



COMMONWEALTH of VIRGINIA
Alzheimer's Disease and Related Disorders Commission

Commission Members

August 15, 2006

Chairman
Russell H. Swerdlow, M.D.
Charlottesville, VA

Vivian Bagby
Richmond, VA

Robert Bullock, J.D.
Alexandria, VA

Thelma Bland Watson, Ph.D.
Richmond, VA

Constance Coogle, Ph.D.
Richmond, VA

Bill Kallio
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Ian Kremer
Oak Hill, VA

Marilyn Pace Maxwell
Big Stone Gap, VA

Cathy Saunders
Richmond, VA

Robert Schaefer
Chesterfield, VA

Lorna Wass
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E. Ayn Welleford, Ph.D.
Richmond, VA

The Honorable Marilyn Tavenner
Secretary of Health and Human Resources
Patrick Henry Building
1111 East Broad Street, 4th Floor
Richmond, VA 23219

Dear Secretary Tavenner:

On behalf of the members of the Alzheimer's Disease and Related Disorders Commission, I want to thank you for reviewing our 2006 Annual Report (attached) and for your ongoing support for our mission. I am also writing to ask that you work with the Governor's Office to have the following items included in the Governor's 2007-2008 budget (background information for these items is also included):

- An appropriation of **\$200,000** in General Funds for the Virginia Center on Aging to restore previous budget cuts, to ensure the continuation of their unique mission, and to increase the number of seed grants awarded through the Alzheimer's Disease and Related Disorders Research Award Fund; and
- An investment of **\$400,000** in General Funds for more effective and efficient utilization of dementia services in the Commonwealth by expanding the Virginia Alzheimer's Commission's Alzpossible Initiative.

You and the entire Administration have partnered with the General Assembly to advance the science of combating dementia and provide better support to people with dementing disorders and their caregivers.

Virginia Department for the Aging

1610 Forest Avenue, Suite 100, Richmond, Virginia 23229

Toll-Free 1-800-552-3402 (Nationwide Voice/TTY) Telephone (804) 662-9333 (Voice/TTY) Fax (804) 662-9354

Much work remains to be done and the Commonwealth must continue its aggressive course if it is to overtake the scourge of Alzheimer's. At the start of this decade, approximately 107,000 Virginians had Alzheimer's; by the end of this decade, more than 145,000 Virginians will have Alzheimer's.

Again, please accept my appreciation and admiration for your vision, wisdom, and compassion as we work collaboratively to serve the needs of the most vulnerable Virginians.

Sincerely,

Russell Swerdlow, MD
Chairman

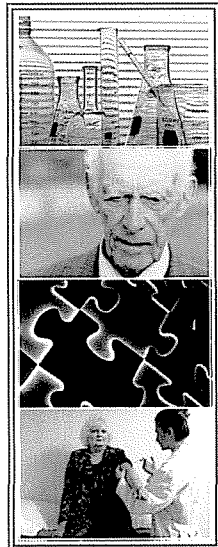
Attachment

C: Julie Christopher, *Commissioner*
Virginia Department for the Aging

Gail Jaspen, Esquire
Deputy Secretary of Health and Human Resources

COMMONWEALTH OF VIRGINIA'S ALZHEIMER'S DISEASE AND RELATED DISORDERS COMMISSION REPORT

July 2006



 **Presented to**
The Honorable Marilyn Tavenner
Secretary of Health and Human Resources



2006 REPORT OF THE VIRGINIA ALZHEIMER'S DISEASE AND RELATED DISORDERS COMMISSION

July 2006

Acting in its advisory capacity, **the Commission recommends actions** to enhance Virginia's ability to effectively and efficiently serve the persons with Alzheimer's disease and their families. Specific short and long term recommendations are included below:

A) SHORT TERM RECOMMENDATIONS

The Commission recommends that the Commonwealth appropriate \$200,000 during the second year of the biennium **for the Virginia Center on Aging** (*created by Virginia General Assembly in 1978, Chapter 170 of the Acts of 1978, Code of Virginia 23-50.15*) **to:**

- (1) restore previous budget cuts in core operations,
- (2) ensure continuance of unique programs, and
- (3) increase the number of seed grant awards in the Alzheimer's Disease and Related Disorders Research Award Fund (ARDRAF).

