REPORT TO THE

HOUSE OF DELEGATES APPROPRIATIONS COMMITTEE

AND THE

SENATE FINANCE COMMITTEE

STUDY ON PROTECTING INDIVIDUALS

WITH ALZHEIMER'S DISEASE

Item 461.B

2000 Appropriations Act

Department of Criminal Justice Services
October 2, 2000

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TO: The Honorable Vincent F. Callahan, Jr. and V. Earl Dickinson,
Co-Chairmen, House Appropriations Committee
The Honorable John H. Chichester, Chairman, Senate Finance Committee

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Item number 461.B of the 2000 Appropriations Act directed the Department of Criminal Justice Services to conduct a study to determine the best methods for providing protection to individuals with Alzheimer's Disease. This study was to include a review of Project Lifesaver and how it may play a part in protecting Alzheimer's victims. The results of our study are hereby submitted for your review.

Sincerely,

Joseph B. Benedetti
Director

AUTHORITY FOR STUDY

In Governor Gilmore's budget for the 2000 legislative session, $75,000 was designated to fund a statewide coordination of the Safe Return Program for Alzheimer's victims and provide training to law enforcement officers. Additionally, the Department of Criminal Justice Services (DCJS) was directed to conduct a study to determine the best methods for providing protection to these individuals, including examination of Project Lifesaver (see Appendix A).

Under Title 9, Chapter 27, Code of Virginia, DCJS is given the authority to administer funding for specialized programs and to provide training for law enforcement officers. Section 9-170 of the Code of Virginia directs DCJS to establish training standards and curriculum requirements to train officers in Alzheimer's related topics

ACKNOWLEDGEMENTS

This study was conducted by Ronald E. Bessent, MSW, Program Administrator of Training and Development, Virginia Department of Criminal Justice Services, with assistance from the following individuals and organizations:

All chapters of the Virginia Alzheimer's Association;

Dr. Robert Koester, Virginia Department of Emergency Management (VDEM);

Col. J. E. Saunders, Commander, Chief of the 43rd Virginia Volunteer Search and Rescue Company, Chesapeake Sheriff's Office;

the Virginia Sheriffs' Association;

and the Virginia Association of Chiefs of Police.

I. EXECUTIVE SUMMARY

The Department of Criminal Justice Services (DCJS) was directed by the 2000 Session of the General Assembly to study the best methods of providing protection to individuals with Alzheimer's Disease (AD). The results of the study and any recommendations are to be submitted to the Chairmen of the Senate Finance Committee and House Appropriations Committee.

Alzheimer's Disease is a progressive, degenerative brain disease that now afflicts more than four million Americans; that number is projected to increase to 14 million by mid-century. Currently, more than 101,000 Virginians suffer from AD. Most people contracting AD are over 65; however, people in their 40's and 50's have also been diagnosed. Symptoms of the disease include loss of reasoning and judgment abilities, behavior changes (often irrational and paranoid), communication problems, difficulty in performing routine activities, disorientation as to time and place (a particular problem related to wandering), problems with abstract thinking, and misplacing things. Over 70% of AD sufferers live at home and, for three-quarters of them, home care is provided by family and friends. The cost of home care for AD patients can be as high as $15,000 per year; the cost of nursing home care ranges from $42,000 to $70,000.

To learn the problems and identify the needs of persons with AD and law enforcement, DCJS conducted two surveys and interviewed several representatives of organizations providing protective services to AD patients. The surveys were given to caregivers of AD patients and to law enforcement administrators. The results of the surveys are located in *Appendices B and C* of this report. Based on information gleaned from the surveys and research done by the Alzheimer's Association and the state's Search and Rescue (SAR) coordinator, we developed these findings:

Wandering by AD Sufferers

- Research indicates that over 50% of individuals with severe AD will wander and become lost; 64% of caregivers responding to our survey reported wandering by family members.

- Research indicates 72% of AD patients who wander do so multiple times. Between 13,000 and 15,000 Virginians are at risk of becoming lost.

- Wandering is an emergency situation and time-sensitive. In one-third of the incidents where the lost person is not found within 24 hours, the result is a fatality. Fatalities increase exponentially after 24 hours.

Training

- Training of more law enforcement officers in matters relating to AD patients continues to be a major concern.

- In spite of funding by the General Assembly and efforts to provide a training curriculum and materials by DCJS, criminal justice academies have not provided adequate training. Only 25% of agency administrators reported their departments had received training. Over 86% of these administrators indicated the need for such training.

Search and Rescue

- State Search and Rescue (SAR), in the Department of Emergency Management, is a critical resource for locating lost Alzheimer's patients, and for locating other citizens who become lost in Virginia.

- SAR services are provided by volunteers who spend or contribute out-of-pocket monies of over $910,000 per year. The value of the time they contribute equates to nearly $5 million.

- Coordination of SAR in Virginia is provided by one part-time employee, and the program is significantly under-funded.

Safe Return

- The Alzheimer's Association's *Safe Return* Program is a nationwide identification, support, and registration service for AD patients that helps family members and law enforcement locate and return lost Alzheimer's patients; however, it is not widely known by law enforcement or family members of AD patients.

- The General Assembly has provided $150,000 over the current biennium for a statewide *Safe Return* Coordinator to educate law enforcement officers and families, and increase registrations in the national data bank.

Project Lifesaver

- *Project LifeSaver* is a new program that utilizes tracking technology to locate lost AD patients quickly (average time is 22 minutes). It has been shown to save needed man-hours in the conduct of searches. More importantly, however, it has a record of saving the lives of AD patients. To date, this technology is given credit for saving 30 lives.

- *Project LifeSaver*, which must be centrally coordinated, is operated by volunteers out of the Chesapeake Sheriff's Office and now serves 16 jurisdictions in Virginia.

- At present, *Project LifeSaver* receives no state funding. Private donations pay for the necessary transmitters; the administering law enforcement agencies pay for the receivers and training. A stable funding source will be necessary if the program is to continue expanding and become statewide.

Coordination of Services

- There is an adequate infrastructure of complimentary services for the protection of AD patients. However, there is no coordination of the different services to ensure efficiency in service delivery.

