

**State of Illinois**

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**Department of Public Health**

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# **Alzheimer's Disease Assistance Plan**

2004 - 2006 Report and Recommendations

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## Acronyms

AD	Alzheimer's disease
ADA	Alzheimer's disease assistance
ADRD	Alzheimer's disease and related dementias
ADRF	Alzheimer's Disease Research Fund
AFCC	Alzheimer's Family Care Center
ALS	amyotrophic lateral sclerosis
AoA	Administration on Aging
ASSIST	Alzheimer's Staff Support Information - Sharing Together
CADR	Center for Alzheimer Disease and Related Disorders
CCP	Community Care Program
CME	continuing medical education
CNS	central nervous system
DNA	deoxyribonucleic acid
ERT	estrogen replacement therapy
FTD	frontal temporal dementia
FY	fiscal year
IDHFS	Illinois Department of Health Care and Family Services
IDoA	Illinois Department on Aging
IDPH	Illinois Department of Public Health
MCI	mild cognitive impairment
NADC	Northwestern Alzheimer's Disease Center
NAS	Neurobehavior and Alzheimer's Disease Service
NIA	National Institute of Aging
NSAID	nonsteroidal anti-inflammatory drug
PPA	primary progressive aphasia
PPN	primary provider network
PPS	primary provider site
RADC	Rush Alzheimer's Disease Center
SCLF	Springfield Combined Laboratory Facility
SIU	Southern Illinois University

## EXECUTIVE SUMMARY

The 1985 Alzheimer's Disease Assistance Act (410 ILCS 405/5) requires the Illinois Department of Public Health (IDPH) to prepare a state Alzheimer's disease assistance (ADA) plan to guide research, diagnosis, referral and treatment services. The plan must contain reports from the Alzheimer's Disease Assistance Centers and the Alzheimer's Disease Research Fund and must be submitted every three years in consultation with the Alzheimer's Disease Advisory Committee. In 2003, the act was amended to require recommendations from the committee to improve state services based on reports provided by state agencies serving persons with Alzheimer's disease and related dementias.

This seventh edition of the ADA plan recognizes Illinois' systematic approach to address the problems associated with Alzheimer's disease and related dementias (ADRD) by:

- increasing public awareness and programs through state agencies;
- developing diagnostic and treatment services through the designation and funding of three regional ADA centers;
- improving patient care and services through the establishment of a statewide services network;
- improving home and community-based services; and
- encouraging and developing new research programs in the state.

The plan includes program goals and recommendations to improve services and outlines the problem of Alzheimer's disease and related dementias (ADRD) and the history and accomplishments of the Illinois Alzheimer's Disease Program. In addition, it identifies and describes the duties and accomplishments of each regional ADA center, the primary provider networks and other providers of service within the state. It also reports the number of persons served, the extent of services provided and the resources required for the delivery of services through the ADA networks established under the Alzheimer's Disease Assistance Act. Also reported are the status, results, costs and funding sources of the state's research programs.

Alzheimer's disease (AD), an incurable, progressive, terminal neurological disease, has no known cause. Although its incidence increases with age, the disease is **NOT** a part of normal aging. Currently, it is estimated that 210,000 Illinoisans have AD with an annual estimated cost (direct and indirect) of more than \$5.2 billion dollars. In 2004, it ranked as the fifth leading cause of death for Illinoisans age 65 and older compared to seventh in 2001.

The incidence and costs are expected to escalate dramatically over the next 30 to 40 years due to an aging population, longer life span and increased health care costs. However, the most devastating cost is to the physical, emotional, social and financial resources of the person with AD and his or her family. AD destroys the person's awareness of people, events and environment. It eventually progresses to

total debilitation and loss of independence, requiring 24-hour care. Since about 75 percent of persons with AD are cared for at home, family and friends face difficult physical, emotional and financial burdens during the prolonged duration of the disease. From diagnosis, a person with AD lives an average of eight years and as long as 20 years or more.

It is estimated that by the year 2025, there will be almost 240,000 persons with AD in Illinois. This increase, however, will not be met by a corresponding growth in the number of available caregivers. Changes in family structure including families having fewer or no children, increased numbers of single-person and single-parent households, and increased geographic mobility of family members, will mean fewer persons with AD will be cared for in the home. In 2005, Medicaid/Medicare data indicated 70 percent of residents (116,230) in Illinois nursing homes had cognitive impairment. (This report included all 166,043 individuals who spent time in an Illinois nursing home in 2005.) Estimates of the number of residents with AD in assisted living facilities are not available.

The Illinois Alzheimer's Disease Program was established by the 1985 Alzheimer's Disease Assistance Act (410 ILCS 405/) and Alzheimer's Disease Research Act (410 ILCS 410/). The program, administered by the IDPH, includes four components --

- Regional Alzheimer's Disease Assistance Centers;
- Alzheimer's Disease Advisory Committee;
- State Alzheimer's Disease Assistance Plan; and
- Alzheimer's Disease Research Fund.

Each Alzheimer's Disease Assistance (ADA) center is responsible for establishing a comprehensive system of regional and community-based services for the identification, diagnosis, treatment, education and research of ADRD. In August 1997, Public Act 90-404 (410 ILCS 405/3, /4 and /5) changed the definition of a regional ADA center to "any postsecondary higher educational institution with a medical center and having a National Institutes of Health and National Institutes on Aging sponsored AD Core Center. Any Regional ADA Center which was designated as having a National AD Core Center but no longer carries such a designation shall continue to serve as a Regional ADA Center." The bill also required two regional ADA centers be located in the Chicago metropolitan area and provided a funding formula for the three centers. Illinois' regional ADA centers are staffed by nationally and internationally recognized experts in diagnosis, treatment and research. Illinois is a leader in this effort and home to two of the 29 federally funded centers. Illinois funding provides an infrastructure and plays a significant role in the centers' efforts to secure valuable research monies from other sources. **During the past three state fiscal years (July 1, 2004, through June 30, 2006), for every dollar provided by Illinois to the regional ADA centers, more than \$8.3 was realized in additional funds.**

The Alzheimer's Disease Advisory Committee has 21 voting members experienced in research and delivery of services to persons with Alzheimer's disease and related dementias. IDPH's director or designee serves as one of the voting members and as chair of the committee. In addition to the 21 voting members, the directors (or their designees) of four state agencies serve as non-voting members. Past and present members of the advisory committee have contributed immeasurably to the success of the Illinois Alzheimer's disease initiative. Their medical and technical expertise was essential for developing program rules and regulations and making programmatic and funding recommendations to the Department. The advisory committee continues to make annual recommendations for funding Alzheimer's Disease Research Fund applications and to hear reports from ADRF researchers, regional ADA centers and state agencies serving persons with ADRD. Please refer to Appendix 1 for the advisory committee membership.

The Alzheimer's Disease Research Fund (ADRF) enables IDPH to provide support for research toward finding a cure, cause or treatment for ADRD. Illinois taxpayers may contribute to this special fund through their state income tax returns. In 21 years, Illinois taxpayers have contributed more than \$3.2 million, from which grants have been awarded to 136 Illinois researchers.

Stopping this disease, which robs individuals of their quality of life, will require continued effort, but the Illinois Alzheimer's Disease Program is making a significant contribution, both in Illinois and nationally.

## **PROGRAM GOALS**

The overall goals of the Illinois Alzheimer's Disease Program are to prevent, delay or reduce institutionalization due to Alzheimer's disease and related dementias by providing increased --

- access to basic clinical evaluation(s) including interviews with family/informal caregivers, in relation to ongoing case management;
- physician and other health care professional education to improve accurate diagnosis and appropriate treatment and referrals as early in the disease process as possible;
- counseling and education for family/informal caregivers to provide information on available support services and the importance of maintaining their own health;
- general public education on the importance of early diagnosis, treatment and maintaining the person with Alzheimer's disease and related disorder's participation in healthy aging/lifestyle choices and in health care, financial and legal decisions;
- access to adult day care, respite and homemaker services, assisted living, transportation and other community-based services; and
- funding for research to prevent/delay disease onset, progression and disability.

## RECOMMENDATIONS AND RATIONALE

1. Invest funds in the state's research infrastructure.

Rationale: Developing a stronger research infrastructure would increase Illinois' competitive edge for the estimated \$50 billion available nationally for Alzheimer's disease and related dementia (ADRD) research. Given the magnitude of the problem posed by AD, relatively small reductions of risk for AD will have major public health implications for the state and its residents. Effective interventions to improve memory and physical function or delay the rate of decline could lead to substantial cost savings for both formal and informal care.

2. Review funding for the centers.

Rationale: Funding has been relatively static since FY 1998 and ADRD costs are outpacing inflation including the centers' cost to provide mandated services.

3. Review by the Committee of how other states encourage return of federal money.

Rationale: Federal money returned to Illinois could be used for increased research and support for persons with ADRD and their families/caregivers.

4. Increase the "dementia capable" workforce through development of standards, increased funding for training and education programs and increased pay for workers that recognizes their value.

Rationale: Dementia-capable care requires knowledge and competency for everyone who provides care for persons with ADRD. Few health care providers have received dementia specific education/training. The need for a trained workforce will increase as the population ages and the number with ADRD increases. Caring for someone with dementia is challenging. Standards, reflecting dementia care research and the experience of experts in the field, would provide minimum, uniform requirements to assure the quality of education and training programs. According to the Alzheimer's Association, training and education for the workforce providing care to persons with ADRD can improve quality of life for the person with ADRD and improve workers' job satisfaction resulting in decreased stress, increased motivation and decreased staff turnover.

5. Increase funding for the continuum of long-term care (LTC) - home and community-based services, assisted living and nursing home.

Rationale: With ADRD there is increased risk of reliance on Medicaid. Promoting financial planning and purchase of LTC insurance by individuals could reduce reliance on Medicaid. Increased funding and access for home and community-based services (e.g., homemaker, adult day service, respite and REACH type programs) would decrease the risk of nursing home placement and use of Medicaid.



6. Increased access to caregiver respite and training including support groups (caregiver and early stage) and increased support for younger families with children.

Rationale: Studies indicate a positive effect on quality of life and delayed nursing home placement with caregiver respite, training and support. Younger families with children dealing with early onset AD have additional support needs which include dealing with role changes, childcare and caregiving responsibilities, job and financial issues and related stress.

7. Increased public education including non-AD and early onset.

Rationale: Public education is linked to understanding the importance of early diagnosis; the effects of ADRD on the individual and their family/caregivers; availability of home and community-based services and the importance of participation in research.

8. Address the issues related to family dynamics including increased stress, conflicts and generational issues.

Rationale: Family/caregiver and health care professional training should address issues related to family dynamics. There is limited access to counselors and they lack training on ADRD related issues.

9. Develop driving guidelines for persons with dementia.

Rationale: Driving is an issue that causes a great deal of stress and conflict for the person with ADRD and their family/caregivers. The loss of independence associated with relinquishing driving privileges must be weighed against safety issues. A confounding issue is the inability of the person with ADRD to recognize the danger due to lack of judgment or insight and to remember the loss of driving privileges.

10. Encourage participation in research to improve treatment(s).

Rationale: Participation in research as a person with ADRD or healthy control is crucial to improving treatment(s) as well as identifying a cause or cure. The shift of research emphasis to prodromal (precursor) disease is based on the realization that established AD cannot be reversed and the realistic hope lies in primary and secondary prevention. There is an urgent need to identify reliable markers that can either predict AD or detect it at its earliest stages. Because the differences from advanced age to prodromal AD can be subtle and prevention is more difficult to ascertain than symptomatic improvement, there is an urgent need for very large and uniformly characterized ADRD populations and normal controls to participate in large-scale research.

## THE PROBLEM

When first described by German neurologist Alois Alzheimer in 1907, Alzheimer's disease (AD) was considered a rare disorder. Today, dementia is recognized as a clinical syndrome and **NOT** a characteristic of normal aging. AD is the most common cause of cognitive deterioration in the elderly population and is an incurable, progressive, terminal neurological disease. In the advanced stages of the disease, persons with AD require total care and must depend on others to perform the simplest of mental and physical activities.

Today, Alzheimer's disease affects more than half million Illinoisans, including 210,000 people with the disease plus family members and caregivers. By 2025, an estimated 240,000 people in Illinois will have AD – a 14 percent increase over 2000 (Herbert et al. Neurology 2004; 62; 1645-). The immense public health problem of AD is put into perspective when realizing that more than 14 million persons in the United States may have the disease by the year 2050.

The cause(s) of AD is unknown and there is no known prevention or cure. Although the incidence of AD increases with age, it has been known to strike those as young as 30 years of age. AD that develops in persons younger than age 65, may be a very rare inherited form. There is no treatment to delay or stop AD's deterioration of brain cells. However, current studies indicate those who are physically active, eat a healthy diet and keep mentally active are less likely to have cognitive decline. High blood pressure, cigarette smoking and loneliness also have been linked to increased AD risk. Currently, there are five drugs approved to treat AD that temporarily slow the worsening of symptoms for about six to 12 months in about 50 percent of persons taking them. In Illinois for persons age 65 years and older, AD was the fifth leading cause of death in 2004, compared to seventh in 2001.

While AD is the most common type of dementia (50 – 70 percent of cases), other types of dementia contribute to this public health issue and include –

- vascular dementia (caused by decreased blood flow to the brain and considered the second most common type);
- mixed dementia (abnormalities of both AD and vascular dementia);
- Parkinson's disease;
- dementia with Lewy bodies;
- frontotemporal dementia;
- Creutzfeldt-Jakob disease;
- normal pressure hydrocephalus; and
- mild cognitive impairment.

