

December 2003

# LEGISLATIVE TASK FORCE ON ALZHEIMER'S DISEASE

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## PURSUANT TO HOUSE JOINT RESOLUTION 14

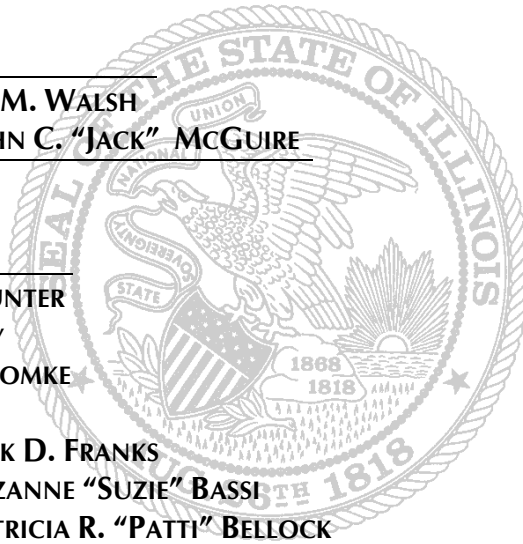
Co-chairs:

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Senator **LAWRENCE M. WALSH**  
Representative **JOHN C. "JACK" MCGUIRE**

Other members:

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Senator **MATTIE HUNTER**  
Senator **BILL BRADY**  
Senator **LARRY K. BOMKE**

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Representative **JACK D. FRANKS**  
Representative **SUZANNE "SUZIE" BASSI**  
Representative **PATRICIA R. "PATTI" BELLOCK**



ILLINOIS HOUSE OF REPRESENTATIVES

**MICHAEL J. MADIGAN**, *SPEAKER*  
**TOM CROSS**, *MINORITY LEADER*

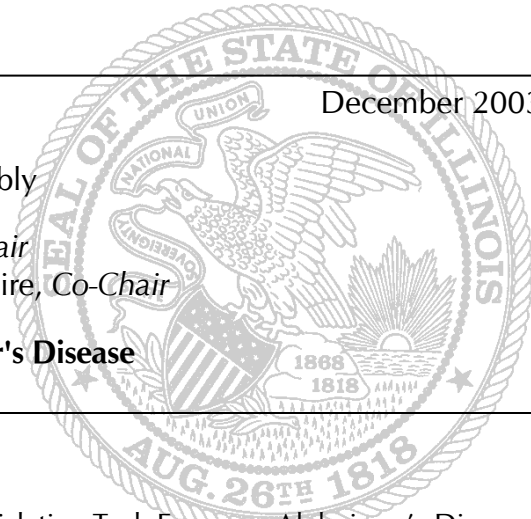
ILLINOIS SENATE

**EMIL JONES**, *PRESIDENT*  
**FRANK W. WATSON**, *MINORITY LEADER*

# MEMORANDUM

December 2003

to: Members of the 93<sup>rd</sup> General Assembly  
from: Senator Lawrence M. Walsh, *Co-Chair*  
Representative John C. "Jack" McGuire, *Co-Chair*  
re: **Legislative Task Force on Alzheimer's Disease**



Pursuant to **HOUSE JOINT RESOLUTION 14**, the Legislative Task Force on Alzheimer's Disease submits the following report for your consideration in the upcoming 2004 spring session.

Alzheimer's disease was given a great deal of attention 17 years ago by the 84<sup>th</sup> General Assembly. An 11-bill package, called the "Alzheimer's Initiative," responded to this serious health problem and was enacted by unanimous votes of the House and Senate. Since then, additional laws to reinforce existing programs and services have been enacted. This legislative history underscores the high priority given to Alzheimer's disease. As the number of Illinois cases steadily rise, the legislature must continue its focus on the prevention and treatment of Alzheimer's disease.

As the report indicates, the National Institute on Aging predicts that 13.2 million older Americans will have Alzheimer's disease by 2050 unless new ways are found to prevent or treat the disease. This compares to the current estimate of 4.5 million. This prediction of a dramatic increase has major implications for Illinois, in terms of the state's ability to respond appropriately and effectively.

State agencies, with responsibilities under current law, presented testimony that did not reflect a full commitment to this serious health problem. The proposed cut in funding for the Alzheimer's Disease Centers for fiscal year 2004 adds concern about how much priority will be given to Alzheimer's Disease.

If Illinois expects to respond in the most appropriate and most effective way to this growing health problem, state agencies and their affiliates must devote additional resources and strengthen their resolve.

This report includes recommendations for members of the task force to follow-up on this year. Hopefully, you will continue to share our concern and commitment to the growing health problems associated with Alzheimer's disease.

ILLINOIS HOUSE OF REPRESENTATIVES

**MICHAEL J. MADIGAN**, *Speaker*

**TOM CROSS**, *Minority Leader*

ILLINOIS SENATE

**EMIL JONES**, *President*

**FRANK W. WATSON**, *Minority Leader*

## HOUSE JOINT RESOLUTION 14

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**WHEREAS**, Alzheimer's disease is a progressive degenerative disease of the brain that affects numerous Illinois citizens; and

**WHEREAS**, Over 200,000 citizens of Illinois are afflicted with Alzheimer's disease; 10% of persons over the age of 65 and nearly 50% of all nursing home residents have Alzheimer's disease or a related dementia; and

**WHEREAS**, 70% of people with Alzheimer's disease live at home, and 75% of these individuals depend upon the care of family and friends; frequently, the family caregivers; health is compromised due to the stress of providing care; and

**WHEREAS**, Alzheimer's disease is extremely costly; the average lifetime cost of Alzheimer's disease is \$174,000 per person; the cost of home care can exceed \$18,000 per year and the cost of nursing home care averages \$42,000 per year; and

**WHEREAS**, A significant function of government is to promote the health, safety, and welfare of its citizens; therefore, be it

**RESOLVED, BY THE HOUSE OF REPRESENTATIVES OF THE NINETY-THIRD GENERAL ASSEMBLY OF THE STATE OF ILLINOIS, THE SENATE CONCURRING HEREIN**, that the Illinois Legislative Alzheimer's Disease Task Force is created, to consist of 8 members of the Illinois General Assembly appointed as follows: 2 members of the Senate appointed by the President of the Senate, one of whom shall serve as co-chairman; 2 members of the Senate appointed by the Minority Leader of the Senate; 2 members of the House of Representatives appointed by the Speaker of the House of Representatives, one of whom shall serve as co-chairman; and 2 members of the House of Representatives appointed by the Speaker of the House of Representatives, one of whom shall serve as co-chairman; and 2 members of the House of Representatives appointed by the Minority Leader of the House of Representatives; all Task Force members shall serve without compensation but shall be reimbursed for their reasonable and necessary expenses from funds appropriated for that purpose; and be it further

**RESOLVED**, That the mission of the Task Force shall be to help optimize the quality of life for people who suffer from Alzheimer's disease and their families through advocacy, education, support, and services, while actively promoting research to eliminate the disease; the Task Force shall examine, along with any other issues it chooses to investigate with respect to Alzheimer's disease, the following issues: (1) the disease's facts, prevalence, and costs; (2) the financial barriers to essential care; (3) the continuum of care, including medical assessment or diagnosis, drug therapy, caregiver training and support, home and community based care, adult day services, residential care options, and hospice care; and (4) the training and qualifications of those who work with individuals with Alzheimer's disease; and be it further

**RESOLVED**, That the Task Force shall receive the assistance of legislative staff, may employ skilled experts with the approval of the President of the Senate, and shall report its findings to the General Assembly on or before December 1, 2003.

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## Legislative Task Force on Alzheimer's Disease

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### BACKGROUND — FINDING

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The 84<sup>th</sup> General Assembly in 1984 gave special attention to Alzheimer's Disease. The House Appropriations Committee and the Legislative Research Unit collaborated on a major conference which generated an 11-bill legislative package that was approved unanimously by the House and Senate in 1985 – and which became known as the *"Alzheimer's Initiative."*

The Legislative Research Unit compiled a report on the conference and subsequently issued other special research reports on the implementation of that initiative. An update has been prepared for the task force, a copy of which has been incorporated into this report.

The task force conducted 2 hearings: November 18, 2003, in Springfield; and December 10, 2003, in Chicago. The first hearing included each of the state agencies having primary responsibility for implementing the *"Alzheimer's Initiative"* and administering related programs to provide a progress report. The General Assembly gave this matter a high priority 17 years ago, and the agencies were instructed to provide an update on the progress made in implementing that initiative – to determine if the programs and services developed by the state agencies reflect that priority. The reports of the agencies did not demonstrate any particular progress, nor priority commensurate with the original interest and intent of the General Assembly. The National Institute on Aging recently announced that: "Scientists project 13.2 million older Americans will have Alzheimer's Disease by 2050 unless new ways are found to prevent or treat the disease. ... [T]he number of older people with Alzheimer's Disease – now at 4.5 million – will grow dramatically as the population ages. The most notable increases will be among people age 85 and older, when my mid-century 8 million people in that age group may have the disease." A copy of the press release about these projections issued by the National Institutes of Health is attached to this report. This is a much greater incidence than predicted when the General Assembly first addressed this topic. If Illinois expects to respond in the most appropriate and most effective way to this growing health problem, state agencies and their affiliates must renew their commitment to the priority that was stated 17 years ago.

House Joint Resolution 14, that created this task force, was proposed by the Alzheimer's Association. The second hearing included testimony from that association, its members, caregivers, and various service agencies. That testimony underscored the need for a greater state commitment than has been recently demonstrated by the agencies which currently have primary responsibility for the conduct of research and the provision of programs and services that grew out of the original *"Alzheimer's Initiative."*

Attachments to this report also include the written testimony submitted to the task force at the 2 hearings, together with the primary recommendations submitted for consideration by the General Assembly. Additional reference material provided by state agencies and the state-funded Alzheimer's Disease Centers is not attached, but is available upon request.

The Legislative Alzheimer's Disease Task Force was created to obtain a current snapshot of the status of the "*Alzheimer's Initiative*" and to receive updated information and recommendations for ensuring that Illinois will be able to respond to the dramatic rise in the numbers of people who will be affected. Considering the consequences, the state cannot be complacent about the current effort. Illinois must renew its commitment and develop a more aggressive state plan and ensure that the framework of programs and services established by the 84<sup>th</sup> General Assembly is functioning and capable of meeting the challenge of this serious public health problem.

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## RECOMMENDATIONS

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### ALZHEIMER'S DISEASE ASSISTANCE ACT

Current law 410 ILCS 405/2 includes findings that do not reflect the most recent data regarding the predicted increase in the number of cases of Alzheimer's disease and related conditions. It is now estimated that 4.5 million Americans have the disease, compared to the original estimate of 1.5 million, and this now includes more than 200,000 Illinoisans, compared to the original estimate of 111,000. The existing law should be updated.

### ALZHEIMER'S DISEASE ASSISTANCE CENTERS

The 84<sup>th</sup> General Assembly enacted the Alzheimer's Disease Assistance Act that expressly stated the following:

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It is the intent of the General Assembly, through implementation of this Act, to establish a program for the conduct of research regarding the cause, cure and treatment of Alzheimer's disease and related disorders; and, through the establishment of Regional Alzheimer's Disease Assistance Centers and a comprehensive, statewide system of regional and community-based services, to provide for the identification, evaluation, diagnosis, referral and treatment of victims of such health problems.

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The centers would be the key element of Illinois' plan to combat the disease. Each center received start-up funding with the promise of additional funding as the full intent was realized.

The centers at the SIU School of Medicine, Rush and Northwestern University Medical School have succeeded in the creation of nationally-recognized programs which utilized the initial state funding to create an infrastructure and foundation for leveraging substantial federal and private funding, well-beyond the state's investment. The centers have generated \$9 for every \$1 of state funding, with prospects for an even greater return assuming that the state's commitment remains strong for this enterprise. To insure that the original legislative intent is realized, and to take full advantage of the progress that has been made over the past 17 years, the General Assembly should not only stabilize the existing level of funding – as recently done through the restoration of the Governor's veto of funding for fiscal year 2004 – but provide additional funding for fiscal year 2005. The centers have submitted proposals to expand their current effort, including plans to increase program and service capacity in underserved African-American and Hispanic communities, and to enroll additional minorities into existing research programs. These proposals should be given full and immediate consideration by the Governor and General Assembly.

### MEDICAID PAYMENTS TO ALZHEIMER'S DISEASE CENTERS

Beginning in fiscal year 2004, the Illinois Department of Public Aid initiated payments to the centers under a methodology that does not distinctly recognize Alzheimer's disease as a separate payment category. Payments are made by simply increasing the existing rates to adjust for

the additional programs and services under the regular quarterly payments. This was an initial (expedited) strategy agreed upon when financing was restructured this year so that payments would be provided through the federally-reimbursable Medicaid program, rather than as direct grants from the state General Revenue Fund. The past year's experience, especially the Governor's veto of the original appropriation, underscores the need to implement a more specific and dedicated methodology. The General Assembly should restructure financing for the centers under the Excellence in Academic Medicine Act (30 ILCS 775/).

#### INTER-AGENCY COORDINATION

For fiscal year 2004, funding for the Alzheimer's Disease Centers was transferred to the Illinois Department of Public Aid to enable the state to obtain federal Medicaid reimbursement for the state-sponsored expenses of the centers. Oversight of the centers, however, remained with the Illinois Department of Public Health. The annual Alzheimer's Disease Assistance Plan must include information regarding this funding, but there is no mandate for these separate functions to be coordinated. The Governor's veto of the original appropriations for the centers for fiscal year 2004 underscores the problem when there is no effective communication, nor sensitivity about the value of the existing program by the funding agency. The Department of Public Aid, as the single state Medicaid agency, must give full consideration to the goals and objectives of the annual plan and the work of the Alzheimer's Disease Advisory Committee which advised the state on program and service priorities. The primary role of the Illinois Department of Public Health in the development of the plan should be taken into full consideration by the Illinois Department of Public Aid.

#### FAMILY CAREGIVER SUPPORT

Senate Bill 1620 creates the CAREGIVER SUPPORT ACT. The bill, as amended, creates the Family Caregiver Act. It directs the Department on Aging to contract with Area Agencies on Aging and other appropriate agencies to provide family caregiver support services. Most important, it amends the existing Respite Program Act so that it applies to frail or disabled adults who are at least 60 years of age and adds long-term care facilities to the types of locations where respite care can be provided. It also permits the department to seek and obtain state, federal, and private funds to finance the services. The legislation passed the Illinois House unanimously and is pending in the Illinois Senate. The original law was developed in concert with the Alzheimer's Association, and the proposed revisions are considered a critical element of any comprehensive plan intended to meet the needs of Alzheimer's victims and their families.

#### ALZHEIMER'S DISEASE ADVISORY COMMITTEE

The original Alzheimer's Disease Assistance Act (410 ILCS 405/6) includes 21 voting members appointed by the director of the department, as well as 5 nonvoting members, including the director (as chairman) and other members experienced in research and the delivery of services to victims and their families. Other members include 4 licensed to practice medicine in all of its branches, 1 representative of a postsecondary educational institution which administers or is affiliated with a medical center in the state; 1 representative of a licensed hospital; 1 registered nurse; 1 representative of a long-term care facility under the Nursing Home Care Act, 1 representative of an area agency on aging, 1 social worker, 1 representative of an organization established under the Illinois Insurance Code for the purpose of providing health insurance, 5 family members or representatives of victims of Alzheimer's disease and related disorders, and 4 members of the general public. The primary function of the committee is to review the annual



Alzheimer's Disease Assistance Plan prepared by the Department of Public Health. The function of this committee should be expanded to include oversight and evaluation of the services provided by the various state agencies and to solicit additional findings and recommendations for improving state programs and services.

#### DEMENTIA TRAINING

Senate Bill 1434 of the 91<sup>st</sup> General Assembly (Public Act 91-744) required the Illinois Department of Public Health, in cooperation with the Department on Aging or any other appropriate federal, state, or local agency, to develop specialized training and experience criteria for persons who provide health or home care to victims of Alzheimer's disease or other dementia-related disorders, including but not limited to cognitive and motor skill disorders, stroke and related complications, Huntington's disease, Pick's disease, Parkinson dementia complex, and senility. The department was also required to study the effectiveness of certifying an appropriate private certifying body, persons who provide health or home care to victims of Alzheimer's disease or other dementia-related disorders. The department is still in the process of implementing this law. Without further delay, the department should provide funding to issue the dementia training manual for the demonstration project; and target additional training on dementia-specific issues.

#### ADULT DAY SERVICES

There is clearly a statewide shortage of adult day care in Illinois, attributed to a large extent to the availability of state funding and the adequacy of the rates of reimbursement paid by the Department on Aging to adult day providers. A mid-year rate increase in this fiscal year was a step in the right direction to stem the loss of providers. Additional increase in rates by the Illinois Departments of Human Services and Aging are still necessary, and there should be no disparity in those rates to ensure full access to care regardless of the age of the Alzheimer's victim. Each agency should also adjust transportation rates for adult day services from \$4.15 to \$6.15 per trip to ensure access to services. Adult day reimbursement rate should at least be increased \$8.32 per hour.

#### MEDICAID REIMBURSEMENT- MINIMUM DATA SET (MDS)

The Illinois Department of Public Aid has recently promulgated a change in the methodology for Medicaid reimbursements to long term care facilities, so that payments are more sensitive to the medical condition and the intensity of services provided to each resident. This new system, referred to as the "MDS" system, needs additional refinement to more fully take into consideration the special needs of Alzheimer's patients, with special consideration given to additional amounts of staff time that must be devoted to such cases. Research has shown that the most significant distinction between regular and specialized care units for residents with Alzheimer's or dementia is the increased staff time residents on the specialized units receive in their care. Only programs on file with the department under the Alzheimer's program disclosure act should be reimbursed under this item. Facilities would receive additional money, as it becomes available, for having a special care unit and that money would be subject to a federal match.

#### CENTER FOR MINORITY HEALTH SERVICES

The Illinois Department of Public Health is required to administer a Center for Minority Health Services (20 ILCS 2310/2310-215). The duties of the center should be revised to include advocacy and promotion of the increased risk of Alzheimer's disease among minority populations.

