

Texas
Council on
Alzheimer's
Disease
and
Related
Disorders

2008
Biennial
Report

M

essage from the Chair

On behalf of the Texas Council on Alzheimer's Disease and Related Disorders, I am pleased to present our 2008 biennial report of activities and recommendations. Over the past two years, the Alzheimer's Disease and Related Disorders Program has had many successes, and a few challenges. This report will detail the highlights of FY 2007 and FY 2008.

Alzheimer's Disease (AD) is an age-related, degenerative brain disorder that manifests itself in problems with memory, thinking, and behavior severe enough to interfere with everyday life. Over time, as cognitive and functional abilities decline, individuals with AD are rendered dependent on others for all of their care. Bodily functions eventually shut down and they succumb to death.

There is growing concern among the public about AD, with very good reason. The likelihood of developing AD increases with age. At present, there are approximately five million Americans and 280,000 Texans who have been diagnosed with AD. With the first of the 76 million baby boomers reaching age 65 in 2011, AD and other age-related diseases will increase dramatically. The National Alzheimer's Association estimates that at the current rate 552,000 Texans will have AD by 2025, and 14 million Americans will have AD by 2050 in the absence of prevention or cure.

The imminent surge in the number of people with AD poses particular challenges and opportunities to Alzheimer's professionals and advocates. For example:

- Clinicians are challenged to identify and treat individuals with AD at the earliest stages of the disease to delay its progression. Aside from prevention and cure, this strategy offers the best opportunity to contain healthcare costs and help persons with AD remain independent for longer periods.
- Researchers are challenged to work towards Alzheimer's prevention and cure, but also to find ways to delay the onset of symptoms until later in the life span. People may live with a diagnosis of AD longer but with less disability and more independence.

The National Alzheimer's Association estimates that at the current rate, 552,000 Texans will have AD by 2025, and 14 million Americans will have AD by 2050.

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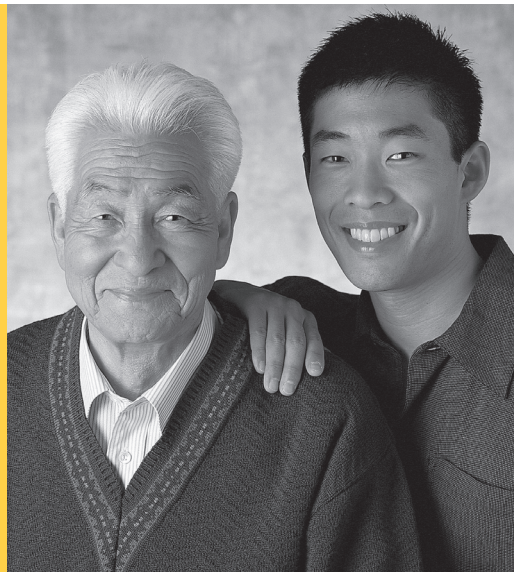
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- AD stakeholders must take every opportunity to advocate for programs and services to support individuals with AD and family caregivers. Continued funding of home and community-based services will sustain the family caregiving system, and contain costs by keeping individuals at home. Increasing reimbursement rates to long-term care providers to elevate staffing levels, improve wages and benefits, and add dementia training will help assure the availability and quality of long-term care.

AD is clearly a growing national and international health problem. Investing in research, programs that support individuals with AD and their caregivers, and improving the quality of long-term care is critical as we work toward ending this devastating disease.

Debbie Hanna
Chair

Alzheimer's Disease

An Urgent National Health and Research Priority

Significance of Alzheimer's Disease

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 everyday life and necessitate full time care. The hallmark symptoms of memory loss, disorientation, and diminished thinking ability follow a downward spiral to include 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 diminished bladder and bowel control. As more and more of the brain is affected, areas that control basic life functions like swallowing and breathing become irreversibly damaged, eventually resulting in death. The course of the disease and the rate of decline will vary from person to person, ranging from an average of eight years to more than 20 years from the onset of symptoms.