Based on current estimates, 336,000 to 420,000 Illinoisans have ADRD. Using current estimates, there could be 20 million to 28 million individuals with ADRD in the United States by 2050. Many researchers and clinicians have documented the co-existence of AD and other dementing diseases.

Current studies indicate –

- quality of life is maintained/increased with active medical management including inclusion of coexisting conditions and appropriate programs and support services;
- the health of the brain is closely linked to the health of the heart and vascular system; and
- regular physical activity and a healthy diet (low in fat and high in fruits and vegetables) helps maintain cognitive health.

Barriers to appropriate assessment, diagnosis and treatment include:

- stereotypes/myths (e.g. memory problems are normal aging and nothing can be done).
- cost (e.g. some of the tests and assessments required to rule out AD are not covered by insurance including Medicare).
- lack of specialists (e.g. required medical assessment is time consuming and many physicians are not up-to-date on the protocol).

The cost in Illinois is estimated at more than \$5.2 billion per year, which includes medical expenses, nursing home and home care costs, and lost productivity. For the more than seven out of 10 persons with AD who live at home, 75 percent of the home care is provided by family and friends. The rest is “paid” home care costing an average of \$12,500 per person per year with the vast majority paid by families. The overall costs are expected to escalate dramatically over the next 30 to 40 years due to an increase in the aging population, life span and health care costs. In 2005, the Alzheimer’s Association and National Alliance for Caregiving estimates Illinois had 357,850 unpaid caregivers for persons with ADRD providing almost 309 million hours of unpaid care at a total value of more than \$3 billion.

However, the most devastating cost is to the physical, emotional, social and financial resources of the person with AD and his or her family. AD destroys a person’s awareness of people, events and environment, progressing to total debilitation and loss of independence, requiring 24-hour care. Family and friends face difficult physical, emotional and financial burdens while providing care during the prolonged duration of the disease, an average of eight to 10 years after diagnosis but as many as 20 years.

Families struggle to keep the person with AD at home as long as possible but, for many, the lack of community-based services, financial assistance and/or the toll on the caregiver’s health, force institutionalization of the person with AD. Caregivers for most persons with AD are a spouse, child or other family member. As the disease progresses, caregiving requirements can become overwhelming and have a negative effect on the caregiver’s family life, physical and mental health, career and finances.

Most persons diagnosed with AD are 65 years or older; however, an increasing number are being identified in their mid-40s and 50s. An estimated 1 percent to 10

percent of persons with AD have early-onset (young-onset), representing 2,110 to 21,100 Illinoisans. Experts attribute the increased diagnosis of early-onset AD to better diagnostic techniques and increased public awareness of the disease. For persons with early-onset AD and their families, the social and financial impact is greater. They are faced with resigning from a job before retirement age and the inability to maintain or continue family responsibilities.

By 2025, there will be about 240,000 persons with AD in Illinois. The number of caregivers available will be affected by changes in family structure, including families having fewer or no children; increased numbers of single-person and single-parent households; and increased geographical mobility of family members. The cost of care is expected to escalate

National data indicated 70 percent of Illinois nursing home residents had some level of cognitive impairment -- 31 percent very mild/mild and 39 percent moderate/severe (U.S. Department of Health and Human Services, Centers for Medicaid and Medicare, Nursing Home Data Compendium 2005 Edition). This report included all 166,043 individuals who spent time in an Illinois nursing home in 2005. Based on these figures, 116,230 Illinois nursing home residents in 2005, had cognitive impairments (51,473 very mild/mild, 64,757 with moderate/severe). In 2003, 62.2 percent of Illinois nursing home residents' care was paid by Medicaid with an estimated cost of \$621 million for persons with cognitive impairment. The individuals' lifetime cost to Medicaid could be enormous considering the long duration of AD, which increases the likelihood of Medicaid eligibility. This cost is expected to escalate as the aging population and life expectancy increase.

#### Illinois Facilities Licensed for Nursing Care Only

	2001	2002	2003	2004	2005
Number of Facilities	791	781	764	765	756
Licensed Beds	109,673	108,614	107,380	107,404	106,028
Beds in Use	87,830	86,798	85,239	85,322	83,870
Occupancy Rate	80.0%	79.9%	79.4%	79.4%	79.1%
Residents With AD as the Primary Diagnosis	12,824	12,006	11,950	11,489	11,029
Residents Age 65 and Older	71,913	70,182	67,988	66,441	64,355
Total Patient Days of Care	32,116,381	31,945,253	31,353,988	30,775,866	30,703,212
Total Patient Days Paid by Medicaid	19,814,067	19,741,181	19,489,779	18,793,048	18,626,071
Percentage of Patient Days Paid by Medicaid	61.7%	61.8%	62.2%	61.1%	60.7%
Residents on Medicaid	53,684	53,435	52,708	52,194	51,222

Source: Long-Term Care Facility Profiles Summary 2001 – 2005 (point in time survey), Health Systems Development, Illinois Department of Public Health

The overall number of licensed beds and occupancy rate of Illinois nursing homes has been decreasing. This could be attributable to the increased availability of assisted living and supportive living facilities (SLFs). In December 2006, there were 188 licensed assisted living facilities with 8,489 total units. Of these 10 were AD specific facilities with 236 units; 42 facilities had 825 AD designated units out of 3,296 units; and 136 facilities had 4,957 units with no AD designated units. SLFs provide a form of assisted living that offers combined housing, personal and health-related services for Medicaid eligible individuals who would otherwise qualify for institutional care in a nursing home. Since the SLF program began, participation has grown dramatically. There are currently 75 approved SLF sites with 5,881 units (Medicaid and private pay).

## **ILLINOIS ALZHEIMER'S DISEASE INITIATIVE**

A growing awareness of the societal impact of AD led to the adoption of a resolution in October 1983 by the Illinois House of Representatives (83rd General Assembly) requesting the Illinois Department of Public Health study the current state of knowledge, care and treatment of AD in Illinois. In the last quarter of 1984, interested members of the House Committee on Appropriations II convened a statewide conference to explore possible state policy responses.

The conference, "Alzheimer's Disease: State Policy Directions," cosponsored and hosted by Southern Illinois University School of Medicine, was held in Springfield on December 10, 1984. It brought together legislators, legislative staff, experts in research on AD, medical professionals involved in the care of persons with AD, families of AD patients, policy makers in state government agencies and professional service providers.

Out of the dialogue generated by the conference, a number of legislative proposals were developed and introduced in the General Assembly; 15 bills dealing with AD passed during the 1985 spring session of the 84th General Assembly. Five state agencies were given the responsibility of implementing various portions of the Alzheimer's initiative. The following is a brief review of each agency's assigned responsibilities and past and present ADRD related activities. Other agencies/organizations' related services are also included.

### **REPORTS OF STATE AGENCIES SERVING PERSONS WITH ADRD**

#### **Department of Public Health**

The Illinois Department of Public Health (IDPH) was authorized (410 ILCS 405/) to designate and award grants to two post-secondary higher educational institutions having a medical school affiliation with a medical center for the purpose of establishing ADA centers. Each ADA center is responsible for establishing a comprehensive system of regional and community-based services for the identification, evaluation, referral and treatment of persons with ADRD; providing education; and doing research. This legislation also authorized IDPH to create and administer an Alzheimer's Disease Advisory Committee to assist in program development and oversight. A list of members is included as Appendix 1.

IDPH was mandated (410 ILCS 410/) to establish a process of awarding ADRF grants funded from a voluntary state income tax contribution. The overall goal of the research supported by these funds is to help find a cure, cause and/or treatment for the disease.

The 1985 Alzheimer's Disease Assistance Act required IDPH to prepare a state plan to guide research, diagnosis, referral and treatment services within each ADA network service area. In 2003, the Act was amended to require recommendations from

the Committee to improve state services based on reports provided by state agencies serving persons with Alzheimer's disease and related dementias. The ADA plan must be updated every three years.

Activities of IDPH's Alzheimer's Disease Advisory Committee (page 22), ADA centers (page 23) and the ADRF (page 41) are addressed in detail later in this text.

During the 90th General Assembly, the Alzheimer's Special Care Disclosure Act became law. It requires disclosure to the Department of information concerning the form of care and treatment as part of the renewal licensure process by facilities licensed under the provisions of the Nursing Home Care Act, Community Living Facilities Licensing Act and Life Care Facilities Act. Facilities were required to submit the initial disclosure information by June 30, 1998. The total number of facilities licensed under the Nursing Home Care Act that have submitted information as of June 30, 2006 was 189 compared to 207 on June 30, 2003. This total includes facilities licensed as SNF/NF and Sheltered Care.

The Alzheimer's Association convened a blue ribbon panel of nurses, physicians, social workers, activity professionals and educators from the nursing home industry, academia, advocate groups and others to develop standards for these specialized units. The Department was contacted with a request that these standards be incorporated into the Skilled Nursing and Intermediate Care Facilities Code (77 Ill. Adm. Code 300). Department staff worked with the Alzheimer's Association to craft minimum standards based on the blue ribbon panel's work.

This rulemaking was first brought to the Long-Term Care Facility Advisory Board in July 2002, and approval for publishing the first notice was narrowly defeated. After several revisions, in September 2003, the rulemaking was approved and the first notice was published. Changes in the Skilled and Intermediate Care Facilities Code became effective on October 20, 2004. This rulemaking added a new Subpart U: Alzheimer's Special Care Unit or Center Providing Care to Persons with Alzheimer's Disease or Other Dementia.

Licensure requirements of Subpart U apply to Skilled and Intermediate Care facilities that are subject to the Alzheimer's Special Care Disclosure Act. These facilities have submitted the required disclosure information which requires a facility that offers to provide care for persons with Alzheimer's disease through an Alzheimer's special care unit or center to disclose information to the Department and to the clients concerning the services offered by the facility. These rules include admission criteria for the Alzheimer's unit; resident assessments and care planning; provision for ability-centered care; activity programming; staffing requirements that include required orientation and training; environment of the unit; quality assessment and improvement; and variances to enhance residents' quality of life.

During the 91<sup>st</sup> General Assembly, legislation was enacted creating licensing categories for assisted living and shared housing facilities. Submission of the

Alzheimer's Special Care Disclosure Act documents is a condition of licensure. In 2001, licensing for these new categories of facilities began. As of March 26, 2007, twenty-four shared housing and 176 assisted living establishments are licensed. Fifty-three of the 176 licensed assisted living establishments and one of the 24 shared housing establishments have submitted documents required under the Alzheimer's Special Care Disclosure Act and are recognized Alzheimer's units

Also enacted during the 91<sup>st</sup> General Assembly, Public Act 91-744 required IDPH develop specialized training and experience criteria for persons who provide health or home care to persons with Alzheimer's disease or related dementias. In addition, the law required IDPH study the effectiveness of certifying, through IDPH or an appropriate private certifying body, persons who provide health or home care to persons with ADRD. The Department developed the criteria and presented its findings and recommendations to the governor and the General Assembly in 2001.

The Department concluded that certifying certified nurse aides as having completed specialized training for the care of persons with ADRD was not feasible at this time due to limited resources. Certification would require the establishment of a certification and recertification curriculum, staff to approve and monitor these programs, establishment of a data base and staff to maintain the data base. This program would be too labor intensive to be absorbed into current program activities. Therefore, certification of individuals who provide health or home care to persons with ADRD does not seem to be a viable alternative at this time.

However, it should be noted that the 120 hour certified nurse's aide program, attended by nursing facility and home health aides, has a 12-hour component dedicated to the care of persons with ADRD. In addition, and in cooperation with the Alzheimer's Association, a train-the-trainer program has been finalized. This training program addresses the need for additional specialized training for those providing health and home care to persons with ADRD.

The Department identified and received permission to use the training manual developed by the Alzheimer's Association, which would be ideal for health care providers to use in training staff to care for persons with ADRD. The Department had intended to conduct the train-the-trainer workshops using this training manual in the summer and fall of 2002 as part of abuse prevention seminars. Due to budget restrictions, the Department was required to cut back on these workshops and forced to eliminate this training. However, the Illinois Alzheimer's Association assumed responsibility and currently provides workshops on a variety of subjects related to dementia care.

Other legislation during the 91<sup>st</sup> General Assembly authorized establishment and licensing of an Alzheimer's disease management center as an alternative health care delivery model. The Alzheimer's Disease Management Center Demonstration Program Code (77 Ill. Adm. Code 225) was adopted March 31, 2002. Plans have not been



submitted for review and the Department has had no recent contacts with the developer of this program.

A \$1 million appropriation in the state's Fiscal Year 2007 budget, to IDPH was targeted for AD training and services for adult day services (ADS). The following grants were awarded to the –

- Alzheimer's Association –Greater Illinois Chapter for \$150,000 to provide Master Training and train-the-trainer sessions for the "Best Friends Approach to Alzheimer's Care;" (The Best Friends Train-the-Trainer session has been completed by 336 people, including approximately 80 ADS staff.)
- St. Anthony's Adult Day Care Center in Alton, Illinois for \$150,000 to enhance ongoing provision of ADS for elders in their service area; and
- Alzheimer's Association-Greater Illinois Chapter for \$700,00 in conjunction with the Illinois Day Service Association to develop a request for proposal process and award the funds to ADS programs across the state for enhancing services.

In June 2001 and June 2005 the Department was awarded an Alzheimer's Disease Demonstration Grants to States (ADDGS) from the U.S. Administration on Aging (AoA) for two, three-year periods (July 1, 2001 through June 30, 2004 and July 1, 2005 through June 30, 2008). The grants were/are a partnership between the Department and IDoA. The projects were/are a systems approach for coordinating and integrating current community-based services to provide support to persons with ADRD and their families/caregivers. Services included ADA centers' clinical services, education and research participation opportunities; community-based services through the IDoA; and the Alzheimer's Association's caregiver training, support groups and leader training, Safe Return registration and education. The objectives of the project were/are:

- to increase the number of persons with ADRD receiving appropriate assessment, diagnosis and treatment;
- to identify persons with ADRD through outreach to community agencies/organizations including faith-based;
- to provide training and support for caregivers; and
- to provide needed home and community-based services.