- Often the local programs are not working in concert with one another due to lack of communication and differences in focus.

Based on these findings, the following recommendations are forwarded:

Recommendation 1: The Administration and the General Assembly should continue the current level of budget allocation to DCJS for Alzheimer's related training and for a statewide *Safe Return* coordinator.

Recommendation 2: The General Assembly may wish to pass a resolution restating their emphasis on Alzheimer's training for criminal justice personnel. The resolution should urge all law enforcement academies to implement in-service training for incumbent officers over a period of four years to assure total coverage. After four years, Alzheimer's training should be offered periodically on an as-needed basis.

Recommendation 3: The Department of Criminal Justice Services (DCJS) should continue current efforts to develop new Alzheimer's training programs for criminal justice personnel; and, through its Alzheimer's training coordinator, continue to provide assistance to training academies in developing lesson plans and training materials, and assist in acquiring resources for training delivery.

Recommendation 4: The *Search and Rescue* function of the Virginia Department of Emergency Management (VDEM) should receive favorable consideration from the General Assembly. Legislation should recognize SAR as the state's coordinating search-and-rescue function within VDEM; and provide that SAR provide training standards for volunteers, establish a standardized system, and collect and share data on searches for AD patients conducted in Virginia.

Recommendation 5: The General Assembly may want to consider providing $117,059 in additional funding to enable SAR to meet increased training needs of law enforcement and volunteer recruits.

Recommendation 6: Greater emphasis should be placed on registering AD patients with *Safe Return*. In addition, *Safe Return* and law enforcement should collaborate to register AD patients in the *Safe Return* data bank, and collect identifying information at the local level that could assist law enforcement officials in the event of an emergency. It should be emphasized that registration in such a program would be entirely voluntary.

Recommendation 7: *Project LifeSaver* is now solely funded by private donations. To make it a statewide program will require two full-time staff members and one part-time staff member to coordinate the program, provide operating expenses, and establish a training program. Total recommended funding: $159,911.

Recommendation 8: All coordination of *Project LifeSaver* should continue through the 43rd Virginia Volunteer Search and Rescue Company. The General Assembly should recognize *Project LifeSaver* as the primary program responsible for the establishment of training standards for operators of the CareTrak technology.

Recommendation 9: The General Assembly may wish to establish a statewide advisory board to research and review the needs of Virginia's Alzheimer's population, determine policies and procedures to meet these needs, coordinate resources, and recommend enhancements for resource development and service delivery. At a minimum, membership of the commission should include representatives from the following organizations:

Alzheimer's Association of Virginia
Virginia Department for the Aging
Virginia Association of Chiefs of Police
Virginia's SAR coordinator
Virginia Health Department
Virginia's Senate
Three family members of Alzheimer's patients
Virginia's *Safe Return* coordinator
Department of Social Services
Virginia Sheriffs' Association
Va. Criminal Justice Training Directors Association
Department of Criminal Justice Services
Virginia's House of Delegates

II. PROTECTION OF INDIVIDUALS WITH ALZHEIMER'S DISEASE

A. Purpose and Design

The purpose of this study is to determine the best method(s) for providing protection for individuals with Alzheimer's Disease. This study considered various agency resources that may play a role in protecting these individuals and assisting their families. Sources of assistance include law enforcement, *State Search and Rescue*, *Safe Return*, *Project LifeSaver*, and the Alzheimer's Association. Each its own unique value, yet there is a commonality of purpose. This study identifies what each can contribute and how they can be coordinated for effective service delivery.

In conducting this study, the Department of Criminal Justice Services (DCJS) drew upon the work of its Alzheimer's Curriculum Committee. This committee, composed of representatives from various Alzheimer's Association chapters, law enforcement, criminal justice training academies, and the *State Search and Rescue,* developed training programs for law enforcement officers as well as dispatchers. The training included much statistical information on Alzheimer's Disease and data on searches for lost Alzheimer's patients. Additional interviews and site visits were conducted with the Virginia Department of Emergency Management, *Search and Rescue*; and the Commander of *Project LifeSaver*. Further information was obtained through two surveys: one for the state's law enforcement community, and one for the caregivers of Alzheimer's patients. The purpose here was to obtain the different perspectives on critical needs and potential assistance to meet those needs. The results of the surveys are located in *Appendices B and C* of this report.

B. Goals and Objectives

Item 461.B of the 2000 Appropriations Act directed DCJS to ". . . conduct a study to determine the best methods for providing protection of these individuals (Alzheimer's patients), including a review of *Project LifeSaver*." The specific objectives of this study focused on:

- Identification of the scope of the problem.
- Identification of potential resources currently available.
- Determination of how existing resources can compliment each other.
- Determination of what additional support is necessary to provide protection for these individuals.

Since there appear to be sufficient systems in place to provide assistance to both law enforcement and the families of Alzheimer's patients, the focus here was to determine the adequacy of support for those systems and how they could come together for mutual support. Thus, the underlying objectives specifically address the following issues:

1. What specifically is needed by Alzheimer's caregivers, and is the need being met by existing agencies?

2. What is needed to improve law enforcement's response to situations involving Alzheimer's Disease?

3. Are adequate resources being provided to the organizations providing services?

4. Is there a coordinated system in place for service delivery, or can a system be developed to more efficiently utilize existing resources?

5. What, if any, role should state government play in providing assistance to either individuals directly or to service providers?

C. Background

As the nation's population ages, the incidence of age-related dementia problems will rise. The most common form of dementia is Alzheimer's Disease (AD), which causes progressive degeneration of the brain. Alzheimer's Disease affects memory, thought, behavior, personality, and muscle control. Most people contracting AD are over 65; however, people in their 40's and 50's have also been diagnosed. Symptoms of the disease include loss of reasoning and judgment abilities, behavior changes (often irrational and paranoid), communication problems, difficulty in performing routine activities, disorientation as to time and place (a particular problem related to wandering), problems with abstract thinking, and misplacing things.

