



Texas Council on Alzheimer's Disease and Related Disorders

**2010
Biennial
Report**



2010 Biennial Report of activities
and recommendations in
accordance with the
Texas Health and Safety Code,
Chapter 101, 70th Texas Legislature.

Message from the Chair

Alzheimer's disease is an age-related, progressive and fatal brain disease that manifests itself in problems with memory, thinking, and behavior severe enough to interfere with everyday life. Alzheimer's disease gets worse over time, and as cognitive and functional abilities decline, individuals are rendered totally dependent on others for all of their care.

The Texas Council on Alzheimer's Disease and Related Disorders (Council) is composed of 17 members including 12 voting members who are appointed by the Governor, Lieutenant Governor, and Speaker of the House. Five non-voting members represent the Health and Human Services Commission (HHSC), Department of State Health Services (DSHS), and Department of Aging and Disability Services (DADS).

The Council's work could not be accomplished without the direct support of DSHS staff. Their tireless work is an inspiration and tremendous asset to the Council. The Council members join me in their continued effort to address the burden of this chronic and devastating disease on our Texas citizens and those who care for them.

On behalf of the Council, I am pleased to present the 2010 Biennial Report of activities and recommendations in accordance with the Texas Health and Safety Code, Chapter 101, 70th Texas Legislature. Over the past two years, the Council has had many successes, and a few challenges. This report will detail the highlights of FY 2009 and FY 2010.



Debbie Hanna
Chair

Texas ranks second nationally
in the amount of
uncompensated care
provided by caregivers.

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Alzheimer's disease exacts an enormous toll on individuals, families, the healthcare system, and American businesses.

Executive Summary

Approximately 340,000 Texans are now living with Alzheimer's disease (AD), and that number is expected to increase to 470,000 by 2025.¹ Nationally, Texas ranks third in the number of AD cases and second in the number of AD deaths.¹ Additionally, Texas ranks second nationally in the amount of uncompensated care provided by caregivers.¹ By year end (2010), the direct and indirect costs of AD and other dementias are projected to amount to more than \$172 billion.¹

Alzheimer's exacts an enormous toll on individuals, families, the healthcare system, and American businesses. It is a serious problem affecting many aspects of our society. Until AD can be prevented and/or cured, the impact of this disease will continue to intensify.

The Council's dedicated and experienced members combine their skills in discharging their legislative mandate by:

- Recommending needed action for the benefit of persons with Alzheimer's disease and related disorders and their caregivers.
- Encouraging public and private family support networking systems for primary family caregivers.
- Disseminating information on services and related activities for persons with Alzheimer's disease and related disorders to the medical and health care community, the academic community, primary family caregivers, advocacy associations, and the public.
- Actively participating in and making recommendations to interagency workgroups that promote successful aging for Texans.
- Encouraging research to benefit victims of Alzheimer's disease and related disorders.
- Facilitating coordination of state agency services and activities relating to victims of Alzheimer's disease and related disorders.

During the past two years, the Council made significant progress in its work, including:

- Developing the first-ever Texas state plan on AD.
- Establishing the Texas Alzheimer's Disease Partnership, a group of more than 100 dedicated partners who are committed to working on coordinated, statewide action to address the burden of AD in Texas.
- Expanding partnerships with AD support programs in Texas.
- Extending the reach of AD research into South Texas by adding the University of Texas Health Science Center at San Antonio (UTHSC-SA) to the Texas Alzheimer's Research Consortium.

In collaboration with an extensive network of partners, the Council has identified the following priority issues that require immediate attention during the next biennium:

1. Implement the *2010-2015 Texas State Plan on Alzheimer's Disease*.
2. Support ongoing research efforts to find the causes/risk factors to delay onset, and to prevent and/or cure AD.
3. Advance infrastructure and capacity building efforts in Texas to be commensurate with the state's increasing burden imposed by AD.

Alzheimer's Disease – An Urgent National Health and Research Priority

Significance of Alzheimer's Disease

AD is a progressive, and at present, irreversible brain disorder that is characterized by a steady decline in cognitive, behavioral, and physical abilities severe enough to interfere with daily life. Hallmark symptoms of AD are memory loss, disorientation, and diminished thinking ability followed by a downward spiral that includes problems with verbal expression, analytical ability, frustration, irritability, and agitation. As the disease progresses, physical manifestations include loss of strength and balance, inability to perform simple tasks and physical activities, and incontinence. As more of the brain is affected, areas that control basic life functions like swallowing and breathing become irreversibly damaged, eventually leading to death. The disease's course and progression rate vary from person-to-person, ranging from an average of five to eight years to more than 20 years from the onset of symptoms.