COST FOR THE PROJECT: \$200,000 (\$60,000 for lost core budget, \$100,000 for unique programs, and \$40,000 to increase the number of seed grant awards in the ARDRAF) - (see attached details).

B) LONG TERM RECOMMENDATIONS

Our long term recommendations focus on increasing the **effective and efficient utilization of dementia services and public dollars throughout the Commonwealth** and include the expansion and support of Virginia's Alzheimer Commission AlzPossible Initiative (VACAPI) (the operative arm of the Commission, organized into "cores," each addressing a particular area of need):

- a. *Services Core* - the Services Core has established a Telemedicine Memory Disorders Clinic. This clinic ascertains the educational and practical needs of physicians caring for patients with dementia throughout the Commonwealth.
- b. *Database Core* - the Database Core is charged with creating a registry of persons at increased risk for Alzheimer's disease. This registry will provide investigators studying aging and Alzheimer's disease with access to a unique research resource.
- c. *Research Core* - the Research Core is responsible for coordinating research efforts involving the Database Core, and for organizing multi-institutional, innovative attempts to improve the state of Alzheimer's disease management.
- d. *Education Core* - the Education Core will ascertain the educational needs of patients, caregivers, nurses, and other non-physician personnel caring for Alzheimer's disease patients and other persons with dementia throughout the Commonwealth. These efforts will guide educational initiatives designed to improve the status of those with dementia.
- e. *Policy Core* - a major problem throughout the Commonwealth includes the disconnection between infrastructural resources, state financial resources, and the constituencies needing them. The Policy Core will explore the reasons for this disconnect, as well as ways to minimize it.
- f. *Administrative Core* - The Administrative Core provides practical support to the other cores and maintains the VACAPI website. This website represents a key communication portal between the citizens of the Commonwealth and the Initiative, and regular monitoring of the website is required.

COST FOR THE PROJECT: \$400,000 (see attached details)



www.vda.virginia.gov/alzcommission.htm

VACAPI

Virginia Alzheimer's Commission AlzPossible Initiative

www.alzpossible.org

COMMISSION

The Virginia Alzheimer's Disease and Related Disorders Commission is composed of 15 non-legislative citizen members. The Commission advises the Governor and the Secretary of Health and Human Resources on issues related to Alzheimer's disease and related disorders, as well as acting as an advocate for affected individuals, their families and caregivers.

COMMISSION MEMBERS

Chairman: Russell H. Swerdlow, MD, Charlottesville

Vivian Bagby, RN, MS, Richmond

Robert Bullock, JD, Alexandria

Thelma Bland Watson, PhD, Richmond

Constance L. Coogle, PhD, Richmond

Ian Kremer, JD, Oak Hill

Janet R. Lynch, PhD, CPHQ, Chesterfield

Bill Kallio, Richmond

Marilyn Maxwell, MSW, Big Stone Gap

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Lorna Wass, Gloucester

Martha Watkins, Luray

E. Ayn Welleford, PhD, Richmond

Ex-Officio: Julie Christopher

Commissioner, Department for the Aging

Staff: William Peterson, PhD, Janet Schaefer and Cecily Slasor

Department for the Aging

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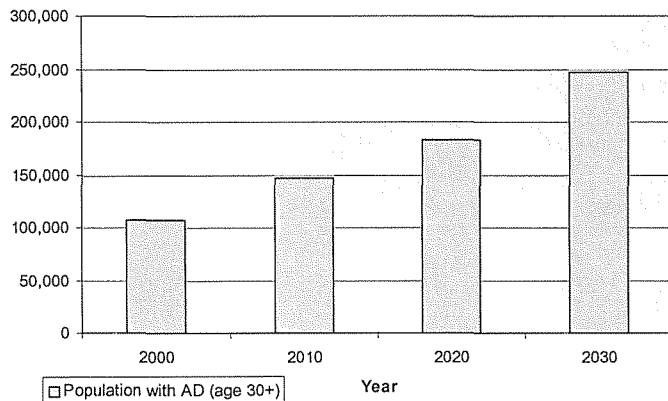
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THE 2006 REPORT OF THE VIRGINIA ALZHEIMER'S DISEASE AND RELATED DISORDERS COMMISSION: ACTIVITIES AND RECOMMENDATIONS OF THE COMMITTEE

