

Texas Council on Alzheimer's Disease and Related Disorders



Biennial Report 2000

J. C. CHAMBERS
Chairman, Texas Board of Health

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Executive Deputy Commissioner

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Message from the Chairman of the Texas Council on Alzheimer's Disease and Related Disorders

On behalf of the Texas Council on Alzheimer's Disease and Related Disorders, I am pleased to present this report of recent activities. The Alzheimer's Council was created by the Texas Legislature in 1987 to address the needs of the increasing number of Texans who have Alzheimer's disease and those who care for them.

Alzheimer's is a disease which destroys the brain, robbing those affected of memory and judgment, leaving them totally incapable of functioning on their own, cognitively or physically. Alzheimer's disease continues to have a devastating impact on Texans. The statistics are alarming.

- ▶ 280,000 people in Texas have Alzheimer's disease or a related disorder.
- ▶ 552,000 Texans are projected to have Alzheimer's disease by 2025, unless a cure or prevention is found.
- ▶ One in ten Texans over 65, and nearly half of those over 85 have Alzheimer's disease.
- ▶ One in three Texas families is impacted by the emotional, physical, and financial devastation that Alzheimer's disease leaves in its wake.

With increasing life expectancy and continued population growth in Texas, the number of people affected by diseases of aging, including Alzheimer's and related disorders, will skyrocket this century in the absence of prevention or cure.

The Alzheimer's Council is committed to recommending needed action for the benefit of persons with Alzheimer's disease and their caregivers; working collaboratively with other public agencies and private organizations to identify and address issues and gaps in services; and promoting statewide coordinated research to help identify preventive measures, effective treatment, and one day, a cure for this debilitating and terminal disease.

James W. Hinds
Chairman

Alzheimer's Disease: A Growing Concern for Texans

Alzheimer's Disease (AD) is a devastating illness that is rapidly becoming one of the major health issues in America. Currently, 4 million Americans have AD and that number is projected to exceed 14 million by the middle of this century. In Texas, 280,000 individuals have AD; that number is expected to reach 552,000 by 2025, unless a cure or prevention is found.

AD is a progressive degeneration of the brain that causes a steady decline in memory, thinking and behavior which becomes severe enough to interfere with everyday life. How rapidly the disease progresses varies from person to person, but all sufferers experience confusion, personality changes and impaired judgment; eventually they can no longer care for themselves. AD is a terminal illness: As the disease progresses, more and more of the brain is affected, and eventually the areas that control basic life functions, like swallowing and breathing, become irreversibly damaged. Although there are medications that may alleviate some of the symptoms, there is at present no prevention or cure for the disease.

AD is the most common cause of dementia in people age 65 and older. According to the National Alzheimer's Association, one in ten people over 65, and nearly half of those over 85 have AD. These numbers gain significance when they are placed against the backdrop of increasing life expectancy. Currently, 13 percent of the United States population are 65 or older. The U.S. Bureau of Census estimates that this percentage will accelerate rapidly beginning in 2011, when the first baby boomers reach age 65, and will reach 18 percent of the total population by 2025. With this expected growth in the aging population, the number of people affected by diseases of aging, including Alzheimer's, will surge exponentially in the absence of prevention or cure.

An increase in the number of individuals with this debilitating disease would significantly effect an already economically and emotionally burdened society. According to the National Alzheimer's Association, AD currently costs the United States \$100 billion a year. Neither Medicare nor private health insurance cover the type of long-term care most patients need. In fact, seven out of 10 people with AD are cared for at home, often by an elderly spouse whose own health may be at risk, or by adult children who have competing demands of child care or jobs outside the home.

One in three Texas families is affected by AD. As this insidious disease slowly robs an individual of his identity, family members also suffer the loss of their loved one. Financial constraints, changes in roles and lifestyle, and caregiver stress place further burden on families. The impact of AD on the lives of individuals and families, the health care system, and society as a whole is enormous. The challenge to find the cause, prevention and cure for AD is imperative. Texas and the United States must make a firm commitment to step up AD research efforts and provide increased community support for individuals with AD and those who care for them.

Advances in Alzheimer's Disease Research

Although the risk of Alzheimer's disease (AD) increases with age, AD is not a normal part of aging. AD and other dementias are diseases that affect the brain. At present it is not known what causes AD; however, there is considerable research being conducted worldwide to find the cause and treatment or prevention of this disease. At the last international meeting on research on AD, there were over 1300 presentations by scientists working on this problem, with considerable excitement about the new findings that were discussed.

Much has been learned about AD. During the disease process, the brain of a patient develops characteristic signs of the disease. These are plaques (aggregates of material that accumulate around dying neurons) and tangles (twisted fibers found within neurons). Understanding why neurons in the brain lose their connections and die, leaving the plaques and tangles, is key to understanding what causes this disease.

Much research is being conducted on the plaques and tangles to understand how and why they are formed. It is thought that a longer form of one of the proteins (the beta amyloid peptide) accumulates within the plaques. Pharmaceutical companies are looking at compounds that prevent this longer form from occurring, with the idea that they may be able to prevent the formation of the plaques. One of the proteins (termed tau) in the neurofibrillary tangles has been modified from the normal state; in its abnormal state, it causes the tangles to form. This abnormality of tau may be a cause of a form of dementia in which the patient has language and behavioral problems before loss of memory (the Frontotemporal dementias).

There are genetic factors that are also involved in the disease. These genetic factors may be causative or risk factors. In some families where multiple members are affected with the disease, there is a genetic cause. Three genes have been identified as being mutated or changed in patients who develop clinical signs before the age of 65 years. These early-onset cases account for about five percent of the Alzheimer's cases. Most patients develop the clinical signs after the age of 65 years.

The genes APOE4 and APOC1 A are risk factors for AD: about 40 to 45 percent of patients have both APOE4 and APOC1 A. Studies conducted at the Texas Tech University Health Sciences Center indicate that late-onset AD may be very complex; multiple genes may be involved. The goal of these studies is to identify the mutated genes and then correlate the clinical symptoms with the genetic findings; it is believed that this is key to future treatment or prevention.

Scientists are working on a vaccine which they have found removes the plaques in an animal model of AD. They are in phase I clinical trials in humans to determine whether the drug is safe. Initial results are promising.

