

**BLINDED VETERANS ASSOCIATION
TESTIMONY**

BY

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**HOUSE COMMITTEE ON VETERANS AFFAIRS
SUBCOMMITTEE ON
OVERSIGHT AND INVESTIGATIONS**



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INTRODUCTION

Chairman Mitchell, Ranking Member Roe, and Members of the House Veterans Affairs Subcommittee on Oversight and Investigations, on behalf of the Blinded Veterans Association (BVA), thank you for this opportunity to present our testimony regarding the large numbers of military vision injuries and the bureaucratic problems associated with implementing the Congressionally mandated National Defense Authorization Act (NDAA) of 2008. The legislation established the joint Department of Defense (DoD) and Department of Veterans Affairs (VA) Vision Center of Excellence (VCE) and Eye Trauma Registry.

Established in 1945 and Congressionally chartered in 1958 as the only Veterans Service Organization exclusively dedicated to serving the needs of our Nation's blinded veterans and their families, BVA sincerely appreciates the invitation extended to our organization to present testimony. We are also grateful that the Operation Iraqi Freedom (OIF) and Operation Enduring Freedom (OEF) blinded veterans present this morning, and who will later share their stories, have also been welcomed.

OBSTACLES TO VCE IMPLEMENTATION

OIF and OEF service members with both penetrating eye trauma and Traumatic Brain Injury (TBI) visual impairment have had to wade through a DoD bureaucracy. DoD has given us the impression that, for them, an entire year's time to create an organizational charter is actually not that long. Persistent excuses for lack of action range from "no plan was approved for VCE" to, of course, "no funding has been found to create VCE."

When NDAA was enacted in January 2008, an immediate reaction from senior level Assistant Secretary of Defense for Health Affairs officials was that VCE was an "unfunded mandate by Congress" that would cost "an estimated \$5 million that we do not have built into this year's budget." If this were the case, Congress should have then asked why these funds were not requested in either last year's May 2008 War Supplemental (H.R. 2462) when \$162 billion was provided for, among other things, "wounded warrior care" or, better yet, in the FY 2009 Defense Appropriations to cover this year's start-up costs. Instead, both in June and again in early August at the Skyline Drive office of the Assistant Secretary of Defense for Health, and then once again on September 24, senior officials repeated the claim that finding even the bare minimum of \$3 million to fund start-up costs for the Vision Center of Excellence presented a very tough challenge.

For four years, BVA has attempted to bring to the attention of the Armed Services Committees, the Defense Appropriations Committees, both VA Committees, DoD Health Affairs, and the Veterans Health Administration (VHA) the ever-increasing prevalence of combat eye trauma and TBI visual dysfunction among service members. We have become increasingly concerned about the growing numbers of both the battle wounded who have penetrating direct eye trauma (13 percent of all evacuated wounded have experienced eye trauma) and/or TBI-related visual complications (64 percent with TBI have tested positive for visual dysfunction).

Responses to these pleas have included “the need to wait until the next plan is approved,” “NDAA reports come late for review,” “inability to find office space,” and the aforementioned “lack of requested funding.” The cumulative result of these responses has been delayed action.

The Pentagon did appoint the first Director of VCE in November 2008. Colonel Donald Gagliano is a highly qualified and dedicated 29-year Army career ophthalmologist who served in Iraq for one year. Also appointed was an equally well-qualified VA Deputy Director of VCE, Dr. Claude Cowan. BVA fully supported both appointments. The two officials have entered these challenging positions with virtually no office space, little staffing support, zero funding for three months, no organizational charter, and thousands of combat eye-wounded service members and veterans spread across various military medical facilities and VA medical centers. Thanks to MILCON/VA Appropriations Chairman Chet Edwards, VA received a \$2 million appropriation for IT support. Although Senate MILCON/VA Appropriations Chairman Tim Johnson also helped provide an additional \$6.9 million to VHA, questions persisted for months regarding a plan on how to use these funds.

