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# THE ALZHEIMER'S PROJECT: A CALL TO ARMS

**THE ALZHEIMER'S Project**  
San Diego unites for a cure and care



## ACKNOWLEDGEMENTS

*The Alzheimer's Project: A Call to Arms* grows out of the dedicated efforts of San Diego's world-class researchers, Alzheimer's care providers, County and City elected leaders, caregivers, healthcare providers, public safety personnel and many others who contributed their time, expertise and experience to put the region on track for tackling the challenges posed by this debilitating and heart-breaking disease.

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## EXECUTIVE SUMMARY

The San Diego County Board of Supervisors in 2014 established The Alzheimer's Project, an unprecedented regional initiative to address the toll of the disease on families, communities and our health care systems. The devastating impact of Alzheimer's is expected to escalate as the region's elderly population surges.

In her 2014 State of the County address, Chairwoman Dianne Jacob turned the spotlight on this epidemic – the 60,000 San Diegans living with Alzheimer's, the emotional and physical toll on caregivers, and the disease's position as the third leading cause of death in the region. She highlighted the importance of supporting our world-class researchers in their quest to find effective treatments and a cure.

The Chairwoman also emphasized the need to plan now to help ease the burden of this disease on individuals, their families, caregivers, our healthcare systems, and the entire region. She called for the creation of The Alzheimer's Project to improve care and accelerate the search for a cure.

Following Chairwoman Jacob's call to action, Supervisor Dave Roberts teamed up with her on the initiative. The Board unanimously launched The Alzheimer's Project on May 6, 2014. The goal: To develop recommendations for Board consideration at a special December 2, 2014 conference.

The Project is guided by a steering committee led by Chairwoman Dianne Jacob and co-chaired by Supervisor Dave Roberts, with other key leaders providing their expertise and strategic guidance, including San Diego Mayor Kevin Faulconer, Darlene Shiley (The Shiley Foundation), San Diego County Sheriff Bill Gore, Mary Ball (Alzheimer's Association), Michael Lobatz, M.D. (Scripps Health), and Nick Macchione (County Health and Human Services Agency).



*Chairwoman Dianne Jacob turned the spotlight on this epidemic—the 60,000 San Diegans living with Alzheimer's...and the disease's position as the third leading cause of death in the region.*

The Alzheimer's Project has brought together for the first time an unparalleled team of experts and decision-makers, including world-renowned researchers, caregivers, healthcare providers and community organizations.

Project participants set goals in six major areas:

- **Care** – Develop a countywide plan, along with an inventory of current resources, to improve the network of services for those with Alzheimer's and their caregivers.
- **Clinical** – Improve medical care for patients with the disease and related dementias, with an initial emphasis on establishing screening, diagnostic and disease management standards for primary care physicians.
- **Cure** – Boost funding and partnerships for research, along with community participation in clinical trials.
- **Education/Awareness** – Create a multi-faceted education and public awareness campaign, including an understanding of the warning signs and importance of early diagnosis, and presentations and training for public safety and social service personnel.
- **Legislation** – Expand the County's Legislative Program to support legislation that increases funding for research and provides resources for caregivers, family members, and those with the disease.
- **Funding** – Identify and pursue opportunities for additional resources to support the regional strategy.

This report includes detailed recommendations in each of these areas. The proposals are meant to serve as a launching point for a multi-year effort to help the growing number of San Diegans affected by the disease – and to conquer it once and for all.



## TRouBLING TRENDS

The latest numbers paint a dramatic picture of the impact of Alzheimer's disease on San Diego households, our healthcare system and the region. The statistics clearly point to the need for immediate action.

