Texas Council on Alzheimer's Disease and Related Disorders Biennial Report 2018

As Required by

Texas Health and Safety Code,

Section 101.010

Texas Council on Alzheimer's

Disease and Related Disorders

September 2018

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Executive Summary

The Texas Council on Alzheimer's Disease and Related Disorders (Council) was established in 1987. Texas Health and Safety Code, 101.010, requires the Council to submit to the Governor, Lieutenant Governor, Speaker of the House of Representatives, and members of the Legislature a biennial report of activities and recommendations.

This report documents the activities of the Council during fiscal years 2017-2018. The following are highlights of the Council's activities.

- The Council invited Olivia Mastry from Dementia Friendly America to speak at a meeting of the Texas Alzheimer's Disease Partnership in 2016 regarding the concepts of Dementia Friendly Communities.
- In fiscal year 2017, the Council
  - voted to include the concepts of Dementia Friendly Communities in the Texas State Plan on Alzheimer's Disease, and
  - recognized the role of Council members as dementia friendly ambassadors in promoting the dementia friendly concepts in their communities.
- In fiscal year 2018, the Council voted to
  - include the University of Texas Medical Branch Galveston and University of Texas Health Science Center at Houston as members of the Texas Alzheimer's Research and Care Consortium (TARCC),
  - convert the TARCC cohort to the voluntary site participation grant funded enrolling and studying Texas Hispanics; and
  - name University of Texas Southwestern to manage the investigator grant program grants award process.

The Council identified the following recommendations for fiscal years 2019-2020:

- sustain and support ongoing coordinated Alzheimer's research,
- continue support for quality care,
- engage in strategic collaborations, and
- expand local caregiver services and supports.

1. Introduction

As directed by [Texas Health and Safety Code, Section 101.007](#), the Texas Council on Alzheimer's Disease and Related Disorders (Council) shall engage in the following activities.

- Advise the department and recommend needed action for the benefit of persons with Alzheimer's disease and related disorders and for their caregivers.
- Coordinate public and private family support networking systems for primary family caregivers.
- Disseminate 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.
- Coordinate a volunteer assistance program primarily for in-home and respite care services.
- Encourage research to benefit persons with Alzheimer's disease and related disorders
- Recommend to the Department of State Health Services (DSHS) disbursement of grants and funds available for the Council.
- Facilitate coordination of state agency services and activities relating to persons with Alzheimer's disease and related disorders.

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, and members of the Legislature.

The following report outlines the activities of the Council in fiscal years 2017-2018 as well as recommended actions for 2019-2020.

2. Background

Alzheimer's disease (Alzheimer's) is the fastest-growing health threat in the country.[1] In 2018, it was estimated that5.7 million Americans, of all ages, are living with Alzheimer's. This includes an estimated 5.5 million people age 65 and older and approximately 200,000 individuals under age 65 who have younger-onset Alzheimer's. In Texas, 380,000 people age 65 and older have Alzheimer's.[2] Recognizing this threat, the Texas Legislature established the Texas Council on Alzheimer's Disease and Related Disorders (Council). For additional information about the Alzheimer's burden in Texas, see Appendix A.

As directed by statute, the Council is composed of 15 members including 12 voting members who are appointed by the Governor, Lieutenant Governor and Speaker of the House. Three non-voting members represent the Health and Human Services Commission (HHSC) and the Department of State Health Services (DSHS). For a detailed list of Council members see Appendix B.

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[1] Global Burden of Disease Study 2010, *Lancet*, 2012.
[2] Alzheimer's Association. *Alzheimer's Disease Facts and Figures 2018*.

3. Council Activities - Fiscal Years 2017-2018

Over the biennium, the Council has met four times: October 3, 2016; May 18, 2017; February 8, 2018; and August 22, 2018.

The following new Council members were appointed over the 2017-2018 biennium.

- November 2017
  - ➢ Dr. Vaunette Fay, PhD
  - ➢ Ana Guerrero Gore
  - ➢ Dr. Char Hu, PhD
  - ➢ Terrence Sommers
- February 2018
  - ➢ Joe A. Evans, Jr.
  - ➢ Eddie L. Patton, Jr., MD
- March 2018
  - ➢ Byron Cordes, LCSW, C-ASWCM
  - ➢ Mary Ellen Quiceno, MD, FAAN
- Rita Hortenstine was appointed Council chair in February 2018.