### LONG-TERM CARE INSURANCE

In an effort to assist persons to not have to go on Medicaid and spend down their assets to cover their long-term care expenses, the state should allow for an income tax credit equal to 15% of the premium costs of long-term care insurance.

### CLEARINGHOUSE

Initiate a pilot project, through the Department of Public Health, to expand information and assistance services currently available via the 1-800 number of the Alzheimer's Association. The pilot project would demonstrate that people should be able to contact one central location to seek help and obtain answers to their questions.

### FAMILY COUNCILS

The Department on Aging should support and actively promote the presence of family councils in all long-term care facilities and assisted living establishments.

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**IMPLEMENTATION OF ALZHEIMER’S LAWS — 2003 UPDATE**  
**ILLINOIS LEGISLATIVE RESEARCH UNIT**

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The following report updates a 1991 report on the state’s response to Alzheimer’s disease, specifically Section II of that report which examined the reasons for the initial group of Illinois laws related to Alzheimer’s disease in 1985, summarized those and later enactments, and discussed state agency responsibilities under those laws.

New and updated information submitted by the various state agencies is presented below, including a summary of laws enacted since that 1991 report. Also included are revisions and updates suggested by state government agencies having Alzheimer’s-related responsibilities and programs.

ALZHEIMER’S LAWS

In 1985, 11 Alzheimer’s laws were enacted in Illinois. They were in 4 broad categories:

- providing support for medical research;
- increasing disease awareness and services;
- improving patient care; and
- increasing financial aid to patients.

Two further Alzheimer’s laws (not including those amending the 1985 laws) were enacted in 1987.

Seven more Alzheimer’s laws were enacted between 1991 and 2003. Two of these laws, Public Act 87-974 and Public Act 90-404, amended earlier Alzheimer’s laws. The others created new programs and/or responsibilities.

TABLE 1 lists the major Alzheimer’s laws enacted in Illinois since 1985. (Four of the 1985 laws were enacted by almost identical House and Senate bills. In those cases, both Public Acts are listed below.)

TABLE 1: ILLINOIS ALZHEIMER’S LAWS

Category	Name or Description	Public Act (1985 unless otherwise noted)
Support Research	Alzheimer’s Disease Assistance Act	84-378; 84-513; 90-404 (1997)
	Alzheimer’s Disease Research Fund	84-324
	Information Gathering and Autopsies	84-381; 84-420
	Insurance Task Force	84-382
	Pilot Project Grants	84-380

Category	Name or Description	Public Act (1985 unless otherwise noted)
Increase awareness of services and the disease	Alzheimer's Task Force	84-379; 84-512
	Insurance Task Force	84-382
	Alzheimer's Special Care Disclosure Act	90-341 (1997)
Improve Patient Care	Alzheimer's Disease Assistance Act	84-378; 84-513
	Alzheimer's Task Force	84-379; 84-512
	Pilot Project Grants	84-380
	Quality Incentive Payment	84-383; 84-421
	Respite Programs	84-511; 87-974 (1992)
	Long-term Care Programs	84-207
	Eligibility for Services	84-183
	Nursing Home Prescreening	85-775 (1987)
	Training for Nursing Home Staff	85-940 (1987)
	Alzheimer's Special Care Disclosure Act	90-341 (1997)
	Assisted Living and Shared Housing Act	91-656 (1999)
	Specialized Caregiver Training	91-744 (2000)
Alzheimer's Disease Management Center	91-838 (2000)	
More Financial Aid to Patients	Asset Protection	84-183
	Medicaid for Alzheimer's Patients	84-773
	Insurance Task Force	84-382
	Alzheimer's Medications Added to Pharmaceutical Assistance Program	91-699 (2000)

Source: Prepared by Legislative Research Unit from laws cited.

### LAWS SINCE 1991

Seven Alzheimer's laws that have been enacted since our 1991 report are briefly described below:

- Respite Care Programs

Public Act 87-974 (1992) amended the respite care demonstration program originally authorized in 1985 by Public Act 84-511. It created a Respite Program Act to give families relief from the responsibilities of caring for frail and disabled adults. Its provisions included funding for these services, in-home respite care, and respite care worker training.

- Specialized Medical Care

Public Act 90-341 (1997) enacted the Alzheimer's Special Care Disclosure Act. It requires any health-care facility offering specialized care in Alzheimer's treatment to inform the public about the facility and its programs.

- Research Support

Public Act 90-404 (1997) amended the Alzheimer's Disease Assistance (ADA) Act enacted in 1985. It modified the definition of a Regional Alzheimer's Disease Assistance Center to include any postsecondary higher educational institution having not only a medical school affiliated with a medical center, but also (the following was added) a National Institutes of Health and National Institutes on Aging-Sponsored Alzheimer's Disease Core Center. Regional ADA Centers designated as having federal Alzheimer's Core Centers were to continue serving as Regional ADA Centers even if the federal designation was lost or dropped.

The Act also specified how grants to Regional ADA Centers for Alzheimer's-related research were to be distributed.

- Assisted Living and Shared Housing

Public Act 91-656 (1999) created the Assisted Living and Shared Housing Act to permit development of housing facilities operated as residential environments with services designed to meet residents' changing needs and preferences. It has numerous special provisions that regulate facilities providing such services to persons with Alzheimer's disease or dementias.

- Pharmaceutical Assistance

Public Act 91-699 (2000) added medications used in treating Alzheimer's disease to the categories of prescription drugs covered under the Illinois Department of Revenue's Pharmaceutical Assistance program.

- Caregiver Training

Public Act 91-744 (2000) directed the Illinois Department of Public Health (IDPH), cooperating with the Department on Aging and others, to develop specialized training and experience criteria for persons providing health or home care to persons suffering from Alzheimer's or other dementia-related disorders.

- Patient Care

Public Act 91-838 (2000) authorized the formation, on a demonstration basis, of an Alzheimer's disease management center as an alternative health care delivery model. Such a center would be a designated site providing a safe and secure setting for Alzheimer's victims. Care at the center would be directed to treat behavioral problems and mood disorders using nonpharmacologic approaches, such as environmental modification, task simplification, and other activities.

## STATE AGENCIES' DUTIES

The 1991 report examined the Alzheimer's-related activities and duties of seven Code departments (Public Health, Aging, Public Aid, Rehabilitation Services, Insurance, Revenue, and Mental Health and Developmental Disabilities) and one other state agency (Guardianship and Advocacy Commission).

Each agency was contacted and asked to update and/or revise the information in the previous report. (Public Act 89-507 (1996) combined a number of agencies in the human services area into a new Illinois Department of Human Services (DHS). The former Departments of Mental Health and Developmental Disabilities, and Rehabilitation Services, became part of DHS.) Each such agency except IDPH responded to our request. The information obtained is summarized below.

#### Department on Aging (DOA)

The Department on Aging reports that the 23-member task force to evaluate state Alzheimer's programs was inactive for some years before being repealed in 2000. The department also reports that the functions of the DOA Advisory Task Force were incorporated into its existing Community Care Program Advisory Committee, and the 3-year pilot projects mentioned in our 1991 report never got an appropriation.

The department sent a description of its current activities related to Alzheimer's disease, which is presented below in condensed form.

- Administers the Community Care Program (CCP), which helps frail elderly persons 60 or older (including those with Alzheimer's disease) with basic tasks and support so they can live at home, delaying placement in nursing homes. CCP is funded by state appropriations, with partial federal reimbursement under a Medicaid waiver. The more than 15,000 persons with cognitive impairments in CCP are about 30% of that program's caseload.
- Contracts with Heather Hill Hospital, Health and Care Center to provide basic and advanced "dementia care mapping" training to selected CCP adult day service providers. Dementia care mapping is a method for evaluating and improving the quality of care for people with dementia in formal settings such as adult day service centers. It uses detailed observations over several hours by one or more evaluators, using a specially designed instrument to measure the condition of people with dementia.
- Offers the Senior HelpLine (a statewide toll-free number, (800) 252-8966, offering both voice and TTY) to provide information and referrals to aged persons and their families and caregivers. The Senior HelpLine staff mails an Alzheimer's information packet, containing pamphlets and brochures from the National Institute on Aging, to everyone who requests information on that subject.
- Cosponsors an annual conference with the SIU School of Medicine's Center for Alzheimer Disease and Related Disorders and the Land of Lincoln Chapter of the Alzheimer's Association. The conference offers continuing education to nursing home administrators, social workers, registered nurses, and counselors.
- Supports the Family Caregiver Support Program to help meet the needs of persons who care for their family members over age 60. In fiscal year 2003 this program used \$5.8 million to provide information and assistance to caregivers for obtaining available services; counseling, support group organization, and caregiver training; respite care to relieve caregivers; and limited supplemental services — serving an estimated total of 105,073 persons.
- Through the Aging Network, funds and provides congregate or home-delivered meals, linking of older adults to services, and nutrition education for persons with chronic health conditions.

- Helps residents of nursing homes through the Long Term Care Ombudsman Program, and protects older persons living at home through the Elder Abuse and Neglect Program.

### Department of Public Aid (DPA)

The Quality Incentive Payment Program created by Public Act 84-383 and Public Act 84-421 (1985) allowed DPA to make quality incentive payments to nursing facilities, rewarding them for providing care above the minimum standards — including programs designed for the needs of Alzheimer’s patients. The program was repealed by Public Act 87-14 (1991).

Another 1985 law, Public Act 84-773, authorized DPA to establish and implement a pilot project to determine the feasibility of authorizing Medicaid reimbursements for diagnostic and treatment of Alzheimer’s. However, the department found no evidence that this pilot project was ever done.

DPA pays nursing homes for long-term care under the Medicaid program. According to information submitted on each resident by nursing facilities to DPA, some 9,000 are currently identified as having Alzheimer’s disease.

The department could not verify or confirm information in the 1991 report on 2 DPA-funded demonstration projects that were to explore new ways to provide long-term care. One was reportedly at the Alzheimer’s Disease Family Care Center at the Westshire Retirement and Health Care Center in Cicero. The second was a project through Southern Illinois University’s Division of Continuing Education to address the needs of downstate Illinois.

In 1991, DPA rules allowed the spouse of a person applying for Medicaid to keep up to \$62,580 in assets without making the sick spouse ineligible for Medicaid payments for nursing home care. That amount has now risen to \$90,660 due to adjustments for inflation. Rules in effect in 1991 also provided that the spouse at home could keep enough of the nursing-home spouse’s income to have \$1,565 per month. That amount has also risen, due to inflation, to \$2,267.

Public Act 89-499 (1996) authorized the department to test the viability of establishing supportive living facilities (SLFs) that integrate housing with health care, personal care, and other supportive services. SLFs are designed to provide an alternative to nursing home placement. DPA is now considering modifying its regulations to allow SLFs to better accommodate Alzheimer’s residents.

### Department of Human Services (DHS)

The former Departments of Rehabilitation Services, Mental Health, and Developmental Disabilities are now part of DHS.

- Office of Rehabilitation Services

The department’s Office of Rehabilitation Services (ORS) provides services designed to prevent unnecessary institutionalization of persons with severe disabilities, including Alzheimer’s and related disorders. The ORS Home Services Program provides a variety of services to help customers stay in their homes. Persons must apply for services before age 60 to be eligible for this ORS program; those who are 60 or older are referred to the Department on Aging. A person who turns 60 while in the ORS program can choose to remain in it or switch to the Department on Aging’s program.

An ORS spokeswoman reported that the Home Services Program had 206 customers with Alzheimer's disease in fiscal year 2001. Services provided included personal assistants and homemaker services. Total expenditures were \$522,767 — at a cost per customer of \$2,538.

ORS also provided adult day care services to 8 clients with Alzheimer's disease in fiscal year 2001. The total cost for this service was \$24,375 — for a cost per client of \$3,047.

- Division of Mental Health

As noted in the 991 report, both the mental health and aging fields have worked to fight categorization of Alzheimer's as a mental illness. However, a Division of Mental Health spokeswoman notes that there are secondary mental health aspects to Alzheimer's disease in some patients. The division also recognizes that the stress borne by Alzheimer's caregivers often has mental health effects. The division is looking into programs and services to maintain the mental health of persons serving in that demanding capacity.

#### Department of Insurance (DOI)

The 1991 report described the Task Force on Long-Term Care Insurance — provided for in Public Act 84-232 (1985) — and its May 1990 report and recommendations. The department has noted some changes to the section of the 1991 report on implementation of the task force recommendations. They include:

- We reported that Illinois enacted the National Association of Insurance Commissioners (NAIC) Model Act on Long Term Care in almost identical forms (Public Act 85-1172 and Public Act 85-1174, 1988). These acts regulate health insurance policies for long-term care outside acute-care units in hospitals. DOI notes that more states have since adopted the NAIC model act, bringing a more uniform regulatory environment for insurers and consumers.
- Regarding subsidized long-term-care insurance, the department notes that the Partnership for Long-Term Care Act (Public Act 87-163, 1991) established a private-public insurance program to help persons protect their assets from the costs of long-term care and coordinate the benefits of the program with existing services. Several companies have permission to sell such "Partnership" insurance policies in Illinois, but none are actively marketing them at this time.
- The department's Senior Health Insurance Program (SHIP) — an outreach program to educate citizens on Medicare, Medicare supplement, Medicare managed care, and long-term-care insurance — has trained nearly 700 volunteer counselors located in 180 SHIP offices statewide.
- The department has adopted a revised NAIC model rule regulating the long-term-care insurance industry. The regulations contain rate stabilization provisions and guidelines for actuarial data to be submitted to the department for review. They also provide that long-term-care policies must cover Alzheimer's treatment.
- In 1991, the department was working on a Buyers' Guide to Long-Term Care Insurance. That publication, "Long-Term Care Insurance Information," is now complete. Among other information, it lists insurers offering long-term-care insurance in Illinois. It is available at the following address on the Department's Web site: [http://www.ins.state.il.us/Ship/LTC\\_2002.pdf](http://www.ins.state.il.us/Ship/LTC_2002.pdf)



NAIC has developed a “Shoppers’ Guide to Long-Term Care Insurance.” The department provides copies of it to the Department on Aging and Illinois consumers.

Department of Revenue

The Department of Revenue continues administering its income tax checkoff program allowing taxpayers to contribute to the Alzheimer’s Disease Research Fund, from which the Illinois Department of Public Health makes grants. Annual contributions must total at least \$100,000 for the Fund to remain on the tax form. Almost \$2.7 million has been contributed to the fund since 1985. TABLE 2 lists annual contributions reported so far.

TABLE 2: ALZHEIMER’S RESEARCH FUND CHECKOFF CONTRIBUTIONS

Tax Year	Amount Donated	Tax Year	Amount Donated
1985	\$114,850	1995	\$119,277
1986	173,026	1996	130,165
1987	164,603	1997	102,721
1988	169,823	1998	161,503
1989	169,784	1999	222,860
1990	185,781	2000	166,146
1991	103,651	2001	181,614
1992	124,415	2002 *	190,364
1993	108,116	TOTAL	\$2,697,291
1994	108,592	* Through October 24, 2003	

Source: Compiled by Legislative Research Unit from Illinois Department of Revenue, “Table 13: Checkoff Dollars Donated by Tax Year,” in *Annual Report of Collections and Distributions, Fiscal Year 2001*, pp. 20-21; and “Income Tax Checkoffs” (computer printouts for weeks ending December 20, 2002 [tax year 2001], and October 24, 2003 [tax year 2002]).

Guardianship and Advocacy Commission

The commission is the legal guardian for 597 clients with Alzheimer’s disease or related disorders. Last fiscal year, the commission spent \$401,184 assisting Alzheimer’s clients, an average \$672 cost.

ADA CENTERS INFORMATION

State-supported outpatient treatment for Alzheimer’s is offered primarily at three Regional Alzheimer’s Disease Assistance (ADA) Centers and their associated networks of primary provider sites. The Centers offer services such as diagnosis and treatment, consultation, and referral for patients and their families; education for caregivers; and a patient database for researchers. IDPH is required to establish regional ADA centers and develop standards for their functioning. As mentioned above, IDPH did not provide revised or updated information for this letter. The following material, describing the state’s 3 regional centers, is from our 1999 Research Response on Alzheimer’s incidence, treatment, and research, which we quickly updated using IDPH’s “Alzheimer’s Disease Assistance Plan 2000” report.

## REGIONAL ALZHEIMER'S DISEASE ASSISTANCE CENTERS

Much outpatient treatment for Alzheimer's disease in Illinois is offered through the state's Regional Alzheimer's Disease Assistance Centers. The centers were established to provide "a comprehensive, statewide system of regional and community-based services, to provide for the identification, evaluation, diagnosis, referral and treatment of victims of [Alzheimer's]." An institution of higher education having a medical school in affiliation with a medical center is designated as a regional center if it has or had an "Alzheimer's Disease Core Center" sponsored by the National Institutes of Health (NIH) and National Institutes on Aging (NIA). There are required to be at least 2 Regional Centers serving the Chicago area and at least 1 serving the rest of the state. The state has 3 Regional Centers:

≡ The Rush Alzheimer's Disease Center.

≡ The Northwestern Alzheimer's Disease Center.

(The above 2 centers are federally-sponsored core centers and serve Cook, DuPage, Grundy, Kane, Kankakee, Kendall, Lake, McHenry, and Will counties.)

≡ The Southern Illinois University (SIU) Center for Alzheimer's Disease and Related Disorders, no longer designated as a federal core center, serves the rest of the state.

The centers are required by law to provide:

- comprehensive diagnosis and treatment facilities and services, including professional medical staff trained in disciplines related to Alzheimer's; support staff trained as caregivers to people with Alzheimer's; appropriate and adequate equipment; and transportation services for outreach to the service area and to give patients access to services;
- consultation and referral services for Alzheimer's patients and their families;
- research programs and facilities to be used in studying the cause, diagnosis, and treatment of Alzheimer's;
- training, consultation, and continuing education for caregivers, including relatives of patients;
- a centralized data system to be used as an information clearinghouse to help victims, families, researchers, and others interested in Alzheimer's assistance; and
- research programs designed to qualify for federal funding.

