



**Texas Council on
Alzheimer's Disease
and Related Disorders
Biennial Report 2020**

DRAFT May 19

**As Required by
Texas Health and Safety Code,
Section 101.010**

**Texas Council on Alzheimer's
Disease and Related Disorders
September 2020**

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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 2019-2020 with additional information from 2018.

The following are highlights of the Council's activities.

- In 2018, the Council voted to
 1. approve grant funding in the amount of \$5,872,036.00 to support thirteen Texas Alzheimer's Research and Care Consortium (TARCC) research grants (see Appendix C), and
 2. elect Terrence Sommers as Council Vice Chair.

- In 2019:
 1. The Council voted to
 - a. approve the University of Texas Health Rio Grande Valley for membership to the Texas Alzheimer's Research and Care Consortium (TARCC), and
 - b. elect Eddie Patton, Jr., as Council Vice Chair.
 2. The Council Chair appointed Byron Cordes, Vaunette Fay, and Ana Guerrero Gore to a 3-person biennial report work group. The purpose of the work group is to take recommendations provided by the entire Council using an input form and condense duplicate recommendations to create a list for the entire Council to review. The work group will not have a quorum of the Council and will not vote on any matter.

- In 2020:
 1. Council members provided input for the biennial report discussion via individual email. DSHS convened the 3-person work group via conference call on February 25, 2020, to consolidate the Council

member input to send to the Council. The work group did not have a quorum of the Council and did not vote on any matter.

2. The Council identified the following recommendations for fiscal years 2021-2020:

NOTE TO COUNCIL: The recommendations the Council approves at the next Council meeting will be included here.

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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 2019-2020, with additional information from 2018, as well as recommended actions for 2021-2022.

2. Background

In 2020, an estimated 5.8 million Americans age 65 and older are living with Alzheimer's. In Texas, approximately 400,000 people age 65 and older have Alzheimer's.¹ 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 are appointed by the Health and Humans Services Commission (HHSC) and the Department of State Health Services (DSHS). For a list of Council members, see Appendix B.

¹ Alzheimer's Association. Alzheimer's disease facts and figures. <https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf>. 2020. Accessed April 13, 2020.

3. Council Activities – Fiscal Years 2019-2020

Over the biennium, the Council met three times: January 30, 2019; October 28, 2019; and April 1, 2020. The second meeting of calendar year 2020 will occur in the fall. Additional information from 2018 is included.

The following new Council members were appointed over the 2019-2020 biennium.

- November 2018
 - ▶ Sudha Seshadri
- July 2019
 - ▶ Jessica R. Hyde
- September 2019
 - ▶ Michael Gayle
- December 2019
 - ▶ Angela Turner
 - ▶ Laura DeFina (reappointed)
- Rita Hortenstine's term as Council Chair expired in December 2019.
- Marc Diamond was appointed Council Chair in December 2019.

The following individuals are no longer on the Council.

- Francisco Gonzalez-Scarano (stepped down July 2018)
- Toni Packard (retired 2018)

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

- The Council voted to approve \$5,872,036 in grant funding for TARCC sites. Appendix C lists the title of the grant, university recipient, principal investigator (PI), and approved grant amount (2018).
- The Council voted to include the University of Texas Health Rio Grande Valley as a member of TARCC (2019).

In 2018, the Council voted to elect Terrence Sommers as Vice Chair.

In 2019:

- The Council voted to elect Eddie Patton, Jr. as Council Vice Chair.
- The Council Chair appointed Byron Cordes, Vaunette Fay, and Ana Guerrero Gore to a 3-person biennial report work group. The purpose of

the work group is to take recommendations provided by the entire Council using an input form and condense duplicate recommendations to create a list for the entire Council to review. The work group will not have a quorum of the Council and will not vote on any matter.

In 2020:

- Council members provided input for the biennial report discussion via individual email. DSHS convened the 3-person work group via conference call on February 25, 2020, to consolidate the Council member input to send to the Council. The work group did not have a quorum of the Council and did not vote on any matter.
- In [REDACTED] 2020, the Council voted on [REDACTED] recommendations for the Biennial Report (2020).

4. Council Recommendations – Fiscal Years 2021-2022

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

NOTE TO COUNCIL: The recommendations and strategies the Council approves at the next Council meeting will be included here.

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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 2021-2022 include [REDACTED].

NOTE TO COUNCIL: Recommendations approved by the Council at the next Council meeting will be included here.