According to the Alzheimer's Association, there are currently over 4,000,000 Americans affected by AD. Some estimates place the number of people with AD as high as 6,000,000. This represents approximately 10% of people over the age of 65 and nearly 50% of those age 85 or older. Over 101,000 people in the Commonwealth of Virginia have AD, and this number is growing. Nationally, it is anticipated that, by 2050, over 14,000,000 people will have AD unless a cure or prevention treatment is found. Currently, AD is the fourth leading cause of death among adults.

From an economic perspective, AD costs between $80-$100 billion a year. Neither Medicare nor private health insurance covers the long-term type of care most AD patients need. This is a critical factor, given that a person with AD can live from 3-to-20 years, or more, from the onset of symptoms. On an average, it costs a family over $12,500 per year -- out-of-pocket -- to provide care for a family member with AD. Seven out of ten people with AD live at home, with 75% of home care being provided by family and friends. Those who require nursing home care are facing an average cost of $42,000 per year, but this often can exceed $70,000 per year. With an average lifetime cost per patient of $174,000, AD is the third most expensive disease in the country. According to a survey of caregivers of AD patients, one of their biggest concerns is being able to obtain and afford competent respite day care for their loved ones (72%, see *Appendix B*).

In addition to the financial burdens on families, Alzheimer's patients who wander and become lost create a substantial financial impact on local law enforcement. Local law enforcement officials responding to our survey reported that even short searches (less than an hour) cost several hundred dollars, with more extensive searches costing anywhere from $1,000 to $15,000. A lengthy search of greater than 24 hours could easily exceed $30,000 (see *Appendix C*). Most (58%) reported searches range from one-to-twelve hours, costing localities thousands of dollars a year.

While the financial impact is quite substantial, allocated resources are minimal. For example, local law enforcement agencies do not routinely budget for extraordinary situations such as searches for lost Alzheimer's patients. The *State Search and Rescue* (SAR) unit of the Virginia Department of Emergency Management (VDEM) has a total budget of less than $100,000 to conduct training, respond to emergency searches statewide, recruit volunteers, and purchase search-and-rescue equipment. Further, although the state has now funded a statewide coordinator for the *Safe Return* program through the Alzheimer's Association, the *Project LifeSaver* program has not received any state support except for a $5,000 grant from DCJS.

According to our informal sample of 65 police and sheriff's agencies, over 94% indicated that they have individuals with Alzheimer's Disease living in their jurisdictions (see *Appendix C*). This, in turn, generates service calls for a variety of reasons. The majority of the calls are to locate and return missing family members (37%). Other calls involve providing medical assistance (14%) and a variety of other Alzheimer's related problems such as trespassing, indecent exposure, missing money, etc.

The most critical service provided by law enforcement is locating lost individuals. Nearly 80% of the chiefs and sheriffs responding reported being involved in searches for lost Alzheimer's patients. Fortunately, 80% were found safe; but 20% were found either injured or deceased. The critical factor was the timeframe in which the person was found. Based on SAR research, over 50% of individuals with severe dementia wander. This was substantiated by 64% of caregivers surveyed who indicated that their family members had wandered (see *Appendix B*). Of all cases, over one-third of the patients not found within 24 hours were found deceased. Conversely, of those individuals found within 12 hours, none were found deceased or injured. Thus, it is critical that law enforcement be trained properly and respond immediately to situations involving Alzheimer's patients.

As mentioned above, training is also key to law enforcement's ability to respond to Alzheimer's-related incidents. In the survey of law enforcement administrators, more training was the most frequently mentioned area when asked what would help them the most. Over 25% stated training would be most helpful, followed by identifying information on individuals with Alzheimer's in their communities (22%), and tracking devices (12%) (see *Appendix C*). Only 25% indicated that their staffs had received training on either dealing with Alzheimer's Disease or conducting searches. More than 86% of those responding indicated they would like their academy or DCJS to provide this training.

To summarize, we know that the problems associated with AD are progressing. Over 101,000 people in Virginia have the disease now and this number is expected to grow as the population continues to age. One of the most critical safety issues for both caregivers and law enforcement personnel is that of wandering. This is the biggest threat, outside of the disease itself, to the Alzheimer's patient.

D. Current Programs/Problem Identification

Aside from financial burdens, the most pressing concern for caregivers and law enforcement in protecting AD patients is wandering. This section focuses on current training and programs available to address this issue, including services provided by the Alzheimer's Association and the *Safe Return* Program, VDEM's *Search and Rescue (SAR)*, and *Project LifeSaver*, with support from local law enforcement agencies and DCJS.

Wandering By Persons With AD

According to a 1997 SAR report on Needs Assessment of Search and Rescue in Virginia, 16% of all searches conducted were for Alzheimer's patients. Of the over 101,000 people in Virginia with AD, it is estimated that between 15,000 and 18,000 are at risk for wandering and becoming lost. According to research, 72% of wanderers repeat this behavior. Of the caregivers that responded to the DCJS survey indicating that their loved one had wandered, 64% indicated that the patient had wandered two or more times (see *Appendix B*). Wandering is an emergency situation, with 1% of cases reported to law enforcement ending in fatalities. As the SAR report indicates, AD patients die from exposure; thus, time becomes a critical factor. Over one-third of persons not found within 24 hours will not survive. Survivability after 24 hours drops significantly -- only 50% survive after 36-to-48 hours. If SAR is not contacted for 50 hours, the subject is usually found deceased. It is thus essential that SAR be contacted in a timely manner. Law enforcement needs better training on the concept that a lost Alzheimer's patient is an emergency search situation, and SAR should be contacted immediately after preliminary searches fail to locate the person.

Training

Since 1998, training has received increasing attention. The 1998 General Assembly amended Section 9-170 of the Code of Virginia to give DCJS and the Criminal Justice Services Board the authority to set training standards for law enforcement officers on AD. Additionally, $40,000 was appropriated to DCJS to provide training for law enforcement. DCJS utilized this funding to develop and implement several Alzheimer's training programs at different levels. Working in conjunction with the Alzheimer's Association, law enforcement, the Virginia Criminal Justice Training Directors' Association, and SAR, a training program including lesson plans and supporting material was developed for inclusion in training for entry-level officers. This material was distributed to all academies in September 1998.