Other researchers are studying what happens during the aging process; that is, can they document a buildup of chemicals such as free radicals that cause damage to the neurons. There are also studies on whether inflammation may play a role in damaging neurons. Thus there are clinical trials evaluating the effects of vitamin E (which would interact with the buildup of chemicals) and ibuprofen (to fight inflammation) on the disease process.

Different groups of Alzheimer's patients may have distinct responses to the various drugs that are on the market or will be coming soon to the market. One group of Alzheimer's patients may be helped by a drug while a second group may not be helped. Medical treatment will have to be designed to meet individual needs at multiple stages of the disease process. This type of pharmacogenomics will help the families by customizing medicines for their loved ones and reducing the expense of paying for inappropriate medicines.

The long-term goal of all these studies is to understand what causes this disease and to identify patients early before clinical symptoms start. It is only through research that we will find the cause, prevention, and cure for this devastating disease. Until the cure is found, clinical and behavioral research will help us enhance the quality of life for patients and caregivers.



Texas Council on Alzheimer's Disease and Related Disorders

History and Overview

Recognizing the need for additional research and health care services for persons and families affected by Alzheimer's disease in Texas, the 69th Texas Legislature passed HCR-88. This resolution encouraged the Texas Department of Health to organize and develop an Alzheimer's network and provide supportive and educational programs to help patients and families cope with Alzheimer's disease (AD).

In 1987, the 70th Texas Legislature passed House Bill 1066, which created the Texas Council on Alzheimer's Disease and Related Disorders (Council). The Council was established to serve as the state's advocate for persons with Alzheimer's disease and those who care for them.

Council Mission

- ▶ *Recommend needed action for the benefit of persons with Alzheimer's disease and related disorders and their caregivers.*
- ▶ *Disseminate information on services and related activities to the medical and academic communities, caregivers, advocacy associations, and the general public.*
- ▶ *Coordinate services and activities of state agencies, associations, and other service providers.*
- ▶ *Encourage statewide coordinated research.*

The Council is composed of sixteen members who are appointed by the Governor, the Lieutenant Governor, and the Speaker of the House. The Council includes five public members, seven professional members, and four members representing respectively the Texas Department of Health, Texas Department on Aging, Texas Department of Mental Health and Mental Retardation, and Texas Department of Human Services.

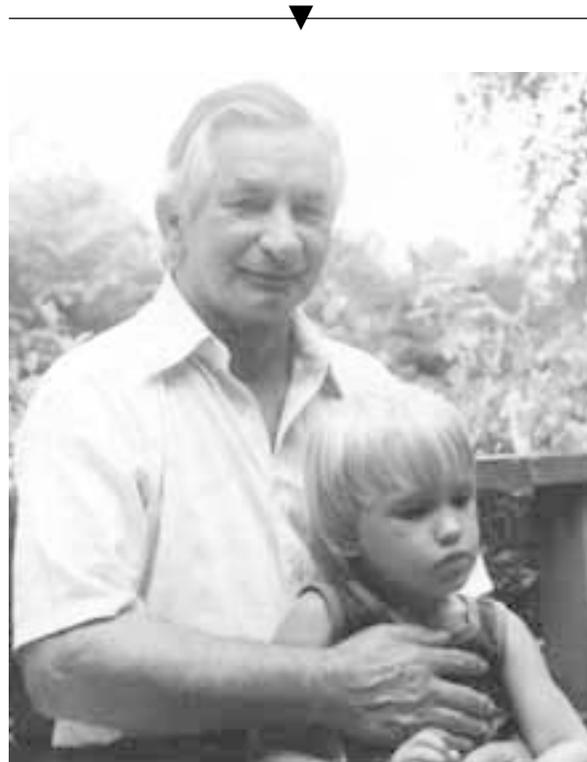
The first official meeting of the Council was held in Austin, Texas on January 18, 1988. Members began to address the mission of the Council, which is to provide a position of leadership in recommending needed action for the benefit of persons with AD and their caregivers; disseminate information on services and related activities to the medical and academic communities, caregivers, advocacy associations, and the general public; coordinate services and activities of state agencies, associations, and other service providers; and encourage statewide coordinated research.

Since its inception, the Council has worked to develop a growing awareness of the tremendous toll that this disease takes on Texas families and the individuals and institutions that are working to both eliminate this disease and care for those with AD. Awareness and education efforts include production of a biannual newsletter, "Texas Alzheimer's News," written in collaboration with the

Alzheimer's Association Coalition of Texas; maintenance of a toll-free information line and Web site; distribution of comprehensive informational packets to the public and health professionals; co-sponsorship of community education activities; and planning and conducting periodic statewide conferences. "Texas Alzheimer's News" is distributed to more than 4,000 adult day care, assisted living and nursing facilities, physicians, ombudsmen, and family caregivers. It is also available on our Web site: <http://www.tdh.state.tx.us/osp/alz.htm>, which receives more than 600 hits per month. Over 300 calls for technical assistance and referral to community services are received each month on the toll-free information line, and some 75 packets are mailed to requestors each month.

In legislative efforts, the Council was instrumental in establishing voluntary certification of long-term care facilities serving individuals with AD and in establishing a Consortium of Alzheimer's Disease Centers in Texas. An annotated listing of key Alzheimer's disease legislation is included as Appendix E.

The Council, in its efforts to coordinate the Alzheimer's services and activities of state agencies and associations, has formed solid partnerships with many service organizations, including the Alzheimer's Association, the Texas Department of Human Services, the Texas Department on Aging, and the Texas Department of Mental Health and Mental Retardation. The Council has partnered with and supported the legislative agendas of these organizations. In return, the agencies have demonstrated commitment and support of Council activities.