State grants are provided to the regional centers to help fund research and provide service to Alzheimer's patients and their families. In fiscal years 1995 through 1997, the centers at Rush and SIU each got \$1,008,900 annually. (Northwestern was not designated a regional center until August 1997.) Beginning in fiscal year 1998, the centers at Rush and SIU have each received \$1,405,933, and the Northwestern Center \$205,933.

### RUSH ALZHEIMER'S DISEASE CENTER

The regional center at Rush-Presbyterian-St. Luke's Medical Center in Chicago provides and promotes care of people with, or at risk of developing, Alzheimer's and their families through clinical care, education, community services, and research.

Outpatient treatment is provided at the center and through a primary provider network of 20 sites. These sites evaluated 1,300 persons for possible dementia in 1999. There are 5 major activities of the clinical program:

- New patients with possible dementia are clinically evaluated using a telephone conversation, medical history, neurologic examination, neuropsychologic testing, and interview.
- Conferences are held with patients and their families to discuss test results, make recommendations, and answer questions.
- Patients return for follow-up clinical evaluation annually, or more frequently if necessary.
- The Center tries to maintain telephone contact with all patients.
- A diagnosis of Alzheimer's can be confirmed by a post-mortem brain autopsy through participation in the Rush Brain Bank. The Brain Bank also facilitates research into the neurobiologic causes of Alzheimer's.

Research at Rush focuses on:

- identifying risk factors for Alzheimer's;
- understanding the presentation and course of, developing tests for, and preventing disability and institutionalization due to Alzheimer's;
- investigating the underlying neurobiologic causes of Alzheimer's; and
- developing treatments for the disease.

### ALZHEIMER'S FAMILY CARE CENTER

Rush operates an Alzheimer's Family Care Center, offering dementia-specific adult day care, and education and support for families of Alzheimer's patients. The program of day care serves about 76 clients.

### SIU CENTER FOR ALZHEIMER'S DISEASE AND RELATED DISORDERS

The Regional Center at the SIU Medical School in Springfield has 7 specific aims:

- to provide diagnostic services, treatment, and case management to Alzheimer's patients and their families through a network of 20 primary provider sites (listed in Appendix A);

- to provide training, consultation, and continuing education to lay people, students, and medical professionals;
- to maintain a centralized database of patients and control subjects;
- to support research by providing support staff, carefully diagnosed patients, and non-patient control subjects;
- to provide information on Alzheimer's and aging to legislators, the public, and the media;
- to recruit neurologically healthy older people and patients with very early dementia for aging research; and
- to enlist primary provider sites in areas of research such as clinical drug studies and recruitment of control subjects.

SIU offers comprehensive patient care through a network of 21 primary provider sites (PPSs) at hospitals and clinics throughout Illinois, mostly in rural areas. In the 3 years through 2000, the Center in Springfield and its PPSs served 2,416 new patients. All patients seen through the network are entered in a computer database, which by 2000 had information on over 6,000 patients.

Research at SIU focuses on cognitive changes in normal aging and their relation to dementia; development of therapies for Alzheimer's; and disturbances of motor function in patients with dementing diseases. Like Rush, SIU has a Brain Bank to provide postmortem diagnoses and facilitate research on Alzheimer's disease.

#### NORTHWESTERN ALZHEIMER'S DISEASE CENTER

Northwestern University's Regional Center uses a research-driven model of care. The center's goals are to provide patients with benefits of the latest research developments, and to cure and eventually prevent Alzheimer's.

The center's clinical arm compiles information on dementia patients and control subjects. Clinical services include individualized evaluations and referrals to specialists. Caregivers and family members have access to educational and supportive resources.

The center also autopsies Alzheimer's patients; operates a brain bank; gives diagnostic information to families and physicians; and makes information available to researchers. There is a particular interest in the relationship between clinical symptoms and the underlying anatomy of brain pathology.

Finally, the center provides education and information transfer to lay people and professionals, including training opportunities in research and patient care. The center has held "memory health fairs" to provide information on topics such as Alzheimer's, nutrition, stress management, and caregiver resources. It also offers weekly seminars on Alzheimer's, and an annual AD day featuring research by the center's investigators.

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## ILLINOIS LEGISLATIVE ALZHEIMER'S DISEASE TASK FORCE — LIST OF WITNESSES

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TUESDAY, NOVEMBER 18, 2003  
ROOM A-1 STRATTON OFFICE BUILDING — SPRINGFIELD, ILLINOIS

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### ORAL TESTIMONY

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CHARLES JACKSON..... *Deputy Director, IL Department of Public Health*

DR. ROGER ELBLE..... *Director, Center for Alzheimer's Disease and Related Disorders  
SIU School of Medicine-Springfield*

DR. DAVID A. BENNETT ..... *Director, Rush Alzheimer's Disease Center  
Rush University Medical Center-Chicago*

DR. MARSEL MESULAM ..... *Director, The Cognitive Neurology and Alzheimer's Disease Center  
Feinberg Medical School Northwestern University-Evanston*

KELLY CUNNINGHAM..... *Division Manager of Long Term Care, IL Department on Aging*

JOANNE THOMAS ..... *President, IL Association of Area Agencies on Aging*

LYLE VANDEVENTER..... *Office of Rehabilitation Services, IL Department of Human Services*

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### RECORD OF APPEARANCE ONLY

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JUDITH A. ERICKSON..... *Family member of an Alzheimer's patient*

TINA WEITZEL ..... *Memorial Medical Center-Springfield*

HOWARD D. SHOCKEY ..... *Chaplain, Pleasant Hill Village*

GREG KYROUAC..... *Director of Outreach Programs, SIU School of Medicine*

KATHY LEE..... *Director of Psychiatry, Memorial Medical Center –Springfield*

MATT KEPPLER ..... *Public Policy Director, Alzheimer's Association*

JUDY BUCHANAN ..... *Chair, Alzheimer's Association-IL Chapter Network Committee*

MAY MEISTER ..... *Family member of an Alzheimer's patient-Peoria*

MARLENE RUSH ..... *Director, Alzheimer's Association*

G. KENT BARNHERSER ..... *President and CEO-Alzheimer's Association*

SUSAN ANN MOWBRAY ..... *Family member of an Alzheimer's patient-Springfield*

MIIN W. WHITAKER ..... *Family member of an Alzheimer's patient-Springfield*

CYNTHIA L. KIRAKOS ..... *Mental Health Centers of Central IL*

DR. SHERRY ROBINSON ..... *SIU School of Medicine*

**WEDNESDAY, DECEMBER 10, 2003**  
**ROOM 16-503 — JAMES R. THOMPSON CENTER — CHICAGO, ILLINOIS**

ORAL TESTIMONY

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JUDY BUCHANAN ..... *Chair, Alzheimer's Association-IL Chapter Network Committee*  
MARTY AND LAURIE BAHR..... *Family experience with early onset Alzheimer's disease-Bartlett, IL*  
BARBARA J. CARLO .....*Ada S. Niles Adult Day Care Center, IL Adult Day Services Association-Chicago*  
LINDA BROOKS ..... *Director of Nursing, Carlton Home HealthCare*  
JONATHAN LAVIN .....*Executive Director, Suburban Area Agency on Aging-Oak Park*  
JUDY ERICKSON .....*Family Caregiver-Morton*  
TRACIE EPKINS.....*Family Caregiver-Morton*  
MARLENE RUSH ..... *Executive Director, Alzheimer's Association-Central IL Chapter*  
JACKIE BOWERS .....*Program Director, Alzheimer's Association-Central IL Chapter*  
MELANIE CHAVIN .....*Vice-President, Alzheimer's Association-Greater IL Chapter*  
SARAH GRABOWSKI.....*Social Worker, University of Chicago*  
JUANITA TUCKER .....*Family Caregiver-Chicago*  
GREG KYROUAC.....*Director of Outreach Programs, SIU School of Medicine*  
DR. LESLIE DENNIS ..... *Northwestern University Early Stage Alzheimer's Support Group*  
GILLIAN DE VANE..... *Northwestern University Early Stage Alzheimer's Support Group*

RECORD OF APPEARANCE ONLY

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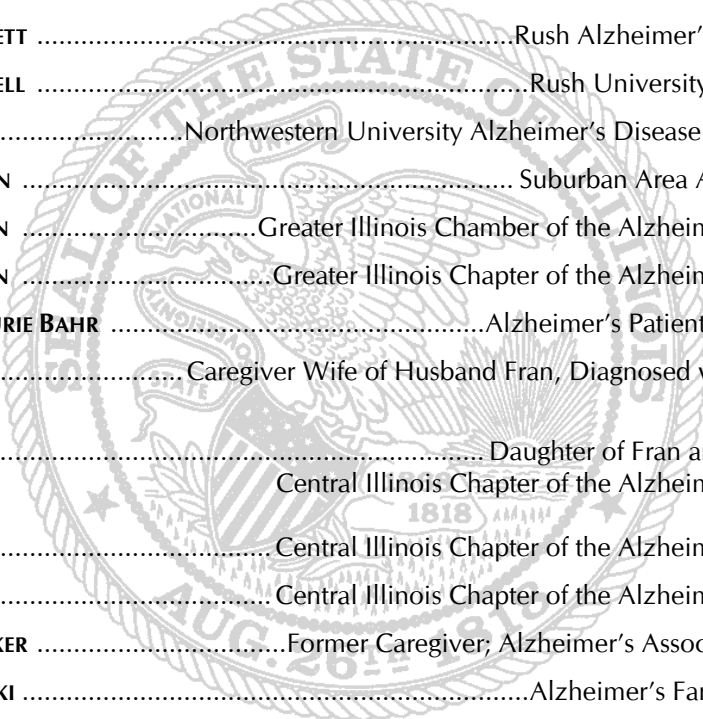
VOYER HOWELL.....*Alzheimer's Patient-Chicago*  
KATHLEEN HORTON ..... *Spouse of an Alzheimer's Patient-Chicago*  
NANCY BERRY ..... *Executive Director, St. John's Home and Community Care-Collinsville*  
EVA-DINA DELGADO..... *Office of the Mayor of Chicago*  
TAMARA KNIGHTEN..... *Administrative Assistant, Alzheimer's Association*  
ANYA KOMPARE ..... *Alzheimer's Association National Office*  
FRAN HANKIN ..... *Alzheimer's Association*  
MR. MATT KEPPLER ..... *Public Policy Director-Alzheimer's Association*  
BARBARA HANSON DENNIS ..... *Spouse of an Alzheimer's Patient-Chicago*  
DEBRA D. GREINER ..... *Director, Alzheimer Services-Dekalb County Rehab and Nursing Center*  
KENT BARNHERSER ..... *President and CEO-Alzheimer's Association-Greater IL Chapter*  
WILLIE ROBERTSON, JR. .... *Private Citizen-Chicago*  
DEBBIE TRUEBLOOD WITT ..... *Government Relations Manager-IL Home Care Council*  
PHILLIP DAVIS ..... *Regional Alzheimer's Disease Assistance Center-SIU-School of Medicine*  
SUSAN FOSTER..... *Rush Alzheimer's Disease Center*  
DANIELL MELE ..... *Rush Alzheimer's Disease Center*  
KATHERINE MCELROY..... *Rush Alzheimer's Disease Center*  
DAVID BENNETT ..... *Rush Alzheimer's Disease Center*  
PAM SMITH ..... *Rush Alzheimer's Disease Center*  
LATOYA ARTIS..... *Rush Alzheimer's Disease Center*  
JOSEPH DEVANE ..... *Private Citizen*  
KARLENE WENZ ..... *Director of Government Relations-Northwestern University*  
DARBY MORHARDT..... *Northwestern University Alzheimer's Disease Center*  
JOSEPH LUGO ..... *IL Department of Aging*  
MICHAEL J. DONNELL..... *IL Association of Area Agencies on Aging*  
WILLIAM L. KEANE ..... *Mather Institute on Aging-Evanston*  
BRIDGET DOUGHERTY ..... *IL Association of Area Agencies on Aging*

## Written Testimony Submitted at Public Hearings

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Springfield — November 28, 2003

Chicago — December 10, 2003



**RODGER J. ELBLE** ..... Southern Illinois School of Medicine  
**GREG KYROUAC** ..... Southern Illinois School of Medicine  
**DAVID A. BENNETT** ..... Rush Alzheimer’s Disease Center  
**ROBERT . BORWELL** ..... Rush University Medical Center  
**M. MESULAM** ..... Northwestern University Alzheimer’s Disease Center, Chicago  
**JONATHAN LAVIN** ..... Suburban Area Agency on Aging  
**JUDY BUCHANAN** ..... Greater Illinois Chamber of the Alzheimer’s Association  
**MELANIE CHAVIN** ..... Greater Illinois Chapter of the Alzheimer’s Association  
**MARTY AND LAURIE BAHR** ..... Alzheimer’s Patient; Caregiver Wife  
**JUDY ERICKSON** ..... Caregiver Wife of Husband Fran, Diagnosed with Alzheimer’s  
**TRACIE EPKINS** ..... Daughter of Fran and Judy Erickson  
Central Illinois Chapter of the Alzheimer’s Association  
**MARLENE RUSH** ..... Central Illinois Chapter of the Alzheimer’s Association  
**JACKIE BOWERS** ..... Central Illinois Chapter of the Alzheimer’s Association  
**JUANITA L. TUCKER** ..... Former Caregiver; Alzheimer’s Association Volunteer  
**SARA GRABOWSKI** ..... Alzheimer’s Family Care Center  
**BARBARA CARLO** ..... Ada Niles and St. Albie’s Adult Day Services  
**LINDA BROOKS** ..... Carlton Home HealthCare; Illinois Home Care Council





**RODGER J. ELBLE, MD, PHD**  
PROFESSOR AND CHAIR OF NEUROLOGY  
DIRECTOR OF THE CENTER FOR ALZHEIMER DISEASE AND RELATED DISORDERS  
SOUTHERN ILLINOIS UNIVERSITY SCHOOL OF MEDICINE

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ALZHEIMER DISEASE ASSISTANCE CENTERS: SERVICE AND EDUCATION

In July 1985, the 84<sup>th</sup> General Assembly passed nearly identical bills in the House (House Bill 301) and Senate (Senate Bill 388) to establish regional Alzheimer Disease Assistance Centers for the metropolitan Chicago area and the remainder of the state. Two centers now exist in Chicago, one at Northwestern University under the direction of Dr. Marsel Mesulam and the other at Rush Medical School under the direction of Dr. David Bennett. SIU School of Medicine is the center for downstate Illinois. The Alzheimer Disease Assistance Centers were mandated to develop standards for the evaluation, diagnosis and treatment based on best medical evidence and to disseminate and implement these standards throughout the state in cooperation with an outreach network of "primary providers". An autopsy program, brain bank and other facilities for research were also required. Thus, the 84<sup>th</sup> General Assembly wisely recognized that service, education and research are inextricable and that the entire state needed to be served. In the next few minutes, I will summarize the progress made in clinical service and education. Drs. Bennett and Mesulam will discuss research and the importance of restoring funding for this program.

The 84<sup>th</sup> General Assembly recognized that two or three academic centers would not have the capacity to care for the 210,000 patients and their families in Illinois, and the General Assembly also recognized the considerable need for educating health care providers and the general public about Alzheimer disease. Thus, the primary provider outreach networks emerged out of necessity and were intended to provide community-based clinical services and educational programs and to participate in research to the extent they were capable. The primary provider program now includes more than 65 medical centers and physicians in the Chicago metropolitan area and 26 medical centers located throughout the remainder of the state (appendix). These primary providers serve minorities and the most rural areas of the state.

The Alzheimer Disease Assistance Centers view the primary provider system as a healthcare cooperative. The goal has always been to establish a free exchange of knowledge among the three centers and the primary providers, thereby enhancing research at the three centers and the standard of care throughout Illinois. Information about Alzheimer disease is increasing at a rate that is overwhelming for the most dedicated specialists. It is simply unreasonable to expect the average physician or allied healthcare professional to distill all of the information that appears in the literature each day. In 1985, there were no treatments for Alzheimer disease, and now there are five. In addition, new diseases have been discovered that were previously mistaken as Alzheimer disease, and Parkinson disease was discovered to be the second most common cause of dementia. This knowledge boom is increasing by the day, and the three centers have therefore developed innovative programs to disseminate information to the general public and the primary providers. A few examples include:

- Internet-based programs for disseminating practical information pertaining to the diagnosis and treatment of Alzheimer disease and other causes of dementia. These programs include videotapes of patients, self-assessment quizzes, and hyperlinks to important articles and web sites. The ultimate goal is to network healthcare providers throughout the state with the three assistance centers.

- Educational programs for staff and managers of retirement communities, senior housing developments, assisted living facilities, and case coordination agencies to improve quality of care, improve job satisfaction and reduce staff turnover.
- Large educational symposia for healthcare professionals and the general public in which the latest advances in diagnosis and treatment are showcased.

The three centers and their primary providers conduct hundreds of educational programs each year with an average yearly total attendance of 27,000 people (9000 people per center). These programs have facilitated the implementation of best medical practices throughout Illinois.

I will now turn to the actual delivery of care. During the past three years, the three centers have evaluated 4204 new patients and 7389 established patients. While these numbers are impressive, I wish to explain why these numbers will increase at least 4-fold in the next 10 years.

First of all, we are all getting older and medical science is successfully pushing our life expectancy to advanced ages that were rare less than a century ago. Reaching 100 is now sufficiently common that an announcement on national TV by Willard Scott is no longer guaranteed. Alzheimer disease and most other forms of dementia are most common in the elderly, and epidemiologic studies estimate that 30% of people 80 and older have dementia, with Alzheimer disease accounting for at least half. The number of people in this age group will increase 2-fold over the next 30 years, resulting in a 2-fold increase in the number of patients seeking medical attention.