An estimated 5.3 million people are living with AD - 340,000 of those are Texans. It is the seventh leading cause of death in the U.S. and has an economic burden that exceeds \$172 billion annually.¹ Texas ranks third in the number of AD cases and second in the number of AD deaths.¹ A new person develops AD every 70 seconds, and current projections indicate that this rate will increase to one new case every 33 seconds by 2050.¹ In 2009, there were an estimated 10.9 million unpaid caregivers in the U.S., most of who were family members.¹ In Texas, 852,820 unpaid caregivers are providing care to the estimated 340,000 individuals with Alzheimer's - this equates to 971,191,823 hours of unpaid care at a cost of \$11.2 billion per year.¹

The impact of AD presents many challenges. Although AD is not a normal part of aging, it is considered an age-related disorder. AD affects up to 13 percent of people 65 and older and increasing to 50 percent at 85 and older. These rates take on increasing significance when we consider that the U.S. population older than 65 is expected to increase from its present 13 percent to 18 percent by 2025. The number of people 65 and older with AD is estimated to reach 7.7 million in 2030, almost a 50 percent increase from the 5.3 million who are currently affected. By 2050, without prevention or cure, the number of individuals 65 and older with AD is projected to reach between 11 and 16 million. With the first of the 76 million baby boomers reaching 65 in 2011, AD and other age-related diseases will rank among the leading causes of morbidity and mortality. At least 14 million baby-boomers will develop AD or a related disorder in their lifetime, doubling the number of persons with this disease today. This will have significant economic and human ramifications for an already burdened society.

Direct and indirect costs for medical and long-term care, home care, and loss of productivity for caregivers are currently estimated at \$172 billion per year in the U.S.² This figure may be conservative when one considers the results of the Koppel Report, that looked specifically at AD related expenditures by American businesses.³ The report focused on two areas: (1) the cost to businesses for family caregivers, and (2) the business share of health and long-term care expenditures for people with AD. Caregiving costs included absenteeism, productivity losses, and replacement costs of workers who care for loved ones with AD, and were estimated to be \$36.5

billion per year. Additionally, the business share of healthcare for people with AD, plus taxes toward federal funding of AD research were calculated at \$24.6 billion each year. The combined total equals \$61.1 billion annually. The study also compared current figures with a similar study published in 1998, when business expenditures were calculated at \$33 billion for the year.^{2,3} Costs almost doubled in this timeframe. Further, these cost projections were based on the current estimate of Americans who had AD and are projected to rise exponentially with an accelerated growth in the aging population.

Costs to American businesses are staggering, but represent just a portion of total healthcare and long-term care expenditures for AD. They do not, for example, reflect the billions of dollars spent by state and federal governments on Medicare and Medicaid, nor the out-of-pocket expenses incurred by family caregivers. Much of the care provided to individuals with AD is considered custodial care and insurance policies typically do not cover it. What economic value do we assign to the efforts of the millions of informal caregivers who provide long-term care at no charge to their family members?

The human toll on AD patients and the informal network of family and friends in charge of their care is inestimable. Of the more than five million Americans with AD, approximately 76 percent live at home receiving most of their care from family members. Each caregiving experience presents its own special circumstances and challenges. Care provided for a person with AD can be extremely stressful. Caregivers frequently become isolated, over-burdened and depressed. One study noted that a person providing care to someone with dementia is twice more likely to have a significant adverse experience than someone who cares for a person who isn't suffering with dementia.⁴ The same study noted caregivers' frequent need for assistance in both providing direct care and in managing the needs of the person with AD. Caregivers were also found to have more health problems than others at their age because of the physical and emotional demands of caregiving. Caregiving is also known to have negative effects on employment, income and financial security.¹

AD exacts an enormous burden on individuals, families, the healthcare system, and American businesses. It is a serious problem affecting many aspects of our society. Until we can prevent and/or cure it, the impact of Alzheimer's will continue to intensify.

Progress Through Research and Advocacy

Much has been learned about the causes of AD, resulting in a more clearly recognizable clinical pattern. The findings have helped to clarify differences between normal age related memory changes, Mild Cognitive Impairment (MCI), AD and other dementias. MCI involves memory impairments, but with preservation of daily functional ability. AD causes fundamental changes in multiple realms of cognition and behavior, even early in its course. It is this loss of function that defines the transition into AD. Better understanding of the course and presentation of the disease has led to earlier detection and more definitive diagnoses.