The Virginia Commission on Alzheimer's Disease and Related Disorders advises the Commonwealth on the care of persons with Alzheimer's disease, dementia due to other causes, and the caregivers of such persons. This is an enormous constituency, which represents one of the largest consumers of state Medicaid resources.

Virginians (Age 30+) with Alzheimer's Disease



Source: VDA/Alzheimer's Association

During the last fiscal year, Virginia non-Medicaid spending on Alzheimer's disease programs included:

- (1) \$150,000 for a pilot research grant program;
- (2) \$75,000 to educate members of the criminal justice system about Alzheimer's disease;
- (3) \$70,000 for an assisted living supplement program; and
- (4) \$500,000 for a "general respite program" administered through the Virginia Department for the Aging.

As in past years, for this fiscal year several million dollars were also allocated to an Alzheimer's disease assisted living waiver program. Due to major infrastructure limitations, the majority of this money went unspent and thus was returned to the Commonwealth.

This year the Commission polled organizations and individuals managing or otherwise caring for persons with Alzheimer's disease. We ascertained perceived strengths and weaknesses throughout the Commonwealth. To summarize an overall strength of the state, it does appear the Commonwealth is making a reasonable and commendable effort to provide services to the patients and caregivers requiring them. Substantial investment in improving the status of those with Alzheimer's disease, other dementias, and the lives of their caregivers was made. A related strength is the apparent availability of services and resources for these constituencies. However, there does appear to be a disconnection between the available services, the money available for providing the services, and constituencies that stand to benefit from the services. As it has in past years, this disconnect leads to inefficiencies in resource delivery, as well as marked frustration for those having to navigate the consequences of a dementing disorder.

For illustration, we are presenting statistics published in the Alzheimer's Association fact sheet at www.alz.org:

- An estimated 4.5 million Americans have Alzheimer's disease. The number of Americans with Alzheimer's has more than doubled since 1980.
- The number of Americans with Alzheimer's disease will continue to grow - by 2050 the number of individuals with Alzheimer's could range from 11.3 million to 16 million.
- Finding a treatment that could delay onset by five years could reduce the number of individuals with Alzheimer's disease by nearly 50% after 50 years.
- In a Gallup poll commissioned by the Alzheimer's Association, 1 in 10 Americans said that they had a family member with Alzheimer's and 1 in 3 knew someone with the disease.
- Increasing age is the greatest risk factor for Alzheimer's. One in 10 individuals over 65 and nearly half of those over 85 are affected. Rare, inherited forms of Alzheimer's disease can strike individuals as early as their 30s and 40s.
- National direct and indirect annual costs of caring for individuals with Alzheimer's disease are at least \$100 billion, according to estimates used by the Alzheimer's Association and the National Institute on Aging.
- Alzheimer's disease costs American business \$61 billion a year, according to a report commissioned by the Alzheimer's Association. Of that figure, \$24.6 billion covers Alzheimer health care and \$36.5 billion covers costs related to caregivers of individuals with Alzheimer's, including lost productivity, absenteeism and worker replacement.
- More than 7 out of 10 people with Alzheimer's disease live at home, where almost 75 percent of their care is provided by family and friends. The remainder is "paid" care costing an average of \$19,000 per year. Families pay almost all of that out of pocket.
- Half of all nursing home residents have Alzheimer's disease or a related disorder.
- The average cost for nursing home care is \$42,000 per year but can exceed \$70,000 per year in some areas of the country.
- The average lifetime cost of care for an individual with Alzheimer's is \$174,000.
- Medicare costs for beneficiaries with Alzheimer's are expected to increase 75 percent, from \$91 billion in 2005 to \$160 billion in 2010; Medicaid expenditures on residential dementia care will increase 14 percent, from \$21 billion in 2005 to \$24 billion in 2010, according to a report commissioned by the Alzheimer's Association.
- The federal government estimates spending approximately \$647 million for Alzheimer's disease research in FY 2005.

