety.
- Phase III trials enroll several thousand people to confirm a drug's effectiveness, compare it to existing treatments, and collect more information about safety and common side effects.

In many cases, one group in a Phase II or Phase III trial receives the investigational treatment, while another group—the control group—receives a placebo (an inert substance or “sugar” pill) or an existing standard treatment.

If a drug performs well in all phases of an investigation, the developer submits to the FDA a new drug application (NDA) containing all the scientific information gathered during preclinical and clinical studies. An average NDA exceeds 100,000 pages. After evaluating the submission, the FDA grants or denies approval.

Clinical trials may offer participants significant benefits, including access to



ing health centers during the trial. Many participants and caregivers also value the sense of taking an active role in health care decisions and contributing to medical research. On the other hand, investigational treatments may cause unforeseen side effects, and the treatment may turn out to be ineffective or may not work for everyone. Participation can also require a significant time investment from enrollees and their caregivers.

People considering enrollment in a clinical trial now have a powerful tool for identifying and exploring possibilities—the World Wide Web. One of the newest Internet resources is ClinicalTrials.gov, an on-line database created by the U.S. National Institutes of Health (NIH) that lists medical studies investigating Alzheimer's disease and a wide range of other conditions. ClinicalTrials.gov usually lists more than a dozen studies relevant to Alzheimer's disease, ranging from drug trials to brain imaging studies. Some of these studies are conducted at the NIH, but many are held at research centers throughout the United States. For more information about NIH trials, visit the

ClinicalTrials.gov Web site at <http://clinicaltrials.gov> or call (301) 496-6308 to request their question-and-answer sheet.

Another Internet resource is the Alzheimer's Disease Educational and Referral Center (ADEAR) of the U.S. National Institute on Aging. Visit their Web site at <http://www.alzheimers.org/> and scroll to Clinical Trials Database. Also, the Alzheimer's Association provides trial information on its Web site at [www.alz.org](http://www.alz.org). Visit the Family Caregivers and Friends section, then click on Treatment Options for a list of clinical trials. You may also request printed copies of our list of open trials by calling (800) 272-3900. 

## FDA Approves New Alzheimer Drug

**O**n April 21, rivastigmine (Exelon<sup>®</sup>) became the third drug approved by the U.S. Food and Drug Administration (FDA) to treat symptoms of Alzheimer's disease. The two previously approved Alzheimer drugs are tacrine (Cognex<sup>®</sup>) and donepezil (Aricept<sup>®</sup>). In clinical trials, participants taking rivastigmine showed greater improvement than participants receiving a placebo (inactive treatment) in memory, activities of daily living, and general behavior. Overall, the drug helped slightly more than half of the people who took it.

Rivastigmine is approved for mild to moderate Alzheimer's. Like tacrine and donepezil, it relieves symptoms by

inhibiting breakdown of acetylcholine, a nerve communication chemical that becomes deficient in people with Alzheimer's. Because numbers of functioning nerve cells decline as Alzheimer's progresses, rivastigmine may be less helpful in advanced stages of the disease.

Common side effects, which usually decline with ongoing treatment, include indigestion, nausea and vomiting, fatigue, and weight loss. People who want to consider rivastigmine should discuss potential risks and benefits of the drug with their doctors and their families. For a fact sheet about rivastigmine, call the Alzheimer's Association at (800) 272-3900. 

## R<sub>X</sub> CORNER



### Drug Update

Janssen Pharmaceutica announced in March that Sweden is the first European country to approve the company's new drug **galantamine** (Reminyl<sup>®</sup>), which improved cognitive function for some individuals with Alzheimer's disease in clinical trials.

Galantamine increases levels of the neurotransmitter acetylcholine in the brain in two ways—by inhibiting action of the enzyme acetylcholinesterase, which breaks down acetylcholine, and by stimulating certain nerve cell receptors to release more of the chemical. Janssen's new drug application for U.S. approval of galantamine is currently under review by the U.S. Food and Drug Administration (FDA).

Elan Corporation announced Phase I clinical trials in the United States and the United Kingdom to test the safety and tolerability of its investigational Alzheimer vaccine AN-1792. In animal studies published in the July 1999 edition of *Nature*, AN-1792 prevented buildup and reduced the level of amyloid plaques in the brains of mice genetically engineered to mimic the human plaque formation that characterizes Alzheimer's.

