Table of Contents

Executive Summary ..........................................................................................................................1
  Texas Council on Alzheimer’s Disease and Related Disorders .....................................................1
  Progress in the Council’s Work .....................................................................................................1
  Council Recommendations, FY 2015-2016 ................................................................................2

Introduction ....................................................................................................................................2
  Statutory Requirement ..................................................................................................................2

Background .....................................................................................................................................3
  Creation of the Council ..................................................................................................................3

Council Activities ..........................................................................................................................3
  Awareness and Education .............................................................................................................3
    Websites ......................................................................................................................................3
    Toll-Free Helpline .......................................................................................................................3
  Advocacy ......................................................................................................................................4
  Statewide Strategic Planning .........................................................................................................4
  Partnership Development ..............................................................................................................4
  Coordinated Alzheimer’s Disease Research ..................................................................................5
    Darrell K. Royal Texas Alzheimer’s Initiative ..............................................................................5

Conclusions .....................................................................................................................................5
  Council Recommendations, FY 2015-2016 ..............................................................................5

Appendix A: Council Roster ..........................................................................................................7

Appendix B: Coordinated Alzheimer’s Disease Research ..............................................................8
  Texas Alzheimer’s Research and Care Consortium (TARCC) .......................................................8
  TARCC’S Current Research Objectives .......................................................................................8
  TARCC Achievements ..................................................................................................................9
  An Early Return on the State’s Investment ..................................................................................10

Appendix C: Alzheimer’s Disease Background .............................................................................12
  Alzheimer’s Disease - An Urgent National Health and Research Priority ..................................12
    The Burden of AD .....................................................................................................................12
    Progress Through Research and Advocacy ...............................................................................12
    Public Health Challenge and Research Priority .........................................................................13
Executive Summary

Texas Council on Alzheimer’s Disease and Related Disorders

Alzheimer’s disease (AD) is the fastest-growing health threat in the country.\(^1\) Out of the more than 5 million Americans with AD, 330,000 of those individuals are Texans.\(^2\) The Texas Council on Alzheimer’s Disease and Related Disorders (Council) was established in 1987 to serve as the State’s advocate for persons with AD, their caregivers, and related professionals. HB 1066, 70th Legislature, Regular Session, 1987, requires the Council to submit to the Governor, Lt. Governor, Speaker of the House of Representatives, members of the Texas Legislature, the Long-Term Care Coordinating Council for the Elderly, and board, a Biennial Report of activities and recommendations.

This report documents highlights from fiscal years 2013 and 2014.

Progress in the Council’s Work

During the past two years, the Council:


- Began to update the *Texas State Plan on Alzheimer’s Disease* for 2015-2020.

- Published and disseminated the first Texas guidelines for the early detection, diagnosis, and pharmacological treatment of AD.

- Coordinated the activities of the Texas Alzheimer’s Disease Partnership, a volunteer group of more than 150 individuals who actively advance the state plan and promote awareness of AD in Texas.

- Advanced strategies within the 2010-2015 *Texas State Plan on Alzheimer’s Disease*.

- Directed state-appropriated funds to the Texas Alzheimer’s Research and Care Consortium (TARCC), as mandated, for AD research in Texas.

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Council Recommendations, FY 2015-2016

The Council has identified the following priority issues for the next biennium:

- Sustain and support ongoing research efforts to identify modifiable risk factors to help delay the onset of, prevent, and/or cure AD.

- Increase collaborative AD research among Texas researchers.

- Advance Texas’ infrastructure and capacity to be commensurate with the state’s increasing burden of AD through creating both public and private innovative partnerships.

- Optimize the system of care and support for AD caregivers.

- Update the Texas State Plan on Alzheimer’s Disease for 2015-2020 to reflect the importance of evidence-based approaches to prevention and treatment.

- Continue to engage in strategic collaboration with Texas researchers, clinicians, directors of AD research centers and centers on aging, medical schools, medical professionals, state public health experts, and community partners.

Introduction

Statutory Requirement

Pursuant to HB 1066, 70th Legislature, Regular Session, 1987, which was codified in §101.010, Texas Health and Safety Code, “before September 1 of each even-numbered year, the council shall submit a biennial report of the council's activities and recommendations to the governor, lieutenant governor, speaker of the house of representatives, members of the legislature, Long-Term Care Coordinating Council for the Elderly, and board.”

The report highlights the Council’s activities as members discharge their legislative mandate by:

- Recommending needed action for the benefit of persons with AD 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 AD and related disorders to the medical and healthcare 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 AD and related disorders.

• Facilitating coordination of state agency services and activities relating to victims of AD and related disorders.