An estimated five million Americans currently have AD. With the aging of the U.S. population, the number of those with AD is increasing rapidly and is projected to exceed 14 million by 2050. An estimated 280,000 Texans have AD with a projected 552,000 expected by 2025.

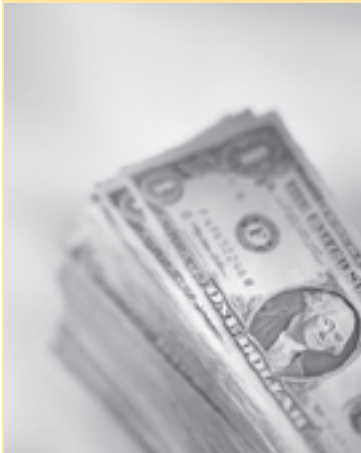
Although AD is not a normal part of aging, it is considered an age-related disorder, affecting up to 10 percent of people at age 65 and increasing to 50 percent at age 85 and older, although some people have been diagnosed with the disease as young as their 30's or 40's. These prevalence rates take on 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. 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. Alzheimer's is already the seventh leading cause of death and the third leading cause of disability in Texas. This has significant economic and human ramifications for an already burdened society.

Direct and indirect costs, for example, medical and long-term care, home care, and loss of productivity for caregivers, are currently estimated at \$148 billion per year in the U.S. This figure may be conservative when one considers the results of a 2002 report commissioned by the National Alzheimer's Association that looked specifically at AD-related expenditures by American businesses.¹ 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 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.

¹ Koppel, Ross, Alzheimer's Disease: Cost to U.S. Business in 2002, Alzheimer's Association; June 2002.

Direct and indirect costs for medical and long-term care, home care, and loss of productivity for caregivers are currently estimated at \$148 billion per year in the U.S.



with AD. Caregiving costs include absenteeism, productivity losses, and replacement costs of workers who care for loved ones with AD, and are 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 are calculated at \$24.6 billion each year. Combined, this equals \$61.1 billion annually in the costs to businesses. The study also compares current figures with a similar study published in 1998, when business expenditures were calculated at \$33 billion for the year.ⁱⁱ Costs have almost doubled in this timeframe. These costs will rise exponentially with an accelerated growth in the aging population.

The costs to American businesses are staggering, but they 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 these expenses. 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 five million Americans with AD, approximately 70 percent live at home, receiving most of their care from family members. While each caregiving experience presents its own special circumstances, a 1997 national survey conducted by the National Alliance for Caregiving and the American Association of Retired People (AARP) pointed out the unique challenges faced by those providing care for individuals with AD.ⁱⁱⁱ Typically, AD caregivers provide more help with activities of daily living, are more likely to report physical and emotional stress, and experience considerable financial strain.

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

Progress Through Research and Advocacy

Much has been learned about the pathophysiologic basis 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.

ⁱⁱKoppel, Ross, Alzheimer's Cost to U.S. Business, Alzheimer's Association; 1998.

ⁱⁱⁱFamily Caregiving in the U.S. Findings from a National Survey, National Alliance for Caregiving and AARP; June 1997

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 the 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 the Alzheimer's Association and other stakeholders have put AD in the public eye. Increased public awareness and the demand for elder care services in general has led the Senate Appropriations Committee to recently propose an increase in the national appropriation for AD research, as well as funding for family caregiving programs and services.

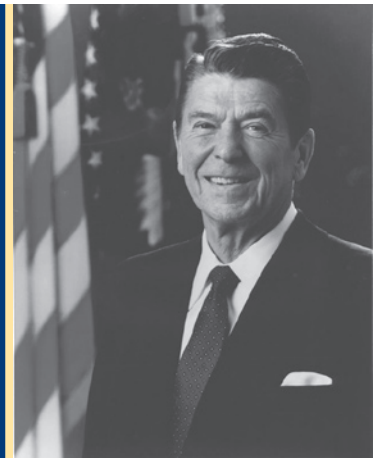
Public Health Challenge and Research Priority

AD poses a particular public health challenge and research priority because of its detrimental effects on the individual, 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 in AD diagnosis and in symptomatic and disease-modifying treatments, there is a long way to go toward prevention and eventual cure.