### Ongoing Clinical Drug Studies

Ongoing Clinical Drug Studies:  
Drug studies currently recruiting participants with Alzheimer's disease include:

Donepezil (Aricept<sup>®</sup>) and Estrogen  
Melatonin  
Galantamine (Reminyl<sup>®</sup>)  
Estrogen

Studies recruiting individuals with mild cognitive impairment include:

InDDEx study  
Memory Impairment Study

To obtain information about these studies, contact your local chapter or call (800) 272-3900 and ask for the "Drug fact sheets," or visit the Association's Web site at [www.alz.org](http://www.alz.org) and visit the Family Caregivers and Friends section, then click on Current Research and Drugs in Clinical Trials.

## Ohio Alzheimer council wins back-to-back boosts in respite funding

Officials with the Ohio Council of the Alzheimer's Association had a nagging fear as they laid plans for their 1999 legislative session. They wanted to boost annual respite funding from the then-current \$3 million to \$7.5 million for the years 2000–2001.

But they foresaw a potential problem: During the last legislative session, in 1997, Ohio Alzheimer advocates had successfully pressed their representatives to nearly double state money for respite care. Now they feared their past success could be their undoing. “We thought we might appear greedy,” says Sharen Eckert, director of strategic initiatives for the Alzheimer's Association's Cleveland Area Chapter. “Because we received such a large increase the session before, we were nervous about how we might be perceived.”

At the same time, they also knew that during the decade leading up to their 1997 success, increases in state respite funding had been nil. All the while, the number of Ohio residents with Alzheimer's continued to rise (to more than 200,000) and the need for respite care grew more acute. Many families still needed assistance. So representatives from the 13 Ohio chapters that make up the Ohio Council of the Alzheimer's Association decided to push on with the 1999 campaign for more state money. State Representative

Barbara Boyd (D-9th), a former caregiver herself, supplied the strategy for the effort.

“We had a [council] meeting at my house, and I told them, “You have to put a face on the issue,” says Boyd. “Legislators have to meet the caregivers, the people with Alzheimer's, and their children. That's what brings the issue home. So bring caregivers and others in from the districts, have them contact and meet their representatives. When you do that, legislators can connect with your needs, and you can ask for support.”

Early in the campaign, council officials activated their statewide grassroots organization called AdvoCare, which consists mostly of caregivers. They asked each of the 300 AdvoCare members to write to their state representatives.

Lois Pickett of Cleveland, an AdvoCare member and former caretaker, wrote several letters. “Basically, we were trying to raise awareness of the need for increased respite care,” says Pickett.

The letter-writing effort dovetailed with what council officials consider the centerpiece of their campaign. Among the messages AdvoCare members sent their legislators were invitations to a Memory Day luncheon. It was set for

February 16, 1999, the day after President's Day, when legislators typically have light schedules. For the lawmakers' convenience, council officials arranged to host the event in the statehouse atrium, which connects the House and Senate buildings. Family caregivers would sit with their respective legislators and discuss their experiences with Alzheimer's disease.

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*Legislators have to meet the caregivers, the people with Alzheimer's, and their children... So bring caregivers and others in from the districts, have them contact and meet their representatives.*

*When you do that, legislators can connect with your needs, and you can ask for support.*

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As the legislative session wore on, council officials saw encouraging signs for added respite money but as yet no commitment. “Prior to the luncheon, Governor Taft had spoken about the

need for increased funding for caregivers,” reports Valerie Ridgeway, the Cleveland Area Chapter’s director of public policy. “But we saw nothing in writing. And when we got our hands on the proposed budget, the [respite funding] line item had not been increased.”

The Ohio Alzheimer council developed standard talking points and fact sheets to help caregivers prepare for the luncheon. The emphasis was on conveying a consistent message.

On the morning of February 16, 45 caregivers and staff from the Cleveland Area Chapter boarded a bus for the two-hour drive to the state capital of Columbus.

“On the ride down,” says Ridgeway, “we watched the ‘Two Advocates’ video produced by the Association’s public policy division in Washington, D.C. It’s about how two normal people can influence federal legislation. Then we talked about what it’s like to meet with legislators. We wanted to help our people be at ease.”

At the luncheon 300 caregivers and Alzheimer advocates met with 110 (of the 132) state legislators. “At my table,” says AdvoCare member Lois Pickett, “I and others, including a mother and son, spoke to State Representative Dale Miller (D-19th) about our experiences in caregiving.”

State Representative Barbara Boyd stepped up to the microphone and talked about her mother, who died last fall after battling Alzheimer’s for five years. Earlier, those at the luncheon had heard from Ohio Department of Aging Director Joan Lawrence. Lawrence spoke of a friend who had

been diagnosed with the disease in her mid-50s. “I watched her go from being a bright, beautiful, quiet person into [a loud, aggressive] person who couldn’t put her thoughts into words.” Turning to the family members and others who traveled across the state to attend the luncheon, Lawrence added, “It’s the people here in this room who are the important ones—the Alzheimer caregivers. You are the heroes and heroines that we should be enormously grateful for.”