Council Activities

Consortium of Alzheimer's Disease Centers

House Bill 1504, passed during the 76th legislative session in 1999, directed the Texas Council on Alzheimer's Disease and Related Disorders (Council) to establish a Consortium of Alzheimer's Disease Centers (Consortium) in Texas. The Consortium is initially composed of Alzheimer's Disease Centers at Baylor College of Medicine, Texas Tech University Health Sciences Center, University of North Texas Health Science Center at Fort Worth, and University of Texas Southwestern Medical Center. The purpose of the Consortium is to create a systematic approach to the provision of uniform clinical services and to the sharing of research data. Specifically, the Consortium will:

- Offer clinical services to all patients of the Consortium's clinical centers, notwithstanding the independent status of each participant;
- Establish a database to:
 - Make data available to Consortium centers;
 - Provide a resource index to facilitate research projects; and
 - Provide data on patient health outcomes to appropriate state agencies and to researchers in Texas; and
- With the aid of the Council and the National Alzheimer's Association and its Texas chapters, develop and distribute to patients, caregivers, and healthcare professionals educational materials and services, and inform patients of any research projects and therapeutic trials open for their participation.

As directed by H.B. 1504, the Council established a steering committee for the purpose of advising the Council on activities related to the Consortium. The steering committee is composed of a representative from each of the four centers and the Chairman of the Council. See Appendix C.

General Counsel at the Texas Department of Health, with guidance from the steering committee, drafted a Memorandum of Understanding (MOU) delineating roles and responsibilities of the Council and the Consortium. The MOU was adopted by all four participating centers. See Appendix D.

Because new appropriated funds did not accompany H.B. 1504, the Council requires a focus on efforts to secure monies to fully implement the provisions of the legislation. Among these provisions are:

- Provide funds to Consortium participants to assist them in developing clinical centers that meet the standards of the Consortium.
- Establish a data coordinating center to be based at Texas Tech University Health Sciences Center, including personnel to administer and coordinate data collection, analysis, and dissemination.
- Develop, print and distribute educational materials to professional and family caregivers, patients, and the public.
- Conduct site visits and ongoing evaluation of Consortium activities.

According to H.B. 1504, the Council may receive state appropriated funds for the purpose of supporting the research activities of the Consortium. The Council may also solicit and accept gifts, grants, and donations for the Consortium. Efforts in 2001 will be directed toward acquiring appropriate development and operating funds for the Consortium.

Alzheimer's Disease in the New Millennium: Developing a Community of Care

The Council planned and conducted a statewide conference for professional and family caregivers and individuals interested in the treatment and care of Alzheimer's patients on April 27 and 28, 2000. This comprehensive, cutting edge conference included the latest research and treatment options for AD; effective models of care through the stages of AD; and special training sessions for healthcare facility staff and family caregivers. Topics included: advances in treatment and care; the latest in genetic research; legal, financial, ethical, environmental, behavioral, and cultural diversity issues; validation therapy; and care options, quality indicators, and community resources. Speakers included: Marcelle Morrison-Bogorad, Ph.D., National Institute on Aging, Rachelle Smith Doody, M.D., Ph.D., Baylor College of Medicine, Shirley E. Poduslo, Ph.D., Texas Tech University Health Sciences Center, Myron Weiner, M.D., University of Texas Southwestern Medical Center, Naomi Feil, M.S.W., Validation Therapy Institute, and numerous other experts in the treatment and care of individuals with AD and related disorders.

The two-day program drew approximately 300 participants from across the state, including physicians, healthcare facility administrators, nurses, social workers, case managers, activity directors, home health aides, state/county/city employees working with programs for older individuals, ombudsmen, gerontology, medical, nursing, and social work students, and family caregivers. The educational format included lectures, discussion, questions and answers, interactive breakout sessions, panels, case studies, and exhibits demonstrating care options. Continuing education credits were awarded for multiple disciplines.

Participant feedback was extremely positive, with some saying it was the best conference they had attended in many years. The Council plans to build on the success of this conference and the two preceding conferences held in 1993 and 1997 by continuing to offer biennial statewide programs.

Texas Alzheimer's News

The Council is collaborating with the Alzheimer's Association Coalition of Texas (AACT) to produce a biannual newsletter called "Texas Alzheimer's News." The first edition was published in winter 1999, with subsequent issues produced in summer 2000 and winter 2000. Council and Coalition members, along with experts in the field of AD and related dementias, contribute articles of interest to professional and family caregivers. Regular columns include: legislative update; best practices for the treatment and care of AD and related disorders; caregiver profile; and community events and resources. Feature articles have included: research updates; risk factors contributing to the



development of AD; diagnosing AD; understanding and responding to challenging behaviors; and activities planning for Alzheimer's patients. The publication is distributed to some 4,000 adult day care, assisted living and nursing facilities, ombudsmen, physicians, and family caregivers. Issues of Texas Alzheimer's News are also available on the Web at <http://www.tdh.state.tx.us/osp/alz.htm>.

Public Education

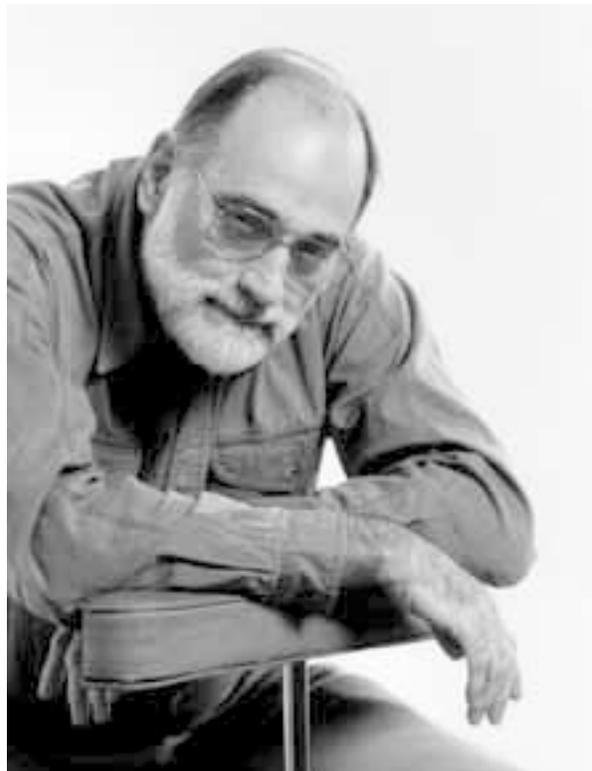
To help achieve one of the Council's primary objectives of providing information and services on AD to the public, Texas Department of Health (TDH) staff developed a Web site and maintain a toll-free information line.