Though much progress has been made in arriving at a differential diagnosis of AD, there remain significant barriers to early detection. 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 the disease, 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 intensify that 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 over emphasized. The earlier the diagnosis, the more likely symptoms will respond to treatment. Additionally, many conditions with dementia-like symptoms are 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 paramount. Stakeholders must continue to advocate for community



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Early

Detection

Increased

Support

Ongoing

Research

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.^{iv} 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. Advocating for these services and identifying new sources for these services become more important in light of the loss of the Community Alzheimer's Resources and Education Program (CARE) in Texas in 2003.

It is imperative to support ongoing research efforts to find the causes and risk factors to delay onset and to prevent and cure AD. As methodologies are refined, scientists and clinicians will be able to investigate and understand the very 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 morbidity and mortality, contain healthcare costs, and protect individuals and families.



Texas Council on Alzheimer's Disease and Related Disorders

Background and Overview

Having the foresight to realize the imminent 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 (Council). 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.

The Council is composed of 17 members who are appointed by the Governor, the Lieutenant Governor, and the Speaker of the House. There are five public members, seven professional members, and five members representing the Health and Human Services Commission (1), Department of State Health Services (2) and Department of Aging and Disability Services (2).

Council Activities

Awareness and Education

Toll Free Hotline

Since its inception, the Council has worked to develop a growing awareness of the tremendous impact that AD and related disorders have on individuals, families and society. Texas Department of State Health Services (DSHS) staff who support the Council and its work, also maintain a toll-free information line that receives over 200 calls each month. More than 100 comprehensive information packets are disseminated to the public each month and numerous referrals are made to local community services.

Website

DSHS staff also maintains a website, which contains general information about AD-warning signs, diagnosis, and treatment—as well as legal and financial issues, options for care, lists of licensed nursing facilities

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Summer 2004

alzheimer's association

Texas Alzheimer's News

A collaborative effort of the Alzheimer's Association Coalition of Texas and the Texas Council on Alzheimer's Disease and Related Disorders

Medicaid Implements Preferred Drug List

Brett Spencer

As mandated by the 78th Legislature (HB 2202), Texas Medicaid Program has established and is incrementally implementing a preferred drug list (PDL). This list will identify drugs in each class of medications that can be prescribed without prior Medicaid approval.

The state has established the Texas Pharmaceutical and Therapeutics (P&T) Committee to decide the drugs to be included in each class. This committee is made up of physicians and pharmacists selected by the governor to make recommendations to the state regarding whether a particular drug is safe, effective, and should be included on the PDL.

The P&T Committee has been very receptive to input from both the Alzheimer's Association Coalition of Texas (AACT) and the Texas Council on Alzheimer's Disease and Related Disorders. The AACT authored a letter recommending that the class of drugs in

which Alzheimer's medications would be included should be listed "Alzheimer's Treatment Drugs" as opposed to "Cholinesterase Inhibitors". This change in language would better accommodate the new Alzheimer's treatment drug, memantine (Namenda). The Committee listed the class "Alzheimer's Agents".

The Texas Council on Alzheimer's Disease and Related Disorders authored a letter to the P&T Committee to give specific recommendation that all five of the current Alzheimer's treatment drugs be included in the Alzheimer's Agents drug class. Additionally, the Council recommended that all drugs developed in the future and shown to be effective, be included on the PDL.

The Committee included all of the drugs except Cognate, which sometimes causes significant side effects. This drug may still be prescribed with prior approval.

For additional information regarding the PDL, see the HHSIC website:

http://www.hhsic.state.tx.us/hctv/dv/pdpdl_Program.html



Texas Alzheimer's News

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and assisted living facilities certified for the care of individuals with AD and helpful toll-free phone numbers and internet links. More than 600 consumers visit the website each month at www.dshs.state.tx.us/alzheimers/default.shtm.

Biannual Newsletter

The Council, in collaboration with the Alzheimer's Association Coalition of Texas, produces the 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 the diagnosis, treatment, and care of individuals with AD.