The Cleveland Area Chapter’s Valerie Ridgeway and others cite the luncheon as “the turning point” in their campaign. A written summary of the respite funding effort, put out by the Cleveland Area Chapter, notes that

“Days after the event, a 150 percent increase in the Ohio Department of Aging’s Alzheimer line item was introduced.”

This past April 11, the Ohio Alzheimer council hosted another luncheon for state legislators, primarily to thank them for their support. “But the second reason for this luncheon,” adds Ridgeway, “is to remind them that there’s still a need. At the next [legislative] session we want to try to double the money again.” *#*

## New Jersey advocates also post respite funding successes

Alzheimer advocates in New Jersey also have succeeded in boosting respite funding during the past two legislative sessions. New Jersey lawmakers increased Alzheimer respite monies by \$1 million both in 1998 and 1999.

“We visited key legislators and coordinated a grassroots campaign to write letters to members of the Assembly Health Committee and the Senate Senior Citizens Committee,” says Sue Lachenmayr, state public policy coordinator for the New Jersey Alzheimer’s Association’s State Public Policy Coalition.

Still, as in Ohio, New Jersey advocates plan to go back to the legislature for more respite funding. “Despite our success,” continues Lachenmayr, “we still have more than 260 people on the waiting list [to receive respite assistance].”



# SUMMER



# FUN!

Let creativity guide you in planning activities for the person with Alzheimer's



**T**he warmth of sunshine, the smell of fresh-cut grass, the bright striking colors of flowers in bloom—these pleasures should be denied to no one and could be particularly therapeutic for the person with Alzheimer's. "There's a direct benefit to the human spirit to being outdoors," says Lynn Noyes, director of the Family Respite Center in Falls Church, Virginia. "When individuals with dementia at our center come back from walks outside, they come back smiling," she says.

In addition to providing an opportunity for outdoor exercise, the summer atmosphere feeds the senses, and this stimulates the brain, Noyes says. "People come alive during the summer months."

## **Adapt summer pursuits to the person's abilities**

Summer activities can run the gamut from brief walks to picnics to cruises. As with any activity, look to the person's past hobbies or recreational pursuits to determine what the individual would enjoy, says Betty Ransom, director of educational programs for the Northern Virginia Chapter of the Alzheimer's Association. "Keep that individual's likes and dislikes in mind," she says.

Still, don't be afraid to try something new because you never know what people are capable of unless you challenge them. "If we're trying to normalize people with Alzheimer's, we must bring them into our world," Noyes says.

Ransom offers the example of a woman with Alzheimer's, who had always been afraid to enter the water before she had the disease but learned how to swim when she was in the middle stage. "Some people are pliable depending on their personality," she says.

Once you have an idea of the appropriate activity, adapt it to the person's abilities. If someone was an avid golfer and can still swing, you might want to set up a short driving range, no longer than 12 feet, where they can drive golf balls into a net. If someone's physical limitations interfere with engaging in a favorite sport, that person might still enjoy an afternoon outside, watching a baseball game or a tennis match.

If you want to leave dry land, set sail on a boat cruise, but make sure the excursion lasts no more than two or three hours and features indoor entertainment, such as games, dancing, or a musical revue. If your loved one is a music lover, an outdoor concert could be enjoyable if it showcases music that the individual likes. In such a setting, make sure that the person with Alzheimer's is not sitting too close to the stage or speakers so that the person is not startled or overwhelmed by the music. It's best to sit at the end of a row in case the individual wants to leave before the performance is finished.

Of course, the simpler pleasures should not be overlooked. A 10- or 15-minute walk can work wonders because it is not only good exercise but also reduces anxiety. The walk could be even more therapeutic if the person interacts with nature, says Jack Carman, whose Medford, New Jersey, architectural firm, Design for Generations, has created several gardens specifically for people with Alzheimer's. Allow the person to interact with nature in a

garden in an enclosed area that permits roaming, he says. "You want the garden to be safe, with opportunities for someone to interact, such as bird feeders or bird baths. Make sure walkways are level and feature nontoxic plants."

Carman has worked with the Alzheimer's Association to create public gardens in Portland, Oregon, and Macon, Georgia. The gardens opened to the public in the past year.

