

California Alzheimer's Disease Program

The Value of the California Alzheimer's Disease Centers

- Improving health care delivery to persons affected by Alzheimer's disease and their caregivers
- Advancing diagnosis and treatment into Alzheimer's disease and other dementias
- Providing training and education to health care professionals, students, patients, caregivers, and members of the community
- Serving as an ongoing economic stimulus package to help California families and businesses affected by Alzheimer's disease

**Center for Gerontology
California Department of Public Health
Health and Human Services Agency**

Foreword

In 1984, the State of California established the **Alzheimer's Disease Program (ADP)** through legislation that sought to relieve the human burden and economic cost associated with Alzheimer's disease and related dementias and to assist in ultimately discovering the cause, treatment, and prevention of these diseases. The mandate to the ADP was to establish a network of diagnostic and treatment centers at university medical centers throughout the State and to administer a research fund that would increase research into Alzheimer's disease (AD) and related dementias. To accomplish these objectives, the state Alzheimer's disease centers and the **Alzheimer's Disease Research Fund** were established in 1985.

From 1985 to 1998, the state centers were named the Alzheimer's Diagnostic and Treatment Centers (ADDTCs). The name was changed in 1997 to the Alzheimer's Disease Research Centers of California (ARCCs) to highlight the new clinical and translational research activities that had become an integral part of the Centers. In 2009, the California Legislature cut the ADP funding by 50% and directed the Centers to discontinue all research activities and data collection. The Centers were renamed the **California Alzheimer's Disease Centers (CADCs)** to reflect this change in mission.

The ten CADCs are located at the following California university medical centers:

- University of California, San Diego - San Diego
- University of California, Irvine - Irvine
- University of Southern California / Los Angeles - Central Los Angeles
- University of Southern California / Rancho Los Amigos - Downey
- University of California, Los Angeles - Westwood / San Fernando Valley
- Stanford University - Palo Alto
- University of California, San Francisco - San Francisco
- University of California, San Francisco - Fresno
- University of California, Davis - Martinez
- University of California, Davis - Sacramento

Value of the California Alzheimer's Disease Centers

Demographic Projections and Alzheimer's Disease

Alzheimer's disease (AD) is neurodegenerative disease of the brain that begins with memory loss and progresses to total disability and death. At age 65, the risk of Alzheimer's disease (AD) begins to increase rapidly, with the probability of AD and dementia doubling approximately every five years. Based on the demographics of the State of California, the impact of AD will increase dramatically in the next 20 years. The elderly are the most rapidly growing segment of the population, with the first wave of the baby boomers reaching 65 in 2011. With this surge, the numbers of people with AD will grow exponentially; projected to rise from approximately 570,000 currently to 1,150,000 by 2030. AD also affects younger Californians as they struggle to meet the care needs of their elders. And over the course of this disease, especially in later stages, substantially compromises family members' time, quality of life, and even productivity in the work place. An ethnically diverse State with a shifting demographic, California will experience an even greater increase in AD in non-Caucasian populations, with the number of Hispanics with AD tripling, from 95,000 to 277,000 and Asian/Pacific Islanders nearly tripling, from 72,000 to approximately 195,000 by 2030.

The increase in AD presents an enormous challenge to California and will place a great burden on health care, quality of life and the economy. It is essential to provide care to AD patients, disseminate best practices to family and professional AD caregivers, identify means to prevent AD, detect it early, and accurately, understand the role of ethnic diversity in AD, and treat the disease.

Addressing the Impact of Alzheimer's Disease on California

The California Alzheimer's Disease Centers (CADC) were created in response to the recognition that clinical care for persons with dementing illnesses was and is severely inadequate, and the need to improve future care for a devastating illness that will burgeon in step with California's aging population. To this end the Legislature created not clinics, but centers, designed to broadly meet the challenge of reducing the personal and societal impact of these diseases. Consistent with this legislative mandate, the centers have focused on reducing the burden of disease in California by developing comprehensive diagnosis, treatment, education, and support services to persons affected with Alzheimer's disease and their families. The CADCs were selected on the basis of excellence, their ability to assemble talented scientists at the State's medical schools to provide clinical care, to train future health care providers, and to advance knowledge about Alzheimer's disease and related disorders. This vision was implemented in a way that has repaid the State's investment many times over. The Centers:

- **Provide and improve healthcare delivery for persons affected by Alzheimer's disease and their caregivers.** The Centers have specialized in the diagnosis of patients with mild symptoms, the identification of specialized sub-populations among those with dementia, and diagnosis of complex dementia cases referred from the community. As part of this effort in the detection and management of dementia, the CADCs have developed and applied innovations and technologies, including novel imaging methods and new cognitive assessment instruments. These activities have impacted thousands of patients and families in California.

- **Provide training and education to health care professionals, students, patients, caregivers, and members of the community.** Education is one of the paramount missions of the Centers. The CADCs provide education and training of health care professionals as well as to the general public, caregivers, and patients. Through community education efforts, the CADCs have made daily life more manageable for thousands of people who struggle with the demands of caring for a demented loved one. Training for physicians, nurses, physician assistants, and professional care providers includes instruction on dementia subtypes, early detection, and specialized training for caregivers. Trained, professional care providers contribute to the value and economic impact of residential care facilities and day care centers, and deliver care to hundreds of thousands of individuals in need.. Through their training programs the CADCs have shaped the practice of doctors, nurses, psychologists, social workers and other providers who now staff hospitals and clinics throughout the state. By training many medical residents and fellows, the CADCs have steered many trainees to the practice of dementia-related care and have grown the dementia-care workforce. Simply put, the CADCs build the workforce for California through clinical programs, which translates to service for many more patients than just those seen in CADC clinics. (See tables on page four).
- **Meet the needs of underserved populations.** California, perhaps more than any other state, is facing huge increases in the number of elders from minority ethnic and diverse linguistic backgrounds. These seniors (and their families) face numerous barriers to dementia care. Through educational programs, the Centers have raised health-literacy about dementia-related issues, allowing families to provide better care and informing them about how to seek optimal care. To meet the needs of diverse seniors, the CADCs have developed specialized instrumentation to evaluate dementia in this population, including the Cross-Cultural Neuropsychological Battery (CCNB at UCI), the Cognitive Abilities Screening Instrument (CASI at USC) in English, Spanish, Chinese, and Japanese, along with the Spanish and English Neuropsychological Assessment Scales (SENAS at UCD-Sacramento), and the Neuropsychiatric Inventory in Spanish (NPI-UCLA). These new tools set the stage for action and inclusiveness, and allow the CADCs to improve delivery and efficacy of treatments, while expanding education and community outreach to underserved communities. These culturally competent services are not available to these citizens through any other organized mechanism.
- **Guide Public Health Policy.** To improve health care delivery for the elderly and demented, the CADCs continue to address critical issues on health care policy for the State of California. Centers actively participated in the initial development and update of the *Practice Guidelines for Alzheimer's Disease Management*, which describe the standard of primary care for patients with progressive dementia. The CADCs have aggressively disseminated these guidelines. The CADCs collaborative efforts introduced and facilitated the passage of informed consent legislation that enables research with the more severely impaired individuals, including targeted therapies that can improve the quality of life in the later stages of the disease. The Centers through their representatives provide expert opinion and counsel to numerous local and state committees, including the CA State Plan Task Force, which will help develop a blueprint for policy regarding Alzheimer's disease and related disorders for the next 10 years as mandated in SB491.