Scientists have also identified genetic and biological changes that occur with AD, allowing them to pinpoint possible targets for treatment. Advances in pharmacologic treatment may stabilize and delay progression of AD symptoms. This delay in progression helps contain costs associated with medical and long-term care, eases caregiver burden, and allows the individual with AD the opportunity to participate more fully in life and postpone dependency.

The death of Ronald Reagan and the media coverage of his life and illness, coupled with strong advocacy from AD-related organizations and other stakeholders, put AD in the public eye. Increased public awareness and the demand for elder care services in general has led to proposed increases in national research appropriations, as well as targeted funding for family caregiving programs and services.

The aging population is now dramatically increasing the incidence of AD. This will have significant economic and human ramifications. While other causes of death have been declining in recent years, deaths due to AD have been rising. Between 2000 and 2006, deaths due to heart disease, stroke, and prostate cancer declined by 12 percent, 18 percent, and 14 percent, respectively, whereas deaths attributable to AD increased by 47 percent.¹

Therefore, there is a great need for Texas to develop an infrastructure equal to the challenge and to develop capabilities commensurate with the state's increasing burden imposed by AD and related disorders. This requires developing a greater capacity throughout Texas to reach a position of leadership in the global fight against AD.

Public Health Challenge and Research Priority

AD poses a particular public health challenge and research priority because of its detrimental effects on the individual with AD, families, and the economic system. Each of these effects will be amplified in the wake of a burgeoning aging population. Though strides have been made with AD diagnosis and with symptomatic and disease-modifying AD treatments, there is still a long way to go toward prevention and eventual cure of AD.

Though much progress has been made in making a more accurate diagnosis of AD, significant barriers to early detection still remain. Disease-specific areas of cognitive and functional decline render patients less likely to seek care on their own and reduce their effectiveness as reporters of their overall ability. Many individuals with AD do not recognize that they are impaired. This can range from mild denial of impairment to frank unawareness of the disease. In earlier stages of AD, individuals often mask their symptoms by attributing them to old age and by ordering their environment to provide cues to remember people and events. It is often not until the individual's thinking and behavioral difficulties worsen when family members and friends are alerted to a problem and seek medical help. For those living alone, identification of a problem may be further delayed.

The importance of early detection cannot be underestimated - the earlier the diagnosis, the more likely symptoms will respond to treatment. Additionally, many conditions with dementia-like symptoms may be reversible. Early identification and aggressive treatment of AD and other dementias offer the greatest opportunity for cost decreases through timely reduction in the rate of disease progression. Other benefits to early detection include safety of the individual with AD, opportunities for caregiver education, and advanced planning of personal and legal issues while the affected person can still participate.

Increased support for individuals with AD and their caregivers is imperative. Stakeholders must continue to advocate for community and home-based care and support for caregivers. Costs for formal care for patients in treatment facilities are four times higher than for patients treated in the community.³ With earlier detection and improved treatment strategies, disease progression and probable institutionalization can be delayed. Continued advocacy for case management and caregiver support programs is crucial because these programs afford caregivers the assistance they need to help care for their loved ones at home. Advocacy for these services and identification of new sources of these services becomes more important with discontinuation of the Community Alzheimer's Resources and Education Program in Texas.

Ongoing research efforts to find causes and risk factors, to delay onset, and to prevent and cure AD are imperative. As methodologies are refined, scientists and clinicians will be able to investigate and understand the earliest pathological and clinical signs of AD – perhaps 10 to 20 years before a clinical diagnosis is made. Drug development to block progression of symptoms and eventually prevent AD is critical to decrease disability and death, contain healthcare costs, and protect individuals and families.

Advancing statewide, coordinated action to address AD in Texas has become paramount as the prevalence of the disease continues to climb, exacting huge human and economic burdens on Texas citizens and resources. The recently published *2010-2015 Texas State Plan on Alzheimer's Disease* makes a compelling case for increased and coordinated statewide action and provides a clear roadmap for addressing the significant issues AD imposes on Texas. Implementation of the plan will greatly benefit Texans by guiding the state in its efforts to reduce the burden of AD on our citizens and those who care for them.

Texas Council on Alzheimer's Disease and Related Disorders

Background, Overview, and Activities

Recognizing the growing problem of age-related neurodegenerative diseases, the 70th Texas Legislature passed House Bill 1066 in 1987 (Chapter 101, Texas Health and Safety Code), creating the Texas Council on Alzheimer's Disease and Related Disorders. The Council was established to serve as the State's advocate for persons with AD and their caregivers. Specifically, the Council serves to increase awareness of AD and its impact on Texans, participate as a strategic partner and coordinating body for statewide education and research activities related to AD, and support policies and programs that will benefit people with AD and their caregivers.