**"There's a direct benefit to the human spirit to being outdoors. When individuals with dementia at our center come back from walks outside, they come back smiling."**

*—Lynn Noyes  
Director of the Family Respite Center  
Falls Church, Virginia.*

### Things to keep in mind

You can have a successful outing or outdoor activity if you plan well. Even though the activity may be a departure from the typical day of a person with dementia, stick to the rest of the individual's daily routine. Have the person eat and take prescribed medicines at his or her regular time. Remember that behavioral medications can make those with dementia sensitive to the warm weather, so keep water and fresh fruit on hand. "People with Alzheimer's often will not know if it's too hot, so you need to coach them to drink flu-

ids," says Dorothy Seman, clinical coordinator of the Alzheimer's Family Care Center in Chicago.

The person's visual spatial perception may be distorted, so he or she may find it difficult to judge whether the ground is uneven in places and so may trip. "You should scan the ground ahead, if you can, before the person walks," Seman says.

If you are venturing away from home, call ahead and make sure facilities are accessible to people with disabilities. Also, check how far restrooms and parking are from the site of an event or planned activity. You may want to go to an event early when crowds are smaller, Seman says. Perform a trial run of an activity or do it on a smaller scale so that you can identify any potential problems or challenges.

If you are going to take a summer trip by car, it's best to travel in "chunks." Build in time for breaks, when you can stop, get out, and stretch in case the individual with dementia gets restless. If you are staying overnight in a hotel or at a relative's home, make sure the doors are locked because the person with dementia may have trouble sleeping in an unfamiliar environment and may wander.

So, just because your loved one has Alzheimer's, don't assume you should limit his or her summer enjoyment. The options are open regarding the types of summer activities you can plan if you take your cues from the person with the disease. "Caregivers should focus on a person's abilities rather than his or her limitations," Seman says. **#**



*Q & A presents answers to your research or caregiving questions from leading professionals in the field of Alzheimer's disease. In this issue, attorney Janna Dutton discusses legal issues associated with Alzheimer's disease.*

**Q:** My father was diagnosed with Alzheimer's disease last year. What legal issues do I need to be aware of?

**A:** The three main areas that need to be addressed are surrogate health care decision making, property and financial management, and long-term care.

Each of these issues, ideally, requires involvement of the person who has been diagnosed with Alzheimer's. Sadly, most people don't take action until a crisis has occurred; by that point, it's often much more complicated because the person diagnosed cannot participate in these decisions. For that reason, it's best to get a diagnosis early so that the person with the disease can be involved in planning his or her own future.

In your father's case, assuming an early diagnosis, he has to decide who will make health care and financial management decisions for him when he can no longer make them on his own. He could choose a family member, a professional trustee, or more than one person—such as two family members—to act as co-trustees. He has to decide how he wants his estate managed while he's alive and how it's to be distributed at his death.

Then there's the issue of what kind health care he's likely to need and what resources are at hand—whether long-term care insurance is available, whether it's been purchased or provided by a past employer.

He also has to look at a living will and whether any planning needs to be done to accelerate Medicaid eligibility for both in-home care as well as potential nursing home care.

These are some of the issues that need to be addressed—preferably early in the process. Acting sooner can avoid a lot of stress later.

*Janna Dutton, of Janna Dutton and Associates in Chicago, is an elder law attorney.*

*Elder law is a specialized area of the law focusing on guardianship, disability planning, and other related legal areas that typically affect older adults. Legal advice and services may be provided by a referral from a family attorney. Other referral sources can be found through your local chapter of the Alzheimer's Association. To locate the chapter nearest you, call (800) 272-3900, or visit "Your Local Chapter" on the Association's Web site at [www.alz.org](http://www.alz.org). *

### 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 1100, Chicago, Illinois 60611-1676, Attn: Michele Pellissier, or send e-mail to: [michele.pellissier@alz.org](mailto:michele.pellissier@alz.org).



[ALZHEIMER'S DISEASE CENTERS...

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Alzheimer's, continues DeKosky, who chairs the Alzheimer's Association's Medical and Scientific Advisory Board. "In some cases, the patient is unable to give you permission to do research. And that means that you must be extraordinarily careful to always consider what is in the best interest of the patient in addition to making sure you get the work done you set out to accomplish. You are balancing the interests of the patient with the needs of the research."

At the Mayo Clinic, in Rochester, Minnesota, Ronald Petersen, MD, oversees an ADC that focuses, in part, on the early detection of Alzheimer's. Petersen explains, "Using clinical

observation, neuroimaging, neuropsychological tests, and biological parameters, such as blood tests, we're trying to identify, on the one hand, people who have the earliest symptoms of the disease and, on the other hand, people who may be asymptomatic but are at risk."

