



# **Texas Council on Alzheimer's Disease and Related Disorders**

**October 25, 2021**



[Texas Council on Alzheimer's Disease and Related Disorders](#) 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 [Texas Health and Safety Code, Section 101](#). 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

**2020 – 2021 Member Roster**

<b>Name</b>	<b>Membership Category</b>	<b>Term Expiration</b>	<b>Health Service Region</b>
Byron Cordes, LCSW, C-ASWCM, CMC	Public	2023	8
Laura DeFina, MD	Professional	2025	2/3
<b>Chair</b> Marc Diamond, MD	Professional/Physicians	2025	2/3
Joe A. Evans, Jr.	Public	2021	6/5S
Vaunette Fay, PhD, RN, FNP, GNP-BC	Professional	2021	6/5S
Ana Guerrero Gore	Public	2021	6/5S
Char Hu, PhD	Professional	2023	7
<b>Vice-Chair</b> Eddie L. Patton, Jr., MD	Professional	2021	6/5S
Mary Ellen Quiceno, MD, FAAN, FANA	Professional/Home Health	2023	2/3
Sudha Seshadri, MD, DM	Professional/Public Hospitals	2019	8
Terrence Sommers	Public	2023	1
Angela Turner	Public	2025	7
Kelly Fegan-Bohm, MD, MPH, MA	TX Dept. of State Health Services Representative	N/A	7
Valerie J. Krueger	TX Health and Human Services Commission Representative	N/A	7
Michael Gayle, PT, DPT, MA, OCS	TX Health and Human Services Commission Representative	N/A	7
<b>Staff</b> Lynda Taylor, MSW	N/A	N/A	N/A

**1. Call to order, logistics, roll call, and introductions.** The meeting was convened by Dr. Diamond, Chair.

**2. Consideration of March 23, 2021, draft meeting minutes.** The minutes were approved as written.

**3. Department of State Health Services (DSHS) representative report.**

- The requirement for maintaining a population data base of persons with Alzheimer's by DSHS was removed by the Legislature.
- Rules are being reviewed and will result in by laws
- The awareness campaign has been completed (See the Signs/Start a Conversation). Data was made available.
- \$1 million for the biennium was authorized for this Council
- 2021 Care Givers Survey has been developed. There were 360 responses

**4. Health and Human Services Commission (HHSC) representative report**

- 2021 Quality and LTC Conference was held and is available on the HHSC Website [HHS Learning Portal: All courses \(texas.gov\)](https://www.hhs.texas.gov/learning-portal)
- Alzheimer's and Dementia training in the future will be combined for providers.

**5. Texas Alzheimer's Research and Care Consortium (TARCC) representative report**

**TARCC Scientific Update,** Munro Cullum, PhD, ABPP

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

- TARCC scientific direction
- Enhancing awareness of TARCC resources and activities
- Fostering collaborative TARCC data-use projects
- Helping to generate local interest in collaborative projects and grant opportunities
- Encouraging and tracking TARCC grant applications from home institution
- Regular monitoring of progress of each site's TARCC grants and providing semi-annual summary reports to Steering Committee
- Identifying and recruiting external reviewers for TARCC grant applications

- Reviewing TARCC sample / data requests
- Reviewing abstracts and proposals for TARCC scientific meetings
- Interacting with institutional legislative personnel to promote TARCC
- Preparing their respective institution's presentation to the External Advisory Committee during biannual reviews

### **TARCC Investigator Grants Program Update**

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 2021 grant awards, a request for applications (RFA) was issued with applications due December 10, 2021. Please refer to focus areas in RFA handout.

*Most recent 2020 Investigator Grants Program received 69 applications and funded 16 projects.*

- Investigator Initiated Research Grant
- Collaborative Research Grant
- Junior Investigator Research Grant
- Postdoctoral Fellowship Grant
- Predoctoral Fellowship Grant

### **Active Grant Projects are Listed on the TARCC Website**

<http://www.txalzresearch.org/research/investigator-grant-awards/> All TARCC sites represented with funded projects. The investigator-initiated research grants program was designed to support an innovative, translational-based research structure across the state, including established and early-to-mid career scientists at TARCC member institutions