The Alzheimer's Disease Program Web site contains information relating to the care of individuals with AD and related disorders, as well as links to national and state Web sites. The site can be accessed at:

<http://www.tdh.state.tx.us/osp/alz.htm>

TDH staff receive numerous requests for information and referral to community services every day on their toll-free information line. Comprehensive education packets are mailed to callers on a daily basis. Alzheimer's materials are also displayed at community health fairs and conferences throughout the state. The toll-free information number is:

1-800-242-3399



Council Recommendations



Consortium of Alzheimer's Disease Centers

House Bill 1504, passed during the 76th legislative session, directed the Council to establish a Consortium of Alzheimer's Disease Centers. The Council has worked diligently and successfully to develop the structure of the Consortium. A Memorandum of Understanding has been signed by all participating centers. All four centers, which already receive public and private funding to support their research, are committed to assisting the Council in seeking funding from grants, gifts and donations to support the Consortium activities required by H.B. 1504.

The Council recommends that the Texas Legislature support the Consortium by appropriating funds for operating expenses and the establishment of a data coordinating center to be based at Texas Tech University Health Sciences Center.

The Council expects that the following outcomes, important to all Texas residents with Alzheimer's disease and their caregivers, will be achieved as a result of legislative support:

- ▶ Clinical services will be available to patients of the Consortium's clinical centers, notwithstanding the independent status of each participant, meaning more Texans in all parts of the state will have access to optimal care. This can result in significantly reduced costs to the state of Texas;
- ▶ A mechanism for sharing developing information and data will create cross-marketing opportunities, and help to attract more federal and pharmaceutical industry dollars to Texas;
- ▶ A resource index will facilitate research projects;
- ▶ Data on patient health outcomes will be available to other Texas researchers and appropriate state agencies; the database will include information concerning the extent and cost of Alzheimer's disease in Texas that will be useful for state planning purposes;
- ▶ Texas patients and caregivers will be informed of any research projects and therapeutic trials open for their participation;
- ▶ Consortium members will publish consensus papers about current research;
- ▶ Consortium members will recommend directions for future research;
- ▶ The Texas Consortium will gain recognition for its work by publishing an Alzheimer's Disease Research Journal article.

Texas Council on Alzheimer's Disease and Related Disorders

The Council through its activities has demonstrated effective and responsible management of previously appropriated funds. Texas residents with Alzheimer's disease and related disorders and their caregivers, both lay and professional, benefit from educational materials and resources made available through the Council; the Council coordinates services and activities of state agencies, private associations, and other service providers.

With continued funding the Council will continue to provide residents of Texas with current, up-to-date educational materials, inform them of services available, and collaborate with other state agencies and organizations to promote services of the highest quality. Distance learning technologies may be utilized to reach Texans in more rural areas at reduced cost and expense.

Therefore the Council respectfully requests that the Texas Legislature appropriate funds for Council operations for FY '02-03.

Alzheimer's Association Coalition of Texas (AACT)

The Council continues to support the Community Alzheimer's Resource and Education (CARE) Program, a partnership between the Alzheimer's Association of Texas (AACT) and the Texas Department of Human Services (DHS). The 75th legislature mandated DHS to create a pilot project that would identify needs of individuals with Alzheimer's disease, refer them for services, and identify and address gaps in services. The 76th legislature appropriated funds for the original four sites and four new sites. In addition, it appropriated funds to address the identified gaps in services.

The Council supports AACT's request to maintain funding at current levels for the CARE Program with the future objective of establishing at least one CARE site in each DHS region of the state.

The Council supports AACT's request to increase the Medicaid reimbursement rate for nursing facilities to improve the quality of care by increasing wages and benefits for staff as well as providing appropriate training.

The Council supports AACT's recommendation that the Texas Index for Level of Effort (TILE) be reviewed and revised to address the varying needs of nursing home residents with Alzheimer's disease.

Finally, the Council supports the Alzheimer's Alert Resolution recommending that the broadcast media use a consistent statewide method to alert communities of missing persons with dementia.

Appendices



- A** *Council Members*
- B** *Council Strategic Plan*
- C** *Consortium Steering Committee*
- D** *Consortium Memorandum of Understanding*
- E** *Key Alzheimer's Disease Legislation*
- F** *Helpful Telephone Numbers/Web Sites*
- G** *Certified Nursing Facilities for Care of Persons with Alzheimer's Disease*



Appendix A



Texas Council on Alzheimer's Disease and Related Disorders

Member Roster

Nancy Johnson Armour
Dallas

Galen Brewer, M.P.A.
Texas Department of Mental Health &
Mental Retardation
Austin

Rachelle Smith Doody, M.D., Ph.D.
Baylor College of Medicine
Houston

Leon Douglas
Burnet

Johnnie B. Elliot, L.S.W., L.N.F.A.
Brownwood

James W. Hinds, Chairman
Austin

Jack C. Kern
Austin

Minnie Lee Lancaster, M.D.
Grapevine

Ellen MacDonald, M.N., R.N.C., L.N.F.A.
Houston

Leonard W. Morgan, M.D., Ph.D.
Desoto

Shirley E. Poduslo, Ph.D.
Texas Tech University Health Sciences
Center
Lubbock

Susan Syler, R.N.
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Anne Williamson, M.Ed.
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Elaine Braslow, M.Ed.
Texas Department of Health
Austin

Mary Somerville
Texas Department of Health
Austin



Appendix B

Texas Council on Alzheimer's Disease and Related Disorders

Strategic Plan September 17, 1998

Mission

The Texas Council on Alzheimer's Disease and Related Disorders is legislatively established as the state's advocate for persons with Alzheimer's disease and related disorders and those who care for them. The Council's mission is four-pronged:

- I. To recommend needed action for the benefit of persons with Alzheimer's disease and related disorders and their caregivers.
- II. To disseminate information on services and related activities for persons with Alzheimer's disease and related disorders to the medical and healthcare community, academic community, primary family caregivers, advocacy associations, and the general public.
- III. To facilitate coordination of services and activities of state agencies, other service providers and advocacy groups relating to persons with Alzheimer's disease and related disorders.
- IV. To advocate statewide coordinated research and to increase dollars allocated for research to benefit persons with Alzheimer's disease and related disorders.