Acting in its advisory capacity, the Commission recommends actions to enhance Virginia's ability to effectively and efficiently serve the relevant constituencies. Specific short and long term recommendations are included below.

A) SHORT TERM RECOMMENDATIONS

It is our recommendation that the Commonwealth should support the Virginia Center on Aging by:

1. restoring previous budget cuts in core operations,
2. ensuring continuance of unique programs, and
3. increasing the number of seed grant awards in the Alzheimer's Disease and Related Disorders Research Award Fund (ARDRAF).

COST FOR THE PROJECT: \$200,000 (\$60,000 for lost core budget, \$100,000 for unique programs, and \$40,000 to increase the number of seed grant awards in the ARDRAF) - (see attached details).

1. Lost Core Budget

The General Assembly cut the Virginia Center on Aging's GF appropriation by \$122,500 or 33%, taking a total of \$47,500 from FY 2003 and another \$75,000 from FY 2004. One third of VCoA's GF appropriation supports the **Alzheimer's and Related Diseases Research Award Fund (ARDRAF)** (*Code of Virginia 2.2-710*) to stimulate biomedical and psychosocial research on dementia, which affects one-third or more of all Virginians above age 85. This Alzheimer's Research Award Fund is the only state-supported small seed grant research program in Virginia. Because the composite GF appropriation supports both the Center's core operations and the Alzheimer's and Related Diseases Research Award Fund (ARDRAF), both suffered the cutbacks. Two years ago the ARDRAF had been reduced to \$77,500.

Advocacy efforts in the last three sessions of the General Assembly have secured replacement of lost ARDRAF funds and a new infusion of funds so that, effective July 2006, there is \$200,000 available for ARDRAF seed grants. While advocacy efforts for ARDRAF have been somewhat successful, lost funding for the Center's core operations has not been replaced. Administering ARDRAF alone takes a considerable commitment of diminished GF appropriations for core operations, and lost appropriations have required VCoA to reduce its staff.

The Virginia Center on Aging (VCoA), located on the Medical College of Virginia Campus of Virginia Commonwealth University, was created by the Virginia General Assembly in 1978 (Chapter 170 of the Acts of 1978, Code of Virginia 23-50.15) to "be an interdisciplinary study, research, information and resource facility for the Commonwealth of Virginia utilizing the full capabilities of faculty, staff, libraries, laboratories and clinics for the benefit of older Virginians and the expansion of knowledge pertaining to the aged and to the aging process."

This is the only such center in Virginia.

The General Assembly assigned the Virginia Center on Aging three primary functions:

a) Interdisciplinary Study

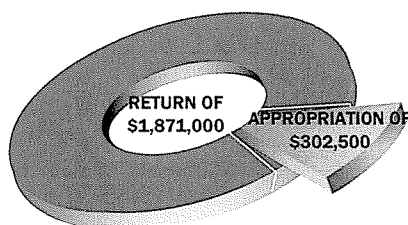
The General Assembly includes continuing education, in-service training, education and training of older persons, and educational preparation of non-gerontology students among the interdisciplinary studies to be initiated by VCoA.

b) Research

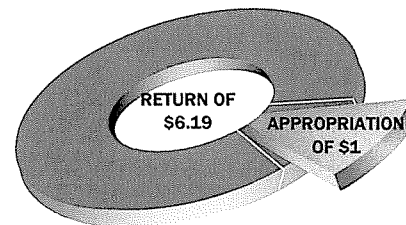
The General Assembly charges the Virginia Center on Aging to conduct research in the field of gerontology and to make the findings available.

c) Information Resource Sharing

The General Assembly mandates VCoA to collect and maintain data on the characteristics and conditions of Virginia's elders, and to be a readily available resource to organizations and agencies serving these elders.