### Alzheimer's Is Fatal

Alzheimer's disease is much more than memory loss and impaired thinking skills; it is a progressive, fatal disease for which there is no cure and only minimal treatment options. And, it is on the rise. Alzheimer's was the third leading cause of death in San Diego County in 2012, exceeded only by cancer and heart disease. At the national level, Alzheimer's is the sixth leading cause of death, and the fifth leading cause for those 65 and older.<sup>1</sup> Many experts in the Alzheimer's field point out that these rankings only reflect a fraction of the deaths attributable to the disease. For example, while pneumonia may be listed on the death certificate as the official cause of death, the neurological impairment caused by Alzheimer's can impair swallowing, leading to food aspiration and the resulting pneumonia and subsequent death. What is especially concerning is that while other diseases such as breast cancer, stroke, and heart disease are on the decline, deaths from Alzheimer's disease increased by 68% between 2000 and 2010.<sup>2</sup>

### The Numbers Are Skyrocketing

Currently 60,000 San Diegans are estimated to be living with Alzheimer's disease or other dementias (ADOD).<sup>1</sup> As people age, their risk of developing Alzheimer's grows. According to the Alzheimer's Association, one in every nine Americans 65 and older has the disease, and one in every three people 85 and older has some form of the disease.<sup>2</sup> In San Diego County, those 85 years and older are the fastest growing age group, projected to increase 40% by 2030.<sup>1</sup>

The number of people with Alzheimer's and other dementias is rising as the size of our elderly population surges, a demographic trend known as the "Silver Tsunami." According to the Alzheimer's Association, by 2050 there will be 16 million Americans with Alzheimer's, with a million new cases each year.<sup>3</sup> For the baby boomers who do not contract the disease, many will be caring for a loved one who will.

In San Diego County, the number of those 55 years and older with ADOD is expected to increase by 56% between 2012 and 2030, from 60,000 to nearly 94,000 residents. Currently, the East County region has the greatest number (14,765) and proportion (12.4%) of residents 55 years and older with



Alzheimer's disease and other dementias. The region with the largest anticipated increase in ADOD is the North Central area, with a projected increase of 76.8% from 2012 to 2030. However, it is estimated that by 2030, nearly one out of four San Diegans 55 years and older with ADOD will live in East County.<sup>1</sup>

### **Women Bear the Brunt of the Disease**

Women are more likely to be diagnosed with Alzheimer's, and more likely to fill the role of caregiver. For every three people with Alzheimer's, two are women. More than three-fifths of unpaid caregivers are women and there are 2.5 times more women than men who provide 24-hour care for someone with Alzheimer's.<sup>2</sup>

### **Caregiving Is Difficult and Costly**

The toll on caregivers is tremendous. They often experience emotional and financial stress, depression, and problems with their own health. Eighty percent of individuals with Alzheimer's are cared for at home by a family member, who may not have the preparation or training and are often overwhelmed by the complexities and challenges of managing the symptoms of the disease, as well as the legal and financial aspects. Then, there is the heartbreak of watching the disease steal the memories, judgment, independence, capabilities, and life of someone you love.

In 2012, there were nearly 137,000 unpaid caregivers, or 2.3 caregivers for each of the local 60,000 residents living with ADOD. These caregivers provided 156 million hours of care worth almost \$2 billion. Due to the negative effects of caregiving on their own health, the cost of providing healthcare to these residents in 2013 was approximately \$75.4 million.<sup>1</sup> At the national level, 15.5 million family members and friends provided unpaid care worth \$220.2 billion in 2013. The cost to treat the physical and emotional toll on caregivers was \$9.3 billion.<sup>2</sup>

If nothing changes, the number of caregivers, the hours of unpaid care and the value of the care provided will continue to rise. By 2030, it is estimated that the almost 100,000 local residents with Alzheimer's will need more than 213,300 unpaid caregivers, providing 242.8 million hours of help per year. The value of that care will be \$3.02 billion, which represents a billion-dollar increase in only 10 years.<sup>1</sup> At the same time, there will be fewer family caregivers available because many baby boomers are single and any adult children often live far away.