Economic Impact of the CADCs to California

From a purely economic perspective, the CADCs more than pay for themselves and contribute directly to the State treasury, serving as an economic stimulus package by helping California families and businesses affected by Alzheimer's disease and related disorders. Alzheimer's disease has many adverse economic consequences including loss of work by younger victims and the working elderly, the loss of work by caregivers staying home to take care of family members, and accelerated nursing home placement from improper care. The Centers also have contributed directly to building a vital workforce to address the professional competence a growing health care need of the State. The cadre of professionals also contributes to the State's economic health and high quality professional jobs. Center training includes that of physicians, nurses, physician's assistants, health care professionals, and research investigators. Since 2000, more than 310,000 professionals and students have received training and education at the Centers via fellowships, residencies, internships, rotations, clerkships, and continuing medical education courses and offerings. The CADCs have built a clinical infrastructure that is tremendously successful in expanding and maintaining large, externally funded research programs that further goals of improving clinical care for Alzheimer's disease. Currently, the average CADC brings into California 5-6 external dollars for every one State dollar invested, amounting to millions of dollars leveraged annually at each Center. Substantial amounts of this money go directly to the State, as the State captures a significant fraction (>50%) in the form of "indirect costs," that is, facilities and administrative overhead cost recovery on these grants. Medical research also feeds new ideas and trained personnel in an industry that brings quality jobs to California. About 85% of the average research grant is spent on salaries, which in turn flow through the State economy, providing economic opportunities to other Californians and bringing income tax dollars back to the State treasury.

Conclusion

The combined impact of the CADC program far exceeds that of any individual Center, and similarly, the investment in the larger program yields a leveraged opportunity for the State; one that addresses critical current and emerging needs of Californians. The CADCs are the focal point for academic input at the State's major medical schools, and each Center contributes special expertise that is disseminated throughout the State. The result is a coordinated effort that pushes forward on multiple fronts, with an impact greater than the sum of its parts working alone.

The Centers are not a cost but an investment with a history of positive returns, proven able meet a present need, and prepared to face the dynamic needs of a growing elderly population. Unique features of the Centers are their capacity to provide superb clinical services to patients and their caregivers, improve diagnostic standards for AD and other dementias, educate the community, train health care professionals, and attract fiscal resources to California. The CADCs have served California and opened new opportunities for improving the quality of life of the elderly, and reducing the burden for those with dementia and their caregivers. It is vital that we maintain and build upon the past accomplishments, continue to stimulate California's economy in these difficult times, and help create a bright and dynamic future for Californians.

Alzheimer's Disease Research Centers of California (ARCCs)*

2000 - 2008 Training and Education Report

A. Professional Training and Educational Activities

Professionals, Students, and Trainees

Average Number of Participants per Year = 67,638

	00-01	01-02	02-03	03-04	04-05	05-06	06-07	07-08	Total
Continuing Medical Education	5,443	7,034	4,852	1,880	37,927	5,804	8,308	4,765	76,013
In-service Training	3,871	3,499	4,089	13,035	2,403	3,547	2,291	1,605	34,340
Presentations to Professional Groups	8,851	38,032	10,006	44,763	12,716	6,623	11,700	11,133	143,824
Fellowships/Residencies/Internships	382	313	301	573	134	123	45	176	2,047
Rotations/Clerkships	185	317	798	167	483	470	511	437	3,368
Academic Classes	1,753	2,329	1,115	3,048	633	835	1,048	983	11,744
Academic Lectures	4,473	6,492	8,499	4,376	5,294	4,630	3,199	2,919	39,882
ARCC-Organized Conferences	2,641	2,039	5,170	2,568	2,414	2,559	3,070	2002	22,463
Presentations/Professional Conferences	57,253	20,800	32,752	26,536	28,596	16,740	13,278	11,469	207,424
Total Participants, Students/Trainees	84,852	80,855	67,582	96,946	90,600	41,331	43,450	35,489	541,105

B. Community Training and Educational Activities

Caregivers, Patients, and Other Community Members

Average Number of Participants per Year = 34,691

	00-01	01-02	02-03	03-04	04-05	05-06	06-07	07-08	Total
Caregiver Training	4,624	2,331	5,148	3,524	3,638	7,657	4,050	4,629	35,601
Support Group Presentations	1,165	1,217	1,086	501	533	712	1,182	1,710	8,106
Development of Support Groups	1,247	5,581	984	714	5,729	8,400	5,139	2,304	30,098
Presentations to Community Groups	13,305	33,456	8,759	19,377	17,907	10,925	25,435	76,722	205,886
Total Number of Participants	20,341	42,585	15,977	24,116	27,807	27,694	35,806	85,365	279,691

* In July, 2009, the Centers were renamed the California Alzheimer's Disease Centers (CADCs)