Secondly, in Sangamon County and throughout the US, fewer than 20% of Alzheimer patients are referred for specialty care and treatment because the treatment options are limited and because an accurate diagnosis frequently is never made.<sup>1</sup> By contrast, Parkinson disease is a neurodegenerative disease for which many treatment options exist, and the choice of medications in the early stages of the disease may affect the course of the disease later on. Consequently, nearly 80% of Parkinson patients are referred for specialty care and treatment. Thanks to research, the treatment options for Alzheimer disease and other dementias are rapidly increasing, and thanks to education, early, accurate diagnosis is becoming increasingly common. The percentage of Alzheimer patients seeking specialty care will approach that for Parkinson disease as the treatment of Alzheimer disease improves and becomes more complicated. Therefore, we expect that the percentage of Alzheimer patients seeking specialty care will increase 4-fold in the next 10 years.

In sum, the changing demographics and increasing need for specialty care will combine to increase patient referrals at least 4-fold over the next 10 years and at least 8-fold in the next 30 years. These projections far exceed the current capacity of our three centers. The three centers and their primary providers now see an average of 1400 new patients per year and 2500 follow-up evaluations per year. In 10 years, the anticipated numbers would be 5,600 new patients and 10,000 follow-up visits per year.

The 1985 Illinois legislation was unique in the United States and served as a template for subsequent legislation in other states. The cost of Alzheimer disease is often expressed in billions of dollars, and the cost to Illinois Medicaid is estimated to be at least \$1 billion. I am sure that the cost of Alzheimer disease in human terms has been witnessed by nearly everyone in this room. Illinois has been a leader in the fight against Alzheimer disease and other forms of dementia, and the three Alzheimer Disease Assistance Centers in Illinois are second to none. All 3 programs are

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<sup>1</sup> Decision Resources database March 2000 and SIU Alzheimer Center database 2003.

committed to the continued growth and development that is needed to meet the expanding needs of Illinois. As you will soon hear from Drs. Bennett and Mesulam, the progress toward effective treatment is very promising, and we wish to thank the Illinois legislature for giving us the opportunity to participate in this important work.

**GREG KYROUAC**

SOUTHERN ILLINOIS SCHOOL OF MEDICINE

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The Alzheimer Disease Assistance Centers have duties assigned to them in order to serve the people of Illinois. I would like to focus on 2 of those, and how we work together with other community organizations and caregivers to accomplish these tasks.

The first duty is to provide diagnostic services, treatment and case management to patients and families throughout Illinois, excluding the Chicago metropolitan area. At Southern Illinois University School of Medicine, special attention is directed to rural areas of Illinois through an outreach program of 26 Primary Provider Sites located throughout Illinois. These sites include hospitals, clinics, adult day care centers, long term care facilities, mental health agencies, local public health departments, and assisted living facilities. The sites are located in communities as large as Rockford and Peoria and as small as Danforth and Vienna.

The program's goal is to provide people with state-of-the-art services as close to home as possible. Medical and social needs of communities throughout the 93-county service area were identified by the case coordinators at the Primary Provider sites. All of our sites, including our Springfield center, work closely with program staff in the Department on Aging and Area Agency on Aging programs and other social service agencies to identify services are available for our patients and families.

We have worked with task forces and work groups to identify and fill service gaps throughout Illinois. I currently serve on the Department on Aging Community Care Program Advisory Committee, and we have seen a decrease in the number of adult day centers serving the state in the past three years. I have served on an interfaith volunteer program and have seen a number of similar groups spring up in other Illinois communities. These grassroots organizations provide, to a small degree, services such as in-home respite and transportation for those who don't qualify for other traditionally funded programs.

The second duty is to provide training, consultation, and continuing education to the public, students, residents, practicing physicians and other health care professionals, thereby enhancing research and the standard of care in rural Illinois. Students from many colleges and universities in Illinois have completed internships at the SIU Alzheimer Center and now provide counseling, social work services and neuropsychological assessments in other areas of Illinois. The students have come from a variety of programs such as clinical psychology, counseling, social work and gerontology. In turn, our students and residents receive valuable training by visiting local community organizations such as the Alzheimer's Association, support groups, adult day centers and long term care facilities.

The SIU Alzheimer Center sponsors and provides training and continuing education to physicians, health care professionals and family members/caregivers for people with Alzheimer disease

throughout down state Illinois in cooperation with the Primary Provider sites and other local organizations. Our faculty members are provided to these groups at no charge, in order to keep their costs down. In the fiscal year ending June 30, 2003, 418 public forums and professional workshops and symposia attended by 9875 people were held in 75 different communities to provide education to the general public and local health care professionals. In May, we co-sponsored our 8<sup>th</sup> Annual Alzheimer disease conference attended by 392 people with Illinois Department on Aging and the Alzheimer's Association. Our 5<sup>th</sup> annual conference co-sponsored with the Alzheimer's Association for Certified Nursing Assistants who work with people with dementia was attended by 140 CNAs. We solicit nominations for the CNA of the Year, and use family members, educators, the Area Agency on Aging, the Alzheimer's Association and the ombudsman program on the review committee. We recruit family members to provide talk at the conference about their experiences with the CNAs who provided care to their loved ones.

The SIU Alzheimer Center and its outreach program devote considerable time to educate the general public, thereby increasing awareness of Alzheimer's disease. Public forums are held each year in Springfield and in Primary Provider site communities. The SIU Alzheimer Center and the Primary Provider sites work closely with each of the 4 local chapters of the Alzheimer's Association serving Illinois. In fact, rather than develop our own brochures and pamphlets about the disease, we have provided family members information developed by the Alzheimer's Association. Dementia caregiver networks of professionals and family members have been developed in Springfield and Collinsville to increase and enhance sharing of information on how to best serve this special population. I have been involved in the statewide Dementia Special Care Summit, and often hear family members talk about the need for more dementia specific care options.

I have been involved with the Springfield office of the Alzheimer's Association for over 8 years, serving on the Board of Directors and the Leadership Council, involved in planning and recruiting volunteers for programs and co-leading a support group for early stage patients and their families. I recently asked some of the early stage members what they wanted me to tell people about their experiences, and here are 2 of the responses:

Judy said to say: "It takes a lot of patience on your part as well as on your supporters. Life is never going to be the same as the person becomes afflicted. I don't think that as it passes that you and those around you will ever quite be the same. There are so many facets to this disease."

Tom said: "Pick up on it. So many people fear or pity. I didn't start here, I made an appointment with the doctor, knew something was afoot. I look back 7-8 years and I have had signs of it. Do something about it; there are medicines that do help in some way. We can't hold it off forever, there's no cure, get the help from the qualified people."

In conclusion, we need to continue to provide the help to the people affected by this disease, and we need to continue work together to effectively serve this population. There are gaps in services that need to be addressed, including the issues of transportation, special care units, respite, and adult day services in the rural areas.

**DAVID A. BENNETT, M.D.**  
DIRECTOR — RUSH ALZHEIMER'S DISEASE CENTER

**ROBERT C. BORWELL**  
PROFESSOR OF NEUROLOGICAL SCIENCES — RUSH UNIVERSITY MEDICAL CENTER

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Alzheimer's disease is among the most common and most feared problems facing older residents of Illinois and their families. Dr. Elble spoke about the enormous costs of Alzheimer's disease to Illinois citizens and to the State, primarily through the Medicaid Program. Finally, you heard how the Program has funded clinical care and educational activities for hundreds of thousands of residents throughout the state over the past 15 years. In addition to providing access to health care, the Illinois Alzheimer's Disease Assistance Program also provides funding for the development of a crucial research infrastructure to combat both the human toll and the enormous costs of the disease.

The research activities at all 3 participating academic institutions depend on state funding in 3 ways:

- First, state funds provide seed money to support pilot and demonstration projects that provide the preliminary data required to secure large externally-funded grants.
- Second, the research activities depend on state funding to provide the education and outreach necessary to support large clinical studies.
- Third, the research activities depend on state funding to support recruitment of senior faculty who conduct high quality research today, and the training of junior faculty and other health care professionals to care for our children and our grandchildren, who will live to old age and are at high risk of common chronic diseases such as Alzheimer's disease.

The research activities focus on disease treatment. For example:

- Preclinical studies that lead to the development of the currently approved pharmacotherapies;
- The study of all of the drugs currently approved by the FDA to treat Alzheimer's disease;
- The study of vitamin E which was shown to delay clinical milestones in Alzheimer's disease;
- Behavioral intervention studies with patients and caregivers to delay costly nursing home placement; and
- Preclinical studies that will help lead the way to better therapies for people with the disease in the future.

The research activities focus on disease prevention. For example:

- Community-based epidemiologic studies to identify modifiable risk factors for Alzheimer's disease;
- The study of medications to delay the onset of Alzheimer's disease; and

- Novel community-based clinical-pathologic studies that will help lead the way to disease prevention.

Evidence that these research activities are successful can be seen in several ways.

- First, all 3 academic institutions participating in the program have been designated as Alzheimer's Disease Research Centers by the National Institute on Aging. Only about 35 such institutions nationwide ever have received such a designation. Illinois is currently one of only 4 states with more than one federally designated center, making Illinois a leader in the fight against the disease, and the federal government a partner with the state, in the financial support these research activities.
- Second, research reports supported by the program are regularly published in the leading medical journals. They are often accompanied by editorials and press releases, and are frequently reported on by the local, national, and international press.
- Third, the research infrastructure supported by the program has resulted in an enormous influx of dollars to the State of Illinois through external funding. Before the budget reductions last spring, Illinois invested \$3.3 million each year in the program. In the past 3 years alone, the program has brought \$86.7 million into the state, nearly all from the federal government, a return of nearly \$9 for each \$1 invested.

Despite the remarkable achievements, the entire \$3.3 million of funding was cut from the Department of Public Health's FY 04 budget, dealing what could have been a death blow to this highly successful program. Recognizing the value of the program while acknowledging economic realities, the legislature restored half of the original funding amount and moved these funds to the Department of Public Aid where they could draw federal matching dollars. This action allowed the state to save \$1.65 million. Despite the legislature's actions, the program's budget was the subject of an amendatory veto and was reduced by one-half. Last week 114 members of the House of Representatives voted to override that veto reduction and restore full program funding. On behalf of the estimated 210,000 patients with the disease in the state, and their family members, we respectfully request the support of the Senate task force members when House Bill 2716 comes up for a vote this week.

Restoration of full funding for this program is of paramount importance during this veto session. However, the number of persons diagnosed with Alzheimer's disease in Illinois is rising rapidly while the funding level for the program has not been increased since 1996. Thus, restoration is but a first step. Currently the state's expenditure on Alzheimer's disease through the Medicaid program alone exceeds \$1 billion each year. This cost does not include the stress and adverse health consequences associated with caregiving. Absenteeism and lost productivity from caregiving costs the state in excess of another \$1 billion each year. This cost does not include the human toll of watching a loved one lose his or her memories. The disease is now so common that it is hard to find a family that has not been personally touched by its devastation. Considering the demographic trends in Illinois, the disease will continue to present an unbearable burden of medical costs on the taxpayers of Illinois – a burden that can only be alleviated through the conduct of high quality clinical care, education, and research. In the very near future this program needs an increase in the funding level, a topic to be addressed by Dr. Mesulam.

The Alzheimer's Program offers the state a meaningful and intelligent choice for combating the effects and the costs of Alzheimer's disease. The program offers hope to hundreds of thousands of

victims of this terrible disease, as well as their family members. At the same time, the program attracts tens of millions of dollars in outside research funds to Illinois – funds that would otherwise go to other states. With your actions this past spring, Illinois now has a partner to help share the costs of this important program – the federal government is matching dollar for dollar the state's commitment to this program. A reduction in the total cost of care for Illinois citizens can only be accomplished by local medical science leadership resulting in better treatments for Alzheimer's disease, and ultimately, the prevention of Alzheimer's disease. Excellence in Alzheimer's disease research must be regarded not as a cost drag on the Illinois budget, but as an investment essential for controlling current, and future, costs of caring for persons with this devastating disease.

THE IMPORTANCE OF STATE FUNDING FOR ALZHEIMER'S RESEARCH ~  
HOW THE STATE INVESTMENT ATTRACTS ADDITIONAL FEDERAL FUNDS ~  
AND FUTURE RESEARCH WITH INCREASED INVESTMENT

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The economic costs of Alzheimer's disease in the state of Illinois reaches into the billions of dollars annually; a cost that is steadily increasing as greater numbers of Illinois residents seek care for this common and slowly progressive disease. This does not include the human toll of the disease which causes untold suffering to more than 200,000 Illinois residents currently afflicted and their family members. Controlling these costs will require better strategies to treat, and ultimately to prevent, Alzheimer's disease which can only be accomplished through high quality medical science leadership. However, the state investment into Alzheimer's research funding, \$1.65 million in FY 04, is only a small fraction of 1% of state expenditures on the disease, despite offering the only real hope of controlling both the economic and human toll of this terrible disease in the future. Despite the success of the state Alzheimer's disease program in attracting millions of dollars in federal research funds and researchers and clinicians to the state, and in providing educational programs and clinical services to hundreds of thousands Illinois residents, much more needs, and can, be done.

The Rush Alzheimer's Disease Center has used state funding in 3 ways to attract and keep federal dollars — as seed money to fund pilot projects, for educational and outreach functions to support community-based research, and to attract new researchers and clinicians to the state. Demographic trends forecast that the burden of Alzheimer's disease in the future will fall disproportionately on racial and ethnic minorities. The proposed research plan, as outlined in this report, will expand a unique study with the potential to bring many more millions of federal funding to the state, while providing education and clinical services for traditionally underserved populations, and providing crucial new knowledge about aging and Alzheimer's disease in minority populations.

USE OF STATE FUNDING FOR ALZHEIMER'S RESEARCH BY THE RUSH ALZHEIMER'S DISEASE CENTER

While many look to pharmaceutical companies and the federal government to discover new treatments and prevention for Alzheimer's disease in the future, most of the actual research using private and federal dollars is conducted at University Medical Centers across the country. Therefore, a high quality medical research infrastructure designed to take advantage of these funding opportunities is necessary to compete for these dollars, and bring these monies to Illinois rather than having them go to other states. The Rush Alzheimer's Disease Center has used the state investment in just that manner, attracting more than \$42 million for research on aging and Alzheimer's disease to the state in the past 3 years alone. Thus, the state investment in research

leads to economic development returning dollars to the state in the form of taxes, in the form of needed educational and clinical services to tens of thousands of residents across Cook and the collar counties, and in the form research findings which will reduce the burden of disease on future generations.

#### HOW THE STATE INVESTMENT ATTRACTS ADDITIONAL FEDERAL FUNDS

The investment of state funds to the Rush Alzheimer's Disease Center provides funding for three essential functions that make it possible to capture these federal dollars. These functions as well as concrete examples of their operation are as follows.

First, state funds provide seed money to support pilot and demonstration projects that provide the preliminary data required to secure large externally-funded studies.

For example, Rush used monies from the state to fund a large pilot study to demonstrate the feasibility of the Rush Memory and Aging Project. This pilot study recruited 200 persons from five retirement communities from our 9-county catchment area into a longitudinal clinical-pathologic study of risk factors for Alzheimer's disease. The state funded annual, detailed clinical evaluations and brain autopsies for four years beginning in 1997. The preliminary data was used to secure a \$9 million grant from the NIH, which was awarded September 1, 2001, to greatly expand the project. The project, which now includes more than 800 persons from about 25 retirement facilities and will eventually expand to about 1,200 persons from 40 facilities, also serves as an infrastructure to support additional studies of aging and Alzheimer's disease. State funds were used to collect preliminary data for two additional grants submitted to the NIH (\$3.6 million and \$2.4 million), and 2 additional grants are already in the planning stages for 2004.

Second, these research activities depend on state funding to provide the education and outreach necessary to support large clinical studies.

The Rush Memory and Aging Project, already working with 25 retirement facilities, will eventually expand to about 40 facilities. These facilities serve an estimated 15,000 older persons with and without dementia. While the grants from the NIH provide funding for the actual research, we use state funding to provide ongoing educational programs to the professional and non-professional staff and the residents of these facilities. These educational programs are greatly needed by these facilities as their residents age in place. They provide an opportunity to improve the lives of thousands of seniors and their families, and they allow the research to be conducted in an atmosphere of mutual benefit. All of this helps ensure success of the research and of ongoing federal funding.

Third, the research activities depend on state funding to support recruitment of senior faculty who conduct high quality research today, and the training of junior faculty and other professional staff to care for our children and grandchildren, who will live to old age and are at high risk of common chronic diseases such as Alzheimer's disease.

Rush recently hired a senior neuroscientist and used state funding to provide laboratory space and equipment to support this researcher's efforts. This scientist submitted a \$2.4 million grant to the National Institute on Aging (NIA) within 16 months of his arrival. By contrast, developing young scientists into independent investigators capable of securing federal funding is typically a 3 to 5-year investment. Rush supported a neurologist-neuropathologist with state funding for 3 years until



she received a grant from the NIH. Two other junior faculty members supported by the state have grants pending at the NIH worth more than \$3.5 million. In the absence of state funding, it would not have been possible to hire and train these individuals, all of whom are likely to repay the investment several fold in federal dollars, and in countless ways through the conduct and findings of their research on aging and Alzheimer's disease.

#### FUTURE RESEARCH WITH INCREASED STATE INVESTMENT

The burden of Alzheimer's disease will fall disproportionately on racial and ethnic minorities in the future. However, very few studies have the required numbers of minority participants necessary to draw research conclusions regarding this group from their studies. This is especially true for clinical-pathologic studies which have played such a crucial role in developing our understanding of the disease. Therefore, Rush is requesting an additional \$1.5 million from the state to enroll racial and ethnic minorities into the Memory and Aging Project (see attached proposal). The infrastructure and community development work required to bring this to fruition cannot be underestimated, while the importance of obtaining cultural diversity in this project cannot be overstated. With this proposed program, additional state funding would provide desperately needed clinical and educational services to underserved communities, while providing research opportunities and future health benefits to these same communities. The ability to implement this biracial, multi-cultural clinical-pathologic study would make it highly attractive to the National Institute on Aging and would undoubtedly lead to substantial increases in federal funding in proportions similar to current research funding levels. This project would keep Illinois in the forefront of Alzheimer's research for many years to come.