Awareness and Education

Toll-Free Hotline

Since its inception in 1987, the Council has worked to develop a growing awareness of the tremendous impact that AD and related disorders have on individuals, families and society. DSHS maintains a toll-free information helpline that receives approximately 2,400 calls per year. Comprehensive information packets are also distributed to the public each month and numerous referrals are made to local community services.

Website

DSHS maintains a website, which contains information about AD, warning signs, diagnosis, treatment, as well as legal and financial issues, options for care, lists of licensed nursing facilities and assisted living facilities certified for AD care, Council meeting agendas and minutes, and helpful toll-free phone numbers and internet links. More than 7,200 consumers visit the website yearly at: www.dshs.state.tx.us/alzheimers/default.shtm.

Biannual Newsletter

The Council, in collaboration with DSHS, produces *Texas Alzheimer's News*, a biannual newsletter, which is mailed to 4,000 nursing facilities, assisted living facilities, adult day care centers, universities, physicians, ombudsmen, and family caregivers. *Texas Alzheimer's News* features research and legislative updates, information on programs and services, and best practices in AD diagnosis, treatment, and care.

Coordinated Statewide Planning

The Council, along with DSHS, began formal work around development of the first, coordinated Texas state plan on AD in March 2009. As AD prevalence continues to climb, exacting huge human and economic burdens on Texas citizens and resources, development of a plan to advance statewide, coordinated action to address this disease in Texas became paramount.

The Texas Alzheimer's Disease Partnership was formed, and met throughout 2009-2010, to develop a five-year strategic blue-print for coordinated statewide action to address AD in Texas. Each plan goal contains targeted steps recommended to comprehensively address AD and its enormous impact on Texans.

In April 2010, the plan was presented to the public, where 125 attendees gathered at the DSHS headquarters in Austin to attend a scientific symposium on AD research, and to learn about the five-year Texas state plan on AD. Public comment was highly supportive of the plan, and meeting participants expressed great interest in working together to implement the plan's recommendations. The plan was officially adopted by the Council, and plan implementation is on target to begin in fall 2010.

Partnership Development

The Council, in its efforts to coordinate, collaborate and support Alzheimer's related services and programs throughout the state, has formed solid partnerships with many service organizations, health organizations, commissions, and agencies.

Council members and DSHS staff serve on boards, advisory and planning committees, guiding the direction and promotion of programs designed to assist individuals with AD and their caregivers. The Texas Caregiver Support Program, Silver Alert Program, and Aging Texas Well Advisory Committee are examples of ongoing collaboration and support.

Most recently, the Council and DSHS formed the Texas Alzheimer's Disease Partnership, comprised of individuals with diverse backgrounds from state, local and community level organizations; academic and research institutions; for-profit non-profit partners; businesses; and the healthcare sector. These partners, with their rich and varied experiences, provided the expertise that created the first Texas AD state plan.

Caregiver Support

The Department of Aging and Disability Services (DADS) and its comprehensive network of 28 Area Agencies on Aging (AAAs) and their local service providers administer the Caregiver Support Program. Under this program, caregiver support services are provided to families to assist them in maintaining their caregiver roles. While AAAs have historically provided support for caregivers, service has been limited in some parts of Texas, especially rural areas. Funding under the National Family Caregiver Support Program has allowed AAAs to expand services to more adequately meet the needs of caregivers in their communities. The program calls for all states, working in partnership with area agencies on aging and local community-service providers, to have five basic services for family caregivers. These include caregiver support coordination, caregiver information services, caregiver education and training, caregiver in-home respite care, and institutional and non-residential support, such as the caregiver's day out program.

For FY 2009 and FY 2010, 95 percent of the funding provided through the National Family Caregiver Support Program was awarded to the State's 28 AAAs to provide direct services and support in the five basic services identified above.

Meeting the challenges of caregiving requires many resources. DADS and its

28 AAAs form a statewide network to provide comprehensive information and services for caregivers. The Council and DSHS assist the Caregiver Support Program by serving as a resource, providing referrals, and marketing the program through the DSHS website and 1-800 telephone helpline.

Advocacy

The Council, in its continued efforts to advocate on behalf of individuals with AD and their families, provides guidance to state agencies on program and policy development. The Council advises HHSC's Pharmaceuticals and Therapeutics Committee on inclusion of AD disease treatment medications to the Medicaid Preferred Drug List.