Additionally, a train-the-trainer program was developed to ensure academies would be able to present in-service training for incumbent officers. Two seminars were held in the Spring of 1999, training over 85 law enforcement and Alzheimer's Association instructors. All training materials, lesson plans, PowerPoint presentations, and supporting aids were distributed in order that these individuals could return to their localities and train other officers. Currently, DCJS is following-up with these instructors to determine what training has been delivered and what still needs to be addressed.

Training was also developed and implemented for dispatchers and communication officers. During the Spring of 2000 four sessions were conducted, training nearly 130 dispatchers and supervisors. They also were given all the materials necessary for them to be able to train personnel in their localities. In addition, plans are underway to train jail officers, magistrates, judges, and private security personnel.

In addition to funding the *Safe Return* coordinator, the General Assembly appropriated $50,000 to DCJS to continue its AD-related training efforts. Clearly, the additional training is still needed (see *Appendix C*). According to the law enforcement administrators responding to the survey, only 25% indicated that their officers had received any training on AD. Furthermore, nearly 90% indicated they would like to receive training on AD for their departments. Also, 25% felt additional training would be the most helpful activity for providing services and protection to Alzheimer's patients. To meet this need,

DCJS has hired a part-time training coordinator to assist criminal justice academies in securing resources for AD training.

Search and Rescue (SAR)

An important resource for protecting persons with AD is the *Search and Rescue* (SAR) arm of the Virginia Department of Emergency Management (VDEM). This function responds on a moment's notice to requests by local law enforcement to assist in finding lost individuals. Unlike the Alzheimer's Association and *Safe Return*, SAR responds to any search situation whether it is for a lost Alzheimer's patient, child, hunter, or any other emergency situations requiring the specialized training and expertise of this program.

The SAR program is managed by a less-than-full-time manager and one part-time administrative assistant. Volunteer searchers are trained by SAR and, according to a report to the 1999 General Assembly (HD 45), they contributed over 20,000 man-hours in 1996 and 57,333 in 1997 to search and rescue efforts. Their services are provided at no charge to local law enforcement, equating to savings of over $300,000 in 1996 and $860,000 in 1997. However, unlike emergency medical or firefighter personnel who generally have resources like vehicles, equipment, and maintenance financed by their jurisdictions, SAR volunteers pay entirely for their response-related expenses. According to the HD 45 report, SAR volunteers spend between $5,000 and $10,000 of their personal funds per year to respond to searches. This includes personal vehicle expenses, search animal maintenance, and search equipment; however, it excludes lost time from work. These factors often limit a volunteer's ability to assist when needed, and also contribute to a high attrition rate. SAR officials indicate that it takes about 300 new volunteers each year to keep up with the turnover. With less than one full-time staff member, it becomes a significant challenge, one which is often unmet, to recruit and train new volunteers and still respond to the needs of local jurisdictions.

In addition to coordinating and conducting searches, SAR provides specialized training to all volunteers as well as to state and local public safety personnel. This training is provided at no charge and ensures a standard response by all SAR volunteers and law enforcement. Trainees learn basic search techniques which minimize confusion during operations, and provide a quicker more effective response. However, because there is only one staff member to coordinate and deliver this training, training sessions are limited. This results in overflow classes, waiting lists, and delays in obtaining needed training. Ultimately, response suffers from the lack of available trained personnel. As mentioned earlier, 300 new volunteers must be recruited and trained each year to cover attrition, excluding law enforcement officers. In 1998, the SAR program was only able to train 227 responders, which included public safety personnel as well as volunteers. Because of limited funding and staff, it has become difficult to train enough volunteers and meet the needs of state and local agencies as well. Currently, local and state public safety personnel are directly competing with volunteers for the same class space. In order to provide the most effective protection and service to Alzheimer's patients, as well as other citizens requiring this critical service, additional funding is needed for staff, equipment, and training. This is viewed as a critical cog in an overall plan to protect individuals with AD. (A summary of the major points of the SAR report can be found in *Appendix D.*)

Safe Return

The Alzheimer's Association is a private non-profit health organization dedicated to research for the prevention, cure, and treatment of AD. It provides education and public awareness on the disease, advocacy for improved public policy, and formation of family support networks and programs at the local level. A major service of the association is to provide support, aid, and assistance to afflicted patients and their families. This organization is well established throughout most of the state and provides a variety of support services to not only patients and their families, but to other local service organizations as well. It has been particularly helpful to local law enforcement agencies in providing informational material and educational seminars. The association's assistance has been a key factor for the development and implementation of training for criminal justice personnel.

Safe Return is an affiliate program of the Alzheimer's Association. It is a nationwide identification, support, and registration service for individuals with AD. As was noted previously, wandering is prevalent with Alzheimer's patients and can be extremely dangerous, even life-threatening. When a person becomes lost, *Safe Return* provides assistance through a multi-level system based on a data bank of identifying information. For a one-time registration fee of $40, critical identifying information is entered into a nationwide data bank. It records the person's name, address, description, photograph, medical information, and contact information. The Alzheimer's patient is provided with an engraved identification bracelet or necklace and iron-on clothing labels. The caregiver is provided with a key chain, lapel pin, refrigerator magnet, stickers, and wallet cards with the *Safe Return* 800 number on them. If a registrant is reported missing, *Safe Return* will fax the person's information and photo to local law enforcement departments. Conversely, if a registrant is found, the citizen or law enforcement official can call the 800 number on the identification jewelry and *Safe Return* will notify the listed contact person.

A major problem with *Safe Return* is getting information not only to caregivers, but to local agency service providers as well. Only 12% of the caregivers responding to our survey (see *Appendix B*) indicated they had contact with *Safe Return*, and only 8% receive services from *Safe Return*. Less than 1% of law enforcement administrators surveyed indicated they had received services from or had contact with *Safe Return* (see *Appendix C*). The General Assembly recognized this problem and during the 2000 Session allocated $75,000 for a full-time *Safe Return* coordinator to provide education and training on *Safe Return* to law enforcement and other local agencies, and to recruit and encourage caregivers to register their family members with the *Safe Return* Program. The position has been filled and operates out of the Northern Virginia Chapter of the Alzheimer's Association. The *Safe Return* program is one of many very useful resources available for Alzheimer's patients, their families, and law enforcement. With the funding allocated by the 2000 General Assembly, this program has the basis to better promote and register individuals for this service.