### **\$52,471,321 Awarded in TARCC Research Funding Since 2005**

\$6,529,703.93	Baylor College of Medicine (2005-2021)
\$2,789,085.50	Texas A&M University Health Science Center (2014-2021)
\$5,542,118.97	Texas Tech University Health Sciences Center (2005-2021)
\$9,402,049.88	University of North Texas Health Science Center (2005-2021)
\$1,718,023.60	UT Austin Dell Medical School (2016-2021)
\$1,954,261.20	UT Health Houston (2005-2009; 2018-2021)
\$611,281.80	UT Health Rio Grande Valley (2019-2021)
\$6,306,330.15	UT Health San Antonio (2009-2021)
\$750,000	UT Medical Branch at Galveston (2018-2021)
\$16,868,466.20	UT Southwestern Medical Center (2005-2021)

### **TARCC Recent Productivity**

- Since 2018, 33 research and fellowship grants have been awarded to TARCC member institutions, an investment of \$14.9 million into neurodegeneration research in the State of Texas
- This investment in TARCC has directly resulted in \$37,248,733 in additional NIH and Foundation-funded projects since the 2019 biennial period
- From 2020 – 2021 there were 4,568 TARCC samples sent to investigators from 23 approved data and sample requests
- Current sample inventory includes: 123,915 aliquots of plasma, 109,265 aliquots of serum, 27,323 aliquots of peripheral blood monocytes (buffy coats), and 4,292 aliquots of DNA. Data requests are reviewed to ensure optimal use of TARCC samples and maintenance of materials for additional requests
- 49 publications, 7 book chapters, 73 posters and talks, and 4 graduate level theses in the last two and a half years covering a wide range of scientific discoveries, from basic science to clinical outcomes

### **TARCC 2022 Scientific Symposium – January 27, 2022**

Planning has begun for the next TARCC Scientific Symposium **January 26-27, 2022** in **Austin**.

- January 26, 2022: The External Advisory Committee, headed by Ron Petersen from the Mayo Clinic, will lead an in-person review of TARCC activities and provide us with feedback and recommendations.
- January 27, 2022: Scientific Symposium at *UT Austin Alumni Center*
- Keynote by Sterling Johnson, PhD, *Professor of Geriatrics and Dementia, University of Wisconsin–Madison School of Medicine and Public Health*
- In Person and Virtual options are planned
- 2022 symposium promises to result in inspiring scientific exchanges and research

TARCC is growing in visibility nationally.

### **Grant Opportunities**

#### **Request for Applications**

Applications Due December 10, 2021 by 5pm CST (Anticipated funding to begin in the summer of 2022) Late applications will not be considered

The Texas Alzheimer's Research and Care Consortium (TARCC) is a collaborative research effort funded by the State of Texas as part of the Darrell K Royal Texas Alzheimer's Initiative. TARCC is

committed to excellence in Research and Care for Texans in an attempt to identify risk factors, diagnostic and prognostic indicators, and eventually, find a cure for Alzheimer's Disease (AD) and related disorders in our lifetime, and to expand the strategies aimed at combatting the epidemic of AD and related neurodegenerative disorders.

TARCC is now pleased to announce its FY2021 Request for Applications (RFA) as part of a research program to support an innovative, translational-based research structure across the state of Texas, and to ensure that a diverse pool of well-trained basic and translational researchers, and clinician-scientists are available in Texas to aid in the fight against Alzheimer's disease and related disorders.

This RFA is open to applications from scientists at TARCC member institutions:

- Baylor College of Medicine
- Texas A&M University Health Science Center
- Texas Tech University Health Sciences Center
- University of North Texas Health Science Center
- UT Health Science Center–San Antonio
- UT-Austin Dell Medical School
- UT Southwestern Medical Center
- UT Health Science Center–Houston
- UT Medical Branch at Galveston
- UT Rio Grande Valley School of Medicine. Applications will be submitted through ProposalCentral and more detailed instructions and specific links will be provided soon.

For detailed information please see: [Microsoft Word - 2021 TARCC Grants Program RFA.docx \(texas.gov\)](#)

## **6. TCADRD discussion and possible action on TCADRD activities, TCADRD's 2022 biennial report, and TCADRD work groups \***

The biennial report will be discussed today but there will not be a vote until the next meeting. The report will be finalized at the March meeting and will be submitted in September 2022.

**For discussion:** This compiled discussion chart of recommendations and strategies for the 2022 biennial report are from the biennial report work group conference call on August 11, 2021.