Background

Creation of the Council

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, their caregivers, and related professionals.

Specifically, the Council increases awareness of AD and its impact on Texans, participates as a strategic partner and coordinating body for statewide education, provides supervision and direction on state research activities related to AD, and supports policies and programs that benefit people with AD and their caregivers.

Council Activities

Awareness and Education

Websites

DSHS maintains a website containing information on AD, warning signs, diagnosis, treatment, legal and financial issues, options for care, and information on licensed nursing and assisted living facilities certified for AD care. Council meeting agendas and minutes, and helpful toll-free phone numbers and internet links are also available on the DSHS Alzheimer’s Disease Program’s website at www.dshs.state.tx.us/alzheimers/default.shtm.

Under the supervision of the Council, TARCC maintains a website with information and updates on research activities, information on TARCC institutions and committees, publications, research recruitment opportunities, contact information, and AD statistics and resources. This website can be accessed at http://www.txalzresearch.org/.

Toll-Free Helpline

Since its inception in 1987, the Council has worked to develop a growing awareness of the tremendous impact AD and related disorders have on individuals, families, and society. DSHS maintains a toll-free information helpline (1-800-242-3399) to provide information, support, and referrals to local community services.
Advocacy

The Council, in its continued efforts to advocate on behalf of individuals with AD and their families, provides guidance to community and state agencies on program and policy development.

Statewide Strategic Planning

Recognizing that AD is a growing public health concern, the Council and the DSHS Alzheimer’s Disease Program began formal work in 2009 on the development of the *2010-2015 Texas State Plan on Alzheimer’s Disease*, the first comprehensive state plan to address the current and future burden of AD on our state. Knowing that this work would require partners and stakeholders from state, local, and community level organizations; academic and research institutions; for-profit and non-profit sectors; businesses; the healthcare sector; and family members of individuals afflicted with AD, the Council and DSHS formed the Texas Alzheimer’s Disease Partnership. This partnership is a volunteer group comprised of individuals with diverse backgrounds and rich and varied experiences, which provided the synergy and expertise to create a strategic blueprint for formulating and implementing a comprehensive and coordinated statewide plan for Texas. The state plan will be updated over the next fiscal year and will reflect the importance of evidence-based approaches to prevention and treatment.

In February 2013, the Council and the DSHS Alzheimer’s Disease Program, with the help and review of many dedicated volunteers of the Texas Alzheimer’s Disease Partnership, developed and released AD management guidelines titled *Clinical Best Practices for the Early Detection, Diagnosis, and Pharmaceutical and Non-Pharmaceutical Treatment of Persons with Alzheimer’s Disease*. These guidelines were developed and peer-reviewed by a group of AD experts working to meet the disease management objectives of the *2010-2015 Texas State Plan on Alzheimer’s Disease*. The hope is that these guidelines will help improve the quality of life of those living with this disease and those who provide care to them. These guidelines can be accessed at *Clinical Best Practices for the Early Detection, Diagnosis, and Pharmaceutical and Non-Pharmaceutical Treatment of Persons with Alzheimer’s Disease*.

Partnership Development

Meeting the challenges of caregiving requires many resources. The Council, in its efforts to coordinate, collaborate, and support AD-related services and programs throughout the state, is engaged in developing partnerships with service organizations, health organizations, commissions, and aging-related agencies. Council members and DSHS staff serve on boards as well as advisory and planning committees to guide the direction and promotion of programs designed to assist individuals with AD and their caregivers. The caregiver support activities of the Texas Department of Aging and Disability Services (DADS), the Texas Respite Coalition, the Silver Alert Program, and the Aging Texas Well Advisory Committee are examples of ongoing collaborations and support. DADS and its 28 Area Agencies on Aging (AAAs) form a statewide network to provide comprehensive information and services for caregivers. The Council assists DADS by serving as a resource, providing referrals, and marketing caregiver activities through the DSHS website.
Coordinated Alzheimer’s Disease Research

Darrell K. Royal Texas Alzheimer’s Initiative

In October 2012, Council members unanimously voted to rename all funded AD efforts under their purview to the Darrell K. Royal Texas Alzheimer's Initiative. This initiative is committed to fostering excellence in research through the legislatively-mandated TARCC; addressing the burden of AD in Texas through statewide strategic planning; promoting collaborative research projects among Texas AD researchers; and coordinating/supporting other state-funded activities as they relate to AD.

Conclusions

Council Recommendations, FY 2015-2016

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

1. Coordinated Alzheimer’s Disease Research
   The Council requests continued recognition and support of coordinated statewide research, as was 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. The Consortium, later named Texas Alzheimer’s Research and Care Consortium (TARCC) by the Council, provides Texas with the infrastructure for sharing vital AD research 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.

