Texas Department of State Health Services

Texas Council on Alzheimer's Disease and Related Disorders (TCADRD)

APPROVED Meeting Minutes V.1 Tuesday, May 9, 2023 9:00 a.m.

Physical Location: Department of State Health Services Robert Bernstein Bldg., Room K-100 1100 49th Street Austin, TX. 78756 TEAMS Virtual Meeting

Table 1: Texas Council on Alzheimer's Disease and Related Disorders member attendance at theTuesday, May 9, 2023, meeting.

MEMBER NAME	YES	NO	MEMBER NAME	YES	NO
Mr. Byron Cordes	Х		Dr. Char Hu	Х	
Dr. Laura DeFina	Х		Ms. Valerie Krueger (Ex Officio)	Х	
Dr. Marc Diamond (Chair)	Х		Dr. Eddie L. Patton Jr. (Vice Chair)	Х	
Mr. Joe A. Evans Jr.	Х		Dr. Mary Quiceno		Х
Dr. Vaunette Fay	Х		Dr. Sudha Seshardi		Х
Dr. Kelly Fegan-Bohm (Ex-Officio)	Х		Mr. Terrence Sommers	Х	
Ms. Ana Guerrero Gore		Х	Ms. Angela Turner		Х
Dr. Michael Gayle (Ex Officio)	Х				

Yes: Indicates attended the meeting. No: Indicates did not attend the meeting.

Agenda Item 1: Call to Order, Logistics, Roll Call and Introductions

Dr. Marc Diamond, Chair, called the Texas Council on Alzheimer's Disease and Related Disorders (TCADRD) meeting to order at 9:00 a.m., welcomed attendees, introduced Department of State Health Services (DSHS) staff and the Health and Human Services Commission (HHSC) Advisory Committee Coordination Office (ACCO) staff. Dr. Diamond turned the meeting over to Ms. Kayla Cates-Brown, ACCO facilitator, to read the meeting logistical announcements and to conduct the member roll call. Ms. Cates-Brown stated the presence of quorum.

Agenda Item 2: Consideration of October 18, 2022, draft meeting minutes

Dr. Diamond referred members to the draft minutes from the October 18, 2022, meeting and called for any edits or discussion of the minutes. Hearing no discussion, Dr. Diamond requested a motion to approve the minutes.

MOTION: Mr. Byron Cordes moved to approve the draft October 18, 2022, minutes as presented in the meeting. Dr. Vaunette Fay seconded the motion. The minutes were approved by roll call vote with 8 yeas (Cordes, DeFina, Diamond, Evans, Fay, Hu, Patton, Sommers), no nays nor abstentions.

Agenda Item 3: Department of State Health Services (DSHS) representative report

Dr. Diamond introduced Ms. Rachel Wiseman, Director, Chronic Disease Unit, who provided members with the DSHS representative report.

Highlights of the report included: DSHS Council Liaison

- Julie Ketelsen, MPH, CHES, was hired in Chronic Disease Unit as a Council Liaison. In this role, she will coordinate and support multiple councils the Unit supports. She will be the main contact for Council members. Ms. Julie Ketelsen will coordinate the logistics of scheduling and conducting Council meetings, maintain the Council roster, welcome and train new Council members, facilitate the development of the Council's legislative report, and other logistical duties.
- Ms. Ketelsen will work in collaboration with Lynda Taylor who will continue with the Alzheimer's Disease Program (ADP) and provide guidance on the programmatic aspects of Council activities, such as the Council's legislative report.
- Ms. Ketelsen will be in contact with the Council after the May 9, 2023, meeting and will coordinate the fall Council meeting as well as activities related to subcommittees.

Building our Largest Dementia (BOLD) Public Health Grant

 On March 23, 2023, DSHS applied for a 5-year funding opportunity through the Centers for Disease Control and Prevention called "Building Our Largest Dementia (BOLD) Public Health Programs to Address Alzheimer's Disease and Related Dementias." This funding opportunity will fund public health departments to increase their capacity to contribute to the field of Alzheimer's Disease and Related Dementias (ADRD). Notification of award is expected by September 29, 2023. If awarded, grant activities would begin September 30, 2023.

House Appropriations Bill - Rider #33

• The House Appropriations Bill includes a rider increasing ADP's funding from \$1,000,000 over the biennium to \$10,000,000. The rider includes one full time employee, the continuation of campaign activities with an emphasis on

reaching healthcare providers, Behavioral Risk Factor Surveillance System (BRFSS) modules related to dementia, support for implementing the Texas State Plan for Alzheimer's Disease, and a competitive grants program for entities providing direct caregiver support and promoting early detection. Nothing is finalized yet. We must wait until the end of session for a confirmed budget allocation.

Texas State Plan for Alzheimer's Disease revision

 As required by Texas Health and Safety Code, Section 99A, the ADP will revise the Texas State Plan for Alzheimer's Disease (state plan) in 2023. Statute requires that the state plan be updated every five years. The revised state plan will be released by September 1, 2024. The ADP will send information to stakeholders about planning meetings for the revision.

Alzheimer's Awareness Campaign Update

 For fiscal years 2022 and 2023, DSHS is working with Sherry Mathews Group (SMG) to enhance the existing Alzheimer's disease awareness campaign. DSHS developed an educational booklet titled *A Family's Guide to Alzheimer's* as part of our Alzheimer's awareness campaign to support people when they and their families face a diagnosis or the possibility of an Alzheimer's diagnosis. The booklet includes information on early detection, starting a conversation when you notice the signs of dementia, getting a diagnosis, and how to find community resources. Versions in English and Spanish are now available in the Alzheimer's Campaign Toolkit on the ADP website.