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## TROUBLING TRENDS *continued*

### The Burden Also Falls on Healthcare Systems

San Diego's emergency departments (ED) and hospitals are heavily impacted by Alzheimer's and other forms of dementia. In 2012, over 19,000 residents 55 years and older were discharged from the ED or hospital with a mention of ADOD in their medical record.<sup>1</sup> Patients who are unable to accurately report their symptoms, interact with medical staff, or who are distressed, disoriented or otherwise cognitively impaired are extremely difficult to treat effectively, resulting in unnecessary tests and extra demands on hospital staff, which can result in additional time and higher costs. Some residents with Alzheimer's are frequent users of the EDs in San Diego County. One local resident grappling with Alzheimer's was discharged 42 times from the ED in 2012.<sup>7</sup>

### Alzheimer's Is Expensive

Caring for those with Alzheimer's is placing a tremendous financial burden on our nation. This year the U.S. will spend an estimated \$214 billion on caring for those with ADOD.<sup>2</sup> Over the next 40 years, Alzheimer's and other dementias will cost the nation \$20 trillion.<sup>3</sup> Currently, almost one in every five dollars of Medicare spending is for those with Alzheimer's and other dementias.<sup>2</sup> By 2050, ADOD-related

*The nearly 17,000 ADOD hospitalizations of San Diego County residents 55 years and older in 2012 accounted for almost \$886 million in direct hospitalization charges.*



costs to Medicare and Medicaid are expected to increase more than five times. A patient with Alzheimer's will cost Medicare three times more and Medicaid nine times more than those without the disease.<sup>3</sup> Families also bear a tremendous financial burden, in addition to the unpaid caregiving and related emotional and physical toll. Out-of-pocket expenses for families caring for a loved one with Alzheimer's or other dementias in 2014 were \$36 billion.<sup>2</sup> Over the next 40 years, the ADOD-related care cost to families is estimated to quadruple.<sup>3</sup>

The economic burden of Alzheimer's and other forms of dementia in San Diego County is staggering. In 2012, assuming a four-year survival after diagnosis, the lifetime cost among San Diegans 55 years and older following the diagnosis was \$13.5 billion. If these San Diegans live for eight years after diagnosis, the cost rises to \$27 billion. These estimates take into account direct and indirect medical costs as well as loss of income and productive services to the economy.<sup>4</sup> Caring for those with ADOD is also very expensive. The nearly 17,000 ADOD hospitalizations of San Diego County residents 55 years and older in 2012 accounted for almost \$886 million in direct hospitalization charges. By 2030, ADOD hospitalization charges among residents 55 years and older are expected to increase to nearly \$1.5 billion. In 2012, San Diegans 55 years and older hospitalized with any mention of Alzheimer's or other dementias during their stay had an average charge of \$52,412 per stay.<sup>4</sup>

For a complete description of Alzheimer's disease and other forms of dementia in the San Diego region, see the two December 2014 reports released by the Health and Human Services Agency: *Alzheimer's Disease and Other Dementias in San Diego County* and *Economic Burden of Alzheimer's Disease and Other Dementias in San Diego County*, available at: [www.SDHealthStatistics.com](http://www.SDHealthStatistics.com).



*A patient with Alzheimer's costs Medicare three times more and Medicaid nine times more than those without the disease.*

## **SIZING UP OUR SYSTEM OF CARE**

The San Diego region has a wide variety of services and resources to help those with Alzheimer's, along with families and other caregivers. As part of The Alzheimer's Project, the County of San Diego conducted an inventory of departments and programs affected by ADOD and/or that provide assistance to those living with the disease. Additionally, 2-1-1 San Diego, in partnership with the Health and Human Services Agency's (HHS) Aging & Independence Services (AIS), the Alzheimer's Association, Southern Caregiver Resource Center and Glenner Memory Care Centers, researched the community services available and their accessibility throughout the county.

### **County Resources**

A broad range of County departments are affected by and/or serve those with the disease. The Health and Human Services Agency has the most frequent contact with and provides the most services of any County Department through its multiple divisions, e.g., Aging & Independence Services (AIS), Behavioral Health Services, Eligibility Operations, Public Health Services, and the Public Guardian arm of the Public Administrator/Public Guardian/Public Conservator. AIS provides the bulk of services for those with ADOD - providing 24 programs serving over 130,000 people each year.