2. Increased Collaborative Research among Texas AD Researchers
   Increasing collaboration in AD research across public, private, state, and federal sectors that cut across disciplines is needed to quicken discovery. Behavioral modifications, such as diet and exercise, and pharmacological interventions must be integrated in order to develop therapies aimed at AD prevention. This type of multi-disciplinary research, typically not funded by national health and science foundations, offers significant opportunities to study disease progression and advance therapeutic strategies. The Council supports using outcome-oriented research projects backed by appropriate funding mechanisms and active collaboration among Texas researchers to identify preventions and therapies.

3. Continued Support for Quality Long-Term Care
   The Council supports maintaining or increasing current levels of nursing-facility eligibility for people with cognitive impairments, specifically AD and other related dementias. The Council requests maintaining or increasing Resource Utilization Groups (RUGS), based on the level of need, to accommodate higher levels of reimbursement for facilities that care for persons with cognitive impairments.
4. **Expanded Community-Based Programs and Services**
   The Council recommends expansion and optimization of home and community-based programs and services for individuals with AD and their caregivers. The Council recommends the 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. Because family caregivers provide most care, expanding these resources will afford caregivers much needed services to assist them in caring for their loved ones with AD.

5. **Update the Texas State Plan on Alzheimer’s Disease for 2015-2020**
   The Council recommends that the state plan be updated to reflect the importance of evidence-based approaches to prevention and treatment. The activities outlined in the current state plan will be enhanced for 2015-2020 to reflect the increasing need to coordinate caregiver support and evidence-based public health information that covers the many aspects of AD. The 2015-2020 state plan will provide the strategic blueprint that, when fully implemented, will enable Texas to better address the complex issues associated with the increasing prevalence of this disease. Texas requires greater capacity to address the huge economic and human toll AD places on our valuable resources and citizens. Limited and competing resources must be carefully directed at comprehensive and coordinated statewide strategic planning. The state of Texas must remain proactive in the face of the burgeoning epidemic of AD.

6. **Engage in Strategic Collaborations**
   The Council recognizes the importance of establishing and maintaining collaborative relationships with experts in AD. The Council and the DSHS Alzheimer’s Disease Program will continue to engage in strategic collaboration with Texas researchers, clinicians, directors of AD research centers and centers on aging, medical schools, medical professionals, state public health experts, and community partners.
Appendix A: Council Roster

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).

Texas Council on Alzheimer’s Disease and Related Disorders 2013-2014 Member Roster

Laura DeFina, MD  
Dallas

Ronald Devere, MD  
Austin

Carlos Escobar, MD  
San Angelo

Melissa L Edwards  
Houston

The Honorable Clint Hackney  
Austin

Grayson R. Hankins, BS  
Odessa

Debbie Hanna, Chair  
Austin

Rita Hortenstine  
Dallas

Ray Lewis, DO, CMD  
Cedar Hill

Susan Rountree, MD  
Houston

Kate Allen Stukenberg  
Houston

Robert A. Vogel  
Midland

Bonnie Curington, PhD, MSW  
Texas Department of State Health Services

Lisa B. Glenn, MD  
Texas Department of Aging and Disability Services

Patricia Moore, MEd, PhD  
Texas Department of State Health Services

Nancy Walker  
Texas Health and Human Services Commission

Toni Packard  
Texas Department of Aging and Disability Services

Staff  
Lynda Taylor, MSW  
Texas Dept. of State Health Services
Appendix B: Coordinated Alzheimer’s Disease Research

Texas Alzheimer's Research and Care Consortium (TARCC)

TARCC, established and supervised by the Council, is part of the state-funded Darrell K. Royal Texas Alzheimer's Initiative. The Texas Legislature made history in 2005 by approving the first state-level appropriation for AD research in the nation. This initial $2 million investment provided start-up funding for TARCC, a collaborative research effort without precedence in Texas. The Council, by statute, established a consortium of AD centers among four of Texas’ 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 TARCC. 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 annual blood and DNA samples at TARCC 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. Participants are assigned a unique number at the TARCC site when enrolled. Central data are de-identified in a HIPAA-compliant manner.