- As designated by Council chair Marc Diamond at the March 23, 2021, Council meeting, the DSHS convened a 4-person work group via conference call on

August 11, 2021. The chair appointed himself, Eddie Patton, Vaunette Fay, and Sudha Seshadri to the work group.

- The purpose of the work group was to take the recommendations provided by the entire Council using an input form (provided individually to DSHS by email) to condense duplicate recommendations and create a list for the entire Council to review. The work group did not have a quorum of the Council and did not vote on any matter.
- Council members who responded to the assignment for input are included.
- Last names of Council members are provided with their comments.

### **Recommendation 1**

**2020 Language:** 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.

**Council Input:** Keep

Cordes, DeFina, Fay, Fegan-Bohm, Hu

**Council Input:** Keep & Amend (in red)

(Patton) Amend: Sustain and support ongoing coordinated Alzheimer's disease (Alzheimer's) research and research into improving the lives of **persons with the disease, as well as the lives of** families and caregivers of persons with Alzheimer's or related disorders.

**Rationale:** Keep, Amend, or Delete

(Fay) This continues to be a major need and focus of the Council.

**Questions** None

### **Strategy 1 for Recommendation 1**

**2020 Language:** 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.

**Council Input:** Keep DeFina, Fay, Fegan-Bohm, Hu, Patton, Seshadri

**Council Input:** Keep & Amend (in red) (Cordes) Amend: 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.**

**Rationale:** Keep, Amend, or Delete (Seshadri) Statewide research initiatives increase the likelihood of providing answers specific for our population, patient characteristics (including race-, ethnic mix)



and healthcare system needs. Improve national funding and results in higher impact publications.

**Questions** (Cordes) Not sure we need to keep the 20+ year clause.

### Strategy 2 for Recommendation 1

**2020 Language:** Support research on Alzheimer's, both basic science research and clinical research, focusing on

- early detection,
- differentiation between Alzheimer's and related dementias,
- differentiation between diverse biological and environmental factors that contribute to cognitive dysfunction, and
- treatment and care for persons living with dementia and their caregivers.

**Council Input:** Keep Cordes, DeFina, Hu

**Council Input:** Keep & Amend (in red) (Fay) Keep – Comment: Feel we need to highlight and stress the clinical research component.

(Fegan-Bohm) Add bullet point: • well-being of caregivers for those with Alzheimer's including physical health, mental health and financial impact

(Patton) Add bullet point: • detection and understanding of the short-term and long-term cognitive effects of Covid 19 infection.

(Seshadri) Amend:

- Early detection and prevention
- ~~Differentiation between Alzheimer's and related dementias~~ Identifying all the contributing and modifying factors underlying each patient's dementia
- ~~Differentiation between~~ Understanding diverse biological and environmental factors (including social determinants of health) that contribute to cognitive resilience and dysfunction
- Treatment, and care, and support for persons living with dementia and their caregivers,
- Support city- state- wide dementia friendly initiatives to expand scope of contributions persons living with dementia can continue making to society

**Rationale:** Keep, Amend, or Delete (Fegan-Bohm) Add the bullet point as an additional area of ongoing research.

**Questions** None

### Strategy 3 for Recommendation 1

**2022 Language:** Support the incorporation of the Alzheimer's optional modules in the annual Texas Behavioral Risk Factor Surveillance System. The two Alzheimer's modules are the Caregiver Optional



Module and the Cognitive Decline Optional Module. Council Input: Keep Cordes, Fay, Fegan-Bohm, Hu, Patton, Seshadri Council Input: Keep & Amend (in red) (DeFina) Amend: Support the incorporation of the Alzheimer's optional modules in the annual Texas Behavioral Risk Factor Surveillance System. The two Alzheimer's modules are the **Alzheimer's and Related Dementia's** Caregiver Optional Module and the Cognitive Decline Optional Module.

**NOTE FROM DSHS:** We have asked about changing the BRFSS modules and learned that they are developed at a national level and are the same in all states.

**Rationale: Keep, Amend, or Delete** (DeFina) If these modules get added, the unique issues of caregiving for dementia should be focused on. The current caregiver module asks about Alzheimer's disease in its primary list and as a secondary condition which is great. The general caregiver module does not address the unique behavioral and social issues experienced by those who care give for those with dementia. However, I acknowledge that there needs to be interest in the caregiving research community to evaluate the answers.

