REPORT OF THE COMMISSION ON

Alzheimer's Disease and Related Disorders Pursuant to House Joint Resolution No. 134

TO THE GOVERNOR AND
THE GENERAL ASSEMBLY OF VIRGINIA

House Document No. 33

COMMONWEALTH OF VIRGINIA
RICHMOND
1987

MEMBERS OF THE COMMISSION

Kenneth R. Plum, Chairman
Peter K. Babalas
Joseph P. Crouch
V. Earl Dickinson
Clive L. DuVal, II
Clarence A. Holland
Joan H. Munford

Citizen Members

Mary Lee Batten
Jim Bruner
Mary Jane H. Crump
Terry S. Jenkins, Ph.D.
Linda Noyes, R.N.
Anne Olshansky
Iris A. Parham, Ph.D.
Saundra E. Rollins
William I. Rosenblum, M.D.
Joan M. Rothrauff
Wilford W. Spradlin, M.D.
John R. Taylor, M.D.
Knox W. Tull

STAFF
Legal and Research

Division of Legislative Services
Brenda H. Edwards, Research Associate
Norma E. Szakal, Staff Attorney
Joyce Crone, Secretary

Administrative and Clerical

Office of the Clerk, House of Delegates

Report of the
Commission on Alzheimer's Disease
and Related Disorders
Pursuant to HJR 134
To
The Governor and the General Assembly of Virginia
Richmond, Virginia
January, 1987

To: Honorable Gerald L. Baliles, Governor of Virginia
and
The General Assembly of Virginia

HISTORY

The 1985 Virginia General Assembly established, via House Joint Resolution No. 309, a Commission on Alzheimer's Disease and Related Disorders to determine the needs of Alzheimer's and other dementia victims and their families and to determine the feasibility of establishing regional dementia centers throughout the Commonwealth. The Commission submitted its report to the 1986 General Assembly, to which was appended its proposed legislation. Of the proposed legislation submitted, all were passed with the exception of House Bill 633, Establishment of Regional Dementia Centers; House Bill 635, the Alzheimer's Registry; and budget amendments. House Bill 633 and House Bill 635 were carried over in the House Committee on Appropriations to the 1987 Session of the General Assembly. The Commission was continued to the 1987 Session by House Joint Resolution No. 134. Following the adjournment of the 1986 General Assembly, Delegate V. Earl Dickinson of Mineral was appointed to replace Senator Benjamin J. Lambert, III of Richmond. Delegate Kenneth R. Plum of Reston and Senator Peter K. Babalas of Norfolk served as Chairman and Vice-Chairman, respectively.

Activities of the Commission

During the 1986 interim, the Commission met to review the status of its proposed legislation, to reevaluate House Bill 633 and House Bill 635 and to discuss the provisions of these bills with relevant state agency heads and state medical schools, to follow up on the implementation of its recommendations, and to determine the appropriate action to pursue relative to the needs of victims and caregivers which were not addressed during the first phase of the Commission's study. Following consultation with representatives of the Department of Education, Department of Mental Health and Mental Retardation, State Health Department, the State Council of Higher Education, the Virginia Community College System, the Board of Medicine, the Medical Society of Virginia, and the state medical schools, the Commission submits the following recommendations.

RECOMMENDATIONS

1. The Commission recommends that a functional, multidimensional Alzheimer's Registry be established in the State Health Department, effective July 1, 1988.

2. The Commission recommends that the University of Virginia and the Department of Mental Health and Mental Retardation continue their joint pilot epidemiological study on Alzheimer's disease and release the findings of such study to the State Health Department upon the implementation of the Alzheimer's Registry.

Discussion

During the first year of its study, the Commission recommended the introduction of legislation to the 1986 General Assembly, House Bill 635, to require the establishment of an Alzheimer's Registry in the State Health Department. House Bill 635 was carried over to the 1987 Session of the General Assembly in the House Committee on Appropriations.

The Commission maintains that the establishment of the Alzheimer's Registry remains a priority. The inability to ascertain pertinent data impedes the determination of the number of dementia victims in the Commonwealth. The lack of essential information is a major obstacle in assessing the needs of victims and caregivers, in advancing scientific and medical research, and in providing sound information to the Governor and the Legislature upon which feasible and cost-effective health planning decisions can be made. The lack of data also would create a long-term drain on the Commonwealth's budget as the needs of victims and ensuing problems associated with dementia are addressed on a crisis-oriented basis.