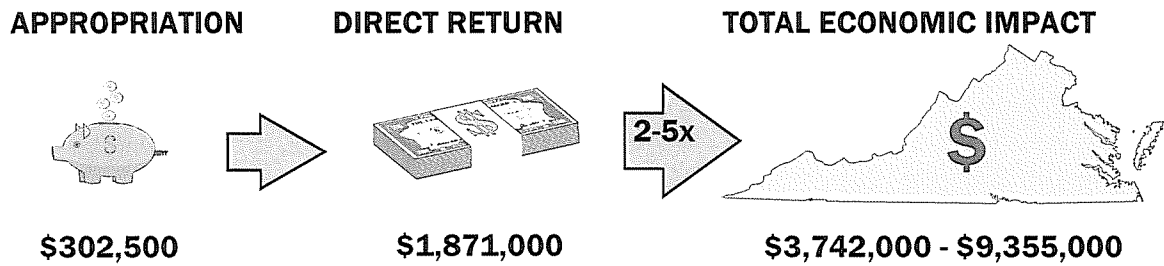


The Virginia Center on Aging's General Fund appropriation of \$302,500 in calendar 2005 brought into the Commonwealth a documented total of \$1,871,000 in direct competitive grant monies, seed grant consequences, and Elderhostel tuition and tourism expenditures by non-Virginians.



Each General Fund dollar invested in the Virginia Center on Aging generated \$6.19 in direct economic returns.

Employing standard economic multipliers (2-5x) to determine subsequent effects, the total estimated economic benefits to Virginia's citizens from Virginia Center on Aging activities in 2005 was between 3.7 and 9.3 million dollars.



2. Unique Programs

VCoA conducts the only training program in Virginia focused on domestic violence against older women for law enforcement and victim witness officers, and the only intersystem coalition to improve services to aging Virginians with lifelong disabilities (mental retardation, cerebral palsy); VCoA receives no GF appropriation for this work. In addition, VCoA has special expertise in the issues of balancing work and eldercare, and would continue work in this area, with a special emphasis on Alzheimer's caregiving, given basic support to do so.

3. Increase Number of ARDRAF Awards

The last several years have seen a number of highly-qualified, well-reviewed ARDRAF proposals not being funded because of limited monies. ARDRAF was able this year to support six awards for the first time. However, the current size of the awards, \$30,000, is increasingly insufficient to meet the rising costs of laboratory animals, assays, scientific equipment, and qualified research support staffs. Therefore six awards of \$40,000 would better enable promising lines of research and support research requirements.

B) LONG TERM RECOMMENDATIONS *for more effective and efficient utilization of dementia services and public dollars throughout the Commonwealth*

It is clear the already substantial personal and societal burden caused by Alzheimer's disease will exponentially grow in the foreseeable future. The Commission recommends an approach taken by other states, which involves establishing centralized mechanisms for the ongoing ascertainment of patient care needs at the state level, as well as mounting coordinated responses to those needs. The intended outcome of this approach is to address weaknesses in patient care infrastructure before they reach crisis proportions. In this regard, in 2004 the Commission created a statewide "Virtual Alzheimer's Disease Center." To date, this work has received financial support from a federal grant obtained by the Virginia Department of Aging (The Alzheimer's Disease Demonstration Grants to States Program).

Over the past year, the Commission has defined and refined this effort so that over the long term it will create a centralized mechanism for ascertaining patient needs and mounting coordinated responses to those needs before they reach crisis proportions. This effort has been formally titled the "**Virginia Alzheimer's Disease AlzPossible Initiative**" (**VACAPI**). Information on this endeavor is available at a dedicated website (www.AlzPossible.org).

To achieve this goal of providing improved education resources, the Commission recommends a one-time investment of \$400,000 for the VACAPI's organizational divisions or "cores," each of which address particular areas of need:

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- a. **SERVICES CORE - the Services Core has established a Telemedicine Memory Disorders Clinic.** This clinic ascertains the educational and practical needs of physicians caring for patients with dementia throughout the Commonwealth.