Project Lifesaver

Project LifeSaver is a relatively new program that utilizes a small transmitter and tracking receiver to locate lost and wandering Alzheimer's patients. The program originated and is operated out of the 43rd Virginia Volunteer Search and Rescue company under the auspices of the Chesapeake Sheriff's Office. The purpose of *Project LifeSaver* is to assist in locating lost and wandering Alzheimer's and dementia patients through the use of state-of-the-art technologies.

Project LifeSaver uses the CareTrak technology, consisting of a small transmitter attached to the patient's wrist and a receiver that tracks the signal of the transmitter. It has already been established that time is a critical factor in finding Alzheimer's patients safe and uninjured. According to a report summary of *Project LifeSaver* developed by Col. J. E. Saunders, Commander of the 43rd Virginia SAR, the average recovery time of lost victims with *Project LifeSaver* is 13-22 minutes (see *Appendix E*). This virtually assures that lost Alzheimer's patients can be found quickly and safe. Additionally, the program can save hundreds of thousands of dollars in search costs for localities. Over 36% of the responding law enforcement administrators report the average cost of a search as being over $2,000, with 15% reporting costs over $10,000. There is no question that this program will save time and money; but most of all lives.

A complete *Project LifeSaver* system costs $5,000. This includes two receivers, two transmitters, and two days of training for operators. The costs of the receivers and training are usually borne by the law enforcement agency of the jurisdiction in which the system is placed. Transmitters cost $263 each and are usually funded by private/corporate donations. There is a $25 per month maintenance fee for batteries and service, which is usually paid by the caregiver. However, if a caregiver cannot afford the monthly fee, sponsors are found so no one in need is refused service. This unique combination of funding creates a true public/ private partnership. However, outside of a $5,000 training grant from DCJS, there has been no state funding support. During the 2000 Session of the General Assembly, a budget amendment from Delegate Blevins for $991,000 was submitted to fund a statewide effort to place *Project LifeSaver* in every county of the state and 20 major cities. This amendment was passed by the House, but removed during conference committee work.

Of the over 101,000 people in Virginia with AD, it is estimated that between 15,000 and 18,000 are at risk for wandering and becoming lost. According to research, 72% of wanderers repeat this behavior. Of the caregivers that responded to the DCJS survey indicating that their loved one had wandered, 64% indicated that the patient had wandered two or more times (see *Appendix B*). Given the scope of potential victims, it seems prudent to cultivate as many resources as possible. *Project LifeSaver* seems to be a most effective resource, yet it is relatively unknown and under-utilized. As of September 1, 2000, there were 92 transmitters placed in 16 different areas. Even with this limited deployment, *Project LifeSaver* has recorded 30 saves in just 18 months (see *Appendix E*).

Project LifeSaver has been limited in scope simply due to a lack of full-time staff. All aspects of the program to date have resulted from the work of volunteers. For example, Gene Saunders, the Commander and Chief of *Project LifeSaver*, is a full-time Captain with the Chesapeake Police Department. Yet he coordinates the program, trains operators, conducts educational promotions for the program, performs fund-raising activities, as well as conducts searches when needed. However, as the program expands, these functions become more difficult to perform on a voluntary basis.

The lack of full-time staff also affects the coordination of placement of transmitters. Since there is only a limited number of different frequencies available, coordinated placement of transmitters is critical to avoid overlapping of frequencies. Because individual law enforcement offices are responsible for the program in their jurisdictions, one department may place a transmitter in its locality too close to one in an adjoining locality with the same frequency. This could cause conflicting signals and potentially

dangerous problems if one of the individuals wanders off. Thus, a single coordinator for designating transmitter frequencies and placement is necessary.

In summary, it is fairly well agreed that the basic foundation for providing service and protection to Virginia's Alzheimer's population is in place. The Alzheimer's Association, *Safe Return*, VDEM's *Search and Rescue*, law enforcement, DCJS, and *Project LifeSaver* all perform unique, but related services for Alzheimer's patients. Each provides a special benefit and has the potential to enhance each other.

III. FINDINGS AND RECOMMENDATIONS

With the number of individuals at-risk increasing and the impact that has on law enforcement and other service providers, the need for enhancement of this infrastructure becomes paramount. Each of the resources mentioned earlier is an important and critical cog in the service to Alzheimer's Disease (AD) patients. The challenge becomes focusing these resources into an effective delivery system. To achieve this objective, several actions must be taken at an individual organization level as well as from a holistic system level.

A. Training

One of the biggest problems identified is that of information dissemination to both the families of AD patients and to law enforcement personnel. Training continues to be a major concern for law enforcement administrators and is needed at all levels. The current Administration and the General Assembly have taken steps to address this issue and significant progress has been made.

Recommendation 1: The Administration and the General Assembly should continue the current level of funding to DCJS for Alzheimer's related training and for a statewide *Safe Return* coordinator.

Recommendation 2: The General Assembly may wish to pass a resolution restating their emphasis on Alzheimer's training for criminal justice personnel. The resolution should urge all law enforcement academies to implement in-service training for incumbent officers over a period of four years to assure total coverage. After four years, Alzheimer's training should be offered periodically on an as-needed basis.

Recommendation 3: The Virginia Department of Criminal Justice Services (DCJS) should continue current efforts to develop new Alzheimer's training programs for criminal justice personnel; and, through its Alzheimer's training coordinator, continue to provide assistance to training academies in developing lesson plans and training materials, and assist in acquiring resources for training delivery.

B. Search and Rescue

One of the most critical services provided to local law enforcement officials is that of search and rescue for lost Alzheimer's patients. The Virginia Department of Emergency Management (VDEM) coordinates the state's *Search and Rescue* (SAR) program. Most of these highly skilled services are provided by volunteers who must use out-of-pocket funds to pay expenses and purchase equipment. VDEM only provides funding for three-fourths of an FTE to coordinate all SAR activities.