The Commission notes the concerns expressed by the State Health Department regarding House Bill 635, particularly the timeliness and the usefulness of establishing an Alzheimer's Registry, the efficacy of a provider-based registry, and the appropriateness of placing the Registry within the Department. It is the Department's position that as no diagnostic test exists for the identification of Alzheimer's disease in living patients, information on the prevalence and etiology of the dementia, which would be provided by a registry, would make the usefulness of this registry questionable. The Department also indicated that it may be beneficial to await the results of the National Institute on Aging's epidemiological study of the disease that is being planned rather than to implement measures which might be duplicative. The Department also noted that although it administers other registries, which are hospital-based, the Alzheimer's Registry would be its first provider-based registry and the viability of a registry dependent upon reporting by providers is tenuous.

The Commission also received testimony from the Medical College of Virginia of the Virginia Commonwealth University and the University of Virginia wherein each institution expressed keen interest in becoming the site for the Alzheimer's Registry provided adequate funds were made available. Research on Alzheimer's disease at both institutions is currently underway, and care and treatment of dementia patients is a component of the health care services available at each institution. The institutions each possess the staff, research and clinical capability to attract additional research funds.

The University of Virginia and the Department of Mental Health and Mental Retardation have agreed to pilot an epidemiological study of Alzheimer's disease. The University will conduct the study of institutionalized patients at Western State Hospital to determine the incidence of Alzheimer's disease among this population. The study will include both clinical diagnosis of living patients and the postmortem examination of brain tissue. Although the pilot will be based on institutionalized patients, the Commission believes that the study is an appropriate beginning to ascertaining the prevalence of Alzheimer's disease in Virginia prior to the establishment of the Registry. Therefore, the Commission encourages the University and the Department to continue their study and as funds become available to broaden the scope of the study to include non-institutionalized patients. The Commission recommends that the findings of the study be released to the State Health Department upon the implementation of the Registry in order that the Health Department may have benefit of the data.

The Commission is cognizant of the difficulty of having to allocate limited resources among several priorities and other needs in the Commonwealth, particularly during the second year of the biennium. It is this dilemma which precludes the Commission's recommending that the Alzheimer's Registry be established at this time. Nevertheless, the Commission reaffirms its position that a functional, multidimensional registry be established by 1989, and that the State Health Department include in its budget request for the 1988-1990 biennium funding therefor to facilitate the compilation of data, the confirmation of diagnoses and the promotion of research. Although the Commission believes that the NIA study will provide needed data on Alzheimer's disease, these data will reflect national incidences only. The Commission believes that it is both appropriate and imperative that the Commonwealth initiate efforts which will yield information specific to Virginia and relevant to the development and implementation of programs to meet the needs of the citizens of this Commonwealth. The Commission believes further that the Alzheimer's Registry is the best method of obtaining accurate data on dementias. Moreover, the Commission believes that any budget request for the Alzheimer's Registry should include funding to enable the Registry to obtain and examine adequate samples of brains from deceased Alzheimer's victims in the Registry in order to ascertain the accuracy and the validity of the diagnosis. In addition, the incorporation of tissue distribution mechanisms in the registry will create a unique benefit to families of dementia victims and medical and scientific researchers in Virginia. Such registry will also assist in budget preparation as public health policies and goals are determined and requisite funding are estimated. In the interim, the Commission recommends that the Virginia Commonwealth University and the University of Virginia consult the National Institute on Aging to ascertain the protocols of its study to determine whether the NIA would be receptive to including Virginia in its study. The Commission recommends that Virginia Commonwealth University and the University of Virginia, together with the Eastern Virginia Medical School, work collaboratively to coordinate the research on Alzheimer's disease at the respective institutions, and to compile such relevant data as may be available on the incidence of dementias in Virginia.

3. The Commission recommends that the Board of Health amend its regulations to require licensed physicians to note significant health conditions, including chronic diseases, and conditions contributing to death but not related to the terminal disease conditions set out in Part I of the Medical Certification on the Death Certificate, and that the Board include this requirement in the instructions for Part II of such Certificate.