Goals and Objectives

1. To create a biennial legislative agenda.
 - a. Identify needs.
 - b. Identify sponsors.
 - c. Develop legislative language.
 - d. Coordinate with overlapping agendas of other groups.
 - e. Advocate to members of the legislature.
 - f. Evaluate outcome and report back.
2. To enhance information that is available within the state's Alzheimer's Disease Program.
 - a. Assess current information available.
 - b. Identify needs based on requests from the public.
 - c. Obtain updated research information.
 - d. Obtain current educational brochures and materials.
 - e. Obtain referral sources for professionals and the public.
3. To provide periodic statewide educational conferences.
 - a. Determine focus and date(s) of conferences.
4. To co-sponsor other regional and statewide conferences.
5. To further develop the state Web site and create an educational brochure about the Council.
6. To identify ways to strengthen collaboration and coordination among state agencies, other service providers and advocacy groups relating to persons with Alzheimer's disease and related disorders.
 - a. Continue to invite representatives of the Alzheimer's Association to Council meetings.
 - b. Arrange educational presentations to Council members.
 - c. Identify service providers and state agencies and define their purpose and interest. Identify stakeholders and their roles and how they can compliment one another.
 - d. Identify gaps and barriers in services.
7. To establish Alzheimer's disease research as a line item in the state budget.
 - a. Identify stakeholders.
 - b. Coordinate efforts with stakeholders.
8. To create additional funding for Alzheimer's disease activities.
 - a. Identify potential funding sources.
 - b. Create/build relationships with funders.
 - c. Develop/write proposals.



Appendix C



Consortium of Alzheimer's Disease Centers

Steering Committee Roster

Rachelle Smith Doody, M.D., Ph.D.

Baylor College of Medicine
Houston

Thomas J. Fairchild, Ph.D.

The University of North Texas Health
Science Center
Fort Worth

James W. Hinds

Austin

John McConnell, M.D.

The University of Texas Southwestern
Medical Center
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Randolph Schiffer, M.D.

Texas Tech University Health
Sciences Center
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Staff

Elaine Braslow, M.Ed.

Texas Department of Health
Austin

Mary Somerville

Texas Department of Health
Austin



Appendix D



Memorandum of Understanding (MOU) Creating the Texas Consortium of Alzheimer's Disease Centers (Consortium)

Whereas the 76th regular session of the Texas Legislature enacted Chapter 101 (HB 1504), and this legislation added Chapter 151 to the Education Code. Among other purposes, Chapter 151 establishes the Texas Council on Alzheimer's Disease and Related Disorders (Council). Chapter 151 requires the Council to:

- Establish the Texas Consortium of Alzheimer's Disease Centers (Consortium) (§151.002).
- Include, at a minimum, four institutions: The Baylor College of Medicine, The Texas Tech University Health Sciences Center, The University of North Texas Health Science Center at Fort Worth, The University of Texas Southwestern Medical Center at Dallas (§151.002(a)).
- Provide funds to the Consortium participants to assist them in developing clinical centers that meet the standards of the Consortium (§151.002(b)).
- Aid the Consortium in developing and distributing material and services for patients, caregivers, and health care professionals (§151.003(b)(3)).
- Establish a steering committee composed of one representative from each Consortium participant to advise the Council (§151.004).
- Establish a data coordinating center to be located at The Texas Tech University Health Sciences Center (§151.005).
- Appoint a physician or other person with a similar clinical background to administer the center (§151.005(c)).
- Review and evaluate the performance of the Consortium participants and data coordinating center at least every five years with the recommendations from the steering committee (§151.008).

The Council may:

- Add additional Consortium participants as necessary (§151.002(a)).
- Receive state appropriated funds for the purpose of supporting the research activities of the Consortium (§151.006(a)).
- Solicit and accept gifts, grants, and donations for purposes of this chapter (§151.006(b)).
- Restrict access to the data maintained by the Consortium or data coordinating center to Consortium participants that contribute data requested by the Council (§151.007(a)).

The Consortium shall:

- Develop clinical centers that meet the standards of the Consortium. (§151.002(b)&(c)).
- Develop standards of operation (implied by §151.002(b)).
- Coordinate and direct its programs to provide to the extent practicable centralized, uniform services among the Consortium participants (§151.003(a)).
- Offer clinical services to all patients of the Consortium’s clinical centers, notwithstanding the independent status of each participant (§151.003(b)(1)).
- Establish a database, working through the data coordinating center (§151.003(b)(2)).
- Develop and distribute material and services for patients, caregivers, and health care professionals (§151.003(b)(3)).

The Council and the four institutional members designated by the legislature agree:

- No money has been appropriated for the work of the Council during the biennium starting on September 1, 1999.
- Each of the institutional members desire to participate in the Consortium, and lend its expertise in helping effectuate the above listed designs of the law.
- Each of the institutional members shall have equal access to, or benefit from, the database.

Bobby R. Alford, M.D., Ph.D.
Executive Vice President
and Dean of Medicine
Baylor College of Medicine

Thomas J. Fairchild, Ph.D.
Director of Special Projects on Aging
University of North Texas
Health Science Center at Fort Worth

Elmo Cavin
Vice President for Fiscal Affairs
Texas Tech University Health Sciences Center

Peter H. Fitzgerald
Executive Vice President for Administration
University of Texas Southwestern Medical
Center at Dallas

James W. Hinds
Chairman
Texas Council on Alzheimer’s Disease
and Related Disorders

Appendix E



Key Alzheimer's Disease Legislation

69th Texas Legislative Session – 1985

▶ **HCR 88 – Finnell and Brooks**

Recognized the seriousness of Alzheimer's disease in Texas and supported efforts of the Texas Department of Health to develop supportive and educational programs to help patients and their caregivers. Encouraged the Department to continue its efforts to organize and develop an Alzheimer's network composed of families, associations, and other concerned individuals to help deal with Alzheimer's disease.

70th Texas Legislative Session – 1987

▶ **H.B. 1066 – Evans and Brooks**

Established the Texas Council on Alzheimer's Disease and Related Disorders and defined the powers and duties of the Council and the responsibility of the Texas Department of Health.