The projects had/have two components targeting different populations – rural and limited English proficient (LEP) elders. During the first project, the rural component targeted the older population in 14 west central Illinois counties (Bureau, Fulton, Henderson, Henry, Knox, LaSalle, Marshall, McDonough, Stark, Tazewell, Warren, Mercer, Putnam and Woodford) and LEP component targeted elders in five language groups (Chinese, Korean, Polish, Russian and Spanish) in the Chicago area. During the current project, the rural component targets Illinois' 13 southernmost counties (Alexander, Franklin, Gallatin, Hardin, Jackson, Johnson, Massac, Perry, Pope, Pulaski,

Saline, Union, and Williamson). The current LEP component targets five language groups (Arabic, Assyrian, Bosnian, Hindi and Urdu).

The project tracks the use of community-based services. Education also is provided to families/caregivers, aging service providers and health care professionals. Outreach into the communities has included seminars for faith-based organizations. Educational materials include fact sheets and resource guides that have been developed and translated by participating agencies/organizations.

## **Department on Aging**

The Illinois Department on Aging (IDoA) was created by the state legislature in 1973 for the purpose of improving the quality of life for Illinois' senior citizens by coordinating programs and services enabling older persons to preserve their independence as long as possible. It is the single state agency in Illinois authorized to receive and disperse Federal Older Americans Act funds, as well as specific state funds, through Area Agencies on Aging and community-based service providers.

The legislative mandate of the IDoA is to provide a comprehensive and coordinated service system for Illinois' approximately 2 million older persons, giving high priority to those in greatest need; conduct studies and research into the needs and problems of the elderly; and ensure participation by older persons in the planning and operation of all phases of the system. In fulfilling its mission, the IDoA responds to the dynamic needs of society's aging population through a variety of activities including:

- planning, implementing and monitoring integrated service systems;
- coordinating and assisting the efforts of local community agencies;
- advocating for the needs of the state's elderly population; and
- cooperating with federal, state, local and other agencies of government in developing programs and initiatives.

In 2000 the amendments to the Older Americans Act included a five-year reauthorization and maintained the original 10 objectives aimed at preserving the rights and dignity of our nation's older citizens. The amendments streamlined, consolidated and granted more flexibility to state units on aging and area agencies on aging for developing comprehensive and coordinated service systems.

The amendments retained the provisions targeting older adults in greatest economic and social need with special attention to minorities and added a new focus on older individuals residing in rural areas. The amendments also retained priority services maintaining the emphasis on access, in-home, and legal services. The amendments also established a new National Family Caregiver Support Program which provides support services to informal (unpaid) caregivers and grandparents raising grandchildren.

IDoA has worked to provide special care services needed by persons with ADRD and their families through the Community Care Program (CCP), which provides home and community-based services to eligible Illinois seniors 60 years of age and older. The core services of CCP are case management, homemaker and adult day service. Without these services, many of the state's frail elderly would face unnecessary institutionalization. Based on identification of the need for caregiver education, specialized training has been developed for families, case managers and in-home workers. The CCP is supported by state general revenue funds, which are partially reimbursed through a federal Title XIX Medicaid Home and Community-Based Services Waiver. On January 1, 2004, the asset limit for CCP and adult day service eligibility and reimbursement rate to service providers increased.

Provisions of the Older Americans Act, as reauthorized in 2000, continue to address vulnerable elder rights protection activities including elder abuse reporting and investigation, nursing home ombudsmen, legal services, outreach and benefits counseling. These services are especially important to persons with ADRD and their families because they are among the most vulnerable population and in greatest need of assistance in protecting their rights.

IDoA, through its Long Term Care Ombudsman Program, advocates for residents of licensed long-term care facilities, as well as supportive housing and assistive living facilities. The rights of residents are of great concern to IDoA, area agencies on aging and the 17 sub-state ombudsman programs. A component of advocacy, as mandated under the Older Americans Act, is to investigate and resolve complaints made by or on behalf of residents of long-term care facilities. Through this element of the program, ombudsmen become aware of and involved in the issues facing residents and family members of residents with ADRD. An IDoA brochure, "Residents' Rights for People in Long Term Care Facilities," is mandated for distribution by facilities to all residents upon admission and annually thereafter.

IDoA also operates the Elder Abuse and Neglect Program, an intervention program developed in response to reports of alleged abuse, neglect or exploitation of older people who live at home. Four out of five alleged victims suffer from one or more barriers to independent living. The greatest number are functionally impaired and many have multiple barriers. In past years, 16 percent of the victims were cognitively impaired and another 14 percent were described as otherwise disoriented. Cognitive impairments make an older person much more vulnerable to abuse and make the investigation and resolution of cases more difficult. Cognitive impairment also decreases the likelihood that abuse or neglect will be reported. In 1999, the Elder Abuse and Neglect Act was amended to require professionals to report suspected abuse, neglect and exploitation of persons 60 and older who, because of dysfunction, are unable to report for themselves. This includes persons with ADRD or other cognitive impairments.

Annually in May, IDoA cosponsors the Annual Conference on Alzheimer Disease and Related Dementias with Southern Illinois University School of Medicine's Center for

Alzheimer Disease and Related Disorders and the Land of Lincoln Chapter of the Alzheimer's Association. This annual conference offers continuing education to nursing home administrators, social workers, registered nurses, counselors and substance abuse counselors. Sessions and workshops focus on new approaches to the challenges presented by ADRD and provided information to help persons with ADRD, their families, health care professionals and service providers.

Other activities of the IDoA Alzheimer's initiative have included the following:

- expanding eligibility for CCP services to include consideration of cognitive impairment. Illinois was the first state to introduce and utilize a standardized assessment of cognitive impairment in determining the eligibility for home and community-based services. The CCP serves more than 15,000 persons with cognitive impairments, which represent approximately 30 percent of the program's caseload in a given year;
- developing, implementing and maintaining a routine training program for case managers on assessment of and care planning for persons with dementia;
- developing and implementing a "scholarship" program for adult day care personnel to attend a one week on-site training at an approved day care program specializing in services to persons with ADRD;
- providing information and referral services to families and providers on services and information available to Illinois residents with ADRD;
- implementing specialized congregate care services in public housing projects that prevent or delay institutionalization;
- evaluating the senior companion service as support to persons with ADRD and their caregivers;
- implementing a money management demonstration project to assist community care clients who are unable to manage bill paying and/or budgeting;
- developing, with the Departments of Insurance, Healthcare and Family Services (formerly Public Aid) and Human Services (Office of Rehabilitation Services), a long-term care partnership insurance policy, that provides financial protection against the cost of such care;
- developing and implementing spousal impoverishment regulations for the Community Care Program; and
- developing a community-based residential facility demonstration to serve tenants with ADRD.

Projected activities of the IDoA Alzheimer's initiative include the following.

1. Increasing the number of seniors receiving in-home and community-based services by -
  - expanding access to community-based services and client-centered options for seniors to prevent and delay institutionalization;

- improving access to the National Family Caregiver Support Program; and
  - encouraging policies to improve and expand housing for seniors with supportive services.
2. Improving access to better health care and the protection of elder rights by
    - directing outreach and training activities to the aging network to increase enrollment in pharmaceutical assistance programs and promote the new medicine discount club program;
    - promoting public health programs and services aimed at allowing seniors to maintain active and healthy lifestyles;
    - protecting seniors and preventing elder abuse, neglect and exploitation; and
    - strengthening the state's Ombudsman Program to ensure that quality standards in nursing and licensed assisted living facilities are adopted.
  3. Promoting responsive management and advanced technologies by improving the agency's Web site to include-
    - providing documents online; and
    - developing a service database by geographic area (e.g., by ZIP code) to link seniors and caregivers to eligible services.
  4. Additional efforts include-
    - expanding the availability of money management and senior companion services;
    - maintaining case manager training efforts on assessment and care planning for clients with cognitive impairments;
    - maintaining training efforts for day care personnel serving clients with cognitive impairments;
    - developing dementia care mapping in selected adult day programs; and
    - increasing the information about the network of services available to older persons with ADRD and their caregivers.

## **Department of Healthcare and Family Services**

The Illinois Department of Healthcare and Family Services (HFS), as the state's single Medicaid agency, administers a Medical Assistance Program for people who need assistance paying their medical bills. To be eligible for this program, a person must be a United States citizen or meet certain non-citizen requirements; reside in Illinois; be aged, blind, disabled or have dependent children; and meet program income and asset requirements.

For eligible individuals, including eligible persons with ADRD, HFS will pay for medically necessary services including prescription drugs and nursing facility care, for those eligible individuals who wish to reside in this setting. Eligible persons who wish to apply for the Medical Assistance Program and reside in a nursing facility must be

screened by IDoA or the Department of Human Services to ensure that a nursing facility level of care is required. Persons with ADRD may qualify for benefits under the Medical Assistance Program if they meet eligibility requirements.

HFS also administers the Supportive Living Program (SLP), a home- and community-based waiver program which serves as Illinois' model of Medicaid-funded assisted living. Persons with ADRD may be served in the SLP setting if the facility is able to meet the individuals' need for care and services.

HFS provides funding to the three Alzheimer Disease Regional Centers through their sponsoring hospitals. Funding for these centers has been static over the past three fiscal years, as indicated in the chart below. HFS collects approximately \$1.5 million in matching federal financial participation on these expenditures.

Regional Center	FY04	FY05	FY06
SIU	\$1,518.0	\$1,518.0	\$1,518.0
Northwestern	\$307.4	\$307.4	\$307.4
Rush	\$1,492.7	\$1,492.7	\$1,492.7
Total	\$3,318.1	\$3,318.1	\$3,318.1

### **Department of Human Services**

To prevent unnecessary institutionalization, the Department of Human Services (DHS), Office of Rehabilitation Services, includes in its eligibility for services consideration of the needs of persons with ADRD 60 years of age and younger. Assessment is based on physical and cognitive function. Services provided include personal assistant, homemaker, maintenance home health, electronic home response, home delivered meals, adult day care, assistive equipment and environmental modification. Persons with ADRD who also have a diagnosis of HIV/AIDS or brain injury could be eligible at any age.

### **Guardianship and Advocacy Commission**

The Illinois Guardianship and Advocacy Commission (GAC) is an executive agency of the state of Illinois. Its three divisions have served Illinois citizens with disabilities since 1980. The Office of State Guardian serves as guardian of last resort when duly appointed by a probate court. It manages the continuing personal and estate needs of more than 5,000 persons with disabilities at home, in community placements and in treatment and nursing institutions. The Legal Advocacy Service provides legal advice and representation to approximately 7,000 individuals each year who are facing or undergoing involuntary hospitalization and treatment and in appeals of hospitalization and treatment orders, primarily when appointed by the court. The Human Rights Authority, through nine regional authorities comprised of citizen volunteers, investigates allegations of violation of disability related laws and works with providers on curative

recommendations, improving the lives of thousands of persons with disabilities. The Central Intake Unit processes more than 6,000 inquiries and program referrals each year.

As of December 2006, the GAC had 5,104 wards and 5 percent of these (274) had a diagnosis of Alzheimer's or dementia. Of the wards with an ADRD diagnosis, there are 145 women and 129 men with 30 under 60 years of age, 38 age 60 – 68, 62 age 70 – 79, 101 age 80 – 89, and 41 age 90 and older. Of these, 197 were Caucasian, 69 African American, 5 Hispanic, 2 other and 1 Asian.

## **Department of Insurance**

The Department of Insurance provides the Senior Health Insurance Program (SHIP). SHIP utilizes community volunteers to help Medicare beneficiaries and their family members on a one-on-one basis with their Medicare and health insurance problems and concerns. The program operates in conjunction with community organizations that serve senior citizens' needs. SHIP counselors also are available to give presentations on Medicare, long-term care, Medicare managed care plans and Medicare supplemental insurance.

## **Other Resources**

There are a number of resources available, both formal and informal, to help caregivers meet the needs of Illinoisans with ADRD. Many families/caregivers find it difficult to locate and coordinate the services necessary to provide a continuum of care. These problems are compounded by a shortage of geriatric physicians and other health professionals who are skilled in providing care and support to persons with ADRD and their families.

Training medical personnel to correctly assess for ADRD can reduce the number of misdiagnoses and improve treatment. Training is also needed for other health care professionals who provide care and treatment to persons with ADRD and their families. Additional resources are needed in the following areas - community-based care, including respite and home care; long-term facilities that provide appropriate care for residents with dementia; and ongoing training and continuing education for physicians, nurses, social workers and other health care professionals.

The Alzheimer's Association (AA), incorporated in 1980, is the first and largest voluntary health organization dedicated to finding prevention methods, treatments and an eventual cure for Alzheimer's, having awarded \$200 million for studies in Alzheimer research since 1982. AA provides information, care consultation, education, programs and services for the public and for people affected by Alzheimer's, including people with the disease, family members, caregivers and health and other professionals.

AA also advocates for increased funding for dementia research and care, and advocates for quality care and quality of life for those affected, alerting policy makers to

ways to enhance Alzheimer research and care and increase awareness and concern in the public about the impact of ADRD.

The mission of the nonprofit, tax-exempt AA is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

There are 78 AA chapters with more than 300 points of service nationwide. The four AA chapters operating in Illinois (see Appendix 2) provide the following programs and services.