4. The Commission recommends that the Medical Society of Virginia urge licensed physicians to complete the Death Certificate in its entirety and that the Society emphasize this need in its continuing education programs for licensed physicians.

Discussion

The Commission is concerned that deaths related to Alzheimer's disease and other related dementias are not accurately accounted for given the manner in which the Death Certificate is completed.Although such forms and accompanying instructions provide opportunities for physicians to include pertinent comments and notations respecting the cause(s) of death and the health status of the deceased, many physicians may not be aware of such provisions as few of them are recording all requested information. The Commission believes that more thorough reporting on deaths by physicians would facilitate a better accounting of deaths due to Alzheimer's disease and other related dementias, enhance health planning capabilities relative to program needs and costs, and aid in the development of preventive strategies that may be appropriate pursuant to new research findings and in providing needed services to caregivers.

The Commission believes that the amendment of the regulations of the State Board of Health to require licensed physicians to note significant health conditions, including chronic diseases, and conditions contributing to death but not related to the terminal disease condition of the deceased on the Death Certificate would facilitate a more accurate determination of the number of Alzheimer related deaths in Virginia and provide documentation of the prevalence of other health conditions and causes of morbidity. Emphasis on the need for this requirement could best be addressed through the Medical Society of Virginia's continuing education programs for licensed physicians. This should include education emphasizing the importance of the autopsy to confirm or negate the clinical diagnoses. The diagnosis on the death certificate may then be modified on this basis. Pursuit of this route would provide opportunities to inform physicians of the requirement and generate their cooperation in providing needed data.

5. The Commission recommends the creation of five regional dementia centers throughout the Commonwealth and that the Commission be established in statute, with a sunset, to provide oversight of the implementation of such centers.

Discussion

Testimony presented to the Commission during the first phase of its study substantiates the need for informational and community support services for caregivers, professionals and the public regarding dementias and the needs of such victims and their families. It was determined that these services are not available throughout the Commonwealth. Therefore, the Commission reaffirms its belief that better coordination of services for Alzheimer victims and their families can be provided through the establishment of regional dementia centers that would be located in each of the state's five health systems areas. It is envisioned that the centers will provide psychosocial services, education, information and referral services for professionals, caregivers and the public, in-home or center-based respite care, professional training and community awareness, education of the public and professionals on Virginia's commitment procedure, the role of crisis intervention centers, and information and support services to families regarding autopsies.

In providing programs and services for dementia victims and their families, the public and professionals, it is recommended that the dementia centers determine the needs of this population and the demand for certain services before creating new programs or augmenting existing services to prevent the expensive duplication and fragmentation of programs and services. It is recommended further that the dementia centers consult with the Department for the Aging concerning respite care needs and resources in the Commonwealth prior to initiating new services.

It is also recommended that the Commission be established in statute to provide oversight of the implementaion of the dementia centers. This would facilitate the creation of centers that would be consistent with the needs and purposes identified by the Commission.

6. The Commission recommends that the Department for the Aging encourage local area agencies on aging to adopt an identification program for dementia victims and other elderly disabled citizens.

Discussion

Victims of dementia often experience memory loss. Particularly, Alzheimer's victims, as the disease progresses, experience profound memory loss and require constant supervision. These patients often pace for hours or wander away from home and get lost. They are at risk for many kinds of accidents. These persons may not be able to locate the bathroom in his own house or to find his way about in his own neighborhood. He may forget his name, the names of his relatives and may not recognize his own spouse.

Alzheimer's victims develop a language disorder which makes it increasingly difficult for them to understand what is said or to communicate their needs and thoughts. Throughout the course of the disease the impaired intellectual function often makes these individuals prone to irritability, stubborness, argumentativeness and sudden explosive bursts of temper. They may also become apathetic, unresponsive, depressed or moody.