The following describes Council activities related to the Texas Alzheimer's Research and Care Consortium (TARCC).

- The Council voted Dr. Valory Pavlik to be the Baylor College of Medicine Steering Committee member (2016).
- The Council voted Dr. Munroe Cullum and Dr. John Hart to be External Advisory Compliance Committee Co-Chairs (2016).
- The Council voted to include the University of Texas Medical Branch Galveston and University of Texas Health Science Center at Houston as members of TARCC (2018).
- The Council voted to convert the TARCC cohort to the voluntary site participation grant funded enrolling and studying the Hispanic population in Texas (2018).
- The Council voted to name the University of Texas Southwestern to manage the award process for the investigator grant program (2018).

The Council voted on four recommendations for the Biennial Report (2018).

4. Recommendations – Fiscal Years 2019-2020

The Texas Council on Alzheimer's Disease and Related Disorders (Council) respectfully submits the following recommendations.

Recommendation 1: Sustain and support ongoing coordinated Alzheimer's disease (Alzheimer's) research.

- Continue recognition and support of coordinated statewide research, as the Texas Legislature demonstrated in passing House Bill 1504, 76th Legislature, Regular Session, 1999 (Texas Education Code, Chapter 154), to establish the Texas Consortium of Alzheimer's Disease Centers.
- Support research on Alzheimer's disease, both basic science research and clinical research, focusing on
  - early detection,
  - differentiation between Alzheimer's and other related disorders, and
  - treatment and care.
- Support the incorporation of the Alzheimer's optional modules in the annual Texas Behavioral Risk Factor Surveillance System (BRFSS). The two Alzheimer's modules are the *Caregiver Optional Module* and the *Cognitive Decline Optional Module*.

Recommendation 2: Continue support for quality care.

- Promote interdisciplinary education of health professionals and first responders on management of behaviors (e.g., anxiety, aggression, wandering, etc.) through behavior modification, environmental modifications and medication use, and promoting dementia friendly concepts.
- Support the development of quality care tailored to the needs of persons with dementia and the inclusion of family caregivers in decision making.
- Promote the Alzheimer's Association's 2018 *Dementia Care Practice Recommendations*. The *Dementia Care Practice Recommendations* outline recommendations for quality care practices based on a comprehensive review of current evidence, best practices, and expert opinions.

Recommendation 3: Engage in strategic collaborations.

- Partner with state and county medical organizations and other stakeholders to promote research and awareness campaigns.

- Promote the Centers for Disease Control and Prevention's (CDC) *Healthy Brain Initiative: Public Health Road Map*, to promote brain health as a vital component of public health, and to increase the number of Texans who recognize the direct impact physical health can have on brain/cognitive health.
- Through stakeholder input, continue to develop a state plan to address Alzheimer's every five years.

Recommendation 4: Expand local caregiver services and supports.

- Strengthen the Department of State Health Services' (DSHS) Alzheimer's Disease Program and its role in providing support and resources for persons living with the disease, caregivers, and healthcare professionals.
- Enhance the DSHS Alzheimer's Disease Program website by making it more user-friendly, with links and references to Alzheimer's state and community services. Include a portal with information and resources for healthcare professionals.

5. Conclusion

The Texas Council on Alzheimer's Disease and Related Disorders continues to dedicate time and effort to highlighting the needs of persons living with Alzheimer's disease (Alzheimer's) and other dementias, their family caregivers, and related professionals.

The Council's recommendations for fiscal years 2019-2020 include sustaining and supporting ongoing coordinated Alzheimer's research, continuing support for quality care, engaging in strategic collaborations, and expanding local caregiver services and support.