- 24-hour, toll-free Helpline for information about Alzheimer's and other dementias, emotional support, programs and services, and access to community resources. Confidential care consultation is available for decision-making support, crisis assistance and education. Translation services are available in 140 languages.
- Education for the public and health care professionals
- Training programs for health care professionals
- Support groups
- Safe Return® - the national identification program for people with Alzheimer's who wander and become lost. Alzheimer's Association staff conducts training for law enforcement agencies and transportation providers to assist in identifying people with Alzheimer's and other dementias and accessing Safe Return in the event someone is reported missing or recovered.
- Speaker's Bureau
- Chat rooms and message boards to connect people to share experiences and find support and friendship with others living with Alzheimer's

The AA chapters also publish newsletters, maintain Web sites, provide brochures and publications and participate in community events and public awareness activities. AA chapters also support The Coalition of Hope that includes hundreds of social, labor, ethnic, community and religious organizations helping to increase awareness and advocate for research funding and public policy initiatives.

The 93<sup>rd</sup> General Assembly passed Senate Joint Resolution 0016, creating the Illinois Legislative Alzheimer's Disease Task Force. The mission of the task force was "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 - the disease's facts, prevalence, and costs; the financial barriers to essential care; 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 the training and qualifications for those who work with individuals with Alzheimer's disease;..." The task force met for public testimony in November 2003 in Springfield and in December 2003 in Chicago. The resolution required a report to the General Assembly which can be found at [www.ilga.gov/reports/special/Alzheimers%20Report.pdf](http://www.ilga.gov/reports/special/Alzheimers%20Report.pdf).



## **IDPH ALZHEIMER'S DISEASE ADVISORY COMMITTEE**

On June 4, 1986, the 21 voting members of the Alzheimer's Disease Advisory Committee were appointed by the director of IDPH with concurrence of the governor. The director (or a designee) serves as one of the 21 voting members and chair of the committee.

Voting members are experienced in some aspect (e.g., research, services, etc.) in dealing with ADRD and with those it affects. As mandated by the law, the committee includes four physicians licensed to practice medicine in all of its branches, one representative of a post-secondary educational institution that administers or is affiliated with a medical center in the state, one representative of a licensed hospital, one registered nurse, one representative of a long-term care facility, one representative of an area agency on aging, one social worker, one representative of an organization established under the Illinois Insurance Code for the purpose of providing health insurance, five family members or representatives of persons with ADRD and four members of the general public. The physician appointments include those with specialties in the fields of neurology, family medicine, psychiatry and pharmacology. At least two of the general public appointments must be persons 65 years of age or older. All committee members are volunteers.

In addition to the 21 voting members, the directors (or their designees) of the following state agencies serve as nonvoting members: IDoA, Guardian and Advocacy Commission, IDPA and DHS. A list of members (December, 2006) appears in Appendix 1.

The AD Advisory Committee assisted the Department with development of the rules and regulations for the Illinois Alzheimer's Disease Program (effective April 15, 1987) and reviewing applications and recommending designation and funding for the two original ADA centers.

The AD Advisory Committee meets at least twice a year. At the April meeting the committee reviews applications for funding from the ADRF and makes recommendations for awards. The December meeting agenda includes reports from the three regional ADA centers, current ADRF recipients and state agencies serving persons with ADRD. Additional meetings are scheduled as necessary. Every three years the state AD Assistance Plan is prepared in consultation with the Committee.

## ALZHEIMER'S DISEASE ASSISTANCE CENTERS

The 1985 Alzheimer's Disease Assistance Act directed IDPH, with recommendations from the Alzheimer's Disease Advisory Committee, to develop standards for a service network and to designate two regional ADA centers and primary providers. The Rush Alzheimer's Disease Center (RADC) serves the Chicago metropolitan area, which includes the following counties: Cook, DuPage, Grundy, Kane, Kankakee, Kendall, Lake, McHenry and Will. The Southern Illinois University (SIU) Medical School Center for Alzheimer's Disease and Related Disorders (CADRD) serves the state's remaining 93 counties.

In August 1997, legislation changed the definition of a regional ADA center to "any postsecondary higher educational institution with a medical center and having a National Institutes of Health and National Institutes on Aging sponsored AD Core Center. Any regional ADA center which was designated as having a National AD Core Center but no longer carries such a designation shall continue to serve as a regional ADA center." The bill also required two regional ADA centers be located in the Chicago metropolitan area and provided a funding formula. Based on the new criteria, the third regional ADA center, Northwestern University Medical School's Alzheimer's Disease Center (NADC), was designated.

The four major mandates of the ADA centers are identification, diagnosis and treatment, education and research. Direct grants-in-aid have been awarded by IDPH to finance the mandates at the three centers. The grants-in-aid are from general revenue funds appropriated to IDPH by the Illinois General Assembly. Medicare, private insurance and client fees cover some of the costs of diagnosis, assessment and medical treatment provided by the centers.

Grants-in-aid have supported the operating costs of the center's core functions since February 1987. Funding levels awarded to each center (RADC and SIU CADRD) for the first 11 fiscal years follow.

FY87 --	\$ 85,000
FY88 --	\$ 600,000
FY89 --	\$ 600,000
FY90 --	\$ 930,000
FY91 --	\$ 911,400
FY92 --	\$ 911,400
FY93 --	\$ 751,350
FY94 --	\$ 883,900
FY95 --	\$1,008,900
FY96 --	\$1,008,900
FY97 --	\$1,008,900

Funding levels awarded to each center using the new funding formula (August 1997) follow:

	RADC & SIU CADRD (each)	NADC
FY98 –	\$1,405,933	\$205,933
FY99 –	\$1,405,933	\$205,933
FY00 –	\$1,405,933	\$205,933
FY01 –	\$1,405,933	\$205,933
FY02 –	\$1,405,933	\$205,933
FY03 –	\$1,500,000	\$300,000

For FY2004, SB 0742 changed the mechanism in 410 ILCS 405/7 for funding the regional ADA centers. “For fiscal year beginning July 1, 2003, and each year thereafter, the Department shall effect payments under this Section to hospitals affiliated with each Regional ADA Center through the Illinois Department of Public Aid.” It also mandates “the Department shall include the annual expenditures for this purpose in the plan required by Section 5 of this Act.” The FY04 appropriation was reduced to \$1,650,000 but restored to \$3.3 million during the veto session.

	SIU CADRD	RADC	NADC
FY04--	\$1,518,000	\$1,492,700	\$307,400
FY05--	\$1,518,000	\$1,492,700	\$307,400
FY06--	\$1,518,000	\$1,492,700	\$307,400

The following table shows how the Centers spent their money in FY06.

	RADC	SIU CADRD	NADC
Personnel and Fringe	65%	85%	93%
Supplies	10%	1%	0.5%
Travel	10%	1%	0.5%
Equipment	5%	1%	--
Other	10%	12%	6%

**Currently, for every dollar provided by Illinois to the regional ADA centers, more than \$8.3 is realized in additional funds.**

The three regional ADA centers are required by legislation to provide the following minimal services or facilities -

- comprehensive diagnosis and treatment facilities and services, including specially trained professional medical staff, support staff trained as caregivers to persons with ADRD, equipment necessary for diagnosis and treatment, and transportation services;
- consultation and referral services for persons with ADRD and their families;

- programs and facilities for research to determine the cause, diagnosis, cure and treatment of ADRD;
- consultation, training and continuing education for caregivers, family and health care professionals;
- centralized data collection, processing and storage to serve as an information clearinghouse to assist persons with ADRD, families and researchers;
- programs of scientific and medical research designed to enable the centers to qualify for federal funding; and
- a network of primary provider sites (PPS) to provide access to services for persons with ADRD and their families. The networks are to facilitate development of a system for local delivery and coordination of services.

The three regional ADA centers have established extensive service networks. Each PPS can evaluate a patient with dementia symptoms and provide ongoing care and support for the person with ADRD and their family/caregivers. These community-based programs provide up-to-date diagnostic procedures and have staff trained to assist with problems that develop when a family member has ADRD. Each program also provides a comprehensive psychosocial assessment, makes referrals to appropriate home- and community-based services, and works cooperatively with the primary care physician to provide continuity of care and follow-up services. A list of the three centers including addresses, phone and fax numbers, and Web site addresses is in Appendix 3.

Each of the three regional centers has a unique approach to fulfilling the legislative mandate. One reason for the differences is the geographical areas served. The Rush and Northwestern ADA centers are currently designated as national AD core centers. SIU CADRD was a national AD core center from 1989 -1995. The following description, including the relationship to the national centers and record of the past three years is based on reports from the ADA centers.

## Accomplishments of the ADA Centers – A Three Year Report

The accomplishments of the three regional ADA centers for fiscal years 2004 - 2006 are documented in the following table and narrative.

	NADC	RADC	SIU CADRD	TOTAL
<b>Clinical Evaluations<sup>1</sup></b>				
<b>Initial</b>		1,006	2,770	
<b>Recheck</b>		1,141	5,698	
<b>Total</b>	4,573	2,147 <sup>2</sup>	8,468 <sup>3</sup>	15,838
<b>Gender</b>				
<b>Males</b>	45%	34.3%	37.9%	
<b>Females</b>	55%	65.7%	62.1%	
<b>Race</b>				
<b>White not Hispanic</b>	85%	68.1%	96%	
<b>Black not Hispanic</b>	8%	23.6%	3.2%	
<b>Hispanic</b>	4%	6.3%	0.5%	
<b>Other</b>	3%	1.9%	0.3%	
<b>Primary Provider Sites</b>				
<b>Number of sites (2006)</b>	64	14	26	104
<b>Number of evaluations</b>	n/a	n/a	3,365 <sup>4</sup>	3,365 <sup>4</sup>
<b>Education Sessions</b>				
<b>Number held</b>	461	460	1,254	2,175
<b>Attendees</b>	38,300	30,034	32,688	101,022
<b>External funding for research and education<sup>5</sup></b>	\$55 million+	\$20 million+	\$7.2 million+	\$82.2 million+
<b>Number of publications</b>	407	150+	120+	677
<b>Autopsies/brain bank donations</b>	185	327	78	590

NADC = Northwestern Alzheimer's Disease Center

RADC = Rush Alzheimer's Disease Center

SIU CADRD = Southern Illinois University Center for Alzheimer Disease and Related Disorders

na = not available

1. Medicare, private insurance and client fees cover most of the cost.
2. Does not include 5,200 clinical evaluations done as a component of three large research projects
3. Includes evaluations at PPSs
4. Included in patient demographics
5. Exclusive of state general revenue funds

## **Rush Alzheimer's Disease Center Rush-Presbyterian-St. Luke's Medical Center**

Rush Alzheimer's Disease Center (RADC) takes four approaches to reducing the burden of AD in the state of Illinois. It provides

- *clinical care* for persons in northern Illinois with the disease;
- *educational programs* for family caregivers and professional and non-professional care providers to improve care for persons with AD;
- *community service* for people with AD; and
- a *research infrastructure* that supports clinical and basic science research into the causes and consequences of AD with an emphasis on studies that reduce disability and prevent or delay disease onset.

### Clinical Care

RADC's clinical mission is to provide clinical care for persons with AD and their families, regardless of ability to pay. The multidisciplinary clinical team includes physicians, nurse practitioners and social workers. Through careful and judicious program modifications, RADC continues to provide high quality clinical care to all persons regardless of ability to pay, despite marked changes in Medicare reimbursement. In this difficult financial climate, efforts have been made to reduce the barriers to memory evaluations, especially for older individuals in underserved communities. At the initial visit, all patients undergo formal neuropsychological testing; a knowledgeable informant is interviewed about past medical history and current problems; and all patients and family members meet with a physician with specialized training in aging and dementia. A geriatric psychiatrist and a social worker are available for consultation in complicated cases. Routine follow-up is either with a physician or an advanced nurse practitioner. Nurse practitioners, social workers, physicians and other staff also are available for phone consultations. RADC staff provided 2,147 clinical evaluations during this three-year reporting period. (This number does not include clinical evaluations done as part of the three large research projects.)

### Education and Outreach

The general goals of the Alzheimer's Staff Support Information - Sharing Together (ASSIST) networks are to-

- increase knowledge and improve the skills of those caring for persons with dementia;
- provide a forum for staff to share their experience and expertise;
- promote a philosophy of care that focuses on the remaining abilities of persons with dementia;
- examine policies and interdisciplinary programs to enhance the well-being of persons with dementia and their families; and
- increase awareness of the resources of the RADC and other community resources focusing on dementia care and research. Each ASSIST network includes an advisory board, chaired by RADC staff, that determines the agenda.

Due to a significant overlap in needs, the Nursing Home ASSIST program (which provides services to 300 nursing homes in northeastern Illinois) and the Retirement Home ASSIST program (which provides education for staff members in retirement home settings) merged into the Residential Care ASSIST network. The network also has played an important role in recruiting normal controls for the Rush Memory and Aging Project (MAP). Topics of interest to the group were presented including updates on dementia research, navigating nursing home regulations and mental health and aging. Other programs provided for nursing home staff included –

- the Celebrate the CNA (certified nurse assistant) Conference;
- Unit Director Course (in collaboration with Life Services Network);
- Successful Strategies for Caring for a Person with Dementia, a 15-hour on-site course; and
- train-the-trainer course (with Life Service Network). In the last year, a 12-hour training course was implemented to help assisted living and long-term care facilities comply with new state regulations for dementia care.

The Senior Housing ASSIST facilitates research opportunities and educational efforts for residents living in senior housing facilities. Programs, such as maintaining memory with age, were presented to African American audiences. Community-based educational programs included a conference co-sponsored with the Hispanic Provider Council. The Senior Housing ASSIST network continues to play an important role in nurturing minority participation in various National Institute of Aging studies.