Although such persons may reside in an environment that provides both security and maximum opportunity for free movement, such persons do on many occasions leave the protection of their homes or health care facilities without the knowledge of caregivers. This poses a tremendous threat to the safety of such individuals, especially given their periods of intermittent lucidity and inability to communicate essential information. One means of addressing this problem would be the establishment of an identification program, such as Contact, a telephone crisis intervention program in Petersburg, Virginia. This type of program could be developed in local communities in cooperation with law enforcement agencies, emergency medical services and other safety personnel, civic and community agencies, the media, business and industry, (e.g. utility workers, ad agencies, realtors), neighbors, and health care professionals. It is proposed that such a program might be administered by area agencies on aging. A mechanism would be established to register dementia victims and other disabled elderly persons at local area agencies on aging through the recordation of vital information concerning such individuals. This data would be maintained by the local agency. Families and other caregivers of these persons would then purchase a bracelet which would identify the individual, how to contact the local area agency on aging or whom to contact in case of emergency. A modest fee could be levied for the cost of the bracelet and the program. Local agencies and organizations within the community would be requested to participate in the program by making employees and members aware of the program and its objectives and encouraging them to be observant as they perform their customary duties.

It is envisioned that such a program would stimulate community participation and interest in the well-being of others, minimize possible harmful situations and provide some measure of reassurance to caregivers for the safety of loved ones should that individual wander away. It would also eliminate the stress on victims and those who encounter and seek to assist them.

7. The Commission recommends that the University of Virginia, the Medical College of Virginia and the Eastern Virginia Medical School advertise the existence of the toll-free hot line to provide readily accessible information on dementias to all physicians.

Discussion

It remains the Commission's opinion that there is a need for a more cohesive, coordinated approach to the dissemination of information on dementias to professionals. There also appears to be a need to increase the expertise in some areas of the state in order to improve the quality of care for dementia patients. The toll-free hot line is a valid means of delivering essential information. Currently, the existence of the hot line is not widely known. The Commission recommends that its existence at each of the medical schools be publicized in order that physicians may utilize the number.

CONCLUSION

The Commission is also mindful of the fact that Alzheimer's disease and other dementias place a devastating financial burden upon the families of victims. Under the existing system for the delivery of health care, families must often exhaust their life savings before they are eligible to participate in Medicaid. Certain other public assistance programs have additional criteria for eligibility which in some cases the victims and their families are unable to meet. Although publicexpenditures for Alzheimer's disease is several billion dollars yearly, the families of dementia victims bear a major burden in paying for the patient's medical care. The financial and emotional impact of caring for dementia patients cannot be quantified. Therefore, the Commission believes that there is a need to develop and augment funding mechanisms to assist families in providing needed medical care for dementia victims. Much remains to be accomplished relative to estimating the number of Virginians afflicted with dementia, determining the needs of and services available to dementia victims and their families, and developing alternatives to financing the medical care of such individuals in a cost-efficient manner. Other medical and scientific research and medical/legal issues in long-term care of the chronically ill need considerable deliberation. The Commission emphasizes the significance of the Alzheimer's Registry in ascertaining reasonable conclusions to some of these issues and its capability to yield data which might assist in resolving others. Legislation which the Commission deems appropriate at this time has been appended to this report.

The Commission extends its appreciation to all who assisted in its study.

Respectfully submitted,

Kenneth R. Plum, Chairman

Peter K. Babalas

Joseph P. Crouch

V. Earl Dickinson

Clive L. DuVal, II

Clarence A. Holland

Joan H. Munford

Mary Lee Batten

Jim Bruner

Mary Jane H. Crump

Terry S. Jenkins, Ph.D.

Linda Noyes, R.N.

Anne Olshansky

Iris A. Parham, Ph.D.

Saundra E. Rollins

William I. Rosenblum, M.D.

Joan M. Rothrauff

Wilford W. Spradlin, M.D.

John R. Taylor, M.D.

Knox W. Tull

APPENDICES

A. Proposed Legislation

B. House Joint Resolution No. 309

APPENDIX A

HOUSE BILL NO. 633

AMENDMENT IN THE NATURE OF A SUBSTITUTE

A BILL to amend the Code of Virginia by adding in Chapter 1 of Title 37.1 an article numbered 6, consisting of sections numbered 37.1-62.1 and 37.1-62.2, relating to the establishment of five dementia centers.

Be it enacted by the General Assembly of Virginia:

1. That the Code of Virginia is amended by adding in Chapter 1 of Title 37.1 an article numbered 6, consisting of sections numbered 37.1-62.1 and 37.1-62.2 as follows:

Article 6.

Dementia Centers.