**Questions** None

#### **Strategy 4 for Recommendation 1**

**2020 Language:** Support efforts to bring to Texas one or more National Institute on Aging funded Alzheimer's Disease Research Centers, and other similar national organizations.

**Council Input:** Keep DeFina, Fay, Fegan-Bohm, Hu, Patton, Seshadri Council Input: Keep & Amend (in red) (Cordes) Comment: Keep and possibly emphasize in some way (i.e., Texas has the 4<sup>th</sup> highest percentage of dementia caregivers in the US, yet 21 other states have an ADRC...)

**Rationale: Keep, Amend, or Delete** None

**Questions** None

#### **Strategy 5 for Recommendation 1**

**2022 Language:** Establish a statewide brain banking system.

**Council Input:** Keep Cordes, DeFina, Fay, Fegan-Bohm, Hu, Patton

**Council Input: Keep & Amend** (in red) (Seshadri) Amend: Establish a statewide brain banking system, **and support and grow Hispanic and other minority participation in statewide brain banking system.**

**Rationale:** Keep, Amend, or Delete None

**Questions** None

**NEW Strategies to consider for Recommendation 1** to include in the 2022 Biennial Report **New Strategy 6.** Patton: Establish a research information center so that both patients and physicians can locate research efforts throughout the state.

Rationale Patton: Increase awareness about research efforts to increase enrollment.

**New Strategy 7.** Seshadri: Initiate surveillance for long-term sequelae of SARS-CoV-2 on brain structure and function

Rationale Seshadri: Impact of COVID on future cognition appears likely to be significant and Hispanics, indigenous persons and African Americans may be at highest risk.

## **Recommendation 2**

2020 Language: Continue support for quality care for persons with Alzheimer's and related dementias and their caregivers.

**Council Input:** Keep Cordes, DeFina, Fegan-Bohm, Hu

**Council Input:** Keep & Amend None

**Rationale:** Keep, Amend, or Delete None

**Questions** None

### **Strategy 1 for Recommendation 2**

**2020 Language:** Promote interdisciplinary education of health professionals, first responders, and other essential personnel on how to interact with persons with dementia, management of behaviors (e.g., anxiety, aggression, wandering, etc.) through behavior modification, environmental modifications and medication use, and promoting dementia friendly concepts.

a. Work with city and county officials to promote the concept of dementia friendly cities and communities.

b. Support programs that center on education of police, first responders, and other essential personnel on how to deal with persons with dementia.

**Council Input:** Keep Cordes, DeFina, Fay, Fegan-Bohm, Hu, Patton, Seshadri Council Input: Keep & Amend None

**Rationale:** Keep, Amend, or Delete (Seshadri) Population is aging and there is growing emphasis on aging at home; needs higher level of awareness.

**Questions** None

### **Strategy 2 for Recommendation 2**

**2020 Language:** Support the development of quality care tailored to the needs of persons with dementia and the inclusion of family caregivers in decision making. Recognize and accommodate the needs of diverse populations including the effects of culture, language, and socioeconomic background.

**Council Input:** Keep Cordes, DeFina, Fay, Fegan-Bohm, Hu, Patton

**Council Input:** Keep & Amend None

**Rationale:** Keep, Amend, or Delete None

**Questions** None

### **Strategy 3 for Recommendation 2**

**2020 Language:** Promote the [Alzheimer's Association Dementia Care Practice Recommendations Supplemental issue of The Gerontologist](#). The Dementia Care Practice Recommendations outline recommendations for quality care practices based on a comprehensive review of current evidence, best practices, and expert opinions.

**Council Input:** Keep Cordes, DeFina, Fegan-Bohm, Hu, Patton

**Council Input:** Keep & Amend None

**Rationale:** Keep, Amend, or Delete None

**Questions** None

### **Strategy 4 for Recommendation 2**

**2020 Language:** Promote the Alzheimer's awareness campaign as funded by the 2020-2021 General Appropriations Act, House Bill (HB) 1, 86th Legislature, Regular Session, 2019. HB 1 allocated \$1 million in funding specifically for the development and implementation of a public awareness campaign for Alzheimer's.

**Council Input:** Keep DeFina, Hu Council Input: Keep & Amend (in red) (Cordes) Keep – Comment: I would like to see us advocate for increased funding. (Fay) Keep – Comment: Amend to reflect the most current passage in April 2021 in 87th legislature regular session.