### **Community Resources**

A wide variety of community services and resources are available. Although San Diego is "resource rich" when it comes to services, there are often limitations on those services based on cost, geography, eligibility, the type of service provided and whether it is dementia-specific. Unfortunately, while a type of service may be readily available, such as board-and-care facilities, many may not have the safety features or trained staff to care for someone in the mid- to late-stages of the disease. Since many people are not diagnosed until at least mid-stage, this group constitutes the greatest number of individuals requiring services. The following is a partial listing of the types of community resources available for individuals with Alzheimer's disease and other dementias:

- Behavioral Health Services
- Care Management/Planning
- Day Care Programs/Diagnosis
- Disease/Caregiver Education
- In-Home Care
- Legal/Financial Resources
- Mobile Physicians
- Patient/Caregiver Support

## Service Challenges

The community inventory revealed there are relatively few actual gaps in ADOD services, i.e. services that do not exist in the region; however, there are many barriers to accessing those services, primarily financial, but also geographic. The needs mentioned most frequently were:

- Affordability of Services - All types.
- Caregiver Support - Respite care and access to services.
- Education and Training - Especially for healthcare professionals and others who serve those families dealing with Alzheimer's disease and other dementias.



## SEARCHING FOR A CURE<sup>1</sup>

San Diego has been at the forefront of Alzheimer's research, from the groundbreaking work of George Glenner at UCSD analyzing the beta amyloid protein linked to the disease, to the discovery at Sanford-Burnham of the last drug approved by the U.S. Food and Drug Administration (FDA) to treat it, to the leading-edge research being conducted today in San Diego by world-renowned neuroscientists at the Scripps Research Institute, Salk Institute, UCSD, Sanford-Burnham Medical Research Institute and others.

### What Is Known About Alzheimer's Disease

Alzheimer's is a progressive, fatal brain disorder that damages and eventually destroys brain cells, leading to loss of memory and other cognitive skills, personality changes, and problems performing daily activities. It usually develops slowly and gradually gets worse as brain function declines and brain cells eventually die. Alzheimer's disease is the most common type of dementia, accounting for 50 to 80 percent of dementia cases. Other common types include vascular dementia, dementia with Lewy bodies and frontotemporal dementia.

Although researchers do not know exactly what causes Alzheimer's, most experts believe that the abundance of plaques and tangles in the brain disable or block communication among nerve cells and disrupt processes the cells need to survive. It is this destruction and death of nerve cells that causes memory failure and the loss of cognitive skills, physical abilities and other symptoms of Alzheimer's. Research has established that plaques are deposits of a protein fragment called beta-amyloid that build up in the spaces between nerve cells and that tangles are twisted fibers of another protein called tau, which builds up inside cells. Autopsies show that most people develop some plaques and tangles as they age, but those with Alzheimer's tend to develop far more. They also tend to develop them in predictable patterns, beginning in the areas important for memory before spreading to other regions.

### Existing Treatments

Currently, there are two types of drugs and five specific medications approved by the FDA that treat the symptoms of Alzheimer's — temporarily helping memory and thinking problems in about half of the people who take them. But these medications do not treat the underlying causes of Alzheimer's.

The first type of drugs, cholinesterase inhibitors, prevents the breakdown of acetylcholine, a chemical messenger important for memory and learning. By keeping levels of acetylcholine high, these drugs

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<sup>1</sup>The information included in this section was excerpted from the Alzheimer's Association research center webpage and from their brochure, "basics of alzheimer's disease." See References 5 and 6, respectively.

support communication among nerve cells. The second type of drug works by regulating the activity of glutamate, a different messenger chemical involved in information processing. The effectiveness of these drugs varies. While they may temporarily help symptoms, they do not slow or stop the brain changes that cause Alzheimer's to become more severe over time.

### **Promising Areas of Research**

A worldwide quest is under way to find new treatments to stop, slow or even prevent Alzheimer's, and some of the most promising research is going on in San Diego. In contrast to current drugs that treat the symptoms of Alzheimer's, many of the new drugs in development aim to modify the disease process itself by impacting one or more of the many wide-ranging brain changes that Alzheimer's causes. These changes offer potential targets for new drugs to stop or slow the progress of the disease. Many researchers believe successful treatment will eventually involve a combination of medications aimed at several targets, similar to current state-of-the-art treatments for many cancers and AIDS.