In the fall of 2008, the Council, in negotiations with the University of Texas System and UTHSC-SA, expanded Texas' research base and capacity by inviting UTHSC-SA to participate as a full member in the Texas Alzheimer's Research Consortium (TARC).

Coordinated Alzheimer's Research

In 2005, the Texas Legislature made history by approving the first state-level appropriation for AD research in the state. Their initial \$2 million investment provided start-up funding for the TARC, a collaborative research effort without precedence in Texas. This legislation directed the Council to establish a consortium of AD centers among four of the state's leading medical institutions: Texas Tech University Health Sciences Center (Texas Tech), University of North Texas Health Science Center (UNTHSC), the University of Texas Southwestern Medical Center at Dallas (UT Southwestern), and Baylor College of Medicine (BCM).

In 2007, the Texas Legislature nearly doubled the state's initial investment in the TARC. This made it possible to recruit 500 Texans with AD and 300 healthy control subjects into the Texas Harris Alzheimer's Study to participate in cutting edge biomedical research. Participants regularly undergo a battery of tests and provide blood and DNA samples annually at TARC member sites. The resulting uniformly collected clinical, neurocognitive and laboratory data is combined in the centralized Texas Alzheimer's Data Bank, based at UT Southwestern. TARC has also established the first Texas bio-bank of stored blood, tissue and DNA to support current and future AD research studies. Researchers across the state are able to utilize these unique Texas resources to answer specific questions about AD, both now and in the future, as new information leads to new ideas.

In September 2008, the Council voted to add UTHSC-SA to TARC. This move, coupled with the 2009 state appropriation of \$6.85 million, enabled TARC to begin including a large number of Hispanic individuals into the Texas Harris Alzheimer's Study and extended TARC's reach to South Texas. Inclusion of underrepresented Hispanics significantly strengthens AD research efforts in Texas and the nation. One third of Texans are Hispanic, and according to the Texas State Data Center, Texas will become a majority Hispanic state between 2025 and 2035. With this sizeable Hispanic population, Texas is uniquely positioned to assume a national leadership role in this largely untapped area of AD research.

TARC's Current Research Objectives

Capitalizing on their progress to date, TARC researchers are aggressively pursuing a number of important cutting-edge research objectives aimed at 1) improving efficiency of early diagnosis, 2) clarifying disease mechanisms, and 3) enabling more effective disease prevention. In the current biennium (September 2009– August 2011), TARC has been and will continue working on:

- Development of a serum protein-based tool for predictive AD diagnosis. A blood-based test for detecting AD will allow for earlier and more accurate detection of Alzheimer's. Because of the length of time that Alzheimer's develops prior to onset of symptoms, early diagnosis can greatly benefit development of new treatment therapies and perhaps lead to improved methods to delay or prevent AD onset.
- Discovery of new genes associated with the development of AD. The discovery of new genes associated with Alzheimer's risk is likely to lead to the development of new drugs and therapies that will improve the quality of life of patients with Alzheimer's and ultimately prevent this devastating disease.
- Discovery of genetic variants within inflammatory genes associated with AD development. Identification of inflammatory genes associated with AD will allow for discovering treatments aimed at reducing chronic inflammation levels. Since a number of FDA-approved anti-inflammatory drugs are currently on the market, rapid and effective progress may be made in this arena if inflammatory genes are identified as important AD risk factors.
- Evaluation of the roles of altered cholesterol and insulin metabolism in development of AD. If cholesterol and altered insulin metabolism are shown to be important Alzheimer's risk factors, therapies aimed at moderating these factors may be indicated.
- Resolution of the relationship between cardiovascular risk factors, inflammation and AD. Identification of inflammation as the key trigger resulting in cardiovascular risk factors increasing the risk for Alzheimer's will enable physicians to prescribe more effective heart disease medications to help prevent or delay AD onset.
- Evaluation of the roles of key cardiovascular risk factors in AD development and progression. If elevated blood levels of homocysteine or Lp-PLA2 (two key markers of cardiovascular disease risk) are shown to be important Alzheimer's risk factors, therapies aimed at moderating these factors may be indicated.
- Evaluation of depression and depressive symptoms at various stages of cognitive decline. Research results would allow clinicians to more accurately predict risk for depression among their patients with AD who are at various stages of cognitive decline.

TARC's research activities are reviewed by an external advisory committee of national leaders in Alzheimer's research to assure that TARC adheres to the highest quality research standards and pursues a direction with the greatest potential to break new grounds in AD research.