Biennial Conference

The Council sponsors a biennial Alzheimer's conference for healthcare providers, state and local public health workers, staff from nursing and assisted living facilities, social workers, family caregivers, and others.

The Council and DSHS extend their appreciation to the following organizations for making the 2007 Texas Conference on Alzheimer's Disease and Care: Building the Future/Bridging the Gap—A Practical Approach to Alzheimer's Research a tremendous success: Conference Planning Committee, Alzheimer's Association - Capital of Texas Chapter, Bureau of Speakers, Texas Public Health Association, and the Omni Austin Hotel Downtown.

The conference was held in Austin, Texas, from August 23 through 25. There were approximately 200 attendees from Texas and across the United States. The program focused on current AD research and its potential to impact the lives of AD patients and their families. The conference received excellent evaluations.

Additionally, we thank the conference sponsors and exhibitors. Forrest Pharmaceuticals, Inc. and PamLab, L.L.C. sponsored the conference. The exhibitors included Alzheimer's Prevention Foundation; AseraCare; Central Texas Regional EMS; Eisai, Inc.; Harris County Area on Aging; Services for the Elderly, Inc.; Texas Department of State Health Services - Adult Health and Chronic Disease Group; Texas Department of State Health Services - Alzheimer's Disease Program; Texas Public Health Association; and Texas Tech University Health Sciences Center - The Garrison Institute on Aging.

The speaker presentations from the conference may be found at: www.dshs.state.tx.us/alzheimers/default.shtm.

Partnerships with Alzheimer's Support Programs across Texas

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, including the Alzheimer's Association, the Health and Human Services Commission (HHSC), and the Texas Department on Aging and Disability Services (DADS). Council members and DSHS staff serve on advisory and planning committees, guiding the direction and promotion of programs specifically designed to assist individuals with AD and their caregivers. The Texas Family Caregiver Support Program is an example of Council collaboration and support.

Texas Family Caregiver Support Program

DADS and its comprehensive network of 28 Area Agencies on Aging (AAA) and their local service providers administer the Texas Family Caregiver Support Program. Persons served under this program include individuals ages 60 and older, individuals who care for persons 60 and older, and grandparents caring for children younger than 18.

While AAAs historically have provided support for caregivers, service has been limited in some areas of the state. Funding under the National Family Caregiver Support Program has allowed AAAs to expand services to more adequately meet the needs of caregivers in their community.

Conversations with caregivers across the country have identified these five needed components of a caregiver support program:

1. Inform caregivers about available services
2. Help them identify and access the services of care coordination and benefits counselors
3. Provide caregivers with individual counseling, education, support group organization, and training to help them make informed decisions and solve problems
4. Provide respite care for family caregivers
5. Offer supplemental services to complement those provided by caregivers (e.g., nutrition, transportation, and health maintenance advising)

During FY 2007 and 2008, 95 percent of the funding provided through the National Family Caregiver Support Program went directly to the State's 28 AAAs to provide direct services and support in the five areas identified above.



Texas lawmakers made history in 2005 by approving the first state-level appropriation for Alzheimer's research in the nation. Their \$2 million investment provided start-up funding for the Texas Alzheimer's Research Consortium (TARC), a collaborative research effort without precedence in Texas.

The remaining five percent was used to fund five state-level initiatives:

1. A state caregiver support coordinator to manage the development and coordination of caregiver services and resources statewide
2. Community capacity-building grants to enhance the infrastructure of caregiver services and support
3. Research related to the specific needs of caregivers, racial and ethnic differences in caregiving, and decisions caregivers make in using community resources and services
4. Training and consultation for individual caregivers and AAA benefits counselors in the areas of finance, guardianship, advance directives, and other caregiving issues
5. Development of educational materials related to health, safety and well-being of both caregivers and care recipients

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 Texas Family Caregiver Support Program by developing educational materials for care recipients and caregivers, and marketing the program through its newsletter, website, and referrals.

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. In 2006, the Council authored a letter to the HHSC Pharmaceuticals and Therapeutics Committee recommending that all five of the current Alzheimer's treatment drugs be included on the Medicaid Preferred Drug List.