TARCC has 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 2008, the Council expanded the reach of AD research into South Texas by adding the University of Texas Health Science Center – San Antonio to TARCC. This move, coupled with the 2009 state appropriation of $6.85 million, enabled TARCC to begin including a large number of Hispanic individuals into the Texas Harris Alzheimer’s Study. One third of Texans are Hispanic, and according to the Texas State Data Center, Texas will become a majority Hispanic state between 2020 and 2035. The inclusion of underrepresented Hispanics significantly strengthens AD research efforts in Texas and uniquely positions Texas to assume a national leadership role in this largely untapped area of AD research. Funding for the fiscal year 2014/2015 biennium was increased to $9.2 million and will allow TARCC to expand its research efforts. Through Council action in January 2013, Texas A&M University Health Science Center was added as the sixth member of TARCC.

TARCC’S Current Research Objectives

Collaboration among TARCC institutions has resulted in a unique resource, the Texas Harris Alzheimer’s Research Study. This resource includes data and biological samples gathered from more than 2800 participants diagnosed with AD or mild cognitive impairment, as well as from healthy controls. A novel and important strength of TARCC is the longitudinal nature of this study, where patients are followed annually, and standardized clinical, neuropsychiatric, genetic, and blood biomarker data are collected. Analysis of the longitudinal data set enables TARCC investigators to model changes in cognitive function over time, allowing identification of factors that affect not only risk, but disease progression. The inclusion of individuals diagnosed with
mild cognitive impairment is useful for understanding the sequence of neurodegenerative changes that occur as AD develops. Current research objectives being examined are described below.

- **Identify** genetic factors that affect the development of AD in Hispanic and non-Hispanic Europeans. Hispanics are the fastest-growing ethnic group in Texas and are projected to represent a majority of the state's population by 2020. Very little is known about AD in this population. TARCC is an invaluable resource to state and national AD research efforts because of the genetic and biomarker material collected from a large number of Hispanics.

- **Discover** the underlying biochemical factors and cellular mechanisms that affect disease progression. Identifying the specific cellular and biochemical changes linked to disease progression will shed light on how AD develops and could lead to the development of new drugs and therapies that will improve quality of life of patients with AD and may also diminish the risk of developing this disease.

- **Expand** enrollment into the Texas Harris Alzheimer’s Research Study of individuals diagnosed with probable AD and mild cognitive impairment. As scientific progress moves forward, there is an emphasis on developing early markers to identify those individuals most at risk for AD. Expanding the Texas Harris Alzheimer’s Research Study to include a large number of participants with probable AD and mild cognitive impairment will provide new insights into the development of the disease and suggest tools for early diagnosis as well as highlight novel therapeutic options.

TARCC’s research activities are reviewed by an external advisory committee comprised of five internationally recognized leaders in AD research who ensure that TARCC adheres to the highest quality research standards and pursues a direction with the greatest potential to break new ground in AD research.

**TARCC Achievements**

Each TARCC site recruits individuals who are diagnosed with AD, mild cognitive impairment, or healthy aging controls. Blood samples of TARCC participants undergo advanced analyses of proteins, metabolic, and genetic data. Demographic information, clinical histories, and neuropsychological functioning are also assessed. To date, TARCC has enrolled 2857 participants, of which 1824 are currently active, into the Texas Harris Alzheimer’s Research Study. Active participants include 462 patients with a primary diagnosis of AD, 909 cognitively normal individuals, and 453 subjects with mild cognitive impairment. These numbers include 818 Hispanic individuals. Given this impressive success and current patient accrual rates, TARCC is ahead of schedule to meet its target of active participants by August 2015.

All blood samples are sent to the University of Texas Southwestern Medical Center for processing, DNA extraction, handling, and storage in TARCC’s dedicated bio-banking facility. This facility is also responsible for preparing and shipping samples for all laboratory analyses. Tracking of all tissue samples through all steps is facilitated by the software program Freezerworks to ensure this valuable resource is maintained for current research interests as well.
as for future projects that require stored DNA, whole blood, plasma, and serum on a cohort of well-characterized individuals.

TARCC researchers have been highly productive, producing cutting-edge science and reporting important scientific discoveries. In the past biennium, TARCC researchers have published more than two dozen important papers in high-profile AD journals. These studies provide novel insights into how AD develops as well as how this disease could be effectively treated. A brief summary of these studies is presented below.

- **Improving diagnosis of AD in rural populations.** TARCC scientists published a study in the Journal of Alzheimer’s Disease that described a new marker derived from neuropsychological tests that was characterized in subjects participating in the TARCC research study. The data derived from this study could help with AD diagnosis in rural or other underserved populations without ready access to state-of-the-art neurology care.

- **Validating new blood test for diagnosing AD.** TARCC researchers have developed a novel blood test for Alzheimer’s that uses state-of-the-art microarray analysis of serum proteins to predict disease. The data generated suggests a novel biomarker algorithm is highly sensitive and specific for correctly classifying AD. TARCC investigators have received $640,000 from the National Institutes of Health to further validate these findings.