TARC Achievements

TARC has enrolled over 1,100 participants into the Texas Harris Alzheimer's Study, including 685 patients with a primary diagnosis of AD, 421 cognitively normal individuals and 53 subjects with MCI. These numbers include 94 Hispanic individuals who were enrolled at UT Health Science Center at San Antonio. Given this impressive success and current patient accrual rates, TARC is on track to meet the target of 1,172 active subjects by August 2010 and over 1,400 subjects by August 2011.

TARC researchers have been highly productive, not only in regard to producing cutting-edge data, but by reporting important scientific discoveries. More than a dozen important manuscripts have been published in the past three years that describe:

- Novel tools to help doctors more accurately diagnose AD. TARC researchers have recently developed a novel blood test for Alzheimer's that uses state-of-the-art micro-array analysis of serum proteins to predict disease risk. A National Institutes of Health grant is under review that proposes to validate the ability of this blood test to diagnose AD in an independent group of samples and assess whether this test can predict disease progression as well as discriminate between non-AD forms of dementia. This discovery was recently published in the September 2010 Issue of the Archives of Neurology.⁵
- Methods to better track disease progression. TARC researchers documented a simpler, more accurate method to measure smaller incremental changes in dementia progression through use of an alternative score for measurement of cognitive ability. Owing to the increased range of values, the new score offers several advantages over the previous version, including increased utility in tracking changes within and between stages of dementia severity.
- Associations between inflammation and mental performance. TARC researchers discovered that a pattern of inflammatory proteins exist in AD and is a powerful mediator of cognitive impairment and rate of disease progression. This pattern offers preliminary evidence of one possible biological pathway for cognitive and functional decline among a subgroup of individuals and has direct therapeutic implications.

An Early Return on the State's Investment

Texas-based AD research continues to benefit the state in many ways, such as:

- **Advances in detection.** Using a multidisciplinary/translational approach, that includes blood biomarkers, genetic material, imaging and neurocognitive data, as well as psychological, neuropsychological, behavioral and general medical information, Texas researchers are working to develop new methods for early detection of AD.
- **Ability to predict risk.** Recruitment and follow-up of normal elders along with AD patients will enable scientists to better understand factors leading to increased disease risk. TARC researchers have begun this process by looking at information on biomarkers, lipid metabolism, genetics and clinical testing as they relate to the disease. However, many more factors remain to be examined. Early identification of AD risk will make it possible to create therapies to prevent or delay onset of disease.
- **Better tracking of AD progression.** By leveraging Texas' medical and university infrastructure, Texas-based scientists can identify individual differences among patients that influence the rate of disease progression. Data gathered from these studies will help identify new therapies to slow progression and improve quality of life in patients with AD.
- **The best in personalized medicine.** Texas scientists can use advances created by these Texas-based research initiatives to develop new treatments that address a patient's individual AD "profile," as defined by specific genetic, blood biomarkers and general medical, behavioral, psychiatric, and other risk factors.
- **Advances in basic science.** While great progress has been made, researchers are still searching for definitive answers to questions about the basic mechanisms of AD. Advancing greater understanding of these mechanisms through basic research can benefit Texas by expanding the pipeline of scientific discovery and identifying additional targets for treatment.

FY 2011-2012 Council Recommendations

As the state's appointed advocate for persons with AD and their caregivers, the Council respectfully submits the following recommendations:

Coordinated Statewide Alzheimer's Research

The Council requests continued recognition and support of coordinated statewide research demonstrated by the Texas Legislature when it passed House Bill 1504, 76th Legislature, 1999, (Chapter 154 of the Texas Education Code) establishing the Texas Consortium of Alzheimer's Disease Centers (TARC). TARC provides Texas with an infrastructure for sharing vital AD research information and clinical outcomes. It provides a framework for expanding and expediting the search for answers about the causes, methods to delay onset and stop disease progression, and eventual prevention and cure of AD.

Continued Support for Quality Long-Term Care

The Council supports maintaining current levels of nursing facility eligibility for people with cognitive impairments, specifically AD and other dementias. The Council requests maintenance of Resource Utilization Groups (RUGS), based on level of need, to accommodate higher levels of reimbursement for facilities that care for persons with cognitive impairments.

Expanded Community-Based Programs and Services

The Council supports expansion of home and community-based programs and services for individuals with AD and their caregivers. Family caregivers provide the vast majority of care provided to people with AD. The Council supports expanded availability of affordable respite care, training for caregivers, and other resources to maintain the integrity of the family caregiving system. Elimination of the Community Alzheimer's Resources and Education program left a significant gap in these services for families who need them most. Expanded resources will provide much needed additional services to assist families in caring for their loved ones with AD.