Coordinated Alzheimer's Research

Texas lawmakers made history in 2005 by approving the first state-level appropriation for Alzheimer's research in the nation. Their \$2 million investment provided start-up funding for the Texas Alzheimer's Research Consortium (TARC), a collaborative research effort without precedence in Texas. It teams four of the State's leading medical research institutions on projects that will lead to better diagnosis, treatment, and ultimately prevention of this devastating disease.

The Consortium includes Baylor College of Medicine, Houston; Texas Tech University Health Sciences Center, Lubbock; University of North Texas Health Science Center, Fort Worth; and The University of Texas Southwestern Medical Center, Dallas.

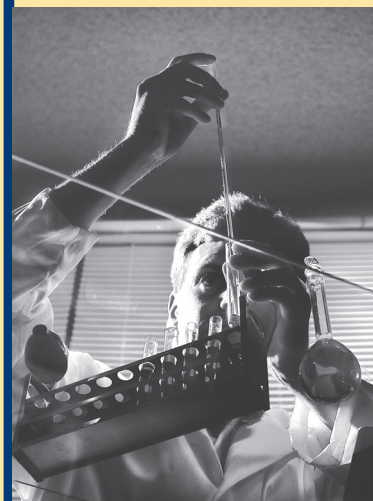
In 2007, the Texas Legislature nearly doubled the state's initial investment in TARC, making it possible to recruit 500 Texas Alzheimer's patients and 300 healthy control subjects to participate in cutting edge research. These volunteers, who must meet well-defined criteria to participate, undergo a battery of tests and provide blood and DNA samples annually at one of the four TARC sites. The resulting wealth of uniformly collected clinical, neuropsychological and laboratory data is combined in the new centralized Texas Alzheimer's DataBank, based at UT Southwestern Medical Center. Researchers can utilize this unique Texas resource to answer specific questions about AD as information leads to new ideas. The Consortium also has used state funding to establish the first Texas bio-bank of stored blood tissue and DNA data to support current and future Alzheimer's research studies.

TARC'S Current Research Objectives

In the current biennium (September 2007-August 2009), TARC has been and will continue working to:

- Identify novel genes, not previously suspected to be related to the origin and development of AD, which may explain the widely observed differences in age at onset
- Identify polymorphisms (variations in genetic content) related to inflammatory function that are associated with age of onset of AD.
- Test the hypothesis that patients diagnosed with AD will demonstrate a significantly different inflammatory profile relative to healthy controls, and that the profile of elderly controls may change over time, increasing their risk for AD.
- Test the hypothesis that inflammation mediates the relationship between cardiovascular disease and AD.
- Test the hypothesis that levels of Lp-PLA2 and homocysteine (substances in the blood already linked to increased risk of stroke and coronary disease) are associated with development and progression of AD.
- Test the hypothesis that clinical and biological markers for chronic hyperinsulinemia (Body Mass Index, concurrent diabetes, insulin, HbA1c, c-peptide) are associated with cognitive performance.
- Identify a biomarker panel that simultaneously takes into account biomarkers of inflammation, genome-wide allelic association analyses, and clinical markers of cardiovascular disease that can function as a valid diagnostic and prognostic tool for AD. [3, 4]

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

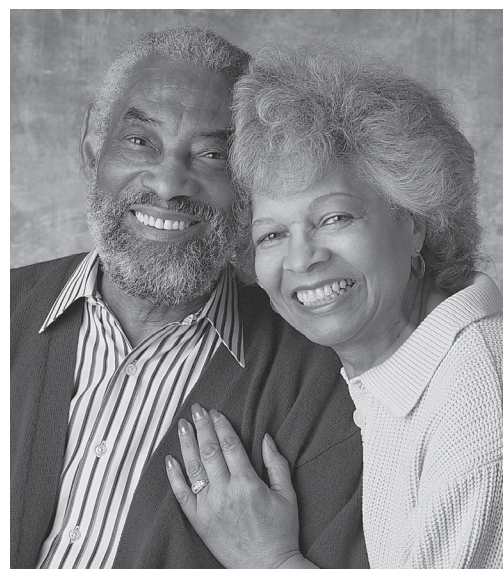


Texas is already benefiting from its investment in Alzheimer's research. TARC researchers are close to developing an improved means of determining whether or not a patient has AD.