▶ **S.B. 1134 – Brooks and Evans**

Provided for an optional system for certifying institutions that provide specialized care for persons with Alzheimer's disease and related disorders.

▶ **H.B. 420 – Kubiak and Brooks**

Amended Section 7, Chapter 413, Acts of the 53rd Legislature (Article 442C, Vernon's Texas Civil Statutes) to establish requirements for inservice training for all employees of nursing homes, custodial homes, and related institutions who have contact with residents, including training on the care of persons with Alzheimer's disease and related disorders for employees who work with these patients.

▶ **S.B. 1371 – Brooks and Evans**

Provided for the adoption of rules and regulations establishing minimum standards for benefits for long-term care coverage under certain accident and sickness insurance coverage and coverage of health maintenance organizations.

▶ **SCR 75 – Brooks and Eckels**

Recognized Alzheimer's disease as a physical disease rather than a mental disorder and encouraged health service providers and reimbursement sources to recognize Alzheimer's disease as a physical disease.

▶ **SCR 76 – Brooks and Hury**

Recommended that state supported educational institutions and appropriate professional organizations develop education, training, and public information programs regarding Alzheimer's disease and related disorders.



- ▶ **SCR 85 – Brooks and Finnell**
Encouraged the legal, banking, and insurance communities to provide education to the general public regarding the value of legal and financial planning for persons with Alzheimer’s disease and their families.
- ▶ **HCR 25 – Kubiak and Brooks**
Provided for the 70th Texas Legislature to request the United States Congress to raise respite care to a higher priority under the Older Americans Act and send copies of the Resolution to the President of the United States, Speaker of the House, President of the Senate, and members of the Texas delegation to the Congress.
- ▶ **HCR 52 – Evans and Brooks**
Declared each November to be Alzheimer’s Disease and Related Disorders Awareness Month in Texas.

71st Texas Legislative Session – 1989

- ▶ **H.B. 468 – Eckels and Parmer**
Required insurance policies covering Alzheimer’s disease, which require demonstrable proof of organic disease, to accept a clinical diagnosis of Alzheimer’s based on history and physical, neurological, psychological and/or psychiatric evaluations, and laboratory studies.
- ▶ **H.B. 2127 – Barrientos and Willis**
Provided for legal representation to all persons for whom proceedings for a permanent guardianship are held. The bill also required the court to attempt to find another suitable temporary guardian before appointing the Texas Department of Human Services as temporary guardian (as laid out in Section 131, Probate Court).
- ▶ **H.B. 318 – Edwards and Denton**
Raised the State’s income eligibility cap for nursing home care under Medicaid to a minimum of \$1,104 per month, and also established the same income eligibility for community care, to the extent permitted by federal law.

72nd Texas Legislative Session – 1991

- ▶ **H.B. 314 – Goolsby and Harris**
Allowed an exemption from jury service for primary caretakers of persons with Alzheimer’s disease or related disorders.
- ▶ **HR 116 – Hill**
Declared February 5, 1991 to be designated “Alzheimer’s Day at the Capitol.”
- ▶ **SCR 79 – Sims**
Requested the Texas Department of Human Services to adjust the Texas Index for Level of Effort so that it reflects the special behavioral needs of cognitively impaired residents in nursing homes, and to adjust the reimbursement rates accordingly.



73rd Texas Legislative Session – 1993

▶ **S.B. 672 – Montford**

Changed terms of Texas Council on Alzheimer's Disease and Related Disorders members from two years to six years.

74th Texas Legislative Session – 1995

▶ **S.B. 436 — Montford**

Required facilities that advertise, market, or otherwise promote that the facility provides services to residents with Alzheimer's disease and related disorders provide a disclosure statement disclosing the nature of its care or treatment of residents with Alzheimer's disease and related disorders.

▶ **H.B. 3120 – Hunter**

Allowed the Texas Department of Human Services to waive the restrictions on implementing new Medicaid nursing facility beds for certain facilities. In particular, a limited number of beds for use in promoting research by the Texas Tech medical school relating to Alzheimer's disease and its treatment would be permitted.

▶ **S.B. 1059 – Harris**

Required the Texas Board of Health to prescribe and enforce standards requiring certain geriatric service providers to undergo appropriate training in geriatric medicine. The bill specifically stated that the Board of Health should require a minimum standard of training on the care of persons with Alzheimer's disease and related disorders for employees who work with those persons.

75th Texas Legislative Session – 1997

▶ **H.B. 2509 – Hilderbran**

Directed the Texas Department of Human Services, in cooperation with all appropriate state and federal agencies and with the establishment of an advisory committee, to develop and implement a pilot program for the treatment of individuals diagnosed with Alzheimer's disease.

▶ **H.B. 2510 – Hilderbran**

Directed the Texas Department of Human Services to establish a classification and license for a facility that advertises, markets, or otherwise promotes that the facility provides personal care services to residents with Alzheimer's or related disorders; but provides that a facility is not required to be classified to provide care or treatment of such residents. This bill also required the Department to adopt minimum standards regarding quality of care, administration, programming of activities, facility operations, and staffing.



76th Legislative Session – 1999

▶ **H.B. 605 – Greenberg**

Required local law enforcement agencies to immediately begin an investigation of a missing person if the subject is a child or if the subject is an adult reported to have chronic dementia, including Alzheimer's dementia, whether caused by illness, brain defect, or brain injury.

▶ **H.B. 1504 – Goolsby**

Directed the Texas Council on Alzheimer's Disease and Related Disorders to establish a consortium of Alzheimer's disease centers at institutions of higher learning to provide centralized, uniform services among the consortium participants.



Appendix F



Helpful Telephone Numbers and Web Sites

TEXAS DEPARTMENT OF HEALTH

- ▶ Alzheimer's Disease Program 800-242-3399
 - Information and referral to local services.
- ▶ Medicaid Hotline 800-252-8263

<http://www.tdh.state.tx.us/osp/alz.htm>

- ▶ Information on symptoms, diagnosis and treatment of Alzheimer's disease and options for care.
- ▶ List of certified Alzheimer's facilities in Texas.
- ▶ Information on Texas Council on Alzheimer's Disease and Related Disorders and Consortium of Alzheimer's Disease Centers.