§ 37.1-62.1. Dementia centers established; Board to monitor; respite, other psychosocial and educational services to be provided.--From such funds as are appropriated for this purpose, there are hereby established five dementia centers, one to be located in each of the five health service areas of the Commonwealth.

For the purposes of this section, the term "dementia center" shall mean a facility administered by a licensed health care facility, an accredited institution of higher education, area agencies on aging, a licensed adult day care center or other certified or licensed nonprofit agency having experience in the delivery of care to dementia patients. The dementia centers shall deliver educational and psychosocial services to patients with dementias and their families. These services shall include, but not be limited to, respite care services to families caring for dementia patients, information and referral services to families caring for dementia patients, professional and community education and information on obtaining brain autopsies for confirmation of diagnoses.

"Respite care" shall mean temporary care for the patient in his home or in a center or other appropriate setting in order to provide a rest for the caregiver.

Each of the centers shall encourage participation by the local chapters of the Alzheimer's Disease and Related Disorders Association. The centers shall collaborate with other disciplines within the health care or academic institution as appropriate, but shall be independent of any and all other activities. Volunteers drawn primarily from the local chapter of the Alzheimer's Disease and Related Disorders Association and any other support group may be utilized by the dementia centers to maximize the use of staff resources.

The Department of Mental Health and Mental Retardation shall contract with the licensed health care facilities, accredited institutions of higher education, area agencies on aging, licensed adult day care centers or other certified or licensed nonprofit agencies having experience in the delivery of care to dementia patients for the provision of the services described in this section and shall monitor the fiscal and substantive activities of the dementia centers. The Department may require such reports from the centers and promulgate such regulations as it deems necessary and appropriate. The Department of Mental Health and Mental Retardation shall also provide technical expertise and administrative oversight pursuant to the regulations and reporting requirements of the Board.

§ 37.1-62.2. Alzheimer's Disease and Related Disorders Commission; membership; oversight responsibilities.--The Alzheimer's Disease and Related Disorders Commission shall, until July 1, 1989, monitor the development and operations of the dementia centers.

The Commission shall consist of twenty members appointed by the Governor, four of whom shall be members of the House of Delegates, three of whom shall be members of the Senate of Virginia, five of whom shall be providers who are members of the Alzheimer's Disease and Related Disorders Association, and eight of whom shall be professionals, one each from the fields of medicine, nursing, mental health, aging, social services, forensic medicine and two other areas related to the healing arts.

The Commission shall monitor the activities of the dementia centers and make recommendations to the centers for improving services to dementia patients and their families.

HOUSE BILL NO. 635

AMENDMENT IN THE NATURE OF A SUBSTITUTE

A BILL to amend the Code of Virginia by adding in Chapter 2 of Title 32.1 an article numbered 9.1, consisting of sections numbered 32.1-71.1 through 32.1-71.4, establishing the Statewide Alzheimer's Disease and Related Disorders Registry.

Be it enacted by the General Assembly of Virginia:

1. That the Code of Virginia is amended by adding in Chapter 2 of Title 32.1 an article numbered 9.1, consisting of sections numbered 32.1-71.1 through 32.1-71.4 as follows:

Article 9.1.

Statewide Alzheimer's Disease and Related Disorders Registry

§ 32.1-71.1. Statewide Alzheimer's Disease and Related Disorders Registry established; records of hospitals, clinics, individual practitioners and others may be supplied to Commissioner.--A. There is hereby established the Statewide Alzheimer's Disease and Related Disorders Registry. Each hospital, clinic, individual practitioner or other agency or facility providing health care may participate in this registry by making available to the

Commissioner or his agents abstracts of their records of patients who have been diagnosed as having Alzheimer's disease or a related disorder. Such abstracts may include the name, address, sex, race and any other pertinent identifying information regarding each patient.