#### PROPOSAL TO ENROLL RACIAL AND ETHNIC MINORITIES INTO THE MEMORY AND AGING PROJECT

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#### SUMMARY

The clinical syndrome of Alzheimer's disease is a complex function of multiple genetic and environmental factors that lead, add, or interact with changes in the brain. Thus, a complete understanding of the disease will come from large longitudinal studies that include all four of these factors: genetic and environmental risk factors, clinical disease, and brain pathology. The Rush Alzheimer's Disease Center has pioneered the design and conduct of such studies with the Religious Orders Study and the Memory and Aging Project. Both studies include large numbers of persons without dementia who agree to annual clinical evaluation and brain donation at the time of death. Through the conduct of these studies we can identify risk factors for disease and we can understand the biology of disease; thus, providing an approach to both disease treatment and prevention. There are no comparable studies being conducted anywhere else in the world making Illinois home to 2 of the most unique and innovative studies of aging and Alzheimer's disease to be found anywhere.

Unfortunately, neither study currently includes sufficient numbers of racial and ethnic minorities for meaningful analyses. The overall goal of this proposal is to develop an infrastructure to enroll large numbers of older racial and ethnic minorities into the Rush Memory and Aging Project.

## BACKGROUND

Over the past several years, 5 drugs have been approved by the Food and Drug Administration for the symptomatic treatment of Alzheimer's disease. However, the extent to which these drugs work in racial and ethnic minorities is unknown because too few minorities participated in these studies for meaningful analyses regarding efficacy.

There are few studies of risk factors for Alzheimer's disease that include large numbers of racial and ethnic minorities. One such study, the Chicago Health and Aging Project conducted by Rush investigators, suggests that the genetic risk factor, the apolipoprotein E  $\epsilon$ 4 allele is a risk factor for Alzheimer's disease among whites but not among African Americans or Hispanics [1]. Several other factors that increase risk of Alzheimer's disease are more common among African Americans including high blood pressure, diabetes, depressive symptoms, and stress [2-6]. Other factors that reduce risk such as participation in cognitively stimulating activities appear to be less common among African Americans [7-9]. These data suggest that much more is needed regarding disease risk in minority populations.

Finally, much of our current knowledge of Alzheimer's disease comes from studying brain tissue from persons with and without Alzheimer's disease. Pathologically, Alzheimer's disease is characterized by the deposition of amyloid and neurofibrillary tangle formation in specific vulnerable regions involved in memory and other cognitive abilities [10-12]. Two other lesions, cerebral infarctions and Lewy bodies, are commonly found in the brain that also contribute to cognitive impairment [13-15]. Through the Religious Orders Study and Memory and Aging Project, we are beginning to learn how genetic and environmental risk factors interact with changes in the brain to lead to clinical Alzheimer's disease [6,16-19]. Since we already know that risk factors may differ among racial and ethnic minorities, enrolling minorities into studies in which we can link risk factors to the common age-related pathologies is crucial to ensuring that findings regarding disease prevention are applicable to the minority population. Unfortunately, due to cultural and historical barriers, the challenge of enrolling racial and ethnic minorities into research has been substantial, and very few minorities participate in such studies.

## SPECIFIC PLAN

A Specific Plan is proposed to develop an infrastructure and perform the community development and groundwork required to enroll 500 racial and ethnic minorities into the Memory and Aging Project. The cost of this effort cannot be underestimated while the importance of obtaining cultural diversity in this project cannot be overstated. Most importantly, a significant investment must be made to overcome barriers that often deter minorities from participating in research in general, and in clinical-pathologic studies in particular. This includes recruiting on a foundation of mutual trust and respect and establishing a collaborative, mutually beneficial relationship between the community and the research team; employing minority team members with extensive ties to the community; identifying key contacts within the community; and providing ongoing culturally relevant community education. The Rush Alzheimer's Disease Center has already taken several steps in this direction, and additional specific plans include:

- Hiring and training of additional professional staff of color, at all levels, to provide regular and sustained community outreach and educational efforts to racial and ethnic minority communities to underscore the need for participation in research in general, and in clinical-pathologic studies in particular will be needed.

- Increase support to the Memory Assessment Clinic at Cook County Hospital, which is run in collaboration with the Rush Alzheimer’s Disease Center. This will help ensure that clinical services for dementia care are available to all persons in our catchment area.
- Expand our senior housing ASSIST Network to provide education and outreach to residential and community organizations that serve large numbers of older racial and ethnic minorities.
- We propose to translate all of our data collection forms into Spanish and adapt our data and analytic infrastructure to handle data in Spanish.
- We will need to perform extensive pre-testing and pilot-testing of the Spanish language forms.
- Hiring and training of additional bicultural and bilingual staff, at all levels, including physician, neuropsychologist, nurse, and research assistants, will be needed for education, outreach, and the conduct of research in the Hispanic community.
- Work with the Secretary of State’s office to identify minority seniors who have already agreed to organ donation for transplant purposes as these persons may be willing to participate in the proposed project.
- To ensure that the relationship between investigators and participants is mutually beneficial, we propose to identify clinical needs of the seniors, and work, within our capacity, to meet those needs. Examples:
  - ≡ As transportation is a major problem for seniors in general, and those with limited economic resources in particular, we could purchase a minibus to transport seniors to and from the Rush Alzheimer’s Disease Center or their personal physician for clinical care. We use this model already at our Adult Day Care Center, the Alzheimer’s Disease Family Care Center on Chicago’s north side.
  - ≡ As genetic risk factors will be documented by a blood draw for DNA, we will send blood for laboratory screening for common medical conditions and provide results to the participants. We use this model already for participants in other studies that require blood draws.
- Success of the program will be measured by securing additional funding from the National Institute on Aging.

In addition to enrolling persons in the Memory and Aging Project, we would also use this infrastructure to enhance minority participation in our other studies, especially clinical trials, and genetic studies, and neuroimaging studies funded by the National Institute on Aging. Thus will provide research opportunities for persons who are not comfortable with organ donation, it will serve to continue to develop research relationships with the community, and it will ensure the ongoing success and continuation of ongoing studies funded by the federal government.

RECOMMENDED BUDGET INCREASE TO RUSH ALZHEIMER’S DISEASE CENTER

We estimate the total cost of implementing this proposal at \$1.5 million annually and we propose a funding increase of \$500,000 per year over the next three years to reach that goal. It is important to

point out that these research efforts will require that the Rush Alzheimer's Disease Center enter into a commitment to ongoing education and care to community residents who enter this study. Thus, the state funding would need to be secured and a firm commitment made by the state as well as the Rush Alzheimer's Disease Center to see this study through to completion. Budget fluctuations, would destroy the state's and Rush's relationship with the community and ensure that we would not obtain federal funding for this project as well as forfeiting those federal funds already obtained.

## CONCLUSION

With this proposed program, additional state funding would provide desperately needed clinical and educational services to underserved communities, while providing research opportunities and future health benefits to these same communities. The ability to implement this biracial, multi-cultural clinical-pathologic study would make it highly attractive to the National Institute on Aging and would undoubtedly lead to substantial increases in federal funding in proportions similar to current research funding levels. This project would keep Illinois in the forefront of Alzheimer's research for many years to come.

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Appendix Materials and References — available on request.

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**M. MESULAM, MD**

NORTHWESTERN UNIVERSITY ALZHEIMER'S DISEASE CENTER, CHICAGO

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My task is to outline the adverse effect of a 50% funding cut. I will itemize these effects under 7 headings.

- In July of 1985, in what turned out to be a bold and forward looking move, the Illinois 84th General Assembly recognized the need to develop standards for the evaluation, diagnosis and treatment of AD. The establishment of these standards and their application to patient care relies on the dedicated work of highly trained personnel. The proposed reduction in funding threatens at least 20 of these specialist positions at the three centers. Some of these positions have already been eliminated as a consequence of the current freeze on funding.
- Standards related to the evaluation and care of AD are rapidly evolving. Many state-of-the-art procedures mandated by these standards are not covered by third parties and the centers rely on state funding to make them available. In the past three years alone, more than 10,000 of our patients and their family members have benefited from such state-of-the-art services. These specialized aspects of care are the most vulnerable to funding cuts.
- Not all patients and families are within reach of the 3 Illinois centers. The training of primary providers leverages the reach of the centers and enables large numbers of additional individuals to receive enlightened care based on the standards established at the centers. The Primary Provider Program will be reduced by 50% if the proposed cuts take effect.
- The definitive diagnosis of AD can be reached only through a costly microscopic examination of the brain at autopsy. The 3 centers rely on state funding for diagnostic autopsies requested by family members. Decreasing this funding would deprive many families of a final diagnosis.

- Centers run clinical trials of promising drugs. The loss of funding will undermine the infrastructure needed to run such trials. Illinois citizens will no longer have as much privileged access to potentially promising drugs and may choose to go next door to the Mayo Clinic, Washington University, University of Indiana, or University of Michigan to join such clinical trials.
- Outreach and educational activities would be devastated by the funding cuts. Access to vital health care information will be reduced throughout the state. Efforts to decrease the disparity of health care received by minorities would be weakened.
- In the past 3 years, the 3 Illinois centers have been awarded more than \$86 million of research funding, bringing into the state almost \$9 of external funding for every dollar of assistance they receive. This has clearly been a sound investment. Research depends on administrative infrastructure, fully diagnosed subjects and brain tissue obtained at autopsy. Each of these three components will be weakened by the proposed cuts. The end result will be to put investigators in the three centers at a disadvantage when competing for NIH and industry-sponsored research grants. Research funding related to AD may dip by millions of dollars per year.

Through the Assistance Act of 1985, Illinois has established a leadership position in the care and research of AD. Centers of excellence take a long time to build but can be disabled rapidly if vital lifelines of support are cut off. Hopefully this will not happen. My colleagues and I are heartened by the news that the House has voted to restore the AD funding to its FY 03 level and we hope that the Senate will also see fit to consider and support such a motion.

For years to come, AD will remain one of the most important health care and psychosocial challenges for Illinois and the whole nation. While the challenges are great, so are the opportunities. In 1985, when the Assistance Act was enacted in Illinois, there were no approved drugs for AD and no known possibilities for prevention. Today there are 5 medications that can be prescribed and we have discovered more than a dozen risk factors, each suggesting a different kind of preventive measure. The 3 Illinois centers have contributed to each of these developments.

This is just the beginning. The pipeline is full of promising initiatives. The development of these initiatives and their translation to patient care will require a coalition of medical schools, state and federal governments, the Alzheimer's Association, and the pharmaceutical industry. Maintaining a leadership position in these developments will need increasingly greater investments in trained personnel, infrastructure, and facilities.

The creation of this task force and your membership on it clearly indicate that Illinois is taking the challenge of AD seriously. Right now our common goal is to prevent a cut in funding. In the near future, however, we hope to be invited back by this task force to testify in favor of increased funding above the FY 03 levels so that we can meet the ever increasing challenges of AD with the most up-to-date approaches that are available anywhere in the world, in a manner that fits the leadership role of Illinois. We believe that such an investment will more than pay for itself by improving the quality of life for patients and families and also by maintaining a major influx of federal research funding that will bring new jobs and new opportunities to the state.

PROPOSED EXPANSION OF SERVICES  
PROVIDED BY THE NORTHWESTERN ALZHEIMER'S DISEASE ASSISTANCE CENTER

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The Northwestern Alzheimer's Disease Assistance Center (NADAC) receives 80% less funding from the State of Illinois than the other 2 centers. The ability of the NADAC to accommodate increasing demands for services is therefore severely limited. The following is a list of services the NADAC would provide to patients and families, should the Alzheimer's disease Task Force recommend, and the General Assembly enact, a larger appropriation for this program:

- Increased educational and patient screening activities in the underserved African-American communities of the south side and the Hispanic communities of West Town and Humboldt Park. We have received repeated requests to provide additional services in these neighborhoods. Increased funding would allow us to establish a satellite clinic in each of these locations for 3 purposes: education, on site screening, and referral to NADAC for those who need more specialized investigations. Subtotal: \$195,000
- Increased physician education. NADAC currently works with approximately 50 primary care providers – a small fraction of the primary care providers that need and want our assistance and continuing educational opportunities so they may extend the most enlightened level of care to their patients. Subtotal: \$40,000
- Improved availability of expert evaluation, diagnosis and treatment. The level of demand for evaluation, diagnosis and treatment exceed our current capacity. As much of the necessary specialized services are not reimbursed by insurance, Medicare or Medicaid, additional state funding would help us make this care available to more Alzheimer's patients in Illinois. Subtotal: \$295,000
- Meeting more of the demand for definitive diagnosis. The demand for diagnostic autopsies overwhelmed our capacity, and as a result we were forced to eliminate a web page offering autopsies to families of Illinois Alzheimer's patients. Many families are now deprived of the only conclusive diagnostic procedure that enables them to define their family health history. This service is generally not covered by private insurance, Medicaid or Medicare. Meeting a higher level of the autopsy requests will require an additional full-time neuropathologist, a technician and \$50,000 of supplies and autopsy costs. Subtotal: \$240,000
- Expanded Facilities. The above service expansions will necessitate additional space (\$130,000/yr) and the appointment of an Associate Administrator. Subtotal: \$200,000

THE IMPORTANCE OF STATE FUNDS  
IN LEVERAGING FEDERAL RESEARCH DOLLARS

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The NADAC received \$9.3 million of new AD-related funding awards during FY 03, mostly from the National Institutes of Health (NIH). As the NADAC's annual share of the program funds is \$300,000, this translates into a ratio of over \$30 brought into Illinois for every dollar of state support the Northwestern Center receives. Our ability to compete with research enterprises across the country for coveted NIH funding is in part due to the administrative infrastructure and essential

patient services made possible by the state monies. Increased state support of the type described previously herein will upgrade this infrastructure and will allow us strategically to recruit physician-researchers and technical staff. These developments will enable NADAC investigators to attract considerably greater funding from the NIH and private sources that in turn will bring new jobs and greater health care access for Alzheimer's patients in Illinois.

**JONATHAN LAVIN**

EXECUTIVE DIRECTOR — SUBURBAN AREA AGENCY ON AGING  
OAK PARK, ILLINOIS

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RESPIRE CARE SERVICES FOR ILLINOIS' CAREGIVERS OF OLDER PERSONS

I am presenting this testimony on behalf of the twelve members of the Illinois Association of Area Agencies on Aging. We are responsible with the Illinois Department on Aging for designing and delivering the Older Americans Act National Family Caregivers Support Program. Together we have set up over 150 Family Caregiver Resource Centers across the state.

The National Family Caregiver Support Program is designed to contribute towards the development of a home and community based long-term care service system that provides supports to older persons and their families in a variety of community settings. The Act recognizes the vital role played by families and friends in providing 80% of long term care support for older adults living in the community

The services authorized under the program include:

- Information about available services;
- Assistance in accessing services;
- Counseling, support, groups and caregiver training;
- Respite care; and
- Supplemental services, on a limited basis.

Throughout Illinois, \$1,417,162 is committed to respite care in 2004. This is matched with local funding of \$106,020 and will collect \$7,513 in contributions from families. This supports 97,786 hours of service for 2,027 persons (\$15.65 total cost per hour).

In suburban Cook County, we established a Respite Registry for families to determine the best approach for supporting their caregiving responsibilities. Listed on this registry are 60 organizations providing reliable and safe care for an elderly loved one while the primary caregiver is able to leave the care situation. Based on the advice of national experts on caregiving, we in suburban Cook County set a higher funding maximum for each respite client family (\$1,500 per year)<sup>2</sup>. Our experience is that the higher authorization level does not equal actual expenditures for every family. We have opened and closed intake for Respite services every year since the program

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<sup>2</sup> The Suburban cap on respite services is the highest in the state. The East Central Illinois Area Agency uses a \$750 cap per caregiver annually and provided 182 caregivers with 5,487 hours of respite services. They too have service agreements with a wide range of providers including comprehensive respite services, adult day services, and temporary placement in a long-term care facility. The majority of respite clients have chosen the comprehensive respite option because it includes supervision and the services of a homemaker for a few hours or overnight.

began. Clearly, the number of families who can benefit from this service is much greater than the 439 reached, but with experience, we are clarifying which families are the priorities for our limited funding. We are increasing awareness that help is available and needed by those who are providing family caregiver support. We authorize respite services through our 10 Case Coordination Units (CCU). Each CCU was funded to establish a Caregiver Specialist position and designated as Caregiver Support Centers under the Department on Aging's program plan. We found that:

- Approximately 439 clients received caregiver respite from October 2002 through September 2003, for a total of 21,388 hours of respite.
- More clients use home care respite services (61.5%) than residential or adult day respite services.
  - ≡ Of the 439 clients served, 51 clients chose Adult Day Services; 118 clients chose residential respite (assisted living or long term care); and the remaining 270 choose home-based respite services.
- Clients are more likely to utilize home services for short 2-6 hour periods of time on an intermittent basis.
- Clients who choose to use residential respite (e.g. assisted living or nursing facility) are more likely to schedule respite for a block of 4-11 days in a row.
- Clients tend to maintain a stable pattern of respite vendor use.
  - ≡ Most clients stay with one care plan and use either a home services or a residential service, but not both together.
  - ≡ Similarly, clients tend to stay with one vendor for respite services.
- When you compare the number of units billed for services per client and count 1 residential respite day as 24 units, the number of units paid for home services was only slightly higher than the number of units paid for residential services.
  - ≡ Looking at a sample from one CCU, from a monetary standpoint, the average cost of 1 day (24 units) in a residential facility is approximately \$140 per day. When examined from a cost per unit standpoint, residential respite care averages approximately \$5.93 per unit, whereas home services ranged from \$18.00 — \$20.00 per unit. In other areas, adult day services averaged \$6.00 per unit, but clients did not often request adult day service.
  - ≡ Despite the aforementioned lower cost per unit for residential respite, clients who use residential respite tend to use significantly more units because they use respite for 24 hour care for extended periods of time (more than 3 full days).
  - ≡ In one CCU sample, the range for total in-home respite was \$54.00 – \$2,440.01 per client, with a mean usage of \$504.86 per client. The range for out-of-home (residential or adult day services) was \$540 - \$1092, with the average of \$917 per client.