ALZHEIMER'S ASSOCIATION 800-272-3900

- ▶ Information and referral services.

<http://www.alz.org>

- ▶ Comprehensive information for consumers and providers on day-to-day care, legal and financial planning, choosing health care providers and facilities, and current research.
- ▶ Links to local chapters in Texas that provide caregiver programs, support groups, literature, and referral to elder care physicians and attorneys, respite services and care facilities.

ALZHEIMER'S DISEASE EDUCATION AND REFERRAL 800-438-4380

- ▶ Information about Alzheimer's disease, its impact on families and health professionals, and research into possible causes and cures.
- ▶ Service of the National Institute on Aging.

<http://www.alzheimers.org>

- ▶ Information about clinical trials, latest research findings, NIA Alzheimer's Disease Centers, and publications.

TEXAS DEPARTMENT OF HUMAN SERVICES

- ▶ Long-term Care Regulatory 800-458-9858
 - Licenses, certifies, and inspects long-term care facilities.

<http://www.dhs.state.tx.us/programs/ltc/index.html>

- ▶ Long-term care regulatory site including information on licensing and certification.



<http://www.dhs.state.tx.us/programs/index.html#sfe>

- ▶ Community based and institutional care services for elderly or disabled individuals.
- ▶ Information on Community Alzheimer's Resources and Education (CARE) Program.

TEXAS DEPARTMENT ON AGING

- ▶ Area Agency on Aging Information and Assistance 800-252-9240
 - Routes calls to 28 area agencies in Texas that provide services for persons 60 years of age and older. Services include health care benefits counseling; case management; nutrition services; transportation; in-home help; senior centers; and Retired Senior Volunteer Program (R.S.V.P.).
- ▶ Ombudsman Program 800-252-2412
 - Investigates and resolves nursing home complaints.
 - Helps with choosing a nursing home.
- ▶ Legal Hotline for Older Texans 800-622-2520
 - Legal assistance including counseling, representation, and document preparation.

<http://www.tdoa.state.tx.us>

- ▶ Links to 28 Area Agencies on Aging in Texas.
- ▶ News releases, statistics, legislative updates and free downloads of TDoA publications.
- ▶ "Aging Texas Well" resources to help plan for the future.

TEXAS HEALTH CARE ASSOCIATION 800-380-2500

- ▶ Long-term, rehabilitative and specialized health care services.

<http://www.txhca.org>

- ▶ Consumer guide to long-term care services. Includes information on legal issues, financing long-term care, and choosing the right care.
- ▶ Best practices articles including nutrition, infection control, quality of care, and medication management.
- ▶ THCA Healthlinks Newsletter.

TEXAS ASSOCIATION OF HOMES AND SERVICES

FOR THE AGING 512-467-2242

- ▶ Housing and services for older adults.

<http://www.tahsa.org>

- ▶ Housing/living options, including independent living, assisted living, continuing care retirement communities, and nursing homes.
- ▶ Community services including home health care, adult day care, health education and wellness programs, and caregiver support and training programs.

- ▶ Best practices articles including nutrition and hydration, infection control, medication management, dementia care, and community resources to enhance quality of life.
- ▶ Educational Institute on Aging schedule of seminars for health care providers.

TEXAS DEPARTMENT OF MENTAL HEALTH AND MENTAL RETARDATION 800-252-8154

- ▶ Consumer services and rights protection.

<http://www.mhmr.state.tx.us/Agency/ServicesInTheCommunity.html>

- ▶ Community programs including services for older adults.

TEXAS DEPARTMENT OF PROTECTIVE AND REGULATORY SERVICES 800-252-5400

- ▶ Hotline for reporting abuse, neglect, or exploitation of children, the elderly, or people with disabilities. Available 24 hours a day, seven days a week.

<http://www.tdprs.state.tx.us>

- ▶ Information on services provided for children, adults, and people with disabilities, including investigation of reports of abuse, neglect, and exploitation at home or in facilities licensed by other state agencies, and arranging for protective services. Protective services may include referral to other programs, respite care, guardianship, emergency assistance with food, shelter and medical care, transportation, and counseling.

OFFICE OF THE ATTORNEY GENERAL

- ▶ Consumer Protection Division 800-621-0508
 - Register complaints against businesses.
 - Report senior fraud.

<http://www.oag.state.tx.us>

- ▶ Elder Texans' page includes information on health and safety, crime prevention, consumer protection, and the Elder Alert Newsletter.

TEXAS DEPARTMENT OF INSURANCE 800-252-3439

- ▶ Information, counseling, and to file a complaint against a private insurance provider.

<http://www.tdi.state.tx.us/consumer/hicap/issues.html>

- ▶ Insurance information, counseling and advocacy for senior Texans including Medicare, insurance fraud, long-term care insurance, publications and key contacts.

MEDICARE 800-633-4227

- ▶ National toll-free number for information and counseling on Medicare.

<http://www.medicare.gov>

- ▶ Official U.S. government site for Medicare information.
- ▶ Medicare health plan comparisons, nursing home checklist, prescription drug assistance programs, and local Medicare events.

HEALTH CARE FINANCING ADMINISTRATION 410-786-3000

- ▶ Federal agency that administers Medicare and Medicaid.

<http://www.hcfa.gov>

- ▶ General Medicare and Medicaid information for consumers, including enrollment, eligibility and program information.
- ▶ Specific Medicare and Medicaid information for researchers and providers.