From the abstracts received, the Commissioner shall establish and maintain a Statewide Alzheimer's Disease and Related Disorders Registry. The purpose of the state registry shall include, but not be limited to:

1. Providing tissue to validate diagnoses and support research on Alzheimer's and related disorders.

2. Collecting data to evaluate the incidence and causes of Alzheimer's Disease and related disorders.

3. Providing data to support research on Alzheimer's Disease and related disorders.

§ 32.1-71.2. Advisory Committee to be appointed; contract for quality assurance.--The Commissioner shall appoint an advisory committee to assist in the design and implementation of this registry which shall include, but need not be limited to, the Commissioner of the Department of Mental Health and Mental Retardation or his designee and one representative of each of the following groups: practicing physicians treating patients with Alzheimer's disease and related disorders; neuropathologists; researchers engaged in clinical investigations related to dementias; basic science researchers engaged in studies related to dementias; nursing home administrators; the Medical College of Virginia; the University of Virginia

School of Medicine; Eastern Virginia Medical School; and the Alzheimer's Disease and Related Disorders Association.

The advisory committee shall assist the Commissioner or his agents in developing protocols, choosing necessary psychometric validation instruments and other technical mechanisms.

From such funds as are appropriated, the Commissioner shall contract with one or more of the three medical schools in the Commonwealth for diagnostic quality assurance of a random sampling of patients. The contractor shall report the results of the postmortem examination or other conclusive test to the family of the deceased and to his attending physician and shall make tissue available to any researcher conducting approved human research in the Commonwealth. The contractor shall hire on a consulting basis and train as necessary an individual or individuals to procure tissue.

§ 32.1-71.3. Fees for nonparticipants for informational services and providing tissue for research.--The Board shall establish and periodically review a schedule of fees to be charged for data or tissue requested by nonparticipating institutions, agencies or individuals. The fees shall be based on the actual cost of producing the data or providing the tissue. Agencies or political subdivisions of the Commonwealth shall be exempt from the payment of any such fees.

The schedule of fees for providing tissue shall be developed in cooperation with the contractor or contractors pursuant to § 32.1-71.2. The contractor or contractors shall keep records and periodically transfer such funds as are collected for providing tissue to nonparticipants to the Department.

§ 32.1-71.4. Confidential nature of information supplied; publication; authority of Commissioner.--The Commissioner and all other persons to whom data is released or tissue provided pursuant to § 32.1-71.1 shall keep all patient information confidential. No publication of information, biomedical research or medical data shall be made which identifies the patients. However, the Commissioner may contact the families and physicians of patients diagnosed as having Alzheimer's disease or a related disorder to collect relevant data and to provide them with information about available public and private health care resources.

The Commissioner may also distribute any protocols or other materials developed by the advisory committee to practicing physicians.

2. That this act shall become effective on July 1, 1989.

HOUSE JOINT RESOLUTION NO.....

Requesting the medical schools of the University of Virginia, Virginia Commonwealth University and the Eastern Virginia Medical Authority to publicize their toll-free hot lines.

WHEREAS, Alzheimer's disease is an insidious, debilitating disease, leaving its victims with irreversible deterioration of cognitive functions and their families perplexed and financially burdened from providing constant care for such individuals; and

WHEREAS, other related dementias are just as devastating to victims and their families; and

WHEREAS, there are apparent deficiencies in the quality of care in remote areas of the Commonwealth and a need for curricular revisions in graduate medical education, continuing education for practicing physicians and additional information services on the dementias; and

WHEREAS, there is also a need for a more cohesive and coordinated system for the dissemination of information on dementias to health professionals so that physicians can provide better, more up-to-date care for dementia victims; and

WHEREAS, the toll-free hot line is one means of delivering such information; and

WHEREAS, few practicing physicians may be aware of the existence of the hot lines; now, therefore, be it

RESOLVED by the House of Delegates, the Senate concurring, That the medical schools of the University of Virginia, Virginia Commonwealth University and the Eastern Virginia Medical Authority are hereby requested to publicize their toll-free hot lines in order that all physicians in the Commonwealth may have access to specialized medical advice on dementias; and, be it

RESOLVED FURTHER, That the Clerk of the House of Delegates prepare a copy of this resolution for presentation to each of the medical schools to apprise them of the sense of this body.

HOUSE JOINT RESOLUTION NO.....

Requesting the Department for the Aging to encourage area agencies on aging to establish identification programs for dementia victims and other disabled elderly persons.