The Suburban Area Agency on Aging commissioned the Buehler Center on Aging, Northwestern University to perform a survey of needs for family caregivers. Following my testimony is a summary of the survey's results to help you better understand the scope of need for family caregiver support in suburban Cook County.

The National Family Caregiver Support Program is not only respite services. In future year's information and assistance, counseling, education, support groups, and respite services for family caregivers will be in higher demand throughout the state. State funds are needed to leverage federal funding under the Older Americans Act and to respond to the growing population of older adults with physical and mental impairments and family caregivers, including spouses and adult children who need support in caregiving for their loved ones.

The Illinois Association of Area Agencies on Aging is supporting Senate Bill 1620, the Respite Care Act that passed the House of Representatives this past spring but did not come to the Senate floor. I4A worked with the Representative Granberg and House staff to draft the Family Caregiver Act to complement the National Family Caregiver Support Program. Senate Bill 1620 was amended to include the bill in the Senate and is now pending.

Senate Bill 1620 creates the Family Caregiver Act, to be administered by the Department on Aging, for the purpose of encouraging family members to provide care for their elderly family members. Requires the department to contract with area agencies on aging and other appropriate agencies to provide family caregiver support services to the extent of available funding. Provides that the services include counseling, training, and respite care. Requires the department to seek federal funding for a demonstration project in collaboration with nursing homes. Also authorizes caregiver support services for grandparents who are primary caregivers for their grandchildren. .... Defines a "frail or disabled adult" as a person age 60 (instead of 55) or older and who either (i) suffers from Alzheimer's disease or a related disorder or (ii) is unable to attend to his or her daily needs without assistance or regular supervision. ...

This legislation, which we will support and offer information on our actual experiences under the National Family Caregiver Support program, will enable Illinois to identify resources that will guarantee the draw down the \$4.7 million in federal funding from the Older Americans Act, and allow a cost effective policy to support Caregivers – the people who provide over 80% of the care to chronically ill older and disabled persons.

#### SURVEY RESULTS FACT SHEET ON CAREGIVING IN SUBURBAN COOK COUNTY

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The information presented here comes from a caregiver needs assessment conducted in 2001-2003 by the Buehler Center on Aging, on behalf of the Suburban Area Agency on Aging. A telephone survey, 21 focus groups, 28 individual interviews, and a survey of clients utilizing caregiver case management services were conducted. In all, over 550 caregivers provided information leading to this report. Information and copies of the complete report may be obtained via e-mail from the Suburban Area Agency on Aging, Oak Park, Illinois. Please email [awiatr@s3a.com](mailto:awiatr@s3a.com) or call the Area Agency for more information.

# SURVEY

## DEMOGRAPHICS

There are 429,925 residents 60 years or older living in suburban Cook County. 37.8% of these seniors are 75 or older. Women are most likely to be care receivers. The mean age of care recipients is 79.35 years. 68.9% of care recipients are over age 75. Fewer than 17% are under age 70.

## INCIDENCE

At least 10.3% of all households in suburban Cook County provide care to older relatives 60 and over.

## RESIDENCE

Almost all seniors in need of care continue to reside in the community, either alone or with the primary caregiver.

## WHO PROVIDES CARE?

Family members are dedicated caregivers. The most frequent caregiving relationship is that of mother/daughter. Most caregivers are married women caring for one or two persons. Fewer than 1/3 of all caregivers report using paid help to meet the need of their older family member or friend. More than 70% report incomes of \$35,000 or more. However, over 20% have incomes of under \$20,000. Care recipients incomes are considerable lower.

## HOW MUCH CARE IS PROVIDED?

Caregiving is a long-term commitment: over 45% of caregivers have provided care for 5 years or more. On average, caregivers, whether working or not, provide approximately 5 hours of care per day to their older family member. Fewer than half of all caregivers work full-time, and as many as 20% report retiring or stopping work due to the demands of caregiving.

## WHAT KIND OF CARE IS PROVIDED?

The most frequent types of care provided include transportation, housework, communication with the care recipient's physician, preparing meals for the care recipient, planning social activities for the care recipient, meeting the care recipient's medical needs, tracking and paying bills, dealing with legal issues, making financial decisions, and arranging for care.

#### WHAT KINDS OF SERVICES ARE USED?

On average, less than 1/3 of all caregivers use any type of service provided by the aging network, including housekeeping, home health care, case management, transportation, shopping services, legal assistance, home delivered meals, respite services, adult day care, emergency response systems or telephone wellness checks.

#### WHAT KINDS OF SUPPORTS DO CAREGIVERS USE?

Caregivers receive support from a variety of sources. Almost 2.3 of all caregivers report turning to faith or prayer for support. Other sources of support include: physicians, family members, local assistance organizations, national organizations, religious institutions, government agencies, social workers, and the Internet.

#### WHAT DO CAREGIVERS WANT?

Almost all caregivers report two important needs: a central place to call for help and some sort of tax break or financial benefit for caregiving. In addition, caregivers would like assistance in dealing with agencies, more hands-on help with caregiving, more social opportunities for care recipients, counseling and intervention for family conflicts, training and education about caregiving, and specific information on the care recipient's impairments and illnesses. Caregivers would also like assistance with their own transportation as well as assistance with babysitting for their children so that they may provide care to their older relative.

#### WHAT INFORMATION DO CAREGIVERS WANT?

Caregivers want information about services for the care recipient and for themselves, information about their legal rights and responsibilities as caregivers, information about Medicare, Medicaid, and medical billing, information about nursing homes and guidelines for selecting a nursing home, and updates on changes in the law related to caregiving.

#### IS CAREGIVING A BURDEN?

Overall, fewer than half of all caregivers reported experiencing a burden due to caregiving. These included stress or other health problems, lack of time for oneself, conflicts with family members, and financial burdens.

### CAREGIVING PROVIDES A NUMBER OF BENEFITS

Caregivers were more likely to report benefits, including a sense of satisfaction related to caregiving, a sense of accomplishment, and a sense of appreciation. Caregivers also reported that they experienced a sense of personal growth from their caregiving experience, felt they were able to reciprocate for the care they had receive in the past, learned greater patience and tolerance, and felt closer to the care recipient as a result of caregiving.

### CAREGIVER HEALTH

Most caregivers reported their health status to be good, very good, or excellent, despite being a caregiver. Stress related to caregiving was reported as having a negative effect on health.

### CAREGIVER CONCERNS

Caregivers expressed concerns about the quality of paid caregivers, their finances and financial futures, their ability to handle the stress and demands of caregiving over the long-term, the safety and well-being of the care recipient, their own health, and the future.

### THE IMPACT OF CAREGIVING ON FAMILIES

Caregivers expressed mixed emotions about their relationships with other family members, particularly siblings. Many were reluctant to ask their own children to assist with care for an older relative, and many felt that their own siblings were not carrying their fair share of the burden or responsibility of caregiving.

#### **JUDY BUCHANAN**

VOLUNTEER, DAUGHTER OF EARLY ONSET ALZHEIMER'S PATIENT

ALZHEIMER'S ASSOCIATION CHAIRMAN OF THE ILLINOIS NETWORK OF MEMBER CHAPTERS

VICE-CHAIR FOR PUBLIC POLICY OF THE GREATER ILLINOIS CHAPTER OF THE ALZHEIMER'S ASSOCIATION

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The Alzheimer's Association is a voluntary health organization dedicated to research for the causes, treatment, prevention and cure of Alzheimer's disease and to providing education and support services to individuals with the disease, their families and caregivers. In Illinois, we represent over 950,000 individuals, their families and caregivers affected by Alzheimer's and related dementia.

These families are dramatically impacted — physically, emotionally and financially. Currently there are over 200,000 Illinois residents with Alzheimer's disease and this number is expected to grow to 300,000 in just 25 years when the baby boomers reach the age of greatest risk for this disease.

With this in mind, the Alzheimer's Association recognizes the urgency and has identified three major goals for our work which are reflected in our Public Policy Platform included with my written testimony. The three overriding goals are:

- To expand and promote home and community based options for care;
- To ensure quality training for dementia care;
- To advocate for quality assurance.

The association recognizes and understands that tough budget decisions must be made, but also recognizes that there are some programs that are not receiving sufficient funding to provide needed services to individuals with Alzheimer's disease, their families and caregivers.

I would like to highlight and provide examples of the needs relative to the three points referenced.

It is estimated that nearly 70% of people with Alzheimer's disease live at home and family and friends provide 70% of the care. While this is the preferred option for many, not all Illinoisans can access the services they need due to limits on program capacity, geographic barriers, and income restrictions. The association is in support of increases for Adult Day Services, especially transportation. We also concur with House Amendment #1 to Senate Bill 1620 to create a Family Caregiver Act which will provide needed respite and other services. In fact, we encourage a look at the critical needs for respite care and suggest that a pilot project be initiated to test some of the models in existence and their costs.

Quality training of direct care staff for all persons with Alzheimer's disease and related dementia is central to quality care. Currently the Association is working with the Illinois Department of Public Health to develop dementia training for persons providing care in both facility and home care settings. We further recommend that at least 20% of required training be refocused on dementia specific issues.

We further recognize that the protections afforded in statute and regulation play a major role in ensuring the quality of care. The Association will continue to review, comment and advance initiatives that strengthen quality service provisions. We support the passage of the Dementia Special Care Unit regulations scheduled to be reviewed very soon by the Joint Committee on Administrative Rules; in addition, we will continue to work with and advocate on behalf of the Alzheimer Disease Centers; and we will, in an effort to ensure quality of services continue to monitor staffing relative to assisted living licensure and oversight.

There is hope in the future — from a 1970s diagnosis for my mother of a condition that was only recognized as Alzheimer's late in her disease; hope stems from the 1983 designation of the first-ever National Alzheimer's Disease Month by President Reagan; there is hope with the current ability to diagnosis with more than 90% accuracy, formerly only available with autopsy; there is hope in the growing body of evidence identifying risk factors which can open the doors to prevention and cure, and most importantly I hope that the state of Illinois will return to and renew their commitment to leadership in providing services to people with this frightening and devastating disease.

This state took the lead in the 1980s to successfully create a framework. An Alzheimer's Disease Research Fund via an income tax check off program was created. This remains active and is expected to generate approximately \$200,000 for FY 2005. In addition, the state established procedures for the collection and exchange of information needed to identify persons with Alzheimer's who could receive services through the Alzheimer's Disease Centers and their provider networks. At this point, I need to thank you for your vote, during the recent veto session, to restore needed funds to the important work of the Alzheimer Disease Centers. However, several of the original initiatives of the General Assembly are not currently active; there is no state wide task force to coordinate services, there is no examination of insurance, and there are no pilot projects as called for to examine the usefulness and costs of programs such as respite. While fiscal constraints may have not allowed for the implementation of some earlier initiatives, those initiatives implemented are demonstrating their importance in responding to this disease; ensuring their continued effectiveness and the needed expansion of services will be the challenge for all of us. With this compelling challenge before us, the Alzheimer's Association would like a task force created to continue to examine Alzheimer's Disease and related dementia further, with an ongoing review of the state's responsibility.

## MYTHS AND FACTS ABOUT ALZHEIMER'S DISEASE (AD)

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**Myth:** Ill-informed medical practitioners say if it is Alzheimer's there is nothing you can do.

**Fact:** There are support programs throughout Illinois that allow individuals with AD to meet with each other and discuss their problems. They can socialize and support each another without embarrassment over their lost skills.

**Myth:** Alzheimer's really doesn't affect that many people.

**Fact:** The American Society on Aging (ASA) notes that nearly 5 million Americans have AD and the number is expected to double in the next 25 years. In the state of Illinois, 214,000 people are afflicted with AD. 88,000 reside in Cook County; over half live in Chicago.

**Myth:** People with Alzheimer's are in their 70s and 80s.

**Fact:** Improved diagnosis techniques have identified individuals in their 50s and 60s with AD.

**Myth:** People with Alzheimer's are in nursing homes or adult day care centers.

**Fact:** About 2/3 of those with AD are living in the community, participating in family life and other activities.

**Myth:** Families can, and will, do what is necessary to care for individuals with Alzheimer's.

**Fact:** Families do the lion's share of the work in supervising those with early stage Alzheimer's, but repeated studies show they need support in the form of emotional support and education, counseling, respite care, and adult day. Support is critical as early diagnosis means many care partners need to work full-time to compensate for loss of income from the individual affected by Alzheimer's.

**Myth:** Individuals with Alzheimer's really cannot communicate well.

**Fact:** Many of those stricken with this disease remain very articulate and aware of diminishing abilities. Structured activities with those of similar abilities improves self-confidence and that all important sense of community.

**Myth:** Individuals with AD really don't have feelings anymore; they aren't sure what's going on.

**Fact:** The social self survives even when damage to the brain creates loss of judgment, ability to calculate and manage finances, tell time, and manage alone. This social self is greatly helped by regular contact with others in the same situation.

**Myth:** Alzheimer's only lasts for a few years before people die.

**Fact:** Individual's with Alzheimer's sometimes live for 15 or 20 years.

**Myth:** Medical research is coming up with lots of new solutions for Alzheimer's.

**Fact:** Great strides are being made in research as well as newer medications, but much of what is in the news is years away from helping those with the disease presently. The immediate supports for those with Alzheimer's are the activities which involve their being with others with similar level of abilities so that they retain a sense of self-worth, humor and joy in life's possibilities that are still available to them.

### HISTORY OF DEMENTIA SPECIAL CARE UNITS IN ILLINOIS

Alzheimer or Dementia Special Care Units (SCUs) exist to better meet the needs of residents with dementia in nursing homes and residential care facilities. Special care unit growth has become a challenge for Alzheimer advocates concerned about the quality of long-term care.

Nearly 60% of nursing home residents have Alzheimer's or another dementia. In recent years the number of nursing homes that have developed dementia SCUs has grown exponentially. Dementia special care units now represent one of the fastest growing parts of the nursing home business.

Until recently, facilities did not have to meet any specific standards beyond the regulations to which all nursing homes are held, in order to promote themselves as having a special care unit.

The lack of specific standards causes confusion for families seeking dementia care. Families may visit two or three facilities with "special care units" that look vastly different from one another. In some cases, the term "special care unit" is used for marketing purposes when the only distinguishing factor is that the unit is segregated from the rest of the facility and is secure. In others, "dementia" is defined loosely, resulting in units that house both persons with Alzheimer's – type dementias and persons with long-term psychiatric conditions. These types of units often do not adequately meet the needs of either population.

A 1993 study of SCUs by the Alzheimer's Association substantiated the concern that some facilities were offering little difference in the care provided in SCUs compared to more traditional nursing home settings.

The study found that:

- Extra costs of the units were not disclosed prior to admission 39% of the time.
- Twenty-nine percent of families did not know if they were paying more for special care than for standard nursing home care.
- Ombudsmen and state surveyors expressed concern about the availability of specialized activities, numbers of staff on duty, staff training, involuntary seclusion or confinement of residents, and the ability of the units to manage problem behaviors.

In the years since this study was commissioned, Alzheimer advocates have worked with Illinois lawmakers and various other groups to address these concerns. This work has resulted in the 90<sup>th</sup> General Assembly enacting House Bill 1486 to create the Alzheimer's Special Care Disclosure Act to require certain health care facilities who claim to provide specialized care or treatment to persons with Alzheimer's disease to make disclosures to the State agency licensing the facility and to clients or potential clients, on request, concerning the form of care and treatment at the facility. House Bill 1486 became Public Act 90-341, effective January 1, 1998.

In June of 2000, Governor Ryan instructed the Illinois Department of Public Health to develop standards for dementia special care units. By July 2000, the Alzheimer's Association began to



facilitate a series of Dementia Special Care Summits. The end result is that Dementia Special Care Unit minimum standards were crafted by a collaborative effort of providers and associations, members of the academic community, research/clinical/medical centers, private consultants, architect and design groups, government/related organizations, and the Alzheimer's Association. The minimum standards are currently in the 1<sup>st</sup> comment period at JCAR.

#### RESOURCE USE BY RESIDENTS IN SPECIAL CARE UNITS

Dementia Special Care Units are specialized settings designed to increase the effectiveness of care for residents with cognitive disorders. By setting aside a nursing home unit for residents with Alzheimer's disease or a related dementia, the facility can more easily devote specialized staff resources for behavioral management, psychological services, or activities designed specifically for the Alzheimer resident. The unit also might be designed with special physical features, such as pathways for wandering or security doors. Because of these specialized features, the SCUs may have more staff or other resources devoted to resident care than would be the case for a regular nursing home unit.

With regard to type, some researchers have discovered higher amounts of nursing assistant labor inputs for residents on special care units versus conventional units (Grant, Pothoff et al., 1998; Holmes and Teresi, 2000). A more recent study of Mississippi nursing home residents, Arling and colleagues (Arling, 2000; Arling and Williams, 2001) found significantly higher resource use for residents on Dementia Special Care Units compared to conventional nursing units. The Alzheimer's Association has contracted with Dr. Greg Arling, University of Missouri-Kansas City, to study cognitive disorders, resource use, and quality of care for nursing home residents. Study results should be available about 1 year from now. We expect similar conclusions from this study.

#### RELATIONSHIP OF SCUS AND MDS

The studies cited in our comments reflect a serious trend of higher resource use in special care units as compared to conventional nursing units in the effort to provide quality care for people with dementia. There are more studies coming out that show the same trend.

The Medicaid reimbursement tool, using the MDS, should add an Alzheimer's/dementia special care unit item (MDS Section P., 1., n.) under special treatments/programs. Research has shown that the most significant distinction between regular and specialized care units for residents with Alzheimer's or dementia is the increased staff time residents on the specialized units receive in their care. Only programs on file with DPH under the Alzheimer's program disclosure act should be reimbursed under this item.

The new the MDS assessment tool to recognize a diagnosis of Alzheimer's disease or a related dementia and a placement in a special care unit.

#### CONCLUSION

In summary, the Alzheimer's Association strongly recommends that the Alzheimer's Task Force support the proposed special care unit minimum standards, and that units covered under these standards be eligible for additional funding under the MDS.