- **Identifying links between cardiovascular risk factors and AD.** Increasing research evidence suggests that cardiovascular risk factors play a role in the development of AD. In particular, inflammatory proteins, which are elevated in response to cardiovascular risk factors, have been implicated in AD development. TARCC researchers are at the forefront of defining how inflammatory proteins can be used for diagnosing AD as well as how they may be targeted for therapeutic intervention.

- **Inclusion of Texas A&M University Health Science Center (TAMUHSC) in TARCC.** The inclusion of TAMUHSC into TARCC has expanded new scientific avenues in AD research. TAMUHSC faculty are currently studying AD development and working on markers for earlier detection, as well as testing specific drugs to prevent or eliminate the disease. Research also is being conducted on the impact of lifestyle and the environment on health and disease.

**An Early Return on the State’s Investment**

The creation of TARCC has set a collaborative-model standard for scientific endeavors statewide. The synergy of six institutions bringing clinicians and scientists together to focus on AD has resulted in enhanced research output and increased research infrastructure devoted to AD. These accomplishments are critical to Texas’ role as an emerging leader in AD research.

TARCC-based AD research benefits the state by contributing to new advances in AD diagnosis, risk assessment, and therapeutic interventions.

- **New advances in AD diagnosis.** 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.

- **New approaches to risk assessment.** TARCC scientists are using advances created by 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.

- **New insights into therapeutic interventions.** While great progress has been made, researchers are still searching for definitive answers to questions about the basic mechanisms underlying AD. TARCC researchers are at the forefront of defining how inflammatory proteins can be used for diagnosing AD as well as targeted for therapeutic interventions. 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.
Appendix C: Alzheimer’s Disease Background

Alzheimer’s Disease - An Urgent National Health and Research Priority

The Burden of AD

AD is an age-related, progressive and irreversible brain disease 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, and the inability to perform simple tasks and physical activities. As cognitive and functional abilities decline, individuals are rendered totally dependent on others for all of their care. As more of the brain becomes affected, areas that control basic life functions like swallowing and breathing become irreversibly damaged, eventually leading to death. Currently, there is no effective prevention, treatment, or cure for AD. New criteria and guidelines for diagnosing AD were proposed and published in 2011, recommending that AD be considered a disease that begins well before the development of symptoms.3

AD affects over 5 million Americans today - 330,000 of those individuals are Texans. It is the sixth leading cause of death in the U.S. and has an economic burden of $214 billion annually. Texas ranks fourth in the number of AD cases and second in the number of AD deaths. A new person develops AD every 67 seconds, and current projections indicate that this rate will increase to one new case every 33 seconds by 2050. According to the 2014 Alzheimer’s Association, Women and Alzheimer’s poll, women are the epicenter of AD. Nearly 3.2 million of the estimated 5 million with AD are women, and women are more likely to have other dementias.4

In 2013, there were an estimated 15 million unpaid caregivers in the U.S., most of whom were family members. In Texas, 1.3 million unpaid caregivers provided care to the 330,000 individuals with AD in 2013. This equates to 1.5 billion hours of unpaid care at a cost of $18.5 billion per year.5 Total payments for healthcare, long-term care, and hospice care for individuals with AD and other dementias are projected to increase from $214 billion in 2014 to $1.2 trillion in 2050 (in 2014 dollars).6

Progress Through Research and Advocacy

Research continues to expand our understanding of the causes of, treatments for, and prevention of AD.7 Scientists have 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 inevitable dependency.

Public Health Challenge and Research Priority

AD is a major public health and research challenge because of its detrimental effects on the health and well-being of the nation’s population. Because there is no cure for AD, the importance of early detection becomes even more critical - the earlier the diagnosis is made, the more likely the individual may respond to treatment. Despite its importance, significant barriers remain to early detection. A missed or delayed diagnosis of AD can lead to unnecessary burdens on the individual and their caregivers.

Ongoing research efforts to find causes and identify risk factors to delay onset and 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 the progression of symptoms and eventually prevent AD is critical to decreasing disability and death, containing healthcare costs, and protecting individuals and families.

Increased support for individuals with AD and their caregivers is crucial. Stakeholders must continue to advocate for community and home-based care and community supports for caregivers, because these programs afford caregivers the assistance they need to help care for their loved ones at home.

Expediting statewide, coordinated action to address AD in Texas remains critical as the prevalence of the disease continues to climb, exacting huge human and economic burdens on Texas citizens and resources. The 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. Continued implementation of the state 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.