Given current understanding of beta-amyloids, the chief component of plaque in the brain, researchers are developing medications aimed at virtually every point in amyloid processing, including blocking activity of related enzymes; preventing the beta-amyloid fragments from clumping into plaques; and using antibodies against beta-amyloid to clear it from the brain. Similarly, the knowledge of the tau protein as the chief component of tangles is prompting research into strategies to keep tau molecules from collapsing and twisting into tangles, a process that destroys a vital cell transport system.

Scientists have learned a great deal about molecules involved in the body's overall inflammatory response and are working to better understand specific aspects of inflammation most active in the brain. These insights may point to novel anti-inflammatory treatments for Alzheimer's disease. Insulin resistance and the way brain cells process insulin may be linked to Alzheimer's disease. Researchers are exploring the role of insulin in the brain and closely related questions of how brain cells use sugar and produce energy. These investigations may reveal strategies to support cell function and stave off Alzheimer-related changes.

In addition to investigating experimental drugs, many clinical trials in progress include various brain imaging studies and testing of blood or spinal fluid. Researchers hope these techniques will one day provide methods to diagnose Alzheimer's disease in its earliest, most treatable stages — possibly even before symptoms appear. Biomarkers may also eventually offer better methods to monitor response to treatment.

## BRINGING TOGETHER THE BEST AND BRIGHTEST

The Alzheimer's Project is a comprehensive, collaborative effort involving diverse stakeholders from multiple sectors affected by Alzheimer's disease and other dementias. Participants include healthcare, County and City government, advocacy groups, caregivers, scientists, private residential and home care providers, law enforcement, philanthropists, community-based organizations serving caregivers and older adults, media representatives, and other concerned community members.

The planning process for developing recommendations for The Alzheimer's Project was guided by a steering committee and four roundtables focused on the key elements of the initiative – Care, Clinical, Cure, and Public Education & Awareness. These groups are comprised of the “best and the brightest” leaders in their respective fields, and all focused on how the San Diego region should respond to this immense health challenge.

### *Steering Committee*

The Steering Committee is chaired by the County Board of Supervisor's Chairwoman Dianne Jacob, and co-chaired by District 3 Supervisor, Dave Roberts. Key leaders provide expertise and strategic guidance, including Darlene Shiley, President of the Shiley Foundation; San Diego County Sheriff William Gore; Mary Ball, President/CEO of the Alzheimer's Association; Michael Lobatz, M.D. of Scripps Health, a leading neurologist and Director of Rehabilitation at Scripps Encinitas; and Nick Macchione, Director of the County's Health and Human Services Agency. In addition to providing overall guidance to The Alzheimer's Project, steering committee members participate in the Care, Cure and Clinical Roundtables.

### *Care Roundtable*

The Care Roundtable includes more than 35 members representing residential, day and home care providers, public safety, caregivers, community-based organizations, healthcare providers, experts in dementia care, and staff from various divisions with the County's Health and Human Services Agency. Chaired by Pam Smith, a long-time advocate for older adults and a recognized leader in the field, this group was charged with developing a plan to improve services for those with dementia and their caregivers. The Care group examined what is currently working well in San Diego's system of care, as well as what needs to be improved. A sub-committee of the Roundtable, including representatives from 2-1-1 San Diego, the Alzheimer's Association, Glenner Memory Care Centers, Southern Caregiver Resource Center, and the County's Aging & Independence Services department, worked together to inventory the current community resources available to those with ADOD, their caregivers and families. Finally, the Care Roundtable formulated and prioritized recommendations for improving the region's ADOD care system, both with and without new resources.



### *Cure Roundtable*

The Cure Roundtable is comprised of approximately 15 of the region's preeminent ADOD researchers, physician-scientists, biotech representatives and the San Diego County Medical Society. Chaired by Supervisor Dianne Jacob and co-chaired by Supervisor Dave Roberts, key members include Mayor Kevin Faulconer, Darlene Shiley and Mary Ball of the Alzheimer's Association. Originally charged with enhancing awareness, partnerships and funding for Alzheimer's research, this group has focused on developing a collaborative regional strategy, integrating the work of researchers and San Diego's unique drug discovery capabilities and identifying funding strategies to support local research efforts. Like the Care Roundtable, the Cure group formulated and prioritized a set of recommendations to accelerate the development of disease-modifying treatments and the discovery of a cure for Alzheimer's disease.