**MARTY BAHR:** I am 54 years old. I have Alzheimer's disease. I am here to tell you, to show you this is not just a disease of the elderly. I was diagnosed about 3 years ago. Looking back, the disease probably began to show itself about 10 years ago.

My symptoms in this early onset stage include:

- Deteriorating vision - Impacts my ability to:
  - Read and comprehend;
  - Function on a computer;
  - Use a cell phone;
  - Drive an automobile; and
  - Perform any task that entails close-up work.
- Short term memory loss:
  - Often don't remember what others tell me or what I tell them;
  - Word finding has become difficult; and
  - I often can't remember names of people or places.

As a result of this, I had to give up working about 5 years ago. I used to be an executive with a large insurance company. I had been responsible for running a region with annual revenues in excess of \$500 million, and 100 + employees reporting to me.

I want to describe to you how I spend my days today, in contrast to how they were spent in my prior life:

- I require much more sleep than I used to, usually not getting up until about 9:30 each morning;
- I make coffee, sometimes now having difficulty with the coffee maker;
- I read the newspaper as best I can, until my eyes become too strained;
- I walk the dog;
- I watch TV until my eyes hurt;
- My daytime friends are the dog and the TV.

I need your help. I'm asking for your help.

Resources and services for younger individuals (those in their 40s and 50s) with early onset Alzheimer's, such as myself, do not currently exist. We still want to be productive contributors to our communities. We are not ready to retire, or be treated like invalids. We don't yet need services such as Eldercare or in-home nursing services. We do need:

- Programs that keep us working as a viable part of the community – and that doesn't mean stuffing envelopes. I used to be an executive...
- Meaningful volunteer opportunities;
- Affordable local transportation services.

I must have something that goes beyond what support groups currently offer, such as:

- Formal classes teaching techniques for memory enhancement.



**LAURIE BAHR:** My deepest regret, and greatest challenge, at this stage of the disease is my inability to spend more time with my husband. However, I need to work. We were and are many years from retirement age. We're not financially independent. We need my income and benefits coverage.

It pains me knowing he is home alone without enough to occupy his time while I'm away at work during the day.

My first and greatest need is to help Marty find regularly scheduled productive, rewarding activities.

Receiving a sentence of Alzheimer's when you're at the height of your productivity is life altering. It initially shocks and numbs the senses because the common understanding is that it happens only to the elderly.

We are working with the Alzheimer's Association to get the word out to you, our legislators; the general public; and the healthcare community that this disease, in fact, exists in middle age.

We need funding for research into finding a cure for the disease; and in the short term, medications that can arrest, if not reverse its progression.

Marty and I need it quickly. He is 54. Our hope is that a cure can be found, or at least, medications developed in time for him to have back a few years of a "normal" life before he slips out of reach, out of communication from me and the rest of our family.

In the meantime, we also need funding and support to help us and others like us meet the financial challenges of in-home care, assisted living facilities, and the like which present themselves 20–30 years sooner than we anticipated.

And, I need you to help me, help Marty make his daily life more rewarding...NOW.

## JUDY ERICKSON

CAREGIVER FOR HER HUSBAND, FRAN, WHO HAS BEEN DIAGNOSED WITH ALZHEIMER'S DISEASE

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My name is Judy Erickson and I am a caregiver. My husband Fran was diagnosed with Alzheimer's at the age of 61, just when we were ready to start our retirement years. At the time I was in very good health, now four years later, I have high blood pressure, diabetes, arthritis and much stress. Caregiving is a 24-7 job. Back to my husband, I knew something was wrong but never imagined it was Alzheimer's. I always thought Alzheimer's was an old people's disease. He has had diabetes for about 10 years so I thought his forgetfulness was diabetes related. Fran was a very successful salesman and started forgetting appointments and getting lost. His boss called me one day and said he was putting Fran on a 3-month medical leave of absence. We were shocked and scared. We went to several doctors; they ran tests, but couldn't pinpoint the problem. We finally went to Mayo Clinic and they diagnosed Alzheimer's. What a shock. We didn't know what to do or where to go. Our son contacted the Alzheimer's office in Peoria and their compassion and knowledge gave us the strength to get where we are today. They gave us videos and literature on the disease. They offer classes on the different stages of Alzheimer's and what to expect from the patient. I've gone to so many classes that they call me "the groupie"! I feel the more you know the easier it is to accept.

Fran had to retire early and it was a sad day when he emptied his desk. He told a neighbor that he was just let out of his job. No one in his office ever called to see how he was after that. People just stayed away and acted like he was not around. The first year Fran was home 24-7. He was either sleeping or very restless. He couldn't be left alone and as his only caregiver, it was really getting to me. I finally held a family meeting with our four children and their spouses and asked for help. They each took one day a month to care for their Dad so I could leave. On that day I traveled to Rock Island to visit my dad. He was in a nursing home in the last stage of Alzheimer's. He passed away in March of 2003. Our children also have worked Sunday once a month. They do odd jobs around the house for me. They have been a great support but it is very hard for me having them care for me instead of me caring for them. Our kids are in their 30s and 40s and are busy with their own lives and families. It is hard on them and each one reacts differently. I'll never forget the day my daughter and I attended an Alzheimer's seminar and during a talk she broke down and cried. The talk was on the stress and fatalities of caregivers and she thought of me and begged me to get outside help.

At that time the Alzheimer's office referred us to an adult daycare. It was a Godsend to me as well as Fran. He went three days a week for two years. I had 28 hours of freedom! The VA helped us with his meds and paid for one day a week at day care. They also got him a wheelchair. He gradually got worse and started having trouble walking and falling. The day care couldn't help him any longer and I couldn't handle him, as he weighed 350 pounds. The doctors had been telling me for several months that it was time and that I had to think of myself. So another family meeting – and another big decision. We moved him to the nursing home in January 2003. Putting a loved one in a nursing home is never easy. The more communication you have with the staff, the better. The nursing home becomes our second home and we need to be treated as family. The home opted to put him in the regular unit and not the Alzheimer's unit. They felt he wasn't a wanderer and was not dangerous. I feel these nurses don't understand and need more training. A couple of weeks ago, an LPN came in his room and told me Fran was in trouble – he grabbed two bratwurst out of a serving pan and ate them real fast. She told him he couldn't have them and to give them to her and he refused. I asked him "Sweetie, were you that hungry" and he put his head down and said "I don't remember doing it". It broke my heart seeing my husband behave as a little boy. I told the nurse he didn't know he did it – he has Alzheimer's – that is why he is at the nursing

home. Another day when I went to see him he was sitting in his chair with his coat on his lap. I asked him where he was going. He said they told him I was taking him out for the day. I said not today – I took you Thursday for Thanksgiving and we had a great time. He was very upset, cussing, telling me I didn't take him before and that he wasn't staying there any longer. It was awful – he was so angry. An aide finally helped calm him down and I left crying. My husband does and says things he never would have in his right mind. He always was very friendly and outgoing – now he stays in his room all the time. At our last care plan session, the girls told me he wanted to go home and they thought he probably could. I think they were encouraging him and it really upset him when I told him he couldn't come home. It seems like the staff doesn't understand Alzheimer's – one day he is perfectly normal and the next he stares at the wall. These things are very upsetting to me and when I get upset I call my kids and they too get upset.

I have taken advantage of the free counseling at Bradley University for caregivers. Sometimes I feel so alone – almost like a widow. Nancy Reagan calls it "The long goodbye" and it truly is. I attend three support groups a month and really look forward to them. I'm able to talk to other family members that are going through what I'm going through. We learn from each other and vent our frustrations and thoughts. Sometimes I wonder about the future – will I end up a bag lady!!

We brought Fran home for Thanksgiving and he seemed to enjoy it. It was almost a normal holiday until I had to watch our sons take their dad back to the hospital (as he calls it). I cried and I know it must have hurt the boys. We will bring him home again for Christmas. We take one day at a time and are thankful that we are together.

Fran is now on Medicaid. My assets are secured under the "spousal impoverishment law". I never expected to live this way. Our golden years have turned to rust!

So in closing, I can't express the importance of the Alzheimer's Association and Support Groups and Daycare. Without them I wouldn't have been able to keep Fran home as long as I did.

When things are bad, we take comfort in the thought that they could always be worse and when they are, we find hope in the thought that they are so bad, they have to get better.

**TRACIE EPKINS**

DAUGHTER OF FRAN AND JUDY ERICKSON; FRAN HAS ALZHEIMER'S DISEASE  
CENTRAL ILLINOIS CHAPTER OF THE ALZHEIMER'S ASSOCIATION

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I guess for me it all started when dad got lost in Morton. A town he had lived in for 30 years, on a road that intersected with the street we have always lived on. He called my sister-in-law and told her he didn't know where he was. She had him describe what was around him and she led him to her house. Just like a little boy, my father couldn't find his way home at age 61.

He had us worried before, but this topped it. We all had so many questions. The doctor visits started. It seemed there was no real answer. I remember thinking he must have a brain tumor. The sad thing is part of me wishes it would have been a brain tumor. At least then I might have had a chance to get my dad back.

Dad was diagnosed with Alzheimer's. At that time we all had so many questions and my brother was smart enough to know where to find some answers. He called the Alzheimer's Association. Jackie gave him lots of information to share with all of us. We got together and tried to figure out a plan of attack. We went to caregiver meetings, seminars, and any class we could to learn more about Alzheimer's.

We were told we needed to get the finances in order as soon as possible. Now who are we to be making financial decisions about our parents when we are just getting on our feet? Dad was just working full time a couple months ago, with no thought of retiring. It had to be done. We had to put the cottage up for sale. Mom and dad loved it out there. We sold dad's truck and car. He really never asked to drive much after he got lost so that wasn't as bad as we thought it would be. Mom had to give up her Cadillac. I think the hardest thing to get rid of was dad's boat. He really loved that boat and we all had so much fun in it. The worst thing was to look in mom's eyes and see how much it hurt to get rid of all these things that brought her family so much happiness.

Mom took great care of dad. She was by his side every minute. All you had to do was look at her to see how worn out she was. She hated asking for help, but finally she couldn't do it alone. Dad started going to adult day care 3 days a week. It was good for both of them. While Mom had her gallbladder surgery it was a blessing for all of us. We were able to work and we knew dad was being taken care of.

It was a very sad day when the day care said they could no longer care for dad because he had been falling. So, here we go again. Mom did all she could for dad and at 350 pounds it was no easy task getting him up and down. At this point we had to bathe and dress dad, remember he is only 64. It reminded me of dressing my son when he was 2. No daughter should have to see their father like that. He is still my dad. It took two or three big guys to get dad out of the tub. It was getting harder and harder to get him up when he fell. Mom's back and knee are shot. She is in terrific pain to this day.

The night the guys couldn't get dad out of the tub another decision had to be made. Dad needed more care than we can give. Not more love, but more care. This was the hardest yet. No one can take care of him like mom, but he needs more.

The search for a nursing home was heart breaking. Being on Medicaid your choices are narrowed down quite a bit. We placed him in a nursing home close to home to make it easier for all of us to visit. It is very hard to see your young father in a nursing home, but we made the best decision we could at the time. Dad is not in the Alzheimer's wing at this time which is difficult because the staff isn't educated enough to understand all his actions. When we went to pick him up for Thanksgiving he wasn't ready to leave. The aide said she had asked dad if he was leaving and he said he didn't know. Like it was his fault. It isn't his responsibility to know. They don't realize that when you have Alzheimer's you don't know.

Alzheimer's is a tragic disease. Not only for the person with the disease, but all of us who touch their life. My hope is that I don't have to put my boys through this in a few years. I realize that I should be happy my father is still with us, but he is not my dad.

I just hope and pray that this cruel disease does not take both my mom and my dad.

**MARLENE RUSH**

EXECUTIVE DIRECTOR — CENTRAL ILLINOIS CHAPTER OF THE ALZHEIMER'S ASSOCIATION

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Judy and Tracie's story clearly illustrates that Alzheimer's disease produces physical, emotional and financial challenges for families. Those challenges increase as the disease progresses.

Respite is the top need for Alzheimer families. The goal is to keep the patient at home as long as possible—that is better for the patients, caregivers and the state. Seventy percent of patients are cared for at home by family caregivers. We ask you to support this system by providing increased training and support for caregivers as the disease progresses. Our first platform issue is to expand and promote home and community-based options.

Judy talked about the importance of daycare services. For one year Judy was the sole caregiver 24/7, then her children each helped one day a month. For two years she used daycare 24 hours per week, but who provided care for the remaining 144 hours each week? Judy, like many other family caregivers, provided care most of the time at no expense to the state.

Since Fran was a veteran, the VA paid for 8 hours of daycare, and also for medications. What about patients who are not veterans?

Judy and Tracie attended 10-15 hours of caregiver education at our agency, took advantage of counseling, joined support groups—all very important opportunities that enhanced their ability to understand and cope with this devastating disease. Research proves that nursing home admittance can be delayed 12-18 months with education and support services.

Their stories about Fran's care in the nursing home illustrate clearly the need for training for dementia care. Quality Training for dementia care is the second priority issue in our platform. It is not appropriate for staff to reprimand Fran for bad behavior or encourage Judy to take him home. The truth is that Fran's brain cells are being destroyed as Alzheimer's disease progresses.

Fran did not qualify for a Dementia Special Care Unit because the nursing home determined that he was not at risk to wander. Would he be handled more appropriately in a Special Care Unit?

Our platform's third priority issue is quality assurance—quality care for persons with memory problems. We are advocating for regulation and enforcement of residential living options, Medicaid reimbursement, Family Councils, and best practices in medical care.

Judy's caregiving issues are very much like other family caregivers, but Judy is approximately 20 years younger than many caregivers. Remember, age is the highest risk for this disease—50% of patients are 85+, and so their caregivers tend to be around the same age. These older caregivers tend to have more health issues themselves that may limit their driving or caregiving duties. It may be harder for them if their sleep is disrupted, and they are part of a generation who does not readily seek outside help until there is a crisis. Due to the stress of caregiving, frequently older caregivers die before their patients.

I admire Judy's can-do upbeat attitude, and her openness and problem-solving with her children. She willingly shares her Alzheimer experience to help other families. Tracie volunteered to join her here today. Judy and Tracie represent the true heroes of this disease—the caregivers. Please keep their needs in mind as you consider legislation and system changes to better meet the needs of Alzheimer families.

**JACKIE BOWERS**

PROGRAM DIRECTOR — CENTRAL ILLINOIS CHAPTER OF THE ALZHEIMER'S ASSOCIATION

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- I. Quality Training for Dementia Care: The single greatest factor of quality dementia care in all settings is the competency of direct care staff. In order to ensure quality care, the Alzheimer's Association supports innovative strategies to train qualified personnel in the home, the community, and licensed care facilities. We, the Alzheimer's Association support:
  - Funding and implementing for Senate Bill 1434 that passed into law and became Public Act 91-744 to develop training and experience criteria for persons providing health care and home care to individuals with dementia-related disorders and to assess the effectiveness of certifying those persons.
  - The goals of 20% of all required training being focused on dementia-specific issues.

I have personally worked in long-term care facilities and psychiatric units for 20 years before joining the Central Illinois Chapter as the Program Director. In those years, I witnessed frustration and increased stress level of staff not knowing how to care for someone with dementia. Providing staff with the knowledge of effective behavior and communication strategies can decrease frustration and provide tools to respond to the resident's needs. Increasing staff understanding would reduce frustration and eliminate potential resident abuse.

A family caregiver shared an unfortunate experience with her mother, who had Alzheimer's disease. She came to visit her during mealtime one day. She found her in her room, in soiled clothing. When she approached the staff she was told, "your mother may not eat in the dining room since she has refused to take a bath and will smell up the whole place." This brought the daughter to tears to think that her mother was being punished for having AD and staff that did not understand the disease.

- II. Public Act 91-744 requires the Department of Public Health to establish a training criteria for persons who provide health or home care to persons with Alzheimer's disease or other dementias.
- III. It is important to focus on both residential and home based care since 30% of persons with AD reside in facilities. The remaining are cared at home by family, home based care, and adult day services.

Through collaborative efforts the 2 Alzheimer's Association chapters in Illinois formed a consortium and developed Dementia Care Training, a training manual for health care professionals.

The manual, with appropriate course outlines, was approved with a few minor changes by IDPH. Qualified leaders have been selected to use the Train the Trainer concept.

There is a timeline to start the next phase of this program:



- Telephone conference, December 16, 2003;
- Final draft of manual to IDPH, January 15, 2004;
- Pilot training in two locations, February 15, 2004;
- Document revised, March 1, 2004;
- Train the Trainer meetings, April 1, 2004; and
- Trainings will commence after the Train the Trainer meeting.

IV. We are enthused by this public act and the progress that has been made. We need your support to stay on track to make this a reality. Quality training promotes quality care.

**JUANITA L. TUCKER**

FORMER CAREGIVER AND ALZHEIMER'S ASSOCIATION VOLUNTEER

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Coming before you today presents quite a different forum for me. As a volunteer with the Alzheimer's Association, my usual role is to be among current caregivers. I share experiences from my time as the primary caregiver for my husband of 47 years, Allan, who died on September 10, 1995, after having Alzheimer's disease for approximately 10 years.

My purpose on sharing is to encourage and help other caregivers as they strive to deal with the demanding and difficult task of understanding and coping with a loved one who is suffering from this insidious disease; to emphasize to them the importance of patience, faith, and hope; the need to hold on to their sense of humor and to continue to treat the afflicted person with dignity and affection regardless of negative responses which they may receive. Above all to remind caregivers of the importance of self care.

While caring for my husband, I was helped so much by the staffs of the Rush Alzheimer's Disease Center and of the Alzheimer's Association. My husband received his evaluation and necessary physical care at Rush and I received my emotional care from the staff of both places.

The Alzheimer's support group as well as the workshops, which I attended along with interaction in other groups, provided me with information about the disease as well as information about the services available by the CTA. This enabled my husband to attend the Alzheimer's Family Care Center which at the time was the only fully Alzheimer's focused adult day care center in the city. It was located on North Milwaukee Avenue (in Chicago) and is now at 6139 N. Cicero. I would not have been able to transport my husband without this service.