Without Warning, an educational support group for individuals with early onset Alzheimer's disease and their care-partners, meets regularly. This group also has been educating professionals in the field of aging by offering a panel discussion so others will know what it is like to be diagnosed with Alzheimer's disease at a younger age.

The Alzheimer's Family Care Center (AFCC) is a model adult day care program for individuals with moderate to severe dementia. AFCC educational activities continue to expand the dementia knowledge base of professionals and the community. An average of 47.5 clients and families are served daily.

The sixth edition of RADC's caregiver manual was completed in 2005. It is provided to each family in the clinic. It also is available for download from the RADC Internet site (see Appendix 3). In order to make education materials more effective for a broader range of caregivers, a low health literacy version of the caregiver manual was developed.

A bank of newsletter articles is maintained so similar information can be published for different newsletter groups. Newsletters were sent to five groups with a circulation of nearly 10,000 persons -- Rush Alzheimer's Disease Center (RADC), Memory and Aging Project (MAP), Religious Orders Study (ROS), the Primary Provider Network (PPN) and the Healthy Aging Newsletter.

RADC's Web site posts information on educational outreach programs and research. The newsletters and Rush Manual for Caregivers are available for download. Research participation opportunities are maintained on the Rush Clinical Trials Web site. RADC's page is one of the top 25 sections visited on the Rush University Medical Center Web site.

The video lending library is maintained by ordering and purchasing videos related to dementia care and is housed in the McCormick Educational Technology Center.

Fourteen centers that specialize in dementia evaluations are Primary Provider Network members. As Alzheimer's disease diagnosis and treatment has shifted to primary care physicians and the role of dementia evaluation centers in the community has diminished, the focus of the Primary Provider Network has shifted to be more inclusive. Approximately five physician-to-physician meetings have occurred per year to assist primary providers integrate dementia care into their daily practices.

RADC sponsors and conducts numerous lectures for professional and non-professional audiences throughout Illinois and the United States. RADC Clinic is a training site for more than 25 health care providers per year including social work students; medical students, graduate students in psychology, and residents and fellows in family medicine, internal medicine, geriatrics, neurology, and psychiatry. Staff in-service training lectures have been provided. RADC has provided 460 education events with 30,034 participants.

#### Brain Bank and Autopsy Service

The brain bank provides post-mortem diagnostic services and crucial infrastructure to support neurobiologic studies of aging and ADRD. Over the past three years, the RADC Brain Bank has provided clinical excellence and expertise in the neuropathologic diagnosis of ADRD and supported an expanding infrastructure essential for the success of ongoing and future clinical-pathological studies and research projects. Autopsies are provided upon request to persons within the clinic, community dwellers who prearrange this service and for participants of research studies with brain donation. The RADC brain bank provides a 24-hour answering service for patients, families, study participants and key personnel. Family members and other designated persons receive personalized letters explaining the post-mortem diagnosis with an attached copy of the final autopsy reports. Phone calls are encouraged for any questions prior to and after the autopsy. Research excellence is achieved and maintained through a system of rapid tissue collection, detailed and accurate dissections and an organized tissue storage system. In addition to brain autopsy, the brain bank collects spinal cords, nerves and muscles to facilitate research into the biological cause of weakness and muscle wasting that often occurs with aging. Distribution of tissue follows strict protocols, which includes a tissue committee advisory board that oversees the distribution of human tissue for research purposes. During the past three years, the brain bank processed 327 brains. Tissue collected and stored by the brain bank supports numerous externally funded research projects conducted by RADC and other Rush investigators and by investigators at other institutions in the state



and across the country.

### Research

RADC continues to provide major infrastructure support to numerous externally-funded studies. Overall, RADC received more than \$20 million in external grant support for the three-year period (not including state funding). RADC has 12 faculty members, more than a dozen additional professional staff with a total of more than 80 personnel. RADC provides important infrastructure support for faculty in several other departments in the medical center and investigators across the country doing research on aging and Alzheimer's disease.

RADC has developed an infrastructure that supports clinical and basic science research into the causes and consequences of AD with an emphasis on studies that reduce disability and prevent or delay disease onset. Disease prevention, or more specifically, delaying disease onset is an ambitious, long-range goal. The approach adopted by RADC is to develop an infrastructure that supports clinical and basic science research into the causes and consequences of AD. Four types of research efforts are underway -

- clinical-pathologic studies of volunteer cohorts;
- clinical trials of older persons with and without AD;
- population-based studies; and
- other clinical studies of persons with AD.

### Publications

RADC investigators have published more than 150 manuscripts in the past three years. Studies have focused on many issues related to AD, but particularly on risk factors for AD and the consequences of AD.

## **Center for Alzheimer Disease and Related Disorders Southern Illinois University School of Medicine**

Southern Illinois University School of Medicine (SIU) Center for Alzheimer Disease and Related Disorders (CADRD) is a unique state-supported center with the following seven specific aims.

1. To provide diagnostic services, treatment and case management to patients and families throughout Illinois, excluding the Chicago area. Special attention is directed to rural areas of Illinois. This specific aim is achieved through an outreach program of 26 Primary Provider Sites (PPSs) located throughout Illinois.
2. 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.
3. To maintain a centralized patient database for monitoring patients and controls evaluated at CADRD and the PPSs.

4. To support clinical and basic research in the fields of dementia and associated locomotor disorders of older people, through the provision of research support staff, carefully diagnosed patients and non-patient controls.
5. To furnish legislators, the public and news media information pertaining to the latest developments and services in the field of aging.
6. To enhance the recruitment of neurologically healthy older people and persons with very early dementia for participation in aging research, including the brain bank program, by training PPS professionals in the most advanced diagnostic methods and by recruiting hundreds of normal older people for research.
7. To enlist the participation of PPSs into one or more areas of research including clinical drug studies and the recruitment of older controls.

### Clinical Care

CADRDR uses a comprehensive, integrated approach to patient care including supportive therapy for the patient and family. CADRD provides psychosocial counseling and frequently refers patients to appropriate social service and mental health agencies.

Information gained from the medical and psychosocial assessments is integrated into an individual treatment plan for each patient and family. This treatment plan typically includes one or more of the following -- home health care, adult day care, respite care, transportation, homemaker and chore services, legal services, financial services, housing assistance, recreational services, institutional care and rehabilitation.

CADRDR is an important focus of referral, consultation, education and research. It assures that any important discovery in diagnosis or treatment can be promptly applied and assessed throughout Illinois. CADRD has its own referral base and has evaluated 1,630 patients in the last three years; 2,212 patients were evaluated in their own communities at PPSs. Only those patients with uncertain diagnoses or a desire to participate in CADRD's research are referred by PPSs. A clinical database packet is completed on each patient, regardless of the site of evaluation. All data are entered into a computerized database. CADRD maintains a database of more than 11,000 patients who have been assessed and followed at CADRD or the PPSs. Over the past three years, CADRD and PPSs have provided 2,770 (988 and 1,782, respectively) initial evaluations and rechecked 5,698 (4,115 and 1,583, respectively) individuals.

Students from several colleges and universities have completed internships at CADRD and provided counseling, social work services and neuropsychological assessments. The students have come from a variety of programs including clinical psychology, counseling, social work and gerontology. Colgate University, University of Indianapolis, University of Illinois at Springfield, and the Illinois School of Professional Psychology-Argosy have used CADRD to provide training for students.

CADRDR sponsors and provides training and continuing education to physicians,

health care professionals and family members/caregivers for persons with AD throughout downstate Illinois in cooperation with the PPSs. CADRD also maintains a Web site (see Appendix 3).

### Primary Provider Sites

CARDR has recruited 26 hospitals and clinics throughout Illinois to participate in the PPS program. The initial goal of this program was 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 through liaisons with the case coordinators. The local coordinators work with CADRD to provide effective professional educational programs and public forums throughout Illinois. During fiscal years 2004 through 2006, 1,254 public forums, professional workshops and symposia were held to provide education to the general public and local health care professionals and to generate interest in CADRD's research programs. This included presentations in 102 different Illinois communities, as well as 33 presentations in other states and countries. The total attendance at all events was 32,688. CADRD serves a large geographical area of mainly rural counties, and the PPSs vary greatly in their resources and interests. Nevertheless, this program is successful and is unique throughout the world. The outreach program ensures elderly people in rural Illinois (approximately 607,000 people age 65 and older) receive the best possible clinical assessment and treatment. Each site is visited at least annually for evaluation and technical assistance.

All PPSs participate in some aspect of CADRD research with most providing research recruitment and evaluation of healthy older people. CADRD has expanded efforts to evaluate and recruit as many persons with mild dementia and normal older controls as possible for clinical and postmortem studies. Participation in such research will enhance the diagnostic skills of the PPSs, which will benefit patients and their families. These goals are being accomplished despite the wide range of skills and resources of the PPSs.

### Education and Outreach

CARDR's outreach program is an educational and clinical cooperative that benefits both the center and the PPSs. The interaction in the diagnosis and treatment of patients provides CADRD with first-hand knowledge of the medical and educational needs of communities throughout Illinois and the PPSs receive information on the latest advances in neurogeriatrics. This cooperative relationship allows CADRD to improve the standard of care in rural Illinois communities and throughout downstate Illinois. CADRD works to deliver the most effective and innovative educational programs possible. These programs are tailored to the needs and interests of individual PPSs. In the past three years a few PPSs have taken advantage of the opportunity to use CADRD's telemedicine capability for second opinions or to review specific cases. Plans include expanding the telemedicine program over the next three years.

CARDR and its outreach program devote considerable time to the education of the general public, thereby increasing awareness of AD. Dementia caregiver networks have been developed in Springfield and Collinsville to increase and enhance the sharing

of information on how to best serve this special population. Public forums are held each year in Springfield and in PPS communities. An annual conference for professionals is held in Springfield in cooperation with the IDoA. CADRD and the PPSs work closely with local chapters of the Alzheimer's Association. CADRD continues to sponsor the International Springfield Symposium on Advances in Alzheimer Therapy, with meetings held in Montreal, Canada in 2004 and Geneva, Switzerland in 2006.

### Brain Bank and Autopsy System

During this 3 year reporting period CADRD performed 78 neuropathologic examinations to diagnose the cause of dementia. Of these, 97 percent had been clinically evaluated by either CADRD clinicians (41) or by PPS (37) with two patients were seen at both. The percentage of PPS patients continues to increase, as anticipated, because of the outreach programs. Families dealing with a dementing illness and interested in a post-mortem examination are increasingly evaluated by CADRD and PPSs. This continued shift to evaluated patients is important as it permits focusing limited resources on patients who can contribute the most to understanding the disease. Currently, 129 individuals have signed intent-to-donate forms through the CADRD/PPS network and an additional 93 have signed intent-to-donate forms as normal controls.

Final (neuropathologic) diagnoses of total CADRD/PPS cases have shown 74 percent had AD, 10 percent had diffuse Lewy body disease and 13 percent had some other dementing etiology. Two cases were normal control subjects with autopsy confirmation. The two cases without a CADRD or PPS clinical evaluation showed AD pathology.

Overall, CADRD/PPS had 75 percent accuracy for the initial clinical diagnosis of a case that turned out to be AD (n=56). Diagnosis of diffuse Lewy body disease continues to be difficult and accounts for 36 percent of overall misdiagnosed cases. An analysis of the Mini Mental Status Exams of autopsy proven diffuse Lewy body disease cases suggests that better discrimination from AD is possible.

From June 2005 through July 2006 a center neuropathologist was not available and all administrative tasks of brain acquisition and storage during this period were assumed by another staff person. The CADRD was still able to offer autopsies and service to the Illinois community was not adversely affected. However, diagnoses and reports to the family were considerably delayed because the part-time contracted neuropathologist was not able to keep up with the volume. In collaboration with Memorial Medical Center, this full-time position has been filled. The backlog of diagnostic work and reports have been completed.

Because of the delayed opening of the Springfield Combined Laboratory Facilities (SCLF) and the simultaneous growth of the Simmons-Cooper Center for Cancer Research, laboratory space was extremely limited. Due to this situation, access to the 350 stored brains from CADRD dementia patients was severely limited during this report period. Lack of space severely limited the ability to send out tissue for research.

This problem has been ameliorated with the opening of the SCLF building and assignment of dedicated space, approximately 400 square feet, to the brain bank.

There is a new emphasis on brain collection. A free neuropathology examination is offered to all individuals that are evaluated at CADRD or PPSs. There is additional effort in following up cases that are subjects of Alzheimer drug clinical trials. Comparing clinical to neuropathological diagnoses with response to drug treatment outcomes is a critical function of CADRD.

### Research

Research at CADRD addresses key issues of cognitive change in normal aging and the relationship to the neuropathology, cholinergic biochemistry and disabilities associated with dementia; preclinical and clinical development of potential cholinergic therapies for AD; the role of estrogen; and locomotor disturbances in patients with dementing diseases. CADRD participates in multiple center research and studies.

### Publications

CARDR investigators have authored more than 120 publications including book chapters, during the past three years.

## **Northwestern Alzheimer's Disease Center Northwestern University Feinberg School of Medicine**

The Northwestern Alzheimer's Disease Center (NADC) was established in 1996 by the National Institute on Aging to serve this population and provide better access to clinical and research programs related to dementia. In 1997, NADC was designated as a Regional Alzheimer's Disease Center by IDPH.

State funding to NADC targets the following goals.