Additionally, all training of volunteers and local law enforcement is conducted through SAR. Due to limited resources, training is not offered often enough to meet the minimum requirements to keep adequate numbers of volunteer searchers trained. This impacts SAR's ability to respond to local law enforcement agencies with adequate volunteer searchers. As these local law enforcement officials have indicated frequently, training in search management and techniques is needed by officers as well as volunteers.

Recommendation 4: The *Search and Rescue* function of the Virginia Department of Emergency Management (VDEM) should receive favorable consideration from the General Assembly. Legislation should recognize SAR as the state's coordinating search-and-rescue function within VDEM; and provide that SAR provide training standards for volunteers, establish a standardized system, and collect and share data on searches for AD patients conducted in Virginia.

Recommendation 5: The General Assembly may want to consider providing $117,059 in additional funding to enable SAR to meet increased training needs of law enforcement and volunteer recruits.

C. Safe Return

In order to gain a better understanding of the needs of the families and individuals with AD, a random survey of 45 caregivers was conducted by various Alzheimer's Association chapters (see *Appendix B*). The problems described were as varied as the individuals, yet the themes of safety and care were obvious concerns. Of the 45 respondents, 64% indicated their family members with AD wandered. Furthermore, they reported that 66% of AD patients wandered two or more times. Most of the individuals had no identification on them (55%), and were in the mid-stage of the disease (76%). However in most of these cases (66%), the local law enforcement agency was not called to assist. This is similar to the findings of the research done by SAR.

From the limited information gained during this study, it is apparent that families of AD patients experience a myriad of problems creating much stress. Obvious issues are centered around providing respite day care and assisted living residential care. While these issues are beyond the scope of this study, the General Assembly may want to have them considered through another study resolution.

Additionally, there is major concern over the wandering problem associated with the early to mid-stages of the disease.

Recommendation 6: Greater emphasis should be placed on registering AD patients with *Safe Return*. In addition, *Safe Return* and law enforcement should collaborate to register AD patients in the *Safe Return* data bank, and collect identifying information at the local level that could assist law enforcement officials in the event of an emergency. It should be emphasized that registration in such a program would be entirely voluntary.

D. *Project LifeSaver*

Project LifeSaver is operated by the 43rd Volunteer Search and Rescue Company out of the Chesapeake Sheriff's Office. All coordination and promotion of the program is conducted by volunteers, with no paid staff. Currently, the program and transmitters are funded totally through corporate and private donations. Individual departments which implement the program in their jurisdictions pay approximately $5,000 for two receivers and the required training on their use. Family members or other caregivers pay only a $25/per month maintenance fee for batteries and other maintenance on the transmitters.

Given the critical importance of finding lost Alzheimer's patients quickly, this system has enormous potential for saving lives. In areas that have implemented the system, the average time for locating a lost victim is 22 minutes. This is significant in view of data that suggest that there are virtually no fatalities if the victim is located within 24 hours. In addition to the time factor, the system will save localities significant expense and manpower associated with extensive searches. Yet *Project LifeSaver* has been initiated in only 16 localities with 92 transmitters placed. In the past 18 months prior to this report, *Project LifeSaver* has recorded 30 saves.

The current problem is program expansion. Because the transmitter frequencies must be coordinated by one entity, expansion becomes difficult due to reliance on an all-volunteer staff. In order for this important program to continue to expand throughout the Commonwealth, additional staff will be required. During the last Session of the General Assembly, a budget amendment was submitted for $991,000 for funding of *Project LifeSaver*. While this amendment did not succeed, other Alzheimer's-related projects were funded. The focus of *Project LifeSaver* has changed from asking the state to fund systems for all counties and 20 cities, to seeking minimum funding for staff and operating expenses to continue expansion efforts. It has been determined that local law enforcement agencies are willing to pay for the systems because they will ultimately save money. Additionally, corporate and private donations are continuing; thus, there is no need for state funding of equipment. However, funding is needed to ensure coordination of the program, expansion continuance, and private fund-raising maintained at a high level.

Recommendation 7: *Project LifeSaver* is now solely funded by private donations. To make it a statewide program will require two full-time staff members and one part-time staff member to coordinate the program, provide operating expenses, and establish a training program. Total recommended funding: $159,911.

Recommendation 8: All coordination of *Project LifeSaver* should continue through the 43rd Virginia Volunteer Search and Rescue Company. The General Assembly should recognize *Project LifeSaver* as the primary responsible program for the establishment of training standards for operators of the CareTrak technology.

E. Coordination of Services

The needs of Alzheimer's patients and their families are extensive and quite varied. In order to assist these individuals, numerous agencies and organizations provide a myriad of services. The Alzheimer's Association, the Virginia Department of Social Services, the Department for the Aging, and the Health Department all offer different types of support and assistance. Local law enforcement agencies, the state's *Search and Rescue*, and *Project LifeSaver* all provide critical and often life-saving protection to AD patients. However, there appears to be no centralized effort to coordinate these numerous services and establish a consolidated effort for service delivery. For the past two years, DCJS has worked with several of these organizations, including criminal justice training academies, to develop and implement training for criminal justice personnel. This, in effect, brought many of these disciplines together for a specific and consolidated effort. However, this should be expanded to review and research the comprehensive needs of Alzheimer's patients and determine the best methods for meeting those needs.

Recommendation 9: The General Assembly may wish to establish a statewide advisory board to research and review the needs of Virginia's Alzheimer's population, determine policies and procedures to meet these needs, coordinate resources, and recommend enhancements for resource development and service delivery. At a minimum, membership of the commission should include representatives from the following organizations:

Alzheimer's Association of Virginia
Virginia Department for the Aging
Virginia Association of Chiefs of Police
Virginia's SAR coordinator
Virginia Health Department
Virginia Senate
Three family members of Alzheimer's patients
Virginia's *Safe Return* coordinator
Department of Social Services
Virginia Sheriffs' Association
Criminal Justice Training Directors Association
Department of Criminal Justice Services
Virginia House of Delegates

APPENDICIES

359 **APPENDIX A**

		Item Details($)		Appropriations($)	
ITEM 462.		**First Year FY2001**	**Second Year FY2002**	**First Year FY2001**	**Second Year** FY2002
	Fund Sources: General	$3,594,335	$3,609,274		
	Special	$713,911	$713,911		

Authority: Title 9, Chapter 27, Code of Virginia; P.L. 94-503, 95-115, 96-157 and 96-509, Federal Code.