The Commission recommends an investment of \$100,000 to expand this clinic statewide.

TELEMEDICINE MEMORY DISORDERS CLINIC (TMDC) SYNOPSIS: The primary intent of TMDC is to provide primary care internists, psychiatrists, and neurologists with access to tertiary dementia sub-specialist expertise, without actually referring the patients themselves. To our knowledge, this TMDC is the first of its kind. We are proceeding with a simplified pilot version. For this pilot version, the state is divided into distinct geographic districts. A "clinic hour" for each district is then specified. Advance notice of the clinic hour is disseminated to district physicians. During the hour, district physicians with questions about dementia diagnosis/management issues are able to join a telephone conference call lead by a tertiary care dementia sub-specialist. In this manner, primary physicians can seek input from the specialist on individual patients felt not to require formal referral, but who might nevertheless still benefit from expert advice. In the pilot version, this telemedicine clinic is staffed by the three memory disorder sub-specialists of the UVA MDC.

KEY PLAYERS: This project represents a joint venture between the Commonwealth of Virginia Commission on Alzheimer's Disease and Related Disorders, its AlzPossible Initiative and the cognitive sub-specialist physician-investigators of the University of Virginia Department of Neurology.

OBJECTIVES: This venture has a three-dimensional focus:

- (1) educate Virginia physicians on the diagnosis and management of patients with cognitive disorders, particularly Alzheimer's disease;
- (2) improve the care of dementia patients throughout the Commonwealth; and
- (3) extend access of patients and physicians to cognitive disorders tertiary resources.

We will accomplish these goals via application of telemedicine technology.

PROJECT BUDGET: \$100,000 - Developing this infrastructure will require salary support for a UVA cognitive disorders sub-specialist, an administrative assistant at UVA, and an ADRDC administrative liaison. Funding for telemedicine technical services, information dissemination, and data base creation are also requested. We hope implementation of the TMDC under this proposal will enable procurement of National Institutes of Health funding.

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- b. **DATABASE CORE** – the Database Core is charged with **creating a registry of persons at increased risk for Alzheimer's disease.** This registry will provide investigators studying aging and Alzheimer's disease with access to a unique research resource.

The Commission recommends an investment of \$100,000 to develop this initiative.

SYNOPSIS: We are in the process of setting up a comprehensive database of children of persons with Alzheimer's disease for the Commonwealth of Virginia. With most ambitious goals, the project will enroll 3000 adult children of Alzheimer's disease sufferers in a decade-long study aimed at finding ways to prevent people like them from developing the memory-robbing illness. The aim of the project is to take this group of people, study them at regular intervals over the years, compare ones that have certain lifestyle habits or are taking certain medications or dietary substances to those who do not, and use scientific methods to analyze results. This database will become a tremendous resource for basic science, clinical and social-behavioral research in Virginia.

RATIONALE: Studying cognitive decline and factors that affect cognitive decline in the non-demented children of persons with Alzheimer's should allow investigators to better define the trajectory of cognitive decline in those who will themselves one day develop Alzheimer's disease. This type of investigation may also help define the relevance of recognized Alzheimer's disease risk factors in this age-related cognitive decline that is occurring even before a clinical diagnosis can be made.

KEY INVESTIGATORS: University of Virginia and Virginia Commonwealth University.

PROJECT BUDGET: \$100,000 to initiate creation of the database. *This includes software and computer hardware costs, costs of information technology consultation, support of a dedicated database manager, and costs relating to recruitment of volunteers.*

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- c. **RESEARCH CORE** - the Research Core is responsible for coordinating research efforts involving the Database Core, and for organizing multi-institutional, innovative attempts to improve the state of Alzheimer's disease management.

This core is planning and facilitating the formation of collaborative scientific teams to leverage existing talents and areas of strength within the Commonwealth with a final goal of applying for and being awarded an Alzheimer's Disease Research Center (ADRC) grant from the National Institutes of Health.