Appendix G



Certified Nursing Facilities for Care of Persons With Alzheimer's Disease and Related Disorders Licensed in Texas

<p>Anderson County Cartmell Home for Aged and Orphans 2212 West Reagan Street Palestine, TX 75801 903-727-8500</p>	<p>Dallas County Christian Care Center 1000 Wiggins Parkway Mesquite, TX 75150 972-686-3000</p>
<p>Angelina County Pinecrest Retirement Community 1302 Tom Temple Drive Lufkin, TX 75904 936-634-1054</p>	<p>Dallas County Manorcare Health Services 3326 Burgoyne Dallas, TX 75233 214-330-9291</p>
<p>Bell County Indian Oaks 415 Indian Oaks Drive Harker Heights, TX 76548 254-699-5051</p>	<p>Dallas County Presbyterian Village North Alzheimer's Special Care Center 8703 Stults Road Dallas, TX 75243 214-355-9600</p>
<p>Bowie County Edgewood Manor Nursing Home 4925 Elizabeth Street Texarkana, TX 75503 903-793-4645</p>	<p>Dallas County Signature Point on the Lake Healthcare Community 14655 Preston Road Dallas, TX 75240 972-726-7575</p>
<p>Cass County Sunbridge Care and Rehabilitation for Linden 1201 West Houston Linden, TX 75563 903-756-5537</p>	<p>De Witt County Stevens Nursing Home 204 Walter Street Yoakum, TX 77995 361-293-3544</p>
<p>Chambers County Arboretum Nursing and Rehabilitation Center of Winnie 1215 Highway 124 Winnie, TX 77665 409-296-8200</p>	<p>Denton County Vintage Health Care Center Alzheimer's Unit 205 North Bonnie Brae Denton, TX 76201 940-383-2361</p>



<p>El Paso County The Montevista at Coronado 1575 Belvidere El Paso, TX 79912 915-833-2229</p>	<p>Gregg County Whispering Pines Lodge Alzheimer's Unit 2131 Alpine Road Longview, TX 75601 903-757-8786</p>
<p>Ellis County Ennis Care Center Alzheimer's Unit 1200 South Hall Street Ennis, TX 75119 972-875-9051</p>	<p>Guadalupe County Seguin Nursing and Rehabilitation Center 1637 North King Street Seguin, TX 78155 830-379-3784</p>
<p>Fannin County Honey Grove Nursing Center Route 2, Box 22 Honey Grove, TX 75446 903-378-2293</p>	<p>Harris County Garden Terrace Alzheimer's Center of Excellence 7887 Cambridge Street Houston, TX 77054 713-796-2777</p>
<p>Fannin County Mullican Care Center 105 North Main Street Savoy, TX 75479 903-965-0200</p>	<p>Harris County Memorial Hermann Spring Shadow Pines 3033 Gessner Houston, TX 77080 713-460-8222</p>
<p>Fort Bend County Pine Haven Alzheimer's Community 1221 Seventh Street Sugarland, TX 77478 281-277-1221</p>	<p>Harris County Seven Acres Jewish Senior Care Services Inc. 6200 North Braeswood Houston, TX 77074 713-778-5701</p>
<p>Grayson County Hilltop Haven Nursing Home 308 East College Gunter, TX 75058 903-433-2415 or 817-430-0162 in Dallas Metroplex</p>	<p>Harris County The Village Healthcare Center 1341 Blalock Houston, TX 77055 713-468-7821</p>
<p>Gregg County Sunbridge Care and Rehabilitation for Gladewater 501 Ames Street Gladewater, TX 75647 903-845-6933</p>	<p>Kaufman County Country View Manor 1900 North Frances Street Terrell, TX 75160 972-524-2503</p>

<p>Lee County Hennesey Nursing Center 1181 North Williamson Giddings, TX 78942 409-542-3611</p>	<p>Parmer County Farwell Convalescent Center 305 Fifth Street Farwell, TX 79325 806-481-9027</p>
<p>Llano County Kingsland Hills Care Center 3727 West Ranch Road 1431 Kingsland, TX 78639 915-388-4538</p>	<p>Potter County Windflower Nursing 5500 West 9th Avenue Amarillo, TX 79106 806-352-7244</p>
<p>Matagorda County Matagorda House Healthcare Center 700 12th Street Bay City, TX 77414 409-245-7800</p>	<p>Rockwall County Rockwall Nursing Center 206 Storrs Street Rockwall, TX 75087 972-771-5000</p>
<p>McClennan County Saint Catherine Center Alzheimer Unit 1700 Providence Drive Waco, TX 76707 254-755-4800</p>	<p>Tarrant County Garden Terrace Alzheimer's Center of Excellence 7500 Oakmont Blvd. Ft. Worth, TX 76132 817-346-8080</p>
<p>Midland County Mabee Health Care Center 2208 North Loop 250 West Midland, TX 79707 915-689-0707</p>	<p>Tarrant County James L. West Presbyterian Special Care Center 1111 Summit Avenue Ft. Worth, TX 76102 817-877-1199</p>
<p>Milam County Renaissance Villa 700 Dyer Street Rockdale, TX 76567 512-446-2548</p>	<p>Tarrant County Manorcare Health Services 7625 Glenview Drive North Richland Hills, TX 76180 817-284-1427</p>
<p>Nueces County South Park Rehabilitation and Nursing Center 3115 Mcardle Corpus Christi, TX 78415 512-853-2577</p>	<p>Tarrant County Stonegate Nursing Center 4201 Stonegate Blvd. Ft. Worth, TX 76109 817-924-5440</p>

<p>Taylor County Windcrest Alzheimer's Care Center 6050 Hospital Drive Abilene, TX 79606 915-692-1533</p>	<p>Uvalde County Amistad Nursing Home Inc. 200 Riverside Drive Uvalde, TX 78801 830-278-5641</p>
<p>Titus County Sunbridge Care and Rehabilitation for Mount Pleasant 1606 Memorial Avenue Mount Pleasant, TX 75455 903-572-3618</p>	<p>Van Zandt County Free State Crestwood Inc. 1448 Houston Street Wills Point, TX 75169 903-873-5400</p>
<p>Trinity County Avalon Place Highway 19 South Trinity, TX 75862 936-594-7521</p>	<p>Wichita County Texhoma Christian Care Center 300 Loop 11 Wichita Falls, TX 76306 940-723-8420</p>
<p>Upshur County Gilmer Care Center 703 North Titus Gilmer, TX 75644 903-843-5529</p>	<p>Wilson County Floresville Nursing and Rehabilitation Center 1811 Sixth Street Floresville, TX 78114 830-393-2561</p>

Source: Texas Department of Human Services, September 15, 2000
1-800-458-9858





Texas Council on Alzheimer's Disease and Related Disorders
Texas Department of Health
1100 West 49th Street
Austin, Texas 78756-3199
(512) 458-7534 or (800) 242-3399
Fax: (512) 458-7254
<http://www.tdh.state.tx.us/osp/alz.htm>

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