- To provide clinical services to cognitively impaired patients and families with special emphasis on outreach to minority communities;
- To provide education on Alzheimer's disease and related dementias to primary care physicians, allied health care professionals, patients, families, and the community at large;
- To give cognitively impaired individuals, their families, and normal healthy older adults the opportunity to participate in dementia research; and
- To make dementia-related autopsy services available to Illinois citizens

### Clinical Evaluation and Service Neurobehavior and Memory Health Clinical Services

The Neurobehavior and Memory Health Clinical Service is the clinical arm of the NADC and provides a multidisciplinary setting where research, training and clinical service are seamlessly integrated. Cognitively impaired patients and their families are seen for diagnostic evaluation and followed clinically by a neurologist, neuropsychologist, neuropsychiatrist and/or social worker, based on need. At time of diagnosis and, if appropriate, the person with dementia and their family are given the opportunity to enroll into the Memory Disorders Research Center (federal Clinical Core).

Since its inception eight years ago, the NADC has had 10,795 patient visits in the Neurobehavior & Memory Health Service, (the clinic of the Northwestern Cognitive Neurology & Alzheimer's Disease Center), 5,223 of which were seen during the 2003-06 reporting period.

ADRD are presently incurable but not untreatable. Each patient visit is viewed as potential for a "therapeutic encounter," whether to help problem-solve, provide emotional support or direct patients and their caregivers to appropriate home and community-based resources. Patients and caregivers have the opportunity for contact with social workers who are available by phone, e-mail and separate clinic appointments. The NADC's Quality of Life Enrichment programs (early stage programs - support group, culture bus) and the Buddy Program, an intergenerational program for newly diagnosed patients and families, are available to all pending program eligibility and are discussed in further detail below. All NADC clients receive quarterly newsletters and invitations to attend annual "Best Practices Innovative Practices & Town Hall Meetings" for updates on dementia research. A staff neuropsychologist offers cognitive rehabilitation services for individuals with mild cognitive impairment (MCI) and educational counseling for patients and family members.

#### Early Stage Memory Loss Support Group for Persons with Alzheimer's and their Families

The early stage memory loss support group for persons with ADRD and their families has reorganized and now offers 12-week support group sessions each summer and winter since 2005. Prior to that time, the early stage support group was offered weekly free of charge. This now fee-for-service support group is offered for family members. These support groups are professionally facilitated by clinical social workers with Ph.D. psychology graduate students with supervision and oversight provided by a licensed clinical social worker. Approximately seven to 10 participants enroll in both the early stage group and the family group sessions. This program has served 34 diagnosed individuals and 30 caregivers during the 2003-06 reporting period. The early stage group members developed a brochure in 2006 that is offered for national distribution by the National Institute on Aging's Alzheimer's Disease Education & Referral (ADEAR) Center.

#### The Culture Bus

As a result of the early stage support group's popularity and the identified gap in services for these patients, NADC collaborated with the Council for Jewish Elderly to develop the "Culture Bus." The bi-annual program offers a set of weekly, cultural excursions throughout Chicago in the spring and fall for individuals participating in the early stage memory loss support group.

#### Primary Progressive Aphasia (PPA) Program

The Neurobehavior and Memory Health Service follows what is probably the world's single largest cohort of PPA patients. Patients with AD and their families can access vast resources of expert opinion. Patients with PPA and other rare dementias face a greater challenge. Few medical experts may have seen this condition and there

are very few resources that address the unique needs of these patients for thorough assessment, clinical management, practical advice about daily living activities and general information about the underlying condition and its differences from typical AD. A multidisciplinary evaluation and treatment program with a strong research component has been initiated for patients with PPA. (The program is described on the NADC Web site (see Appendix 3) and in literature sent to health care providers.) Patients and their caregivers can apply for a two to three day program of integrated neurological, neuropsychological, speech-language and psychosocial assessment. During the course of this program, patients are offered a comprehensive multidisciplinary assessment and specific recommendations on daily living activities. If appropriate, speech therapy or cognitive rehabilitation is suggested and specific goals are outlined. The patient is provided with specially designed educational materials and offered the opportunity to participate in research projects. Clinical findings and recommendations for compensatory communication strategies also are communicated to the patient's local health care providers.

PPA often presents as a form of frontotemporal dementia (FTD). Over the past three years, NADC has developed the FTD/PPA Support & Education Program for families caring for persons with FTD/PPA. Since January 2005, the NADC has hosted five half-day conferences for families. Each half-day session began with an hour of educational lectures covering topics relevant to families providing care for individuals diagnosed with these rare dementias. Following the lectures, participants are offered a support group facilitated by social workers, psychiatrists, clinical neuropsychologists and graduate students in clinical psychology and neuroscience. The group provides participants an opportunity to discuss the challenges of providing care for an individual with FTD or PPA with other families in similar situations. The program provides time to allowing the families to get to know one another in a less structured setting and to interact with clinicians and researchers. Approximately 80-90 family members participate in each of these conferences, many traveling from out-of-state or from overseas.

Feedback from the educational conferences has been very positive. However, the one recurring request was for more frequent support groups. As a result, NADC developed a monthly support group for families caring for individuals with FTD/PPA. This support group began in October 2005 and meets monthly with eight to 12 participants attending.

### Education and Outreach

Over the past three years there have been over 461 presentations by NADC faculty to 38,300 participants which includes both national and international audiences. The audience for these programs is health care professionals, basic scientists, researchers, clinicians and the general community of interested individuals and family caregivers.

In academic year 2005-6, the Buddy Program entered its ninth year with 109 buddy pairs (medical students and diagnosed individuals who live in the community)

matched since inception of the program. The program was honored by the Lifetime Education and Renewal Network of the American Society on Aging; presented with the 2004 MindAlert Award in the Early Stage Dementia Program category at the Joint Conference of the American Society on Aging and the National Council on Aging; was the subject of a local television (WGN) news program; and the associated press interviewed a buddy pair and the story was picked up by MSNBC and CNN. Several articles, national and international, have highlighted this unique and successful program. In 2004, the Buddy Program expanded to include basic scientists who volunteered to broaden their understanding of AD/DRD as it affects the individual and family.

Nearly every laboratory directed by a NADC investigator offers undergraduate rotations, graduate student training and post-doctoral fellowships related to dementia and aging. The Buehler Center on Aging of Northwestern University Medical School also coordinates a very popular summer research program for medical students and graduate students at Northwestern. Many of these students have worked in the area of AD and have been mentored in the clinics and laboratories of NADC investigators. The NADC also offers formal clinical training in neurology, psychiatry, neuropsychology and social work for specialization in AD/DRD.

The Primary Provider Program continues to enroll primary care physicians in the community who evaluate and treat cognitively impaired patients in their practice. Sixty four physicians are now currently enrolled in the program. Most of these physicians are bilingual, an emphasis due to involvement in the AoA AD Demonstration Grant – LEP Community Outreach. All have received diagnostic evaluations and treatment guidelines as well as specific resource information for their patients and families. These physicians receive regular mailings on AD related issues as new information becomes available and receive the NADC newsletter. All physicians are encouraged to contact the NADC clinical staff by phone or e-mail for consultation. Free CME programs are provided to physician groups upon request.

NADC continues to provide multicultural outreach to underserved and minority communities in the Chicago area. In July 2005, the second ADDGS was awarded to the IDPH and the LEP component is a collaborative effort between the IDPH, Coalition for Limited Speaking Elderly (CLESE), the Alzheimer's Association – Greater Illinois Chapter and NADC. This grant targets five language groups - Arabic, Assyrian, Bosnian, Hindi and Urdu. Through this project, the number of persons with memory problems in the LEP communities receiving appropriate assessment, diagnosis and treatment and community-based services increased. Educational programs to ethnic agency staff and communities were provided.

The Chicago Department on Aging's Francis J. Atlas Center is a bimonthly, clinical core enrollment site for healthy elders. To date, there are 55 active research participants from the Atlas Center with a total of 118 African-American research participants at the NADC. Many participants attend the annual Town Hall meeting offered by NADC and additional sessions are periodically offered at the Atlas Center.



NADC staff attend the Southeast Provider Council meeting hosted by the Francis J. Atlas Center. Information on NADC's educational events and research projects are disseminated to south side area aging service providers resulting in numerous invitations to speak at local agencies.

The South Side Dementia Consortium is a group of area service providers serving the primarily African-American older population on the south side of Chicago. The organization is led by the Alzheimer's Association – Greater Illinois Chapter and other founding members including NADC. In spring 2006, the Consortium held the sixth Caregiving Conference, "Memory Loss, Putting the Pieces Together."

NADC continues to build relationships and raise awareness of ADRD in Chicago's Hispanic Community. Outreach and education efforts have grown through strengthening the relationship with the Mexican Consulate of Chicago by providing informational sessions in Spanish to groups of individuals waiting for their consular identification cards. NADC was on the organizing committee for the Consulates "Semana Biunacional de Salud" (Bi-National Health Week, October 2005) and has participated in multiple health fairs.

NADC collaborated with the AA-Greater Illinois Chapter and RADC for two presentations to Hispanic seniors and provided presentations on AD and healthy memory at the West Town Senior Center. NADC joined a new AA – Greater Illinois Chapter initiative - the Hispanic Task Force on AD.

NADC's Web site is a resource for information on AD, PPA and other dementias, as well as links to a number of AD related sites, information on community services and research studies. The site contains pages for caregivers, health care providers, investigators, and patients. Translated educational materials from the two ADDGS projects are available. Scheduled educational events are listed; center research is described; and funding opportunities are highlighted.

### Publications

Over the past three years, NADC faculty have authored more than 250 peer reviewed articles, 22 book chapters, and 135 published abstracts. NADC continues to publish and disseminate a biannual newsletter sent to more than 3,500 patients, caregivers, health care professionals, physicians and scientists and distributed at community meetings. The PPA Program newsletter was combined with NADC's newsletter. NADC continues to provide patient and family education materials to patients diagnosed with ADRD in the Neurobehavior and Memory Health Services Clinic. Individualized educational information is provided based on the person's diagnosis, symptoms and resource needs.

### Autopsy and Tissue Collection

The Neuropathology program within NADC has five specific aims.

- To collect tissues (including brain, CSF, and DNA) from patients with

dementia and normal controls.

- To prepare, evaluate, and archive tissue to support research at Northwestern and with extramural collaborators.
- To provide research-quality diagnosis and databasing.
- To promote the use of tissue resources for appropriate projects.
- To create an “enabling” infrastructure to facilitate multidisciplinary research.

The program has been designed to provide services specialized to the dementia research system at Northwestern, including technical and diagnostic expertise for our high proportion of complex cases such as FTD, and specialized neurohistologic expertise such as efficient production of high-quality whole-brain sections to serve NADC’s research focus on neural networks in dementia.

Seeking autopsy consent is a very sensitive issue. The federal Neuropathology, Clinical and Education Cores prepared a packet addressing the purpose and importance of brain donation that acknowledges the decision’s emotional impact. The packet contains an AA pamphlet and supplements this with autopsy-related frequently asked questions and answers. Whenever possible, pathologic reports are provided within two to four weeks of autopsy. A 24-hour answering service is provided to facilitate the autopsy process.

Through the state grant, diagnostic autopsy services are provided to Illinois dementia patients who are outside of NADC’s clinical and research programs. When postmortem times are appropriate these cases also are included in our tissue bank.

### Research

NADC focuses its research on the early and prodromal stages of AD. Because no single approach is likely to resolve all questions related to dementia, NADC has encouraged a comprehensive representation of both clinical and basic research activities. NADC’s infrastructure supports work on nearly all major themes related to dementia including tau, amyloid, regeneration, neuroglia, inflammation and cholinergic pathways. This work on the cell and molecular biology of dementia is supplemented by work on language, memory attention, molecular biology, visuospatial processing and executive function so that the neurobiological correlates of the aphasia, amnesia, spatial disorientation and personality changes that underlie the dementia can be explored. NADC’s focus on non-AD focal dementias; affiliation with the Northwestern Cognitive Brain Mapping Group; establishment of the Molecular Pathomorphology Laboratory in the Neuropathology Core; and work in many of NADC’s basic and cognitive science laboratories collectively support the special emphasis on the neural system approach to dementia that permeates all activities of the NADC.

The non-AD dementias are disease entities with complex and fascinating pathophysiologies that hold clues to fundamental aspects of human brain organization in health and disease. NADC is committed to continued work in Alzheimer’s disease. However, with the breakthroughs in understanding of the complexity and relationship

among all dementias and as a leader in developing these breakthroughs, NADC's focus for research, education, outreach, and patient/family programs and services will remain broad. Over the past three years, NADC and its affiliated faculty and staff have received \$55,503,353 in funding for research and education external of state general revenue funds.

## ALZHEIMER'S DISEASE RESEARCH FUND

The Alzheimer's Disease Research Fund (ADRF) enables IDPH to provide support for finding a cure or treatment for ADRD. Illinois taxpayers may contribute to this special fund through their annual state income tax returns. Contributions are deposited in the state treasury and appropriated to IDPH for awarding research grants to Illinois physicians, hospitals, laboratories, educational institutions and other health care professionals.

IDPH's administration of the ADRF entails promoting contributions to the fund, soliciting research applications, facilitating the reviews, awarding selected research projects and monitoring the projects. IDPH sends notice of the availability of application guidelines to Illinois researchers, medical schools, college grant management offices, nursing schools and health care professional organizations. Annually in September, the application guidelines are posted on IDPH's Web site and includes information for the general research grant, intended for established researchers in the area of ADRD, and the early researcher grant for researchers who plan to pursue careers in ADRD research.

Annually in January, the opportunity to contribute to the ADRF is publicized through a mailing to tax preparers, long-term care facilities, home health and hospice agencies, hospitals, Illinois' ADRD community, medical schools, nursing schools and health care professional organizations. In 21 years, Illinois taxpayers have contributed more than \$3.2 million to the ADRF. Yearly contribution levels follow.