VISION AND MISSION:

- The principal role of the ADRC will be to **foster and facilitate research** related to cognitive changes in aging. Namely, this will include their physiological and pathophysiological bases, their clinical and experimental expression, their personal and societal impact, cultural influences on their expression, and therapies.
- A concomitant goal is **educational**, providing instruction and information transfer on findings developed by ADRC-affiliated investigators, and the Alzheimer's and related disorders community as a whole. The ADRC will actively seek collaborative participation in educational initiatives throughout Virginia.
- The ADRC will be an integral part of VACAPI, providing **collaborative support** to the efforts to develop this statewide initiative, contributing expertise and resources in partnership with other participating agencies and programs, and acting as a focal point for further development.

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- d. **EDUCATION CORE** - the Education Core will ascertain the educational needs of patients, caregivers, nurses, and other non-physician personnel caring for Alzheimer's disease patients and other persons with dementia throughout the Commonwealth. These efforts will guide educational initiatives designed to over the long term improve the status of those with dementia.

The Commission recommends an investment of \$100,000 pursue this initiative.

It is our recommendation that the Commonwealth should focus on developing education resources for patients, caregivers, health care professionals, social workers and other Alzheimer's disease and related disorder service providers throughout the state. Development of education resources on multiple levels is needed:

- (1) Patients and caregivers require information on available resources;
- (2) Physicians encountering patients with Alzheimer's disease and related disorders require information on the state of diagnosis and management, as well as resource availability;
- (3) Nurses and certified nursing assistants involved in the day-to-day management of persons with dementia require information on patient interpretation and identify and manage disruptive behaviors.
- (4) First responders encountering patients with Alzheimer's disease require information on interpretation and management strategies.

CORE BUDGET: \$100,000 to initiate the four-prong educational plan at the Commonwealth level. *This includes management and coordination fees, hard-costs such as printing, mailing and advertising as well as seminar/training fees.*

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- e. **POLICY CORE** - a major problem throughout the Commonwealth includes the disconnection between infrastructural resources, state financial resources, and the constituencies needing them. The Policy Core will explore the reasons for this disconnect, as well as ways to minimize it.

State government plays a vital role in the lives of people living with dementia. By statute, regulation and funding – or their absence – government shapes the quality, accessibility and affordability of health care. Government can provide financial support for scientific research into the causes, treatment and prevention of disease. Government can regulate the private market for long-term care insurance policies. Government can guide family caregivers through the maze of public and private resources. Government can ensure that assisted living and nursing homes provide good care. Government can provide incentives to expand the number of doctors and nurses specializing in geriatric care.

- f. **ADMINISTRATIVE CORE** – The Administrative Core provides practical support to the other cores and maintains the VACAPI website. This website represents a key communication portal between the citizens of the Commonwealth and the Initiative, and regular monitoring of the website is required.

The Commission recommends an investment of \$100,000 to implement the administrative core.

The objective of this core is to build bridges among all relevant programs, services, departments, institutions and professions. The formation of seamless relationships, a *sine qua non* of the VACAPI, among all relevant programs and/or services throughout the Commonwealth, is the most critical requirement for a vibrant and viable comprehensive initiative. Therefore, this core will make extraordinary efforts to establish the infrastructure for strong links among all the constituents or components of the “Center” e.g., services, programs, clinics and research laboratories.

This core’s plan is to prepare a detailed work outline, defining specific goals and dates (time lines) for completion of various tasks; form subcommittees and complete drafts; identify all existing resources within the Commonwealth, including the talents, expertise and common scientific interest of the participating professionals; enlarge the group of participating institutions/professionals; as the planning proceeds invite an ever-expanding circle of resource people and/or potential participants in the VACAPI programs; evaluate and catalogue current human and material resources, services, programs; determine the needs for additional resources, services, and programs; prepare recommendations for programmatic actions and/or legislative initiatives; formulate a business plan which will become a critical prerequisite for the eventual fund raising campaign for the overall VACAPI;

CORE BUDGET: \$100,000 (*including administrative fees, meeting fees, printing and mailing fees, technical fees*).