**NOTE FROM DSHS:** Senate Bill (SB) 1, 87th Legislature, Regular Session 2021 allocated \$1 million to continue the Alzheimer's awareness campaign over the FY22- 23 biennium.

**Rationale:** Keep, Amend, or Delete None

**Questions** (Patton) Do we have access to these funds for the creation of education material?

**NOTE FROM DSHS:** These funds may only be used for the campaign.

### **Strategy 5 for Recommendation 2**

**2020 Language:** Enhance the Department of State Health Services (DSHS) Alzheimer's Disease Program website by providing additional resources specifically for health care professionals.

**Council Input:** Keep DeFina, Fegan-Bohm, Hu, Patton,

**Council Input:** Keep & Amend (in red) (Cordes) Keep – Comment: Recognize that some of this work has been done.

**Rationale:** Keep, Amend, or Delete None

**Questions** None

### **Recommendation 3**

**2020 Language:** Engage in strategic collaborations.

**Council Input:** Keep Cordes, DeFina, Fegan-Bohm, Hu

**Council Input:** Keep & Amend None

**Rationale:** Keep, Amend, or Delete None

**Questions** None

### **Strategy 1 for Recommendation 3**

**2020 Language:** Encourage partnerships between state and county medical organizations and other stakeholders to promote research and awareness campaigns with an emphasis on geographic areas with the greatest need.

**Council Input:** Keep Cordes, DeFina, Fegan-Bohm, Hu, Patton, Seshadri

**Council Input:** Keep & Amend (in red) (Fay) Amend: Encourage partnerships between state and county ~~medical~~ **health professional** organizations and other stakeholders to promote research and awareness campaigns with an emphasis on geographic areas with the greatest need. (See rationale)

**Rationale:** Keep, Amend, or Delete (Fay) Amend with “health professional” to make it more interdisciplinary and inclusive.

**Questions** None

### **Strategy 2 for Recommendation 3**

**2020 Language:** Promote the Alzheimer’s Association and Centers for Disease Control and Prevention’s [Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map \(cdc.gov\)](#) 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.

**Council Input:** Keep Cordes, Fay, Fegan-Bohm, Hu, Patton, Seshadri

**Council Input:** Keep & Amend (in red) (DeFina) Keep – Amend: Promote the Alzheimer’s Association and Centers for Disease Control and Prevention’s Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map, to promote brain health as a vital component of public health, to increase the number of Texans who recognize the direct impact physical health can have on brain/cognitive health, **and to increase caregiving resources available for Texans.**

**Rationale:** Keep, Amend, or Delete None

**Questions** None

### **Strategy 3 for Recommendation 3**

**2020 Language:** Support and promote the [Texas State Plan for Alzheimer's Disease 2019-2023](#)

(state plan). Texas Health and Safety Code, Section 99.001 directs DSHS to develop and implement a state plan for education on and treatment of Alzheimer's and other dementias. The state plan will be reviewed and modified as necessary every five years.

**Council Input:** Keep Cordes, DeFina, Fay, Fegan-Bohm, Hu, Patton, Seshadri

**Council Input:** Keep & Amend None

**Rationale:** Keep, Amend, or Delete None

**Questions** None

#### **Strategy 4 for Recommendation 3**

**2020 Language:** Invite local representatives to speak at Council meetings about how they are implementing the state plan.

**Council Input:** Keep Cordes, DeFina, Fay, Fegan-Bohm, Hu, Patton, Seshadri

**Council Input:** Keep & Amend None

**Rationale:** Keep, Amend, or Delete None

**Questions** None

#### **Recommendation 4**

**2020 Language:** Expand local caregiver services and supports.

**Council Input:** Keep Cordes, DeFina, Fegan-Bohm, Hu

**Council Input:** Keep & Amend None

**Rationale:** Keep, Amend, or Delete None

**Questions** None

#### **Strategy 1 for Recommendation 4**

**2020 Language:** Strengthen the DSHS Alzheimer's Disease Program and its role in providing support and resources for persons living with the disease, caregivers, and health care professionals.

**Council Input:** Keep Cordes, DeFina, Fay, Fegan-Bohm, Hu, Patton, Seshadri

**Council Input:** Keep & Amend None

**Rationale:** Keep, Amend, or Delete None

**Questions** None

#### **Strategy 2 for Recommendation 4**

**2020 Language:** 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.

**Council Input:** Keep Cordes, Fay, Fegan-Bohm, Hu, Patton, Seshadri

**Council Input:** Keep & Amend (in red) (DeFina) Keep - Amend: **Continue to** 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.