### *Clinical Roundtable*

Although not originally envisioned as a component of The Alzheimer's Project, the importance of a specialized focus on clinical care of patients with the disease and the critical role physicians and other healthcare providers play was quickly identified. The Clinical Roundtable was established to improve medical care for those suffering from Alzheimer's and other forms of dementia and is co-chaired by Michael Lobatz, M.D., a leading neurologist with Scripps Health and Nicholas Yphantides, M.D., M.P.H., the County of San Diego's Chief Medical Officer. Members include clinicians (neurologists, psychiatrists, gerontologists, family practice physicians, pharmacists) representing San Diego's major health systems, physicians in private practice, and the San Diego County Medical Society.

The goal of the group is to develop a consensus on how to screen for, diagnose and treat Alzheimer's disease and other dementias. Three sub-committees have been created to accomplish this, including a team focused on creating standards of practice for diagnostic criteria and workup, a second team working on standards of practice for disease management and mental health, and a third team focused on healthcare provider education and outreach. Rather than formulating recommendations, the Clinical Roundtable will present a progress report at the December 2014 Board Conference.



*The Clinical Roundtable was established to improve medical care for those suffering from Alzheimer's.*



### *Public Education & Awareness*

The Public Education & Awareness effort is being led by the Alzheimer's Association in partnership with Aging & Independence Services' Outreach and Education team and other community and media partners. Chaired by Mary Ball, President/CEO of the Alzheimer's Association, this group was charged with developing an Alzheimer's education and public awareness campaign focusing on the 10 warning signs and early diagnosis of the disease, exploring the possibility of presentations at County libraries and other facilities, and developing a plan for providing ADOD training to public safety and social service personnel. The objectives of the campaign are to educate, engage, build awareness and generate support. Elements of the awareness campaign are already underway with paid and earned media in U-T San Diego and on KUSI and KFMB/CBS channel 8.

## RECOMMENDATIONS

### Cure

- Bridge the gap between academic research and drug development and build a local drug pipeline to accelerate the process of discovering new drugs to treat and prevent Alzheimer's disease
- Fund critical experiments to advance a portfolio of Alzheimer's disease drug discovery projects conceived by San Diego-based research scientists and clinicians
- Focus on finding cures through advancing multiple projects from concept stage (where the research to identify an Alzheimer's drug target/pathway has already been conducted) through to drug candidate, i.e., fund the applied science to find a drug
- Leverage existing drug discovery expertise and equipment in San Diego, e.g., robotic drug screening and medicinal chemistry capabilities at Sanford-Burnham/Scripps
- Beginning in year 3, fund neuroimaging/biomarker capabilities in San Diego to enable new drugs to be assessed for efficacy in models of disease
- Partner with biomedical and life sciences industry to provide capabilities not available in research institutes. Explore risk sharing models of funding and ways to transition projects from the not-for-profit setting to commercial organizations who can conduct clinical development programs.
- Publicize the impending Alzheimer's epidemic and San Diego's potential for crucial breakthroughs in the search for effective treatments and a cure
- Create a San Diego-specific research fund with the goal of raising \$7 million over the next five years to support local Alzheimer's research projects
- Investigate MRI (mission-related investment funding) for projects in private sector
- Increase public and private funding for applied research leading to building a portfolio of first-in-class new mechanism of action drugs designed and developed to treat Alzheimer's disease
- Build a strong base of philanthropy dedicated to Alzheimer's disease and brain aging
- Utilize the Aging Network to identify participants for research studies
- Conduct autopsies or other appropriate examinations to accurately determine prevalence of ADOD as cause of death
- Create a population and public health surveillance system for Alzheimer's disease

*Launch a fund drive called Part the Clouds to spur research innovation and drug discovery.*