Tax Year	Contribution
1985	\$114,850
1986	\$173,026
1987	\$164,603
1988	\$169,823
1989	\$169,784
1990	\$185,781
1991	\$103,651
1992	\$124,415
1993	\$108,116
1994	\$108,592
1995	\$119,277
1996	\$130,165
1997	\$102,721
1998	\$161,503
1999	\$225,860
2000	\$166,146
2001	\$181,614
2002	\$192,173
2003	\$173,386

2004	\$196,597
2005	\$150,601

IDPH, in consultation with the AD Advisory Committee, has selected 136 applications for funding. Many of these projects are pilot studies in preparation for federal applications. A list of research projects funded by the ADRF is in Appendix 4.

## **APPENDICES**

## APPENDIX 1

### ALZHEIMER'S DISEASE ADVISORY COMMITTEE MEMBERS

Eric E. Whitaker, M.D., M.P.H., Chair (designee Jane Kessler, R.N., M.A.)

Kent Barnheiser, Chicago

David Bennett, M.D., Chicago

Mary Buesing, Peoria

Helen Bowler, Schaumburg

Carol Einhorn, R.N., M.S., G.N.P., C.S., C.U.R.N., LaGrange

Jerome J. Epplin, M.D., Litchfield

Larry S. Lindahl, M.D., Peoria

Carolyn Hicks, Chicago

Daniel R. Kuhn, M.S.W., Evanston

M.-Marsel Mesulam, M.D., Chicago

Dennis Q. McManus, M.D., Springfield

Darby Morhardt, M.S.W., Chicago

Mary A. Nagy, R.N., M.S., Schaumburg

Christopher Randolph, Ph.D., Chicago

Sharon Roberts, R.N., B.S.N., N.H.A., M.A., Waukegan

Lisa Sayerstad, Lake Forest

John M. Smith, Carterville

Phyllis Schwebke, L.N.H.A., Rockford

Orlinda Workman, L.S.W., M.S.W., Jacksonville

Rod Curtis, M.D., Department of Human Services

Dr. Mary Milano, Guardianship and Advocacy Commission

Robin Morgan, Department on Aging

Shirley Whitcup, R.N., Department of Healthcare and Family Services

December 2006

## APPENDIX 2

### ALZHEIMER'S ASSOCIATION, INC. Local Chapters Serving Illinois

#### Central Illinois Chapter

606 W. Glen Ave.  
Peoria, IL 61614-4831  
Phone: 309-681-1100  
Fax: 309-681-1101

The Central Illinois Chapter serves: Adams, Brown, Bureau, Fulton, Hancock, Henderson, Knox, LaSalle, Lee, Marshall, McDonough, Peoria, Pike, Putnam, Schuyler, Stark, Tazewell and Warren counties.

#### Rock River Branch Office

215 E. First St.  
Dixon, IL 61021  
Phone: 815-285-1111  
Fax: 815-285-1116

#### Quincy Area Branch Office

639 York St., Room 20  
Quincy, IL 62301  
Phone: 217-228-1111  
Fax: 217-592-3690

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#### Greater Illinois Chapter

4709 Golf Road, Suite 1015  
Skokie, IL 60076  
Phone: 847-933-2413  
Fax: 847-933-2417

#### Bloomington

303 N. Hershey Road, Suite 2A  
Bloomington, IL 61704  
Phone: 309-662-8392  
Fax: 309-664-0495

#### Cartersville

402 E. Plaza Drive, #14  
Cartersville, IL 62918  
Phone: 618-985-1095  
Fax: 618-985-9460

#### Joliet

1150 Essington Road, #109  
Joliet, IL 60435  
Phone: 815-744-0804  
Fax: 815-773-7340

#### Rockford

4777 E. State St.  
Rockford, IL 61108  
Phone: 815-484-1300  
Fax: 815-484-9286



Springfield  
2921 Greenbriar Drive, Suite C  
Springfield, IL 62704  
Phone: 217-726-5184  
Fax: 217-726-5185

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**St. Louis Missouri Chapter**

9374 Olive Blvd.  
St. Louis, MO 63132  
Phone: 314-432-3422  
Fax: 314-432-3824

Illinois Office  
222 Goethe Ave.  
Collinsville, IL 62234  
Phone: 618-346-4073

The St. Louis Chapter serves nine counties in Illinois: Calhoun, Clay, Clinton, Jefferson, Jersey, Madison, Marion, Monroe, St. Clair and Washington.

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**Greater Iowa Chapter**

736 Federal St., Suite 2318  
Davenport, IA 52803  
Phone: 563-324-1022  
Fax: 563-324-6267

The Greater Iowa Chapter serves six counties in Illinois: Carroll, Henry, Jo Daviess, Mercer, Rock Island and Whiteside.

## APPENDIX 3

### REGIONAL ALZHEIMER'S DISEASE ASSISTANCE CENTERS

The Chicago metropolitan regional Alzheimer's disease assistance centers serve the following nine counties: Cook, DuPage, Grundy, Kane, Kankakee, Kendall, Lake, McHenry and Will.

Cognitive Neurology and Alzheimer's Disease Center  
Northwestern University The Feinberg School of Medicine  
320 E. Superior St., Searle 11-450  
Chicago, IL 60611-3008  
Phone: 312-908-9339  
Fax: 312-908-8789  
<[www.brain.northwestern.edu](http://www.brain.northwestern.edu)>

Rush Alzheimer's Disease Center  
Rush-Presbyterian-St. Luke's Medical Center  
600 S. Paulina St., Suite 1028  
Chicago, IL 60612  
Phone: 312-942-4463  
Fax: 312-942-4154  
<[www.rush.edu/rumc/](http://www.rush.edu/rumc/)>

The downstate regional Alzheimer's disease assistance center serves the remaining counties.

Center for Alzheimer Disease and Related Disorders  
Southern Illinois University School of Medicine  
751 N. Rutledge St.  
P. O. Box 19643  
Springfield, IL 62794-9643  
Phone: 217-545-8249  
Fax: 214-545-1903  
TDD (hearing impaired use only) 217-545-4003  
<[www.siumed.edu/cadrd/](http://www.siumed.edu/cadrd/)>

## Alzheimer's Disease Research Fund Recipients

### FY06

1. Britto P. Nathan, Ph.D., Eastern Illinois University  
"Transgenic Models to Study the Role of ApoE in Alzheimer's Disease"
2. Peter R. Patrylo, Ph.D., Southern Illinois University School of Medicine - Carbondale  
"Is synaptic neurotransmission preferentially compromised in the aged CNS during metabolically challenging conditions?"
3. Virginia L. Wilcox-Gok, Northern Illinois University  
"Family Mental Illness and Labor Market Performance: The Family Burden of Alzheimer's Disease, Part 2"
4. Chih-Ju Han, Ph.D., Northwestern University  
"Developing viral and Genetic Approaches to Rescue Alzheimer's Disease"
5. Carmen Westerberg, Ph.D., Northwestern University  
"Recognition Memory in Alzheimer's Disease: Examining the Neural Basis of Preserved Familiarity-Based Recognition in Mild cognitive Impairment"
6. Sylvie Blond, Ph.D., University of Illinois – Chicago  
"Screening for peptides that inhibit amyloid formation during inflammatory conditions"

### FY05

1. Sant P. Singh, M.D., Veterans Affairs Medical Center  
"Diminished Brain Glucose Uptake in Alzheimer's Disease: Role of Plasma Membrane Lipids and Effects of Statins"
2. Britto P. Nathan, Ph.D., Eastern Illinois University  
"Transgenic Models to Study the Role of ApoE in Alzheimer's Disease"
3. Sarah Cole, Northwestern University  
"The Effect of Statins of APP Processing"
4. Kulandiavelu S. Vetrivel, University of Chicago  
The Mechanism and Role of Lipid Raft Association/Residence of PS1/Gamma-Secretase Complex in APP Processing
5. Li Liu, University of Chicago  
"The Role of Alzheimer's Disease Associated Presenilin 1 in Synaptic Structure and Function"
6. Mary Ellen McAsey, Ph.D., Southern Illinois University School of Medicine - Springfield  
"The Effect of Estrogen on Neurite Growth and Synaptic Density"

### FY04

1. Sarah Cole, Ph.D., Northwestern University  
"The effect of statins on APP processing"
2. Scott Counts, Ph.D., Rush-Presbyterian-St. Luke's Medical Center  
"Synaptic gene expression in tangle-bearing cholinergic neurons in mild cognitive impairment"

3. Darren Gitelman, M.D., Northwestern University  
"Anatomic and spectroscopic study of Alzheimer's disease, mild cognitive impairment and normal controls"
4. Pascale Lacor, Ph.D., Northwestern University  
"New molecular basis for memory loss in Alzheimer's disease"
5. Dana M. Small, Ph.D., Northwestern University Medical School  
"Neural correlates of the interaction between motivation and visual spatial attention in Alzheimer's disease, mild cognitive impairment and healthy aging"
6. Robert Struble, Ph.D., Southern Illinois University School of Medicine  
"Chronic estrogen replacement and glial response: In vivo studies of mice"
7. Virginia Wilcox-Gök, Ph.D., Northern Illinois University  
"Family mental illness and labor market performance: The family burden of Alzheimer's disease"

### **FY03**

1. Britto Nathan, Ph.D., Eastern Illinois University  
"How do isoforms of human apoE differentially modulate neurite outgrowth from adult mice cortical neurons in culture?"
2. Pascale Lacor, Ph.D., Northwestern University  
"New molecular basis for memory loss in Alzheimer's Disease"
3. Darren Gitelman, M.D., Northwestern University  
"Anatomic and Spectroscopic Study of Alzheimer's Disease, Mild Cognitive Impairment and Normal Controls"
4. Scott Counts, Ph.D., Rush-Presbyterian-St. Luke's Medical Center  
"Synaptic Gene Expression in Tangle-bearing Cholinergic Neurons in Mild Cognitive Impairment"
5. Dana Small, Ph.D., Northwestern University Medical School  
"Neural correlates of interactions between motivation and visual spatial attention in Alzheimer's disease, mild cognitive impairment and healthy aging"
6. Robert Struble, Ph.D., SIU School of Medicine  
"Estrogen replacement and synaptic density"
7. Madelyn Iris, Ph.D., Northwestern University  
"Los Caminos: Pathways to Alzheimer's Disease - Identifying Factors that Promote or Inhibit Early Detection in Hispanic Elders"

### **FY02**

1. Britto Nathan, Ph.D., Eastern Illinois University  
"How do isoforms of human apoE differentially modulate neurite outgrowth from adult mice cortical neurons in culture?"
2. Robert Schrauf, Ph.D., Northwestern University  
"Language(s) lost among the Hispanic immigrants with Alzheimer's disease"
3. Carolinda Douglass, Ph.D., Northern Illinois University  
"Implementation issues in dementia care mapping(DCM): a case study of DCM's reliability, validity and ease of use in a long-term care setting"

4. Sant Singh, M.D., VA Medical Center  
"Mechanism of abnormal glucose transport in Alzheimer's disease"

#### **FY01**

1. William L. Klein, Ph.D., Northwestern University  
"New Targets for Alzheimer's Drug Discovery"
2. Bruce C. Quinn, M.D., Ph.D., Northwestern University  
"Neurotoxic Mechanisms of Glial Response in Alzheimer's Disease"
3. Sreepadma P. Sonty, Medical Student, Northwestern University  
"Language Network Changes in Alzheimer's Disease and Other Dementia - A Functional Imaging Study"
4. Dimitra A. Loukissa, R.N., Ph.D., Rush University, College of Nursing  
"Physiological Effects of a Behavioral Intervention"
5. Jacqueline E. Payton, B.S., Medical Student, University of Illinois at Urbana-Champaign  
"Functional Analysis of an Alzheimer's Disease-Related Protein"

#### **FY00**

1. Larry F. Hughes, Ph.D., Southern Illinois University School of Medicine  
"The relationship between visual spatial contrast sensitivity and extrapyramidal motor symptoms in Parkinson, Alzheimer and Diffuse Lewy Body Disease"
2. Paul Joshua Reber, Ph.D., Northwestern University  
"Nondeclarative memory and cognitive skill learning in Alzheimer's disease"
3. Adrianna B. Ferreira, M.D., Ph.D., Northwestern University  
"Beta amyloid deposition and neuritic dystrophy: A mechanistic link"
4. Julie Ann Schneider, M.D., Rush-Presbyterian-St. Luke's Medical Center  
"A beta 40, A beta 42 and memory impairment in aging and Alzheimer's disease"
5. Rebecca Jean Sisk, Ph.D., R.N., Bradley University  
"Secondary caregiving: Activities, rewards and costs"

#### **FY99**

8. Bruce Carl Quinn, M.D., Ph.D., Northwestern University  
"Astrocyte-microvasculature interactions in Alzheimer's Disease"
9. Adriana Beatriz Ferreira, Ph.D., Northwestern University  
"Beta amyloid deposition and neuritic dystrophy: A mechanistic link"
10. Julie Ann Schneider, M.D., Rush-Presbyterian-St. Luke's Medical Center  
"A beta 40, A beta 42 and memory impairment in aging and Alzheimer's disease"
11. Craig Weiss, Ph.D., Northwestern University  
"The hippocampal dependency of eyeblink conditioning in the mouse"
12. David Bryan Jacobs, Ph.D., FUHS/The Chicago Medical School  
"Effect of Alzheimer's disease on the posttranscriptional regulation glucose transporter (Glut 1) gene expression"
13. John M. Lee, M.D., Ph.D., Loyola University Chicago  
"Effect of glycosaminoglycans on B-amyloid neurotoxicity"
14. Maria C. Carrillo, Ph.D., Rush-Presbyterian-St. Luke's Medical Center

