

# HHSC: <u>Texas Council on</u> <u>Alzheimer's Disease</u> <u>and Related Disorders</u>, October 12<sup>th</sup>, 2020



The <u>Texas Council on Alzheimer's Disease and Related Disorders</u> advises DSHS and recommends needed action for the benefit of people with Alzheimer's disease and related disorders and for their caregivers.

The Texas Council on Alzheimer's Disease and Related Disorders (Council) was established in 1987 by (<u>Health and Safety Code, Subtitle E., Chapter 101 (HB1066, 70R</u>). Members are appointed by the Governor, Lieutenant Governor, and Speaker of the House.

#### The Council shall:

- 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 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

Byron Cordes, LCSW, C-ASWCM	Laura DeFina, MD
San Antonio	Dallas
Marc Diamond, MD, Chair	Joe A. Evans, Jr.
Dallas	Beaumont
Vaunette Fay, PhD	Sudha Seshadri, MD, DM
Houston	San Antonio
Ana Guerrero Gore	Angela Turner
Galveston	Normangee
Char Hu, PhD	Eddie Patton, Jr., MD, Vice-Chair
Dallas	Sugar Land
Mary Quiceno, MD	Terrence Sommers
Dallas	Amarillo
Valerie J. Krueger	Michael Gayle, PT, DPT, MA, OCS
Texas Health and Human	Texas Health and Human
Services Commission	Services Commission
Kelly Fegan-Bohm, MD, MPH, MA	<u>Staff</u>
Texas Department of	Lynda Taylor, MSW
State Health Services	Texas Department of
	State Health Services

# Members are presented below.



**<u>Call to Order, Logistics, and Roll Call</u>**. The meeting was called to order by Dr, Diamond, Chair.

**Introductions**. Members introduced themselves and a quorum was established.

<u>Council Action to Amend Previously Adopted October 28, 2019, Meeting Minutes</u>. The revised minutes (revised date) were approved.

**Council Action on June 4, 2020, Meeting Minutes**. The minutes were approved as written.

**Department of State Health Services (DSHS) Representative Report**. HB1 funded a \$1 million public awareness campaign and it was released August 24<sup>th</sup>, 2019, in English and Spanish. The program webpage was redesigned to focus on family caregivers. In preparation for the legislative session, DSHS published two reports: Biennial report and Biennial update. Both are available <u>here</u>. In 2019, DSHS surveyed the Texas Alzheimer's Partnership and the results can be found at the above website.

Health and Human Services Commission (HHSC) representative report. The report was tabled for the next council meeting.

# Texas Alzheimer's Research and Care Consortium (TARCC) Representative Report.

Each SC member provides expertise, input, and guidance on the following key issues through quarterly conference calls and annual scientific meetings:

- Enhancing awareness of TARCC resources and activities
- Fostering collaborative TARCC data-use projects
- Monitoring and encouraging progress of each site's TARCC grants and providing semiannual summary reports to the TARCC Steering Committee
- Identifying and recruiting external reviewers for TARCC grant applications
- Reviewing TARCC sample and data requests
- Reviewing abstracts and proposals for TARCC scientific meetings
- Interacting with institutional personnel to promote TARCC
- Preparing presentations to the External Advisory Committee (EAC) during biannual review sessions

**TARCC Investigator Grants Program.** In 2018, with a mature database and upon recommendations from the EAC, TARCC moved from a cohort surveillance model to a grants-based program in order to support the best science in the state and enhance TARCC data utilization and productivity.

For the 2020 grant awards, a request for proposals (RFP) was issued with applications due March 20, 2020.