WHEREAS, victims of Alzheimer's disease and other related dementias are debilitated by profound memory loss, making them high risks for accidents and other unfortunate situations; and

WHEREAS, such persons from time to time wander away from the protection of homes and health care facilities; and

WHEREAS, such occurrences exert tremendous pressure upon victims because they may not be able to identify themselves properly or to remember the names of relatives or recognize their own spouse; and

WHEREAS, victims develop a language disorder which makes it increasingly difficult for them to understand what is said to them, to communicate their needs and thoughts, and to provide coherent, essential information to those who might assist them; and

WHEREAS, the establishment of an identification program for dementia victims and other infirm elderly, such as Contact in Petersburg, Virginia, would provide a clearinghouse for the compilation and dissemination of vital information by which such persons might be quickly identified, hazardous situations to them minimized, and their caregivers assured that reasonable efforts can be made to secure the return of such individuals; now, therefore, be it

RESOLVED by the House of Delegates, the Senate concurring, That the Department for the Aging encourage area agencies on aging to collaboratively develop with law-enforcement agencies, emergency medical services and other safety personnel, civic and community groups, business and industry, health care professionals and other interested parties, an identification program for dementia victims and other disabled elderly persons; and, be it

RESOLVED FURTHER, That the Clerk of the House of Delegates prepare a copy of this resolution for presentation to the Department for the Aging and area agencies on aging in order that they may be apprised of the sense of this body.

HOUSE JOINT RESOLUTION NO. 309

Requesting the General Assembly to establish a Commission on Alzheimer's Disease and Related Disorders to study the concept of a network of regional dementia centers.

Agreed to by the House of Delegates, February 4, 1985
Agreed to by the Senate, February 20, 1985

WHEREAS, Alzheimer's disease and related disorders are estimated to claim more than 40,000 victims in Virginia alone, and there is a great need for social support for their families; and

WHEREAS, a cause or effective treatment for Alzheimer's disease has not yet been discovered, and additional research is needed urgently to understand this condition and its ramifications; and

WHEREAS, there is a need for continuing education among medical, social service, and mental health practitioners as well as for public awareness and education; and

WHEREAS, there is not a statewide data base of relevant clinical information for the purpose of research or service delivery; and

WHEREAS, there is not a network among clinical facilities to share research findings, treatment modalities, or autopsy material; now, therefore, be it

RESOLVED by the House of Delegates, the Senate concurring, That there is hereby established a Commission on Alzheimer's Disease and Related Disorders to study the need for and the feasibility of a network of four to six regional dementia centers to be based in Virginia's academic or health care centers, operated in cooperation with local chapters of the Alzheimer's Disease and Related Disorders Association (ADRDA), and each serve a particular population and build upon its already existing expertise.

The Commission shall consist of twenty members as follows: four members of the House of Delegates to be appointed by the Speaker thereof, three members of the Senate to be appointed by the Senate Committee on Privileges and Elections, five providers who are members of the Alzheimer's Disease and Related Disorders Association to be appointed by the Governor and eight professionals, one each from the fields of medicine, nursing, mental health, aging, social services, forensic medicine and two other areas related to the healing arts, to be appointed by the Governor.

The Commission shall study, in particular, the following activities which might be carried out by these Dementia Centers:

1. Support activities for patients and their families by volunteer peer counselors through the ADRDA;
2. Continuing education and training activities for medical, mental health and social service professionals who work with patients and their families as well as provide public education whenever possible;
3. Identification of community-based resources (e.g., respite care, day care, professional counseling, etc.) for patients with Alzheimer's and related diseases;
4. Assurance of access to specialized medical services (e.g., diagnosis, treatment, medical management, autopsies, etc.) through the existing health care system to all persons including minorities and those living in rural areas;
5. Maintenance of a working relationship with local institutions involved in geriatric assessment and research into all aspects of Alzheimer's and related disorders;
6. Maintenance of communication channels through the national ADRDA and National Institutes of Health to keep abreast of the kinds of research being conducted elsewhere and to facilitate the sharing of findings; and
7. Development of a clinical data base on patients presumptively diagnosed as having Alzheimer's or related diseases in order to promote research dealing with the causes, diagnosis, and treatment of these diseases and their impact upon society.

The Virginia Center on Aging of Virginia Commonwealth University is hereby requested to provide staff support to the Commission.

The Commission shall complete its work and present its findings and recommendations to the 1986 Session of the General Assembly.

All direct and indirect costs of this study shall not exceed $15,000 and are to be payable from the Alzheimer's Disease and Related Disorders Research Award Fund.