In the early 1990s, Petersen and colleagues first identified the condition called mild cognitive impairment (MCI), a memory disorder that often precedes Alzheimer's.

Their current work on MCI attempts to identify which people diagnosed with MCI will eventually develop Alzheimer's. "We think that the vast majority will get Alzheimer's," says Petersen. "For those that do convert,

we will be looking at their behavioral and imaging characteristics early on to see if we can determine who is going to progress more rapidly."

Alzheimer research has come a long way in two decades. Many involved in that research talk about hopes for a cure and treatments to prevent the onset of Alzheimer's. They consider the Alzheimer's Disease Center program as a key catalyst for research.

Says DeKosky: "Speaking not as a director of an ADC but as a scientist and clinical researcher, I can say that without the center's program—its support for basic research and clinical studies—we wouldn't have gotten this far." *ff*

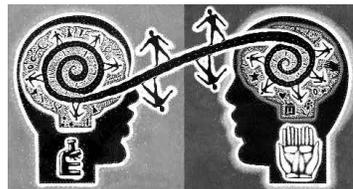
[WORLD ALZHEIMER'S CONGRESS 2000

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*Bridging Research and Care* will offer physicians news of the latest research on diagnosis and treatment as well as practical information about educating and supporting patients and their families. Physicians also will have the opportunity to meet Alzheimer investigators and experts during a scientific poster session. Renowned speakers in the Alzheimer field will highlight key research advances presented during *Pivotal Research* and frame the critical care issues to be presented during *Creative Care*.

You can register on-line for the congress at [www.alzheimer2000.org](http://www.alzheimer2000.org). For additional information, visit the Web site, send an e-mail to [alzheimer2000.org](mailto:alzheimer2000.org), or call (800) 335-5813. *ff*

**World Alzheimer Congress 2000**

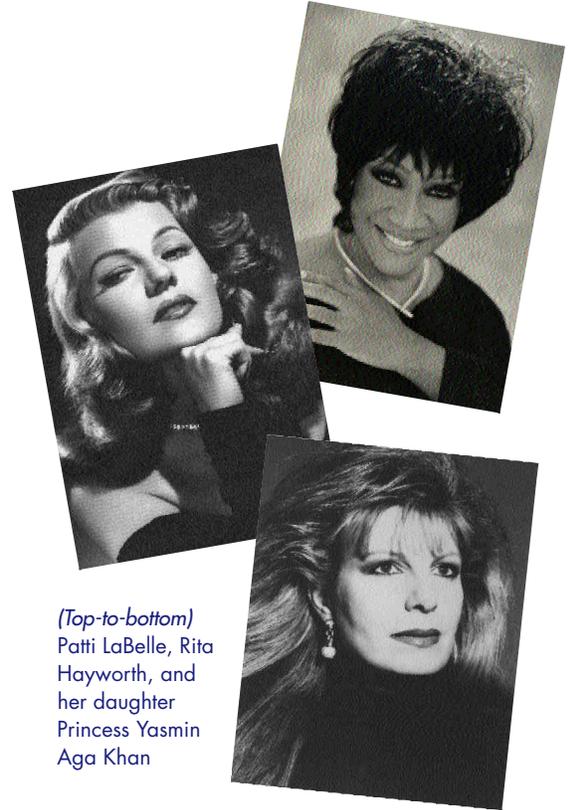


With Change in Mind  
PivotalResearch and Creative Care

## Public Awareness Initiatives

The Alzheimer's Association is engaged in two public education campaigns aimed at increasing people's awareness of Alzheimer's disease. Now in its second year, the Woman and Alzheimer's Disease Campaign, underwritten by Wyeth-Ayerst Laboratories, focuses on women, who, because they generally live longer than men, are most vulnerable to Alzheimer's. The campaign, consisting of magazine ads as well as television and radio announcements featuring Patti LaBelle, discusses warning signs, treatment options, and caregiver tips.

May marked the launch of the Association's Rita Hayworth public education campaign. The effort, supported by a grant from Eisai Inc. and Pfizer Inc, includes radio, television, and print public service announcements urging people to recognize the symptoms of Alzheimer's and to consult a physician if they're concerned about a family member. The PSAs feature Princess Yasmin Aga Khan, daughter of film star Rita Hayworth, herself a victim of Alzheimer's. **ff**



(Top-to-bottom)  
Patti LaBelle, Rita  
Hayworth, and  
her daughter  
Princess Yasmin  
Aga Khan

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