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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 |

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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 disease. Alzheimer's disease is thought to begin 20 years or more before symptoms develop.¹

In 2020, an estimated 5.8 million Americans age 65 and older are living with Alzheimer's.¹ In Texas, approximately 400,000 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 an estimated \$305 billion annually.¹ Texas ranks fourth in the number of Alzheimer's cases and second in the number of Alzheimer's deaths. Nearly 3.6 million of the estimated 5.8 million people age 65 and older with Alzheimer's are women and 2.2 million are men.¹ Women are more likely to have other dementias.¹

In 2019, there were more than 16 million unpaid caregivers in the U.S., most of whom were family members.¹ In Texas, approximately 1.45 million unpaid caregivers provided care to the approximately 400,000 individuals with Alzheimer's in 2019.¹ This equates to an estimated 1.65 billion hours of unpaid care at a cost of approximately \$21.6 billion per year.¹ Total payments for healthcare, long-term care, and hospice care for individuals with Alzheimer's and other dementias are projected to increase from \$305 billion in 2020 to more than \$1.1 trillion in 2050 (in 2020 dollars).¹

Progress Through Research and Advocacy

Research continues to expand our understanding of the causes of, treatments for, and prevention of Alzheimer's.² 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 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

² U.S. Department of Health and Human Services. National plan to address Alzheimer's disease: 2019 update. <https://aspe.hhs.gov/report/national-plan-address-alzheimers-disease-2019-update>. 2019. Accessed April 13, 2020.

the prevalence of the disease continues to climb, exacting huge human and economic burdens on Texas citizens and resources.

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

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

Byron Cordes, LCSW, C-ASWCM
San Antonio

Marc Diamond, MD, Chair
Dallas

Vaunette Fay, PhD
Houston

Char Hu, PhD
Austin

Mary Ellen Quiceno, MD, FAAN
Dallas

Terrence Sommers
Amarillo

Jessica R. Hyde, MS, CHES
Texas Department of
State Health Services

Michael Gayle, PT, DPT, MA, OCS
Texas Health and Human
Services Commission

Laura DeFina, MD
Dallas

Joe A. Evans, Jr.
Beaumont

Ana Guerrero Gore
Galveston

Eddie L. Patton, Jr., MD, Vice-Chair
Sugar Land

Sudha Seshadri, MD, DM
San Antonio

Angela Turner
Normangee

Valerie J. Krueger
Texas Health and Human
Services Commission

Staff
Lynda Taylor, MSW
Texas Dept. of State Health Services

Appendix C. Council Approved Grants for TARCC Sites

Longitudinal Continuation of Hispanic Cohort

- University of Texas (UT) Southwestern, UT Health Science Center San Antonio, Texas Tech University Health Science Center, UT Dell
- PI: John Hart, Jr., M.D.
- Amount: \$2,117,376

Assessing the utility and effectiveness of monitoring technology for reducing caregiver burden for Alzheimer's Disease

- Texas A&M University Health Science Center, University of North Texas Health Science Center, UT Dell
- PI: Marcia Ory, Ph.D.
- Amount: \$439,999

Immune profile investigations of Alzheimer's Disease

- UT Southwestern
- PI: Ryan Huebinger, Ph.D. (Junior Investigator)
- Amount: \$216,562

Tau seeding and strain identification across the spectrum of Alzheimer's Disease and Lewy Body pathology

- UT Southwestern
- PI: Trung Nguyen, Ph.D. (Junior Investigator)
- Amount: \$208,068

Diastolic dysfunction and the development of dementia

- UT Health Science Center San Antonio
- PI: Alicia Parker, M.D.
- Amount: \$220,000

Blood biomarker for Alzheimer's Disease & disease progression: Phospholipids

- UT Southwestern
- PI: Dwight German, Ph.D.
- Amount: \$484,237

Development of a blood test for Alzheimer's disease diagnosis

- UT Health Science Center at Houston
- PI: Sandra Pritzkow, Ph.D. (Junior Investigator)
- Amount: \$220,000

Epigenetic risk factors for age at onset of Alzheimer's & MCI and metabolic dysfunction among non-Caribbean Hispanics and non-Hispanic whites

- University of North Texas Health Science Center
- PI: Robert Barber, Ph.D.
- Amount: \$710,804

Establishing novel blood-based biomarkers for Alzheimer's Disease in the Texas Alzheimer's Research and Care Consortium

- UT Health Science Center San Antonio
- PI: Mitzi Gonzales, Ph.D. (Junior Investigator)
- Amount: \$220,000

Brain targeted RNAi therapy for Alzheimer's Disease

- University of North Texas Health Science Center
- PI: Sangram Raut, Ph.D. (Junior Investigator)
- Amount: \$211,970

Probing the role of glial endocytic genes and ROS on AB42-induced neurotoxicity

- Baylor College of Medicine
- PI: Hugo Bellen, D.V.M., Ph.D.
- Amount: \$383,020

Stem cell-derived anti-inflammatory treatment for Alzheimer's disease

- UT Health Science Center at Houston
- PI: Ines Moreno-Gonzalez, Ph.D. (Junior Investigator)
- Amount: \$220,000

Multi target combinatory therapy for Alzheimer's Disease

- UT Medical Branch at Galveston
- PI: Rakez Kayed, Ph.D.
- Amount: \$220,000