Behavioral Risk Factor Surveillance System (BRFSS) Update

 BRFSS data for 2021 are now available on the DSHS website. You can query the BRFSS data, including data from the caregiving and cognitive decline modules. You can access the data using the Data Query System found at <u>www.dshs.texas.gov/chs/brfss</u>. You can also check on availability of data by contacting the ADP.

Agenda Item 4: Health and Human Services Commission (HHSC) representative report

Dr. Diamond introduced Dr. Michael Gayle, Deputy Associate Commissioner for Program Operations – QA, Regulatory Services Division – Long Term Care Regulation, who provided members with the HHSC representative report.

Highlights of the report included:

• Since January, the long-term care regulatory division provided four webinars related to dementia.

- Announced that he will be stepping down from his role on the Council.
- HHSC will be nominating Karen Keller as Dr. Gayle's replacement.

Agenda Item 5: Texas Alzheimer's Research and Care Consortium (TARCC) representative report

Dr. Diamond introduced Dr. C. Munro Cullum, PhD., Scientific Director of TARCC, who provided members with the TARCC representative report.

Highlights of the TARCC report included:

- Since TARCC converted to a grants-oriented program in 2018, over 200 applications have been received from all participating TARCC sites; 45 grants were awarded totaling over \$20 million dollars.
- In the last biennial investment of approximately \$8.5 million dollars, TARCC investigators generated more than \$37 million dollars in external funding.
- Approximately 90 publications, multiple book chapters, and over 150 posters have come out of TARCC.
- TARCC established a brain bank that is statewide with leadership based out of UT San Antonio and UT Southwestern.
- In January 2023, the annual conference took place in Austin and attended by over 150 people.

Members discussed the following:

- Data on number of investigators and grant submissions. A report regarding this information will be provided at a future meeting.
- Metrics on the number of junior vs senior investigators.
- Each institution has a steering committee representative that has information about TARCC and are charged with sharing that information with their respective institutions.
- A webinar or presentation educating new Alzheimer's programs across the state on how to apply for TARCC grants and research programs.
- TARCC funding must go to one of the TARCC sites. A non TARCC site could sub-contract with the primary TARCC site.
- The next TARCC Symposium will be on February 8, 2024 on the UT Austin campus.

Agenda Item 6: TCADRD discussion and possible action on TCADRD activities; TCADRD 2024 biennial report; TCADRD Bylaws; and TCADRD subcommittees

Dr. Diamond stated the Council will begin working on recommendations for the Council's 2024 biennial report. The Council will use a 4-person subcommittee to consolidate Council input, which is the same process used for the previous biennial report. Dr. Diamond appointed himself, Dr. Eddie Patton, Jr. and volunteers Dr. Sudha Seshadri and Dr. Vaunette Fay to the 4 person subcommittee.

Highlights of the discussion included:

- Ms. Lynda Taylor described the biennial report process and potential timeline.
- Dr. Patton provided an update regarding the TCADRD activities subcommittee
- The sub-committee will continue to pursue an issue brief on social isolation as related to Alzheimer's disease and related disorders.
- Ms. Rachel Wiseman led the member discussion and initial review of the draft TCADRD Bylaws.
- There were questions regarding wording such as coordinate, disseminate, etc. as tasks.
- This language is taken directly from statute.
- These duties are dependent on funding that is appropriated to the Council. If there is not funding, the Council is not able to complete the activities. Information is included in the bylaws to include what the legislature has outlined for the Council.
- The draft bylaws will be reviewed by DSHS legal and ACCO. The Council will potentially vote on the bylaws during the fall meeting.
- The DSHS Commissioner would consult with the Council if termination of a sub-committee was being considered.

Agenda Item 8: Public Comment

Ms. Kayla Cates-Brown announced written public comment had been submitted and shared with the members. Ms. Cates-Brown read the public comment announcement and coordinated with the ACCO production team to complete requests for registered public comment from stakeholders.

- Ms. Susan Eissler, volunteer ambassador for the Association for Frontotemporal Degeneration, provided testimony on the organization and an overview of the disease. She shared the economic costs of the disease when patients lose the ability to work and the significant impact on the family unit. House Bill 1673 requires caregivers in facilities to have a four hour training course in dementia. She would like frontotemporal degeneration content to be included in the training. The organization is a national non-profit that provides many resources to share with the community that are focused on educational awareness of the disease.
- Ms. Jessica Cunningham, caregiver for spouse with Huntington's disease, provided testimony on their caregiving journey with the disease. Ms. Cunningham advocated for increased access to Huntington's Disease

resources and more research funding to assist patients with quality of life, pharmacy and medical therapies.

Agenda Item 7: Health and Human Services Chief Ethics Officer Presentation

Dr. Diamond introduced Mr. David Reisman, Chief Ethics Officer, HHSC who provided members with an ethics presentation.

Highlights of the presentation included:

- Council members can let legislators know they are a member of the Council, but they are not advocating there for the Council.
- Sharing a personal experience is not a conflict of interest.
- If a Council member is asked to speak because of their role on the Council, they are not allowed to receive an honorarium or speaker fee.

Agenda Item 9: Announcements

Dr. Diamond announced the next meeting for the TCADRD will be scheduled for the fall of 2023.

Agenda Item 10: Adjournment

Dr. Diamond provided closing remarks, thanked members and staff, and adjourned the meeting at 10:37 a.m. CST.

Please click on the link to the archived HHSC webcast of the May 9, 2023, TCADRD meeting that will be available for viewing approximately two years from the date the meeting was posted on the HHS website and based on the HHSC records retention schedule. (To view and listen to the entirety of the meeting click on the link below)

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