- A total of 69 applications was received, representing all TARCC participating institutions
- Two external (out of state) expert reviewers provided reviews using NIH-style criteria
- Scientific reviews and applications reviewed by the External Advisory Committee
- 2020 Funding recommendations are pending

#### Active Grant Projects – Awarded in 2018 and 2019

John Hart, Jr, MD – UT Southwestern, Texas Tech University Health Sciences Center, UT Health San Antonio, UT Austin Dell Medical School Longitudinal Continuation of TARCC Hispanic Cohort

Marcia Ory, PhD - Texas A&M University Health Science Center, University of North Texas Health Science Center, and UT Austin Dell Medical School Assessing the utility and effectiveness of monitoring technology for reducing caregiver burden for Alzheimer's Disease

Kelly Dineley, PhD – UT Medical Branch at Galveston Training Fellowship in Aging and AD Research and Care

Robin Hilsabeck, PhD – UT Austin Dell Medical School Neuropsychology Fellowship Program

Laura Lacritz, PhD – UT Southwestern Medical Center Neuropsychology of Dementia Fellowship

Robert Barber, PhD – University of North Texas Health Science Center Epigenetic risk factors for age at onset of Alzheimer's & MCI and metabolic dysfunction among non-Caribbean Hispanics and non-Hispanic whites

Hugo Bellen, DVM, PhD – Baylor College of Medicine Probing the role of glial endocytic genes and ROS on AB42-induced neurotoxicity

Dwight German, PhD – UT Southwestern Medical Center Blood biomarker for Alzheimer's Disease & disease progression: Phospholipids

Rakez Kayed, PhD – UT Medical Branch at Galveston Multi target combinatory therapy for Alzheimer's Disease

Alicia Parker, MD – UT Health San Antonio Diastolic dysfunction and the development of dementia

Mitzi Gonzales, PhD (Junior Investigator) – UT Health San Antonio



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

Ryan Huebinger, PhD (Junior Investigator) – UT Southwestern Medical Center Immune profile investigations of Alzheimer's Disease

Ines Moreno-Gonzalez, PhD (Junior Investigator) – UT Health Houston Stem cell-derived anti-inflammatory treatment for Alzheimer's disease

Trung Nguyen, MD, PhD (Junior Investigator) – UT Southwestern Medical Center Tau seeding and strain identification across the spectrum of Alzheimer's Disease and Lewy Body pathology

Sandra Pritzkow, PhD (Junior Investigator) – UT Health Houston Development of a blood test for Alzheimer's disease diagnosis

Sangram Raut, PhD (Junior Investigator) – University of North Texas Health Science Center Brain targeted RNAi therapy for Alzheimer's Disease

#### Productivity of the Grant Program

- Final steps of having full TARCC dataset available on the Global Alzheimer's Association Interactive Network
- 2019 2020: 2,414 samples sent to investigators
  - 17 data requests in 2020
  - 815 Plasma; 569 Serum; 1,030 DNA
- 2020 TARCC-related publications to date = 22 (35 in 2019)
- Since its inception, TARCC has helped garner \$100,613,930 in federal, foundation, and private grants
- This includes \$47,917,886 awarded since the current TARCC grants program started in 2018

#### TARCC Research Virtual Conference – SAVE THE DATE! Thursday January 28, 2021

- Focus on TARCC investigators, collaborators, and trainees
- Allows for TARCC grant recipients and their labs to share research via talks & posters
  - $\circ$  Awards for best posters!
  - Review latest findings on aging and dementia from TARCC sites
- Encourage introduction and collaborations within and across TARCC
- Update on TARCC database

TARCC is growing in national and international visibility and poised for scientific progress in the fight against dementia, a proud reflection upon Texas research. TARCC is establishing itself in the field through its scientific contributions and unique statewide collaborative approach. There is a need to build on the current momentum and ensure future of TARCC.



# <u>Council discussion and possible action on Council activities, Council's 2022 biennial</u> <u>report, and Council work group</u>\*

Council Duties in Health and Safety Code Chapter 101 The Texas Council on Alzheimer's Disease and Related Disorders (Council) was established in 1987 by Texas Health and Safety Code, Section 101.