- “Single trial analysis of fMRI signal changes in primary sensory and cognitive processes in healthy aging and Alzheimer’s disease”
15. David N. Levin, M.D., Ph.D., The University of Chicago  
“MRI measurements of biomechanical properties of the brain in Alzheimer’s disease”
  16. Gregory J. Brewer, Ph.D., Southern Illinois University School of Medicine  
“Regulation of the amyloid precursor gene in neurons”
  17. Britto Prabagan Nathan, Ph.D., Eastern Illinois University  
In vivo and in vitro effects of apolipoprotein E on axonal extension and synaptogenesis in the central nervous system”

**FY98**

1. Jingru Hu, Ph.D., Northwestern University Medical School  
“Amyloid B and Glial Neurotransmitter Signalling”
2. Sharon Milliken Roberts, R.N., B.S.N., Lake County Health Department  
“Observed interactions of residents with dementia and nursing assistants during bathing”
3. John M. Lee, M.D., Ph.D., Loyola University  
“Effect of Glycosaminoglycans on B-Amyloid Neurotoxicity”
4. David Bryan Jacobs, Ph.D., FUHS/Chicago Medical School  
“Effect of Alzheimer’s Disease on the posttranscriptional regulation of glucose transporter (GLUT1) gene expression”
5. Craig Weiss, Ph.D., Northwestern University  
“Spatial and Temporal Learning in the Mouse: A Model for Age-Related Learning and Memory Impairments”
6. Britto Prabagan Nathan, Ph.D., Eastern Illinois University  
“In Vivo and In Vitro Effects of Apolipoprotein E on Axonal Extension and Synaptogenesis in the Central Nervous System”

**FY97**

1. Sandra Weintraub, Ph.D., Northwestern University Medical School  
“Neurology of Attention and Neglect: Selective Attention in Alzheimer’s Disease”
2. John F. Smiley, Ph.D., Northwestern University  
“Neurochemistry of Monoamines in the Nucleus Basalis of Meynert: A model for Pharmacological Therapies of Alzheimer’s Disease”
3. Lawrence C. Perlmuter, Ph.D., Chicago Medical School  
“Orthostatic Hypotension in Alzheimer’s Disease: An Unrecognized Source of Cognitive Decline”
4. Jinru Hu, Ph.D., Northwestern University  
“Amyloid B and Glial Neurotransmitter Receptor Signaling”
5. Craig Weiss, Ph.D., Northwestern University  
“Spatial and Temporal Learning in the Mouse: A Model for Age-Related Learning and Memory Impairments”

6. Arlene Ouellette Tippey, L.C.S.W., A.C.S.W., Richland Memorial Hospital  
"The Value of Social Work Intervention During the Memory Disorder Assessment"

#### **FY96**

1. Numa Marquez-Sterling, M.D., Northwestern University Medical School  
"Trafficking of the Amyloid Precursor Protein in Cultured Cerebellar Macroneurons"
2. Maria Teresa Sobreviela, M.D., Ph.D., Rush-Presbyterian-St. Luke's Medical Center  
"Neurotrophins in Alzheimer's Disease"
3. Glenn T. Stebbins, Ph.D., Rush-Presbyterian-St. Luke's Medical Center  
"Functional MRI Analysis of Memory in Alzheimer's Disease and Isolated Memory Impairment"
4. Gregory J. Brewer, Ph.D., Southern Illinois University School of Medicine  
"Beta-Amyloid Promoter Response to Free Radicals in Neurons"
5. John F. Smiley, Ph.D., Northwestern University  
"Neurochemistry of Monoamines in the Nucleus Basalis of Meynert: A model for Pharmacological Therapies of Alzheimer's Disease"
6. Jeffrey H. Kordower, Ph.D., Rush-Presbyterian-St. Luke's Medical Center  
"Grafts of Human NGF Secreting Cells in Young and Aged Nonhuman Primates"
7. Martha Claire Morris, Sc.D., Rush Institute on Aging  
"Pilot Study of a Dietary Survey to Examine Nutritional Risk Factors for Alzheimer's Disease"

#### **FY95**

1. Robert Buchanan, Ph.D., University of Illinois - Champaign  
"Medicaid Policies for the Long Term Care Needed by People with Alzheimer's Disease: Survey of the States"
2. Daniel Luchins, M.D., University of Chicago  
"Lack of Access to Hospice Care in End-Stage Dementia"
3. Elliot J. Mufson, Ph.D., Rush-Presbyterian-St. Luke's Medical Center  
"APO E in Primate Model of Alzheimer's Disease"
4. William C. Benzinger, Ph.D., Rush-Presbyterian-St. Luke's Medical Center  
"Relationship of Apolipoprotein E to Tangle Formation in Alzheimer's Disease"
5. Jeffrey H. Kordower, Ph.D., Rush-Presbyterian-St. Luke's Medical Center  
"Encapsulated Gene Therapy for AD"
6. Maria Teresa Sobreviela, M.D., Ph.D., Rush-Presbyterian-St. Luke's Medical Center  
"Neurotrophins in Alzheimer's Disease"
7. Numa R. Marquez-Sterling, M.D., Northwestern University Medical School  
"Trafficking of the Amyloid Precursor Protein in Cultured Cellular Macroneurons"

#### **FY 94**

1. Gregory Brewer, Ph.D., Southern Illinois University School of Medicine  
"Mechanism of Alzheimer Marker Stimulation in Cultured Neurons"

2. Nelly Ryan, L.C.S.W., Southern Illinois University School of Medicine  
“Correlation of Alzheimer Primary Provider System Components with Successful Outcomes”
3. David Hammond, M.D., University of Chicago  
“Amyloid Protein: Role in Causation of Alzheimer’s Disease and Implications for Treatment”

**FY 93**

1. Bruce Wainer, M.D., Ph.D., University of Chicago  
“Two-Step Immortalization of Hippocampal and Septal Neurons”
2. Elliot Mufson, Ph.D., Rush Alzheimer’s Disease Center  
“Nerve Growth Factor Receptor in Alzheimer’s Disease”
3. David Hammond, M.D., University of Chicago Medical Center  
“Amyloid Protein: Role in Causation of Alzheimer’s Disease and Implications for Treatment”
4. Judith McCann, D.N.Sc., R.N., Rush-Presbyterian-St. Luke’s Medical Center  
“An Activity-Based vs. Problem-Based Intervention for Decreasing Disruptive Behavior in Persons with Alzheimer’s Disease”
5. Debra Grosse, Ph.D., Rush Alzheimer’s Disease Center  
“Sources of Memory Failure in Early Alzheimer’s Disease”
6. Barbara Haley, M.A., B.S.N., R.N., Lake County Health Department  
“Mealtime Interventions Address Nutritional Needs of the Alzheimer Client”
7. Gregory Brewer, Ph.D., Southern Illinois University School of Medicine  
“Mechanisms of Alzheimer Marker Stimulation in Cultured Neurons”
8. Greg Sachs, M.D., University of Chicago Medical Center  
“Ethical Aspects of Dementia Research: Informed Consent and Proxy Consent”

**FY 92**

1. John Gabrieli, Ph.D., Northwestern University  
“Analysis of Initial Cognitive Deficit in Alzheimer’s Disease”
2. Greg Sachs, M.D., University of Chicago, Dept. of Medicine  
“Ethical Aspects of Dementia Research: Informed Consent and Proxy Consent”
3. David Bennett, M.D., Rush-Presbyterian-St. Luke’s Medical Center  
“Use of Genetically Altered Astrocytes to Rescue Basal Forebrain Neurons”
4. Bruce Wainer, M.D., Ph.D., University of Chicago  
“Two-Step Immortalization of Septal and Hippocampal Neurons”
5. Barbara Haley, R.N., B.S.N., M.A., Lake County Health Department  
“Feeding Behaviors Inventory”
6. Elliott Mufson, Ph.D., Rush-Presbyterian-St. Luke’s Medical Center  
“Nerve Growth Factor Receptor in Alzheimer’s Disease”
7. David Hammond, M.D., University of Chicago  
“Amyloid Protein: Role in Causation of Alzheimer’s Disease and Implications”



**FY 91**

1. Patricia Hanrahan, Ph.D., University of Chicago  
"National Hospice Care Survey"
2. Marie Caserta, M.D., Evanston Hospital  
"Studies of Murine Trisomy 16 Cortical Neurons: Implications for Alzheimer's Disease"
3. A. V. Plioplys, M.D., Michael Reese Hospital and Medical Center  
"Neurobiology of Down Syndrome: Relation to Alzheimer's Disease"
4. John Gabrieli, Ph.D., Northwestern University  
"Analysis of Initial Cognitive Deficit in Alzheimer's Disease"
5. Leonard Maroun, Ph.D., Southern Illinois University School of Medicine  
"RFLP Karyotyping of Alzheimer's Disease Related Genes in the Rabbit"
6. David Bennett, M.D., Rush-Presbyterian-St. Luke's Medical Center  
"Nerve Growth Factor and Alzheimer's Disease"

**FY 90**

1. David Bennett, M.D., Rush-Presbyterian-St. Luke's Medical Center  
"Nerve Growth Factor and Alzheimer's Disease"
2. Leonard Maroun, Ph.D., Southern Illinois University School of Medicine  
"RFLP Karyotyping of Alzheimer's Disease Related Genes in the Rabbit"
3. John Gabrieli, Ph.D., Northwestern University  
"Analysis of Initial Cognitive Deficit in Alzheimer's Disease"
4. David Hammond, M.D., University of Chicago  
"A Monolayer Cell Culture System for the Study of Tropic Influences on Cholinergic Neurons"
5. Michael Glasser, Ph.D., University of Illinois College of Medicine at Rockford  
"Rural Physicians Diagnosis of Dementia"
6. Daniel Luchins, M.D., University of Chicago  
"PET in the Diagnosis of Presymptomatic Alzheimer's Disease"
7. James J. Chrobak, Ph.D., Loyola University of Chicago Stritch School of Medicine  
"Dopamine-Acetylcholine Interaction Within the Septohippocampal System"
8. Ezio Giacobini, M.D., Ph.D., Southern Illinois University School of Medicine  
"A Cortical Study of Alzheimer Neurochemistry"
9. Carolyn Wilken, Ph.D., Rush University College of Nursing  
"A Nursing Home Comparative Study: Caregivers of Dementia and Non-Dementia Family Members"

**FY 89**

1. Vinod Kumar, M.D., Southern Illinois University School of Medicine  
"In-Home Care of the Cognitively Impaired Elderly"
2. Daniel Luchins, M.D., University of Chicago  
"PET in the Diagnosis of Presymptomatic Alzheimer's Disease"
3. Israel Hanin, Ph.D., Loyola University of Chicago Stritch School of Medicine  
"Investigation of the Aged AF64A - Treated Rat as an Animal Model for Alzheimer's Disease"
4. Bruce Wainer, M.D., Ph.D., University of Chicago  
"Neural Grafting of Clonal Central Cholinergic and Hippocampal Cell Lines"
5. Clifford Saper, M.D., Ph.D., University of Chicago  
"Chemical Neuroanatomy of Alzheimer's Disease"
6. David Hammond, M.D., University of Chicago  
"A Monolayer Cell Culture System for the Study of Trophic Influences on Cholinergic Neurons"

**FY 88**

1. Mark Gurney, Ph.D., University of Chicago  
"Neuroleukin in Alzheimer's Disease"
2. Israel Hanin, Ph.D., Loyola University of Chicago Stritch School of Medicine  
"Investigation of the Aged AF64A - Treated Rat as an Animal Model for Alzheimer's Disease"
3. Vinod Kumar, M.D., Southern Illinois University School of Medicine  
"In-Home Care for the Cognitively Impaired Elderly"
4. Clifford Saper, M.D., Ph.D., University of Chicago  
"Chemical Neuroanatomy of Alzheimer's Disease"
5. Kathleen Sherman, Ph.D., Southern Illinois University School of Medicine  
"Blood Lymphocytes as a Model for Characterizing the Pathophysiology of Alzheimer's Disease"
6. Gregory Brewer, Ph.D., Southern Illinois University School of Medicine  
"Alzheimer's Disease-Like Changes in Hippocampal Cell Culture Model"
7. Ezio Giacobini, M.D., Ph.D., Southern Illinois University School of Medicine  
"A Preclinical Study of a New Series of Alkaloids Potentially Suitable for Treatment of Memory Disorders and Dementia of Alzheimer Type"
8. Leonard Maroun, Ph.D., Southern Illinois University School of Medicine  
"Human Chromosome 21 Beta - Amyloid and D21511 Genes in Familial and Non-Familial Alzheimer's Disease"
9. Bruce Wainer, M.D., Ph.D., University of Chicago  
"Neural Grafting of Clonal Central Cholinergic Cell Lines"

**FY 87**

1. Steven Leventer, Ph.D., Loyola University of Chicago Stritch School of Medicine  
“Investigation of the Aged AF64A - Treated Rat as a Model for Alzheimer’s Disease”
2. Vinod Kumar, M.D., Southern Illinois University School of Medicine  
“In-Home Care for the Cognitively Impaired Elderly”
3. Kathleen Sherman, Ph.D., Southern Illinois University School of Medicine  
“Blood Lymphocytes as a Model for Characterizing the Pathophysiology of Alzheimer’s Disease: Analysis of Calcium and Cyclic Nucleotide Homeostasis in Down’s Syndrome, Aging, and Alzheimer’s - Type Dementia”
4. Mark Gurney, Ph.D., University of Chicago  
“Neuroleukin in Alzheimer’s Disease”
5. Clifford Saper, M.D. , Ph.D., University of Chicago  
“Chemical Neuroanatomy of Alzheimer’s Disease”