The OIF and OEF eye wounded who have recently enrolled in the VA health care and benefits system never should have encountered this difficult process. Quick action by Secretary Gates, in cooperation with Secretary Shinseki and with the full attention of the Senior Oversight Committee, is now vital to correct this mess.

BVA emphasizes that the clinical skills of the DoD professional eye care providers, both ophthalmology and optometry, have been excellent. In many cases, they have been no less than outstanding. Ophthalmology surgery not possible during previous wars has saved the vision of many Soldiers and Marines. Nevertheless, the system that organizes and administers such treatment must become accountable for all battle eye wounded and TBI patients affected. It must answer for the lack of action inherent in its failure to begin staffing procedures that will eventually reach 12 positions, failure to locate office space, and failure to address the issue of construction renovation funding for the National Naval Medical Center.

PREVALENCE AND INCIDENCE OF VISUAL IMPAIRMENTS

As of September 2008, VHA reported 8,747 diagnoses of TBI with approximately 7,500 in diagnostic testing for possible TBI. Improvised Explosive Device (IED) blasts contributed to more than 64 percent of these injuries. As of January 30, 2009, a total of 43,993 service members had been wounded or injured by accidents in Iraq. The number of those wounded in hostile operations and requiring air medical evacuation from Iraq between March 19, 2003 and January 30, 2009 from one early report was 9,375, of which an estimated 13 percent (1,219) had sustained combat penetrating eye trauma. Some 135 of this number have enrolled in VA Blind Rehabilitation Service (BRS) programs. This past November, however, the Military Surveillance Monthly Report contained an article from DoD on eye injuries among members of active components (U.S. Armed Forces, 1998-2008) that detailed, by ICD, diagnostic code searches turning up 4,970 perforating and penetrating eye trauma cases, 4,294 chemical or thermal burns, and 686 damaged optic nerves, most of which were from among OIF and OEF injured.

The number of direct battle eye injuries does not include estimates of all moderate-to-severe TBI service members or veterans who have visual dysfunction, according to VA research of those tested by either neuro-ophthalmologists or low-vision optometrists at a few military and VA centers. We stress that while only a small percentage of the eye injured meet the legal blindness definition of 20/200 or less of visual acuity, those with neurological vision dysfunction from mild, moderate, or severe TBI will require long-term VA eye care follow-up in low-vision clinics. Veterans with a history of ocular battle injuries are also at high risk of developing retinal detachments, traumatic cataracts, glaucoma, and other delayed TBI neuro-visual complications that can occur years after the initial injury.

The top three contributors to combat eye injuries have been Improvised Explosive Devices (IEDs), Rocket-Propelled Grenades (RPGs), and Mortars, with IEDs causing 56.5 percent of all eye injuries in Iraq. Just how many service members have actually sustained moderate-to-severe TBI injuries to the extent that they are experiencing neuro-sensory visual complications is anyone's guess. The estimates in professional journals and other publications indeed change from month to month. The 64 percent figure (those with TBI who have experienced visual dysfunction) represent those with associated neurological visual disorders of diplopia, convergence disorder, photophobia, ocular-motor dysfunction, color vision loss, and an inability to interpret print. Some TBIs result in visual field defects with enough field loss to meet legal blindness standards. We are also finding ever increasing numbers of TBI-caused "functionally blinded" OIF and OEF veterans who, while not legally blind, are unable to perform normal daily activities because of loss of vision. More TBI visual screening, diagnosis, treatment, and new outcome studies should be initiated without delay.

One early VA research study (2005) of OIF and OEF service members who had entered the VA system with an ICD-9 (diagnostic code) search found 7,842 individuals with a traumatic injury of some kind. Consistent with recent media articles and VA reports, the most common traumatic injury diagnoses were hearing loss and tinnitus (63.5 percent). We now know that 94,191 of the more than 1.3 million troops who have served in OIF and OEF are now service-connected for tinnitus while 78,076 are service-connected for hearing loss. A major cause of this hearing loss (60 percent of the cases) is exposure to IEDs. The second most common VA diagnostic code was for visual impairment (27.9 percent). We submit to this Subcommittee that the cases of sensory loss of hearing

and visual impairment as a result of TBI constitute a “silent epidemic” not widely reported by media. They are, nevertheless, the #1 and #2 injuries from OIF and OEF combat.