On one occasion, I used the 5-day respite service provided by the Chicago Department on Aging, to full-time caregivers. Full time care was made available to my husband, which allowed me to enjoy a much needed and appreciated "mini-vacation".

I truly believe that the support and information which I received during my time of caregiving was instrumental in allowing me to change my attitude from one of just hoping only to "survive the situation" into one of "wanting to thrive" and to do the very best job that I could do despite the circumstances.

I will not attempt to enumerate the ways in which caregivers can be helped, there are many. If you can in some way provide them with resources that will lessen the heavy burden, which they may carry whether financial, physical, or emotional, and do this in ways that will allow them to maintain their dignity it would indeed be a blessing.

If research can continue so that hope remains for all Alzheimer patients and caregivers and also for those of us who have not yet been touched but who live with concern for our children, our friends, and ourselves. That too, would warm our hearts. It is more than encouraging seeing that our state legislative body has seen fit to address this dilemma. To each member of the task force, I offer my personal thanks for the dedication and effort, which I am sure, will be given to this assignment.

**SARA GRABOWSKI**

ALZHEIMER'S FAMILY CARE CENTER

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The Alzheimer's Family Care Center is a dementia specific adult day center and, although we are located on the northwest side of the city, we serve people from throughout the city and suburbs. While all adult day centers serve people with dementia, not all are able to accommodate the broad range of functional and behavioral changes that occur in people with dementia.

Recognizing the need for services for people with dementia and their families regardless of their ability to pay, the Chicago Chapter of the Alzheimer's Association, West Side Veterans' Administration, and the Rush Alzheimer's Disease Center collaborated to open the AFCC in June 1987. Since its inception, the center has experienced significant growth, increased numbers of clients, and an increased understanding of the needs of people with dementia and effective ways of providing care. When the National Alzheimer's Association decided that local chapters should not provide direct client services, the Chicago chapter withdrew as a cosponsor of the AFCC, though we continue to work together. The continuing support of the RADDC and the VA, combined with philanthropy, make it possible for us to provide affordable care and programming appropriate for people in all stages of the disease.

When the center opened, the primary goal was to provide respite for families, while providing safe care for people with moderate impairments. It was generally assumed that early in the illness people had no service needs and that people with more severe impairments could not be served in adult day centers. Given these assumptions, the accepted practice was a single activity in a single room. It quickly became apparent that the kind of care that could be provided in an adult day center was limited by this approach. By providing care in innovative ways, we are now able to serve people from early in the illness until the end of life.

Clients at the AFCC are clustered in groups with other clients who have similar skills and abilities. Our activity program is designed to help people use their retained skills and to maintain a sense of well-being despite their cognitive losses. This approach to care requires a broad diversity of activities such as outings, music, intergenerational activities, reminiscence, crafts and cooking, active and table games, intellectual engagement and sensory stimulation, to mention a few.

We have a staff ratio of 1:5 which enables us to provide the personal care needed as the disease progresses, including assistance with eating, walking and toileting. About a 1/3 of our clients are totally incontinent and another 1/3 would be if we did not provide assistance in the bathroom. The

average mini-mental status exam score of our clients is 7, on a scale from 0 to 30. The average mini-mental score in a special care unit of a nursing home is 8. So most of our clients are just as impaired as clients in a nursing home, but their families prefer to keep them living at home. By working closely with clients' families, AFCC staff members help to meet the physical, emotional, and social needs of our clients.

Since all of our clients require a significant amount of care 24 hours a day, they live with family or have paid caregivers in the home. About 56% of family caregivers work, so most of their loved ones are at the center five days a week for 9 or 10 hours a day. About 40% of our clients are cared for by a spouse or adult child who needs a break from the constant physical and emotional burden of caregiving. Caregivers also need time to go to the grocery store, to do the banking and other essential tasks which are not possible to do with their family member in tow. Some family caregivers have chronic illnesses themselves and use the time their family member is at the center to attend to their own health care needs.

The AFCC has long been recognized for providing innovative and excellent care for people with dementia. To share what we have learned and have an impact on the provision of care beyond AFCC clients, we have participated in Special Care Unit and other research projects with the Rush Alzheimer's Disease Center. The AFCC also provides clinical learning experiences for students from the bachelor to the doctoral level in a variety of disciplines. In 1993, the AFCC was selected as a Teaching Adult Day Center by the Illinois Department on Aging and has provided training for professionals from throughout Illinois.

In the past 16 years, with the support and access to the resources of the RADC, the AFCC has pushed the accepted norms to find more effective ways of providing care for people with dementia. For example, each of our staff is trained in Dementia Care Mapping, a process for evaluating the quality of care delivered. AFCC has taken a leadership role in bringing the Dementia Care Mapping practice to adult day centers throughout the State of Illinois. The challenges ahead include continuing the evolution of how care is provided and advancing our understanding of outcomes of care to better serve people with dementia and their families.

While about 40% of our clients are able to afford the center's fee of \$56 a day, we are committed to providing needed care regardless of ability to pay, and work with a variety of agencies to utilize all financial assistance programs available to the client. The center contracts with the Illinois Department on Aging, the Illinois Department of Human Services (for people with dementia over 60), and the Department of Veterans' Affairs, to provide care for people who meet the eligibility criteria for these payer sources. In addition, we have a sliding fee scale, funded by philanthropy, for people who have financial need but do not meet the criteria for any other source of assistance. Despite these resources available to us, the AFCC faces significant financial challenges and would not be able to provide the intensity of care needed by our clients without the support of the Rush Alzheimer's Disease Center.

**BARBARA CARLO**

DIRECTOR — ADA NILES AND ST. ALBIE'S ADULT DAY SERVICES

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I am representing the Illinois Adult Day Services Association. On behalf of the Association, I would like to begin by thanking the Governor and the legislature for supporting a much needed rate

adjustment this past July. Prior to this action 24% of the adult day centers in Illinois have closed in the last 3 years. There have been no ADC closures since July. Although this was a great step forward, it does not mean that adult day centers are in a financially stable situation.

However, today we are here to discuss how adult day services provide care for people with dementia and support for their families. According to research funded by the Robert Wood Johnson Foundation, nationally about 52% of ADS clients have dementia.

It used to be an accepted notion, that people with Alzheimer's disease, like most elderly, were cared for by their families until things got tough, then they went to a nursing home. We now know that only about 5% of people over 65 are in nursing homes and that most care is provided by families and friends, supplemented by community based services.

It is well known that the current costs of Alzheimer's disease to families, communities, states and the federal government are enormous – nationally \$61 billion a year. However, when one considers that that families provide the vast majority of care for people with dementia and most only choose institutional care when the person needs more care than is possible for the family or accessible in the community, it becomes apparent that efforts must be made to augment the care provided by families, not replace it with institutional care. Shrinking state budgets and increasing LTC costs have led many states to review the way they provide and fund LTC both to better control costs and meet the needs of their citizens. One of the trends in many states is to shift priorities to increase funding and availability of home and community based services.

While we know from experience and research that it is possible for community based services to effectively supplement the care for people with Alzheimer's disease provided by families and avoid institutionalization. To date, Illinois, like many other states, has primarily funded care in institutional settings. One of the results of this policy has been inadequate funding for community-based programs and the closure of adult day centers, which limits access to services.

The primary focus of adult day centers is to provide support services which maintain participants in the community. These services are akin to "outpatient nursing home services" and include nursing services provided by staff nurses, therapeutic activities, meals, transportation and supervision. Adult Day Services serve the frail elderly and functionally impaired adults. According to the Illinois Department on Aging, approximately 2/3 of adult day service clients have moderate to severe dementia. The level of impairment can be illustrated by the following statistics from Robert Wood Johnson Foundation research, 24% of adult day center participants need assistance with eating, 37% need assistance with walking and 43% need assistance toileting.

Adult day centers in Illinois are currently facing a number of problems which compromise their ability to provide effective care for people with dementia and to meet the needs of family caregivers.

- While the current rate has prevented closures and provides for safe care, it does not provide the resources needed to provide effective care for people with dementia throughout the course of the disease — in hours of operation, levels of staff and staff development opportunities to most effectively meet the needs of people with dementia and their families.
- Transportation to and from the center is essential to provide many clients access to adult day services, however, transportation is a difficult and costly service to provide.

- ≡ The current CCP reimbursement rate of \$4.15 per trip and is not adequate to cover the cost of transportation — drivers, gas, maintenance, insurance, etc.
  - ≡ Since the transportation rate does not cover direct costs, vehicle replacement is a serious issue. A recent association survey, found that 33% of vehicles used by adult day centers are over 6 years old, 25% are over 8 years old, and 2 were 1987 models.
  - ≡ About 1/3 of centers, which serve a significant number of people with dementia, put a staff person on the bus to provide assistance for clients during transit, like reminders to keep their seat belts on and the need to stay seated while the bus is in motion.
  - ≡ The impact of these fiscal issues on transportation has been felt by participants and their caregivers. In a recent survey, 88% of centers reported that they have reduced their transportation service area due to cost factors. Many reported that they had to eliminate vehicles to cut costs resulting in longer routes, later pick-up and drop-off times and less accommodating transportation schedules. These factors especially impact working caregivers of dementia participants who need to leave for work but can not leave the client unattended.
- There is disparity in ADS rates among state agencies, despite same requirements for care. Currently the Office of Rehabilitation Services hourly reimbursement rate is \$5.52 and the Illinois Department on Aging Community Care Program rate is \$7.02. The disparity of these 2 rates is of great concern for those centers providing services under the ORS contract as well as those receiving ORS services. Many centers do not have an OARS contract, which presents real problems for families of people with early onset Alzheimer's disease.

For these reasons we ask for your support and leadership in the spring session to support the people of Illinois with Alzheimer's disease and their families, specifically:

- Raising the transportation rate for ADS to \$6.15 per trip. The cost to the state is estimated to be \$1 million. Given the current utilization of the Illinois Department on Aging Community Care Program, the department is projected to lapse nearly \$1 million. The Illinois Adult Day Services Association has requested the Governor to utilize those dollars to fund a transportation rate increase for FY 05.
- Supporting parity in payment among state agencies for provision of the same service, increasing the OARS rate to match the Illinois Department on Aging's rate.
- Supporting a reimbursement rate for ADS which covers the cost of care. The current cost of care is \$8.32 per hour. The estimated cost of raising the hourly rate is estimated to be \$2.5 million.

#### REGARDING SUPPORT FOR HOME HEALTH CARE FOR PEOPLE WITH ALZHEIMER'S DISEASE

I want to thank Senate President Emil Jones and the rest of the Illinois General Assembly for organizing the Alzheimer's Disease Task Force and I appreciate the opportunity to appear before you in support of home health care for people with Alzheimer's disease. My name is Linda Brooks and I am the Director of Nursing/ Nursing Supervisor at Carlton Home HealthCare in Geneva, Illinois and I am also a member of the Illinois HomeCare Council.

Illinois HomeCare Council is the voice for home health care in the state of Illinois. Our organization is the nation's first state homecare association, founded in 1960. We represent nearly 200 of Illinois' home health and hospice providers and vendors who deliver quality home health care to thousands of people in our state.

The overarching mission of the homecare industry is to help patients remain independent and to prevent unnecessary institutionalization. Home health care is an important alternative to hospital or nursing home care for thousands of Illinois citizens to help patients to manage chronic conditions, recover from surgery, injury or acute illness, provide end of life care for terminal patients, and to prevent costly nursing home placements. These patients receive individual attention from health care professionals while also receiving the many intangible benefits of care at home.

Alzheimer's disease affects an estimated 1 in 10 people over age 65 and more than 7 of 10 people with Alzheimer's disease live at home. The Alzheimer's Association reports that almost 75% of the home care is provided by family and friends, the other quarter being privately paid care provided in the home. Home health provides services such as caregiving services, respite care, skilled care, caregiver education, and end of life care, which will allow a person to remain in the home for as long and as safely as possible.

#### CAREGIVING SERVICES

One of the services provided by home health agencies for people with dementia is caregiver services. These services include:

- Companion services, which are especially beneficial for people who live alone;
- Personal care such as bathing, feeding, and dressing; and
- And household assistance with cooking and cleaning.

These services are often utilized by families caring for a person with dementia.

#### RESPIRE CARE

According to the 1997 National Alliance for Caregiving/AARP National Caregiver Survey, more than 22 million adults are caregivers, helping older people remain in their homes and other community based settings. But these caregivers have other responsibilities they are trying to

balance, such as caring for their children and working. While caring for a family member is a rewarding experience, it is also a stressful responsibility to bear as caregivers see their loved one's disease progress further every day. One service home health can provide is "respite care,"-temporary relief from the tasks associated with caregiving. Respite care is usually home based care or adult day care. Respite care minimizes the risk of caregiver stress and burnout.

### SKILLED CARE

While home health agencies provide a wide spectrum of services, most of the care our agencies provide is called, "skilled intermittent home health." These services are different from companion or personal care services. These home visits are prescribed by a doctor as medically necessary services to people of all ages who are homebound. Services include skilled nursing, physical therapy, occupational therapy, speech therapy, or a home health aide. These services are covered by both Medicare and Medicaid when a person is homebound.

### CAREGIVER EDUCATION AND TRAINING

One key service provided by home health is training and education for caregivers. When home health is provided to a patient, the nurse will educate the caregiver to provide better care at home, including educating the family on dealing with the diagnosis, the progression of the disease, home safety, proper personal care for the person, proper nutrition and exercise, dealing with hallucinations and wandering, communication and planning.

### END OF LIFE CARE

For a person who is ending his or her days with the disease, hospice can provide end of life care for the patient in the home or other residential setting, such as assisted living or skilled nursing facility. Hospice care is for patients in the last six months of life and the goal is to keep the dying person as comfortable as possible and to help prepare for the death in a way that meets the needs and wishes of the patient and family.

Hospice services include the following:

- Pain and symptom management;
- Advance care planning;
- Information sharing;
- Psychosocial and spiritual support;
- Support for patients' families; and
- Coordination of care.

### CLOSING

In closing, home health care can provide the support services a family caregiver needs to keep the family member with the disease at home as long and as safely as possible. If you would like more information about home health care, I invite you to go to our website at [www.ILHomecare.org](http://www.ILHomecare.org), which includes home health information for consumers as well as a consumer directory for identifying the right home health agency for your family member.





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## Attachment

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## NIH NEWS RELEASE

U.S. Department of Health and Human Services  
National Institutes of Health

National Institute on Aging

### **New Prevalence Study Suggests Dramatically Rising Numbers of People with Alzheimer's Disease**

Scientists project that some 13.2 million older Americans will have Alzheimer's disease (AD) by 2050 unless new ways are found to prevent or treat the disease. According to these latest estimates of the current and future prevalence of AD, reported by Denis A. Evans, M.D., and colleagues of Rush-Presbyterian-St. Luke's Medical Center in Chicago, the numbers of older people with AD – now at 4.5 million – will grow dramatically as the population ages. The most notable increases will be among people age 85 and older, when by mid-century 8 million people in that age group may have the disease.

The projections appear in the August 2003 issue of the *Archives of Neurology*. "These updated estimates from Evans and his group underscore the challenge that we face in the fight against AD," says Marcelle Morrison-Bogorad, Ph.D., NIA Associate Director for the Neuroscience and Neuropsychology of Aging Program, which funded the research. "But I am also optimistic that current research will lead to strategies for intervention early in the disease so that we can keep these projections from becoming a reality."

The estimates were derived from a study of the incidence (number of new cases of AD per year) over 4 years among 3,913 people 65 and older in Chicago. The researchers then calculated the national prevalence of AD (the number of people at any particular time who have the disease) using population projections from the Census and death rates from the National Center for Health Statistics. Their estimates, based on Census Bureau "middle series" population projections, are:

NUMBER OF PEOPLE WITH AD, BY AGE GROUP (IN MILLIONS)				
Year	Age 65-74	Age 75-84	Age 85+	Total
2000	0.3	2.4	1.8	4.5
2010	0.3	2.4	2.4	5.1
2020	0.3	2.6	2.8	5.7
2030	0.5	3.8	3.5	7.7
2040	0.4	5.0	5.6	11.0
2050	0.4	4.8	8.0	13.2

In 2000, 7 percent of those with AD were age 65-74, 53 percent age 75-84, and 40 percent age 85 and older. By 2050, it is projected that 60 percent of people with AD will be 85 and older.

In 2000, among people age 65-74, 17 percent of the cases of AD were classified as severe, compared with 20 percent severe among people 75-84 and 28 percent severe at age 85 or older.

“Declines in death rates after age 65 mean that more people will survive to the oldest ages, where risk of AD is greatest,” notes Evans. “These numbers validate the current thinking that we must do what we can as early as possible in the disease process, prior to advanced age, if we are to head off these very high rates of AD in the future.”

Over a decade ago, Evans and colleagues estimated the national prevalence of AD, based on an East Boston, MA, population study. The new estimates are similar to those earlier findings.

The updated findings were reported by Evans, Liesi E. Hebert, Julia L. Bienias, and David A. Bennett of Rush and by Paul A. Scherr of the Centers for Disease Control and Prevention. The NIA, along with funding this study, also supports the Rush Alzheimer’s Disease Center. The Alzheimer’s Association also provided funding for the prevalence study.

AD is an irreversible disorder of the brain, robbing those who have it of memory, and eventually, overall mental and physical function, leading to death. For more information on such research, as well as on biological, epidemiological, clinical, and social and behavioral research on AD, two new publications are available from the NIA: *2001-2002 Alzheimer’s Disease Progress Report and Alzheimer’s Disease: Unraveling the Mystery*, which includes a CD-Rom animation of what happens to the brain in AD. These publications may be viewed at NIA’s AD-dedicated website [www.alzheimers.org](http://www.alzheimers.org), the Institute’s Alzheimer’s Disease Education and Referral (ADEAR) Center, or by calling ADEAR at 1-800-438-4380.

For general information about aging and health, including materials on exercise specifically aimed at people 50 and older, visit NIA at [www.nia.nih.gov](http://www.nia.nih.gov) or ask for a publications list by calling 1-800-222-2225.

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