460.	Criminal Justice Information Systems and Statistics (30200)			$560,644	
	$560,644				
	Criminal Justice Information System Coordination and Regulation (30202)	$497,424	$497,424		
	Records Management (30203)	$63,220	$63,220		
	Fund Sources: General	$560,644	$560,644		

Authority: Title 9, Chapter 27; Title 19.2, Chapter 23.1, Code of Virginia.

461.	Criminal Justice Training, Education, and Standards (30300)			$1,416,430	
	$1,416,430				
	Correctional Officers Training and Education (30301)			$75,000	$75,000
	Law Enforcement Technical Assistance (30305)			$858,012	
	$858,012				
	Law Enforcement Training and Education (30306)			$483,418	
	$483,418				
	Fund Sources: General			$1,381,430	
	$1,381,430				
	Special			$35,000	$35,000

Authority: Title 9, Chapter 27 Code of Virginia.

A. Out of this appropriation, $75,000 the first year and $75,000 the second year from the general fund is authorized for the Alzheimer's Association Northern Virginia Chapter to support statewide coordination of the Safe Return Program.

B. Out of this appropriation, $50,000 the first year and $50,000 the second year from the general fund is authorized to oversee training of public safety personnel in managing persons with Alzheimer's disease or other memory-related impairments. The Department shall conduct a study to determine the best methods for providing protection of these individuals, including a review of Project Lifesaver. A report on this study shall be presented to the Chairmen of the Senate Finance and House Appropriations Committees by October 1, 2000.

Authority: Title 9, Chapter 27, Article 4 and §§ 9-196.1 and 9-196.12.

A. The amounts for Financial Assistance to Localities for Intensified Drug Enforcement Services include $1,500,000 from nongeneral funds each year for grant., to continue or establish "Weed and Seed" programs in

Appendix B

Questionnaire for Alzheimer's Caregivers

Total Responses: 45 Approximately 35%

1. What stage Alzheimer's Disease does your family member have?

   4 ((%) Early-stage 12 (27%) Mid-stage 9 (20%) Late-stage 20 (44%) Deceased

2. What is the biggest problem you face (or faced) in providing care to your family member with Alzheimer's Disease?
   - Misc. family issues: 10 (22%)
   - Physical problems: 10 (22%)
   - Stress: 4 (9%)
   - Handling AD behavior: 7 (16%)
   - Home safety & wandering: 9 (20%)
   - **Respite/constant care: 19 (42%)**
   - Shortage of competent help: 8 (18%)
   - Funding for care: 4 (9%)

3. What one thing would help the most in providing service to your family member to address this problem?
   - Day care or residential care: 21 (47%)
   - Non financial support: 11 (24%)
   - Financial aid: 5 (11%)
   - Better care facilities: 5 (11%)
     (better educated and trained employees)
   - More information on AD: 4 (9%)
   - General safety issues: 5 (11%)
   - Better educated police: 2 (4%)

4. What one thing would help the most in providing protection to your family member?
   - Affordable day and residential care: 23 (51%)
   - Identification for patient (Safe Return): 9 (20%)
   - Better awareness and training for police: 5 (11%)
   - General safety: 4 (9%)
   - Medical care issues: 3 (7%)

5. Have you or your family received services or had previous contact with any of the following resources?

   39 (87%) Alzheimer's Association 16 (36%) Agency on Aging
   13 (29%) Social Services 5 (11%) Health Department
   9 (20%) Safe Return 0 Project Lifesaver (Care Trak)
   8 (18%) Other: _____

6. Have you utilized any of the services listed above?

40 (89%) Yes, which one(s): 5 (11%) No

39 (87%) Alzheimer's Association 9 (20%) Agency on Aging
8 (18%) Social Services 3 (7%) Health Department
7 (16%) Safe Return 0 Project Lifesaver (Care Trak)
5 (11%) Other: _____

7. Has your family member ever wandered off or become lost? 29 (64%) Yes 16 (36%) No

If yes:
a. Number of times? One: 9 (31%) Two or more: 19 (66%)
b. Were they wearing some form of identification? 12 (41%) Yes 16 (55%) No
c. Was the local law enforcement department called? 10 (34%) Yes 19 (66%) No
d. Stage of the disease when the wandering occurred?
9 (31%) Early 22 (76%) Mid 2 (7%) Late
e. What was the outcome? 26 (90%) Found safe 4 (14%) Found injured 1 (3%) Found deceased
f. What resources were employed in the search? 23 (79%) Family and friends
9 (31%) law enforcement 2 (7%) State Search and Rescue 0 Safe Return
0 Project Lifesaver – Care Trak
g. Who found the missing person?
22 (76%) Family and friends 6 (21%) law enforcement 0 State Search and Rescue
0 Safe Return 0 Project Lifesaver – Care Trak 5 (17%) Other

8/00

Appendix C

Questionnaire on Alzheimer's Disease for Law Enforcement

The Department of Criminal Justice Services has been charged by the General Assembly to conduct a study on the best method(s) for protecting individuals with Alzheimer's Disease or other forms of dementia. In order to provide an accurate and clear picture of the problems faced by law enforcement related to these individuals and their families, I would like to enlist your assistance in helping determine the problems and possible methods for dealing with them. Please answer the following questions and return the completed questionnaire to Ron Bessent at DCJS by August 21, 2000, or fax to (804) 786-0410.

Thank you very much for your assistance in this matter.

Questionnaire for law enforcement:

Total Responses: 65

1a. Do you have citizens in your jurisdiction with Alzheimer's Disease or other forms of dementia? 61 (94%) Yes 3 (5%) No 1 (1%) Don't know

b. If yes, do you maintain a file with their identifying information and other critical data? 13 (20%) Yes 45 (69%) No

2a. Has your department had to respond to any call(s) relating to individuals with Alzheimer's Disease or dementia? 57 (88%) Yes 4 (7%) No

b. If yes, what type of call/service was provided?

- Locate (search & rescue): 24 (37%)
- Medical assistance: 9 (14%)
- Other (misc.): 7 (11%)

c. Average number of calls you get: _2_ week? 3.78 Month? 5.89 Year?