The Council shall:

1. Advise the department and recommend needed action for the benefit of persons with Alzheimer's disease and related disorders and for their caregivers

2. Coordinate public and private family support networking systems for primary family caregivers

3. 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

4. Coordinate a volunteer assistance program primarily for in-home and respite care services

5. Encourage research to benefit persons with Alzheimer's disease and related disorders

6. Recommend to the Department disbursement of grants and funds available for the Council

7. Facilitate coordination of state agency services and activities relating to persons with Alzheimer's disease and related disorders

The TAC Reference is: <u>https://statutes.capitol.texas.gov/Docs/HS/htm/HS.101.htm</u>

#### The Table of Contents for the Biennial Report appears below



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Annendix B. TX Council on Alzheimer's Disease and Related Disorders

**Texas Council on Alzheimer's Disease and Related Disorders Biennial Report 2020 Summary and Introduction.** The Texas Council on Alzheimer's Disease and Related Disorders (Council) was established in 1987. Texas Health and Safety Code, Section 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, as well as recommended actions for 2021-2022.

The following are highlights of the Council's activities.

- In fiscal year 2019, the Council voted to approve the University of Texas Health Rio Grande Valley for membership to the Texas Alzheimer's Research and Care Consortium, and elect Eddie Patton Jr. as Council Vice Chair.
- In fiscal year 2019, the Council Chair appointed Byron Cordes, Vaunette Fay, and Ana Guerrero Gore to a three-person biennial report workgroup to be convened by the Department of State Health Services (DSHS) in early fiscal year 2020.
- In fiscal year 2020, Council members provided input for the biennial report via individual email. DSHS convened the three-person workgroup via conference call on February 25, 2020, to condense duplicate recommendations and consolidate the



Council member input to send to the Council for review. The workgroup did not have a quorum of the Council and did not vote on any matter.

In June 2020, the Council identified the following recommendations for fiscal years 2021-2022.

- Sustain and support ongoing coordinated Alzheimer's disease (Alzheimer's) research and research into improving the lives of families and caregivers of persons with Alzheimer's or related disorders.
- Continue support for quality care for persons with Alzheimer's and related dementias and their caregivers.
- Engage in strategic collaborations.
- Expand local caregiver services and supports.

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 disbursement of grants and funds available for the Council; and
- Facilitate coordination of state agency services and activities relating to persons with Alzheimer's disease and related disorders. Before September 1 of each evennumbered 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. This report outlines the activities of the Council in fiscal years 2019-2020 and their recommendations for 2021-2022.

Follow this link for the <u>Texas State Plan for Alzheimer's Disease 2019-2023.</u>

#### **Council Member Comments:**

• The question is always asked— should we be doing more especially regarding acute issues?



- We all will have our own perspective on how the state can play a strong role.
- Put something forward about how state money could be best used for near-term benefit.
- The main focus has been on research, yet it is only one of the seven mandates.
- We should look at COVID-19 and the impact isolation has had on patients.
- Have monthly calls to discuss issues.
- We do not know how COVID-19 will impact cognition.
- How do we get additional resources/funding?
- Form an exploratory subcommittee to address what other states are doing and examine the possibilities.
- How the council can better get involved in advocating for advancing Alzheimer's services.
- A timeline of three to five months was established for the work of the subcommittee.
- There might be an opportunity to educate the Council with the presentation from experts; experts and topics could be recommended by a subcommittee or through an email process, and then forwarded to the Chair and Vice Chair.

**<u>Council Action on Election of Vice Chair</u>**. The election process (including a roll call vote) was explained to the members and the process was adopted. Eddie Patton was elected Vice Chair.

**<u>Public comment</u>**. There were no public comments offered.

**<u>Announcements</u>**. There were no additional announcements.

**Adjourn**. There being no further business, the meeting was adjourned.

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This summary contains supplemental information from third-party sources where that information provides clarity to the issues being discussed. Not every comment or statement from the speakers in these summaries is an exact transcription. For the purpose of brevity, their statements are often paraphrased. These documents should not be viewed as a word-for-word account of every meeting or hearing, but a summary. Every effort has been made to ensure the accuracy of these summaries. The information contained in this publication is the property of the organization and is considered confidential and may contain proprietary information. It is meant solely for the intended recipient. Access to this published information by anyone else is unauthorized unless the organization grants permission. If you are not the intended recipient, any disclosure, copying, distribution or any action taken or omitted in reliance on this is prohibited. The views expressed in this publication are, unless otherwise stated, those of the author and not those of the organization or its management.