**Rationale:** Keep, Amend, or Delete (DeFina) This is minor, but the website is enhanced so we want it to continue to be managed and updated as needed by the science and available service.

**Questions** None

**NEW Strategies to consider for Recommendation 4** to include in the 2022 Biennial Report

**New Strategy 3.** Patton: Work with DSHS to create educational material concerning the long-term cognitive effects of Covid 19 post Covid syndrome.

**New Strategy 4.** Seshadri: Track if services are reaching most disadvantaged zip codes, persons.

**Comments/Questions:** (DeFina) My suggestions are minor and focus on caregiving which is not my area of expertise. However, during the pandemic, it is critical to ensure that focus on Alzheimer's and Related Dementias caregiving is maintained. Additionally, I have no additions at this time as I believe that during the pandemic, we should continue to ensure that the existing priorities are considered in light of the added impact of the pandemic.

**Comments for Appendix A** (Cordes) Consider including [texas-alzheimers-facts-figures-2021.pdf](https://www.alz.org/files/2021/04/texas-alzheimers-facts-figures-2021.pdf) 1- pager from the Alzheimer's Association. No other comments were provided by Council members

**Update on Workgroup Activities:**



**Texas Council for Alzheimer's Disease and Related Disorders  
Activities Work Group Conference Call Meeting – September 3, 2021  
9:00am**

**Meeting Notes**

**Attendees:**

Eddie Patton, Jr.  
Byron Cordes  
Sudha Seshadri  
Michael Gayle  
Lynda Taylor

**The purpose of the workgroup** meeting was to discuss and create a list of possible actions for the Texas Council on Alzheimer's Disease and Related Disorders (Council) to consider regarding Alzheimer's disease and other dementias. There was no quorum, and the workgroup did not vote on any matter. The workgroup engaged in an informal discussion about various topics of interest. Notes were captured during the call and will be shared with the Council to solicit additional feedback.

**Themes for Action**

The following themes were captured during the discussion:

- **Help people newly diagnosed and their caregivers – Tell the story of the "patient journey"**
  - Because providing education and information about what to do after receiving a diagnosis of dementia is a great need, the idea for an educational video about what to do was proposed for people diagnosed with Alzheimer's and for their caregivers.
  - The video would also serve as education for physicians to know what families need.
  - Emphasize to the audience that there are things they can do.
- **Impact of social isolation on people with dementia and their caregivers**
  - Address the need to provide information to family caregivers who provide support to a loved one with dementia remotely during the COVID pandemic as well as families who provide care from a distance at any time.

**Proposed Initial Activities**

- **Educational video about the "patient journey"**
  - Propose to the Council that they explore the possibility of creating an educational video.
  - The video could be guided by questions such as the following:
    - What do people diagnosed with Alzheimer's and their family caregivers need the most? And at what stages?
    - What is the big picture – how do they handle the situation?
    - What is the easiest way to provide this information to them, especially when first diagnosed?
    - What do healthcare professionals need to know to help their patients?
  - Explore partnership and/or funding possibilities to create the video.
    - Explore working with the Texas Alzheimer's Research and Care Consortium (TARCC) and its research institutions.
- **Issue brief on the impact of social isolation for people with dementia and their caregivers regarding the COVID pandemic and general caregiving at a distance**
  - Propose to the Council that they address this topic in the format of an issue brief.
  - This format would make it easier for Council members to research and write about social isolation and work with Department of State Health Services (DSHS) staff to include in the program website.
  - All materials must go through DSHS review and editing and must also adhere to DSHS communication guidelines. This includes writing in plain language and fully citing information. The process can take several months.
  - The work group will begin researching source material and provide an update at the next Council meeting.

**END OF NOTES**

Include any new ideas below:





There was discussion regarding the videos and that there may already be videos available for use. It was suggested that we look into what is already out there. "We do not have a budget to support this".

**MOTION:** Proceed with the possibility of a Texas Specific video (explore further) prevailed.

**MOTION:** Develop an issue brief on social isolation as described above prevailed.

**7. Election of vice chair** Using a standard procedure adopted by the council, Eddie Patton Jr. was elected vice chair. The Chair is selected by the governor.

**8. Public comment** No public comment was offered.

**9. Announcements.** No announcements were made

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

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