## RECOMMENDATIONS *continued*

### Care

#### *Existing Resources*

- Increase awareness of end-of-life issues, hospice and palliative programs for Alzheimer's Disease and Other Dementias (ADOD)
- Develop community capacity for supporting older adults aging in place who develop ADOD
- Increase dissemination of resource information and improve the system for connecting ADOD patients, care partners, and families with available resources
- Increase awareness/use of FACT as a resource for affordable transportation
- Work with employers to provide education/support for caregiving employees to reduce negative effects on the workplace
- Coordinate a consistent response (post-Search & Rescue) to support families and prevent wandering incidents
- Identify and/or develop preventive assessments to identify those at-risk for wandering
- Explore options for effectively using the Silver Alert system to assist in locating individuals who have wandered
- Develop alternatives for addressing needs of isolated individuals who refuse assistance (self-neglect cases)
- Enhance Caregiver Webinars and caregiver conferences for County employees
- Provide outreach on the use of Employee Assistance Programs for caregivers suffering from stress
- Pilot a workplace demonstration project to support caregivers and maintain productivity
- Include tracking of persons with dementia in the Adult Protective Services case management system (ALEX)
- Increase visibility of the Promoting Independence and Choice program

#### *New Resources*

- Expand availability and affordability of dementia-specific adult day care (ADC) and adult day health care (ADHC)
- Increase affordability of home care
- Increase availability, affordability and appropriate levels of residential care
- Improve system for connecting ADOD patients, care partners and families with resources
- Expand Family Caregiver Support Centers throughout San Diego County
- Use technology to deliver caregiver support services
- Increase culturally and linguistically appropriate caregiver outreach and services for San Diego County's diverse population

## *New Resources* continued

- Increase availability, affordability and appropriate use of respite for caregivers
- Train those who encounter ADOD patients and caregivers in multiple settings to improve responses and treatment
- Enhance and expand the Take Me Home program
- Explore conducting the Healthier Living – Chronic Disease Self-Management program for early stage individuals and caregivers
- Review potential to expand Community Based Care Transition Program (CCTP) to caregivers of persons with dementia regardless of payer source
- Reinstate Spanish-speaking Caregiver Conferences
- Revitalize the Project Care program to ensure vulnerable older adults at home do not fall through the cracks

## *Clinical Progress Report*

- Three subcommittees have formed to conduct research and prepare preliminary recommendations:
  - ◆ **Standards of Practice Diagnosis Criteria and Workup committee** – composed of neurologists and will include literature review, guidelines on proper screening methods, survey of current practices in San Diego County and variations
  - ◆ **Standards of Practice Disease Management & Mental Health committee** - composed of neurologists, psychiatrists, gerontologists, family practice, and pharmacology and will include a survey of current practices, discussion of disease management at different phases, use of medications, and nexus with other mental health issues
  - ◆ **Healthcare Provider Education and Outreach committee** – composed of caregivers, stakeholders, and community based organizations and will look at cross-cultural issues, produce a sample presentation for neurologists/psychiatrists to educate primary care physicians, other health care providers and the general public, and provide physicians materials to educate patients and their caregivers
- Gather stakeholder input – beginning in spring 2015, stakeholders will be invited to forums to discuss the subcommittees' initial recommendations and provide input
- Create standard practice guidelines and educational materials
- Work with the health systems and private practice physicians to facilitate adoption of practice standards for diagnosis and disease management and dissemination of educational materials for physicians and patients
- Work to develop reporting standards and evaluation parameters to prove adoption efficacy of the practice standards over time



## RECOMMENDATIONS *continued*

### *Public Awareness & Education*

- Train County personnel and first responders who serve individuals with ADOD, starting with:
  - ◆ Law Enforcement – Sheriff’s Department and Police Departments throughout the region
  - ◆ All County staff who interact with those who may have ADOD
- Encourage community-based organizations and County Departments to enhance efforts to raise public awareness about ADOD, prioritize messaging to increase understanding of the following issues:
  - ◆ 10 warnings signs of Alzheimer’s disease
  - ◆ Importance of early detection, planning and accessing resources
  - ◆ Safety measures for persons with dementia
  - ◆ Risks associated with caregiving and importance of accessing support and resources
  - ◆ Brain health strategies to improve resistance to the disease
- Conduct a media campaign to increase community outreach on how to recognize and report elder and dependent adult abuse (including self-neglect)
- Focus on Brain Health at Vital Aging Summit
- Partner with the County Libraries to increase public awareness of ADOD
- Create a public education campaign to assist individuals with life and financial planning, especially targeted at potential caregivers