3a. Has your department had to respond to an emergency search and rescue call relating to lost/wandering Alzheimer's or dementia patient? 50 (77%) Yes 10 (15%) No

If more than one, state number in the past year, past two years and put the appropriate number in the blanks of each of the following questions.

2.89 Number in last year 3.5 Number past two years

b. If yes, what was the outcome? 59 (81%) Found safe 7 (10%) Found injured 7 (10%) Found deceased

d. Did the individual have any identification on them, and if so, what?
5 (6%) Yes 27 (37%) No 41 (56%) No answer

e. What resources were utilized in the search?
46 (63%) Family and friends 56 (77%) law enforcement 19 (26%) State SAR 1 (1%) Safe Return 2 (3%) Project Lifesaver – Care Trak 2 (3%) Fire Dept.

f. Who found the individual?
22 (30%) Family and friends 43 (60%) law enforcement 8 (11%) State SAR

1 (1%) Safe Return 3 (4%) Project Lifesaver 5 (7%) Other

g. If the individual was found alive, what was the average time between the time you were notified and time the individual was found?
6 (8%) less than an hour 26 (36%) 1-4 hrs 16 (22%) 5-12 hrs 5 (7%) 12-24 hrs
1 (1%) More than 24 hrs (list___)

h. Please estimate the average cost to conduct the search, include personnel cost.

< $1,000	9 (32%)
$1,000 - $1,999	9 (32%)
$2,000 - $3,000	6 (21%)
$5,000 - $10,000	1 (4%)
> $15,000	3 (11%)

4. Has your agency received any services or had contact with any of the following?
14 (22%) Alzheimer's Association
3 (5%) Safe Return Program
5 (8%) Project Lifesaver
22 (34%) State Search and Rescue
21 (32%) No Answer

5. What would be most helpful to you in providing services/protection to individuals with Alzheimer's Disease or other forms of dementia?
   - Information on AD patients in area: 14 (22%)
   - Tracking devices: 8 (12%)
   - **Training: 16 (25%)**

6. Have you or any member of your department attended any of the Alzheimer's/ dementia specific training sponsored by either DCJS or your academy?

   16 (25%) Yes 40 (62%) No 5 (8%) Don't Know

   If yes, which one(s)?
   11 (69%) Training provided by my academy
   4 (25%) Train-the-Trainer for Law Enforcement
   4 (25%) Alzheimer's Training for Dispatchers

7. Would you like to see DCJS or your academy offer additional training programs dealing with Alzheimer's Disease or dementia?

   56 (86%) Yes 2 (3%) No

Appendix E

43RD. VIRGINIA SEARCH AND RESCUE
(AIRBORNE)
CHESAPEAKE SHERIFF'S OFFICE
1777 West Road
Chesapeake, VA 23323

John R. Newhart — **Office - 757-432-4382**
Sheriff — **Fax - 757-432-4384**
Col. Gene Saunders
Chief of SAR

PROJECT LIFESAVER

APRIL 8, 1999 - August 28, 2000

A. Transmitters Placed 92

1. Locations:
   - a. Chesapeake 40
   - b. Norfolk 03
   - c. Virginia Beach 12
   - d. North Carolina 02
   - e. Suffolk 02
   - f. Portsmouth 03
   - g. Loudon County, VA 01
   - h. Parksley, VA 14
   - i. Pittsylvania County, VA 12
   - j. Eastern Shore, VA 01
   - k. Lynchburg, VA 01
   - l. Carrollton, VA (Isle of Wight) 01
2. Transmitters in assisted living homes:
   - a. Chesapeake 32
   - b. Virginia Beach 04
   - c. Portsmouth 01
   - d. Parksley, VA 14

B. Saves with Transmitters 30
Average Recover Time 22 Minutes

C. Client Situation

1. Alzheimer's 71
2. Autism 08
3. Down Syndrome 01

D. Call-Outs 95

Includes calls to check wrist bands, transmitters

*E. Project Lifesaver established 5-6-00, Pittsylvania County, VA by Sheriff's Office (12 transmitters). 2 Rescues recorded as of date of report.

F. Virginia Beach Police Helicopters joined Project Lifesaver February 2000.

*G. Project Lifesaver to be established - September 20, 2000, in Rockingham County, Virginia, by Sheriff's Office.

*H. Project Lifesaver to be established - October 2000, in Danville, VA by Sheriff's Office.

I. Inquires on establishment from: Henrico County, Northumberland County, Amhurst County, and Toronto, Canada.

*J. Project Lifesaver to be established by City of Suffolk Fire Department -September 2000.

*K Working on establishing in Alexandria, VA with grant from private individual.

L. Project Lifesaver in following states:

1. Virginia - Project originated in Chesapeake
2. North Carolina
3. Vermont
4. New Hampshire
*5. Georgia
6. Illinois

M. Project in development stages in:

* I. New Jersey
*2. Pennsylvania

N. Project established in New Brunswick, Canada.

*Denotes areas where 43rd VA SAR, Chesapeake Sheriff's Office, trained project personnel and assisted in project set-up.

Several Project personnel are Alzheimer's Law Enforcement instructors and assist in training across the state.

Project personnel give talks and demonstrations to educate public on Alzheimer's, Autism, et.al.

Project is supported by donations and private corporate grants. Only government support came from Virginia Department of Criminal Justice Services in 1999. True public-private operation.

Personnel of the 43rd Virginia SAR, Chesapeake Sheriffs Office are volunteers with the exception of a part-time office manager.

Summary:

Project Lifesaver has lived up to its name, which is now resulting in demand to enlarge it within, as well as outside of Virginia. The 43rd Virginia SAR, Chesapeake Sheriffs Office has gone far beyond what could be expected of any part-time volunteer organization with its success with this project. However, for this project to reach its potential, providing lifesaving services to Virginia citizens, it now needs Commonwealth support. The 43rd needs funding to place full-time personnel to continue the service and expansion of Project Lifesaver. Funding should also be considered to aid in the daily operations. While the project should continue to solicit private funding, we should be able to concentrate more effort toward assisting people than project survival.