List of Acronyms

Acronym	Full Name
BRFSS	Behavioral Risk Factor Surveillance System
CDC	Centers for Disease Control and Prevention
DSHS	Texas Department of State Health Services
HHSC	Texas Health and Human Services Commission
TARCC	Texas Alzheimer's Research and Care Consortium

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

The Burden of Alzheimer's Disease

Alzheimer's disease (Alzheimer's) 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 Alzheimer's 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 Alzheimer's. New criteria and guidelines for diagnosing Alzheimer's were proposed and published in 2011, recommending that Alzheimer's be considered a disease that begins well before the development of symptoms. [3]

An estimated 5.7 million Americans of all ages are living with Alzheimer's in 2018. This includes an estimated 5.5 million people age 65 and older and approximately 200,000 individuals under age 65 who have younger-onset Alzheimer's. In Texas, 380,000 people age 65 and older have Alzheimer's. It is the sixth leading cause of death in the U.S. and has an economic burden of $277 billion annually. Texas ranks fourth in the number of Alzheimer's cases and second in the number of Alzheimer's deaths. A new person develops Alzheimer's every 65 seconds, and current projections indicate that this rate will increase to one new case every 33 seconds by 2050. Nearly 3.4 million of the estimated 5.5 million individuals with Alzheimer's are women and 2 million are men. Women are more likely to have other dementias. [4]

In 2017, there were an estimated 16.1 million unpaid caregivers in the U.S., most of whom were family members. In Texas, 1.4 million unpaid caregivers provided care to the 380,000 individuals with Alzheimer's in 2017. This equates to 1.6 billion

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[3] Alzheimer's Association. *Alzheimer's Disease Facts and Figures 2018.*
[4] Alzheimer's Association. *Alzheimer's Disease Facts and Figures 2018.*

hours of unpaid care at a cost of $20.2 billion per year.[5] Total payments for healthcare, long-term care, and hospice care for individuals with Alzheimer's and other dementias are projected to increase from $277 billion in 2018 to $1.1 trillion in 2050 (in 2018 dollars).[6]

Progress Through Research and Advocacy

Research continues to expand our understanding of the causes of, treatments for, and prevention of Alzheimer's.[7] Scientists have identified genetic and biological changes that occur with Alzheimer's, allowing them to pinpoint possible targets for treatment. Advances in pharmacologic treatment may stabilize and delay progression of Alzheimer's symptoms. This delay in progression helps contain costs associated with medical and long-term care, eases caregiver burden, and allows the individual with Alzheimer's the opportunity to participate more fully in life and postpone inevitable dependency.

Public Health Challenge and Research Priority

Alzheimer's 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 Alzheimer's, 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 Alzheimer's 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 Alzheimer's are imperative. As methodologies are refined, scientists and clinicians will be able to investigate and understand the earliest pathological and clinical signs of Alzheimer's, perhaps 10 to 20 years before a clinical diagnosis is made. Drug development to block the progression of symptoms and eventually prevent Alzheimer's is critical to decreasing disability and death, containing healthcare costs, and protecting individuals and families.

Increased support for individuals with Alzheimer's and their caregivers is crucial. Stakeholders must continue to advocate for community and home-based care and

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[5] Alzheimer's Association. *Alzheimer's Disease Facts and Figures 2018.*
[6] Alzheimer's Association. *Alzheimer's Disease Facts and Figures 2018.*
[7] National Plan to Address Alzheimer's Disease, U.S. Department of Health and Human Services, 2017 Update.

community supports for caregivers because these programs give caregivers the assistance they need to help care for their loved ones at home. Expediting statewide, coordinated action to address Alzheimer's in Texas remains critical as the prevalence of the disease continues to climb, exacting huge human and economic burdens on Texas citizens and resources.

Appendix B was updated by the Alzheimer's Disease Program at the Department of State Health Services.

Appendix B. TX Council on Alzheimer's Disease and Related Disorders 2017-2018 Member Roster

Task Force Member Name, Location or Agency Affiliation

Byron Cordes, LCSW, C-ASWCM San Antonio	**Laura DeFina, MD** **Dallas**
Marc Diamond, MD Dallas	**Joe A. Evans, Jr.** Beaumont
Vaunette Fay, PhD Houston	**Francisco González-Scarano, MD** San Antonio – *Letter of resignation submitted to DSHS and appointing official.*
Ana Guerrero Gore Galveston	**Rita Hortenstine, Chair** Dallas
Char Hu, PhD Austin	**Eddie L. Patton, Jr., MD** Sugar Land
Mary Ellen Quiceno, MD, FAAN Dallas	**Terrence Sommers** Amarillo
Valerie J. Krueger Texas Health and Human Services Commission	**Toni Packard** Texas Health and Human Services Commission
Vacant Texas Department of State Health Services	**Staff** **Lynda Taylor, MSW** Texas Department of State Health Services