An Early Return on the State's Investment

Texas is already benefiting from its investment in Alzheimer's research. TARC researchers are close to developing an improved means of determining whether or not a patient has AD. Also, because TARC is simultaneously following AD subjects as well as elderly control subjects who do not yet have AD, it will be able to identify a risk profile for the disease, which may make it possible to initiate early therapies to delay onset.

Also, the State's investment in the TARC is leading to better tracking of Alzheimer's progression. TARC's capacity to examine large numbers of Alzheimer's patients over time means that Texas researchers are in a position to identify the differences between patients that control the rate of disease progression – leading to new ideas about therapies to slow progression and improve patient quality of life. Biomarkers of disease progression, once replicated, could be used in clinical trials to tell whether or not a therapy is working in early stages of development, saving time and money in the drug development process.



Council Recommendations 2009-2010

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 the 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 Consortium of Alzheimer's Disease Centers (Consortium). The Consortium 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 cause(s), 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 AD. Specifically the Council requests maintenance of TILE codes 210 and 211 and/or work to redefine the TILE classes to accommodate a higher level of reimbursement for facilities that care for persons with dementia. If AD were not covered by TILE, people with AD would not qualify for Medicaid nursing facility placement unless they had another co-existing medical condition or until they became medically frail.

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. The elimination of the Community Alzheimer's Resources and Education (CARE) program left a significant gap in these services for the families who need them most. The Alzheimer's Association continues to provide services throughout Texas, but expanded resources would provide additional services to assist families in caring for their loved ones with AD.

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

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Appendices

Texas Council on Alzheimer's Disease
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2007 Member Roster

A

Texas Council on Alzheimer's Disease
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Texas Council on Alzheimer's Disease
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2007 Conference Planning Committee

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Texas Alzheimer's Research
Consortium Steering Committee

D

Helpful Telephone Numbers and Websites

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Appendix A

Texas Council on Alzheimer's Disease and Related Disorders 2008 Member Roster

Ronald Devere, M.D.
Austin

Carlos Escobar, M.D.
San Angelo

Charlene Evans, RN
Harlingen

Debbie Hanna, Chair
Austin

Grayson Hankins
Odessa

The Honorable Clint Hackney
Austin

Davie Lee Wright Johnson
El Paso

Mary M. Kenan, Psy.D.
Houston

Jack C. Kern, C.P.A.
Austin

Margaret Krasovec
Austin

Ray Lewis, DO
Arlington

Robert A. Vogel, M.D.
Midland

Audrey Deckinga
Health and Human Services
Commission
Austin

Angela Hobbs-Lopez, D.O.
Department of State Health
Services
Austin

Jennifer Smith, M.S.H.P.
Department of State Health
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Michael Wilson, Ph.D.
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Staff

Susan Ristine, M.S.H.P.
Department of State Health
Services
Austin

Mary Somerville
Department of State Health
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Austin

Texas Council on Alzheimer's Disease and Related Disorders 2007 Conference Planning Committee

Ronald Devere, M.D., Chair
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Carlos Escobar, MD
San Angelo

Charlene Evans, RN
Harlingen

Davie Lee Wright Johnson
El Paso

Mary Kenan, Psy.D.
Houston

Staff

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Appendix C

Texas Alzheimer's Research Consortium

Steering Committee

Perrie M. Adams, Ph.D., *Margaret D. Harris Professor in Alzheimer's Research*, Associate Dean of Research, Department of Psychiatry
The University of Texas Southwestern Medical Center
Dallas

Rachelle S. Doody, M.D., Ph.D., *Effie Marie Cain Chair in Alzheimer's Disease*, Director, Alzheimer's Disease and Memory Disorders Center
Baylor College of Medicine
Houston

Thomas J. Fairchild, Ph.D., Vice President, Office of Strategy and Measurement
University of North Texas Health Science Center
Fort Worth