### *Legislation*

- Support for the Alzheimer’s Accountability Act that would require scientists at the National Institute of Health to submit an annual Alzheimer’s research budget proposal directly to Congress and the President, specifying the

resources needed to fully implement the National Alzheimer's Plan to achieve the national goal of preventing and effectively treating Alzheimer's disease by 2025

- Support for legislation that increases funding for Alzheimer's disease research and provides additional resources to caregivers, family members and those afflicted with Alzheimer's disease was added to the County's 2014 Legislative Program on May 6, 2014
- Proposed for inclusion in the County's 2015 Legislative Program priorities is a section related to Alzheimer's and action items to support people living with Alzheimer's and their families

### *Funding*

- Respond to funding opportunity announcements, as available, to support the regional strategy to improve ADOD services for those living with the disease, to support Alzheimer's education and public awareness, and to fund local research for treatments and a cure
- Create a San Diego-specific research fund with the goal of raising \$7 million over the next five years, beginning with \$500,000 in 2015, to support local Alzheimer's research projects
- Focus efforts on financing mechanisms for ADOD care and long-term support services for middle income and lower-middle income families (those without sufficient resources to pay for care, but with too many resources to qualify for low-income programs)
- Secure tax incentives to help pay for caregiving and other support services
- Potentially include caregiver expenses for County employees and their families as eligible for pre-tax accounts (similar to healthcare and dependent expenses)
- Establish rebates for home modifications and other types of ADOD support for home-based care (similar to energy efficiency rebates)
- Increase funding for caregiver support centers - advocate to restore funding cut from the Older Americans Act, Title III E, and increase funding for caregiver support services
- Develop a pilot project to demonstrate the impact of lower levels of care for Medi-Cal and Medicare Dual Eligible clients - seek reimbursement for non-medical ADOD services (home care, caregiver expenses, residential care for non-skilled nursing facilities, community-based programs) to demonstrate cost savings to managed care plans of paying for services that keep people at home
- Increase funding for adult day care
  - ◆ Advocate for funding to be restored to the Older Californians Act to support adult day care programs
  - ◆ Negotiate higher reimbursement rates with health plans to make day care programs financially viable

## REFERENCES

1. County of San Diego, Health and Human Services Agency, Public Health Services, Community Health Statistics Unit, 2014. *Alzheimer's Disease and Other Dementias in San Diego County*. Retrieved from [www.SDHealthStatistics.com](http://www.SDHealthStatistics.com).
2. Alzheimer's Association, *2014 Alzheimer's Disease Facts and Figures, Alzheimer's & Dementia*, Volume 10, Issue 2; National Institutes of Health.
3. Alzheimer's Association, *Generation Alzheimer's, the defining disease of the baby boomers*. Alzheimer's Association: Chicago. Print.
4. County of San Diego, Health and Human Services Agency, Public Health Services, Community Health Statistics Unit, 2014. *Economic Burden of Alzheimer's Disease and Other Dementias in San Diego County*. Retrieved from [www.SDHealthStatistics.com](http://www.SDHealthStatistics.com).
5. [alz.org](http://alz.org) / research center. Alzheimer's Association, 2014. Web.
6. Alzheimer's Association, *basics of alzheimer's disease*. Alzheimer's Association: Chicago. 2013. Print.
7. County of San Diego, Health and Human Services Agency, Public Health Services, Community Health Statistics Unit, 2014. *Profile of Alzheimer's Disease and Other Dementias in San Diego County Slide Set*. Retrieved from [www.SDHealthStatistics.com](http://www.SDHealthStatistics.com).