Coordinated Statewide Plan Implementation

The Council supports advancing statewide, coordinated action to address AD as outlined in the recently published *2010-2015 Texas State Plan on Alzheimer's Disease*. This plan provides realistic and thoroughly achievable actions and strategies to be implemented over the next five years, and makes a compelling case for increased action that calls for coordination among all partners. With coordinated, strategic action, Texas will assume a leadership role in comprehensively addressing the current and future burden of AD disease in Texas and the nation.

Continued support for and investment in coordinated statewide research, quality long-term care, expanded community-based programs and services, and coordinated statewide plan implementation offer the best return on investment in containing the economic and human costs of AD.

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Appendix B

The *2010-2015 Texas State Plan on Alzheimer's Disease* was developed in direct response to increasing rates of Alzheimer's disease. Plan objectives provide specific recommendations for addressing the burden of this devastating disease on Texans and those who care for them. Ongoing coordination, information and resource sharing, partnership development, and capacity building are essential for creating a sustained and resourced state-wide system to promote and advance recommendations of this plan.

Goals of the Plan:

- Goal I: Texas will support Alzheimer's disease research.**
- Goal II: Texans will experience improved cognitive health throughout their life spans.**
- Goal III: Texans with Alzheimer's disease will experience improved quality of life through better disease management.**
- Goal IV: Caregivers will experience enhanced levels of support through improved access to Alzheimer's disease/dementia care information and services.**
- Goal V: Texas will improve state and local capacity to address Alzheimer's disease.**

Call to Action:

Understanding the current and future impact of Alzheimer's disease in Texas and working collaboratively to implement the *2010-2015 Texas State Plan on Alzheimer's Disease* is a pressing charge that cannot be taken lightly. Partners and stakeholders at local, state and regional levels are called upon now to adopt and incorporate activities outlined in this plan. By working together on a unified set of ambitious but thoroughly realistic and achievable goals and objectives, the effect of Alzheimer's disease across the state can be reduced and the quality of life of Texans with Alzheimer's disease and their families can be improved.

Telephone and Web Resources

ALZHEIMER'S ASSOCIATION

1-800-272-3900

Information on Alzheimer's disease, care, support, and research.

www.alz.org

- Comprehensive Alzheimer's disease information for family caregivers, healthcare providers, researchers and the media on risk factors, diagnosis and treatment options; day-to-day care; legal and financial planning; insurance coverage; current research; and Association news releases.

www.alz.org/findchapter.asp

- Links to local chapters for available programs and services.

ALZHEIMER'S DISEASE AND MEMORY DISORDERS CENTER BAYLOR COLLEGE OF MEDICINE

1-713-798-4734

Clinical and basic science research; education; and diagnosis and treatment of patients with Alzheimer's disease and related disorders.

www.bcm.edu/neurology/admdc

- Drug trials; research projects; brain donation program; patient appointments and evaluation; and Alzheimer's disease information.

ALZHEIMER'S DISEASE CENTER THE UNIVERSITY OF TEXAS SOUTHWESTERN MEDICAL CENTER

1-214-645-8800

Scientific research into the causes of Alzheimer's disease; and diagnostic evaluation of adult memory problems.

www.utsouthwestern.edu/utsw/cda/dept23589/files/46161.html

- Clinical research studies; patient evaluation process; newsletters; educational events; and caregiver resources.

ALZHEIMER'S DISEASE EDUCATION AND REFERRAL (ADEAR) CENTER

1-800-438-4380

Provides current and comprehensive Alzheimer's disease information and resources from the National Institute on Aging.

www.nia.nih.gov/alzheimers

- Research updates; directory of National Institute on Aging Alzheimer's Disease Centers; clinical trials database; recommended reading list for caregivers; and press releases.

MEDICAID HOTLINE

1-800-252-8263

Toll-free number for general information and counseling on Medicaid.

www.hhsc.state.tx.us/medicaid

- General information on the Texas Medicaid program.

Appendix D

**CENTERS FOR MEDICARE
AND MEDICAID SERVICES**

1-800-633-4227

National toll-free number for general information and counseling on Medicare.
www.cms.gov

- Official U.S. government site for information on Medicare/Medicaid eligibility, enrollment, and premiums.
- Search tools for state-specific information on health plan choices; nursing home comparisons; prescription drug programs; participating physicians; and plan coverage.

**OFFICE OF THE ATTORNEY GENERAL
CONSUMER PROTECTION DIVISION**

1-800-621-0508

Register complaints against businesses; report senior fraud.
www.oag.state.tx.us/consumer/index.shtml

- Senior Texans' information on consumer protection; rights of the elderly; choosing a nursing home; advance planning; health and safety; and Senior Alerts.