Randolph B. Schiffer, M.D., *Vernon and Elizabeth Haggerton Chair in Neurology*, Chair, Department of Neuropsychiatry and Behavioral Science
Texas Tech University Health Sciences Center
Lubbock

Consortium Staff

Jim Hinds, MPA, TARC Project Coordinator
Austin

Steve Waring, DVM, Ph.D., TARC Scientific Coordinator, Assistant Professor of Epidemiology
The University of Texas School of Public Health
Houston

Janis Monger, MA, TARC Public Education Coordinator
Austin

HELPFUL TELEPHONE NUMBERS AND WEBSITES

ALZHEIMER'S ASSOCIATION

1-800-272-3900

Information and referral services.

www.alz.org

- Comprehensive 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

- Link to local chapters for available programs and services.

ALZHEIMER'S DISEASE CENTER AT 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 AT 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.swmed.edu/home_pages/alzheimer/

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

ALZHEIMER'S DISEASE EDUCATION AND REFERRAL (ADEAR) CENTER

1-800-438-4380

Information about Alzheimer's disease, its impact on families and healthcare providers, and research into possible causes and cures.

www.alzheimers.org

- 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/

- General information on Medicaid.
-

MEDICARE

1-800-633-4227

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

www.medicare.gov

- Official U.S. government site for Medicare information on 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/elder/elder.shtml

- Senior Texans' page includes information on consumer protection, rights of the elderly, choosing a nursing facility, advance planning, health and safety, and Senior Alerts.
-

TEXAS ALZHEIMER'S RESEARCH CONSORTIUM

1-512-925-3320

A source of information about state-funded collaborative Alzheimer's 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 research, and a resource list for Alzheimer's patients and their caretakers.

**TEXAS DEPARTMENT OF AGING & DISABILITY 1-800-458-9858
SERVICES, CONSUMER RIGHTS AND SERVICES**

Long-term care facility information, licensing and certification of facilities, and nursing facility complaints.

www.dads.state.tx.us/

- 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.

www.dads.state.tx.us/

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

TEXAS DEPARTMENT OF INSURANCE 1-800-252-3439

Information; counseling; and filing a complaint against a private insurance provider.

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

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

**DEPARTMENT OF STATE HEALTH SERVICES 1-800-252-8154
DIVISION FOR MENTAL HEALTH/SUBSTANCE ABUSE SERVICES**

Consumer services and rights protection.

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

- Community programs, services and standards.

TEXAS DEPARTMENT OF FAMILY AND PROTECTIVE SERVICES 1-800-252-5400

Hotline for reporting abuse, neglect, or exploitation of children, the elderly, or people with disabilities. Available 24/7.

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 DEPARTMENT OF AGING & DISABILITY 1-800-252-9240
SERVICES, AREA AGENCY ON AGING INFORMATION
AND ASSISTANCE**

Routes calls to 28 Area Agencies on Aging in Texas that provide 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.

Appendix E

OMBUDSMAN PROGRAM

1-800-252-2412

Investigates and helps resolve nursing home complaints. Help with choosing a nursing home.

LEGAL HOTLINE FOR OLDER TEXANS

1-800-622-2520

Legal assistance including counseling, representation, and document preparation.

www.dads.state.tx.us/

- Links to 28 Area Agencies on Aging in Texas; Ombudsman Program; Residents' Rights, information on benefits counseling, caregiver resources, and free downloads of Agency brochures and reports.

TEXAS TECH UNIVERSITY HEALTH SCIENCES CENTER

1-806-743-3610

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 Institute for Healthy 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

1-817-735-5484

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

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

- Clinical trials, Geriatric Education and Research Institute, Consortium on Alzheimer's Research and Education, DNA Bank, and Memory Clinic.

**TEXAS DEPARTMENT OF STATE HEALTH SERVICES
ALZHEIMER'S DISEASE PROGRAM**

1-800-242-3399

www.dshs.state.tx.us/alzheimers/default.shtm



Texas Council on Alzheimer's Disease and Related Disorders
Texas Department of State Health Services
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www.dshs.state.tx.us/alzheimers/default.shtm
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