**TEXAS ALZHEIMER'S
RESEARCH CONSORTIUM**

1-512-925-3320

Information about state-funded collaborative Alzheimer's disease research at participating Texas medical schools and health science centers.
www.txalzresearch.org

- Latest research publications by TARC researchers, press releases, a history of state involvement in Alzheimer's disease research, and a resource list for Alzheimer's disease patients and their caretakers.

**TEXAS DEPARTMENT
OF AGING & DISABILITY SERVICES**

1-512-438-3011

Information on long-term aging and disability services.
www.dads.state.tx.us

- Administers long-term services and supports for people who are aging and who have cognitive and physical disabilities. Also licenses and regulates providers of these services, and administers the state's guardianship program.

AREA AGENCIES ON AGING

1-800-252-9240

Services to help older Texans, their family members and caregivers obtain information and assistance for locating and accessing community services.
www.dads.state.tx.us/contact/aaa.cfm

- Information on services for persons 60 years of age and older. Services include healthcare benefits counseling; case management; nutrition services; transportation; in-home help; senior centers; and the Retired Senior Volunteer Program (RSVP).

LONG TERM CARE OMBUDSMAN PROGRAM 1-800-252-2412

Advocates for quality of life and care for residents in nursing homes and assisted living facilities.

www.dads.state.tx.us/news_info/ombudsman/index.html

- Identifies, investigates and resolves complaints made by, or on behalf of, residents and provides services to help in protecting the health, safety, welfare and rights of long term care consumers. Provides information and assistance in choosing the most appropriate living residence.

CONSUMER RIGHTS AND SERVICES

Takes complaints about the treatment of people who receive services in long-term care facilities or in their homes.

www.dads.state.tx.us/services/crs/index.html

- Information for consumers and providers on different types of long-term care facilities; quality ratings and comparisons; how to file a complaint about a facility; and provider training opportunities.

CAREGIVER SUPPORT PROGRAM

Identifies care support services for aging individuals.

www.dads.state.tx.us/services/caregiver.html

- In-home and community-based services for individuals who are elderly or disabled, allowing them to remain in their own homes or communities.

LEGAL HOTLINE FOR OLDER TEXANS 1-800-622-2520

- Legal assistance including counseling, representation, and document preparation.

TEXAS DEPARTMENT OF INSURANCE 1-800-252-3439

Information, counseling, and filing complaints against private insurance providers.

www.tdi.state.tx.us/consumer/hicap/hicaphme.html

- Health information, counseling and advocacy; insurance fraud; and publications for seniors.

TEXAS DEPARTMENT OF STATE HEALTH SERVICES 1-800-252-8154

DIVISION FOR MENTAL HEALTH/SUBSTANCE ABUSE SERVICES

Consumer rights for mental health protection.

www.dshs.state.tx.us/mhservices/MHConsumerRights.shtm

- Community programs, services and standards.

**TEXAS DEPARTMENT OF PROTECTIVE
AND REGULATORY SERVICES**

1-800-252-5400

Takes and investigates reports of abuse, neglect, or exploitation of children, the elderly, and/or people with disabilities.

www.dfps.state.tx.us/

- Services for children, adults, and people with disabilities, including investigation of reports of abuse, neglect, and exploitation at home or in facilities licensed by state agencies; and arranging for protective services. Protective services may include referral to other programs; respite care; guardianship; emergency assistance with food, shelter, and medical care; transportation; and counseling.

**TEXAS TECH UNIVERSITY HEALTH
SCIENCES CENTER**

1-817-735-2506

Scientific research on Alzheimer's disease and aging; patient evaluation and care through their many clinics; and geriatric and long-term care education through the Garrison Institute on Aging.

www.ttuhs.edu/centers/aging/vision.aspx

- Garrison Institute on Aging; DNA Bank; and patient care/clinical services for Alzheimer's disease and Parkinson's disease.

**UNIVERSITY OF NORTH TEXAS HEALTH
SCIENCE CENTER**

1-817-735-5440

Scientific research and clinical trials on Alzheimer's disease and aging; patient evaluation and care through clinics, including a specialty Memory Clinic; and geriatric education.

www.hsc.unt.edu/research/default.cfm

- Clinical trials; research; patient education and care.



Texas Department of State Health Services
Alzheimer's Disease Program
1100 West 49th Street
Austin, Texas 78756
1-800-242-3399
www.dshs.state.tx.us/alzheimers/default.shtm