NEUROLOGICAL IMPACT OF TBI DYSFUNCTION

Perception plays a major role in an individual’s ability to live life. Although all senses play a significant role in perception, the visual system is critical to perception, providing more than 70 percent of human sensory awareness. With hearing being another critical component, IED blast injuries can obviously impair markedly these two key sensory systems.

Vision provides information about environmental properties. It allows individuals to act in relation to such properties. In other words, perceptions allow humans to experience their environment and live within it. Individuals perceive what is in their environment by a filtered process that occurs through a complex, neurological visual system. With various degrees of visual loss comes greater difficulty to clearly adjust and see the environment, resulting in increased risk of injuries, loss of functional ability, and unemployment. Impairments range from loss in the visual field, visual acuity changes, loss of color vision, light sensitivity (photophobia), and loss of the ability to read and recognize facial expressions.

Although one can acquire visual deficits in numerous ways, one leading cause is injury to the brain. Damage to various parts of the brain can lead to specific visual deficits. Some cases have reported a spontaneous recovery but complete recovery is unlikely and early intervention is critical. Current complex neuro-visual research is being examined in an attempt to improve the likelihood of recovery. The re-training of certain areas and functions of the brain has improved vision deficits in some disorders. Nevertheless, the extent of the recovery is often limited and will usually require long-term follow-up with specialized adaptive devices and prescriptive equipment.

The brain is the most intricate organ in the human body. The visual pathways within the brain are also complex, characterized by an estimated two million synaptic connections. About 30 percent of the neocortex is involved in processing vision. Due to the interconnections between the brain and the visual system, damage to the brain can bring about various cerebral visual disorders. The visual cortex has its own specialized organization, causing the likelihood of specific visual disorders if damaged. The occipitotemporal area of the brain is connected with the "what" pathway. Thus, injury to this ventral pathway leading to the temporal area of the brain is expected to affect the processing of shape and color. This can make perceiving and identifying objects difficult. The occipitoparietal area (posterior portion of the head), is relative to the "where," or "action" pathway. Injury to this dorsal pathway leading to the parietal lobe will increase the likelihood of difficulties in position (depth perception) and/or spatial relationships. In cases of injury, individuals find it hard to determine an object's location and may also discover impaired visual navigation.

It is highly unlikely that a person with TBI will have only one visual deficit. A combination of such deficits usually exists due to the complexity of the organization between the visual pathway and the brain. The most common cerebral visual disorder after brain injury involves visual field loss. The loss of peripheral vision can be mild to severe and requires specific visual field testing to be correctly diagnosed. In turn, a number of prescribed devices are frequently necessary to adapt to this loss.

Accompanying such complex neurological effects on the patient is the overwhelming emotional impact of brain injury on the patient and his/her family. BVA would ask Members of the full House Committee to seriously consider the ramifications of such injuries. Brain injuries are known for causing extreme distress on family members who must take on the role of caregivers. According to a **New England Journal of Medicine** report of January 30, 2008, TBI “tripled the risk of PTSD, with 43.9 percent of those diagnosed with TBI also afflicted with PTSD.”

At present, the current system of screening, treatment, tracking, and follow-up care for TBI vision dysfunction is inadequate. Adding visual dysfunction to this complex mix, especially if undiagnosed, makes attempts at rehabilitation even more daunting and potentially disastrous unless there are significant improvements in the screening, treatment, tracking, and follow-up care through the proposed and legislated Vision Center of Excellence.

VCE TO ADDRESS CRITICAL ISSUES

BVA believes that the VCE Eye Trauma Registry is where vital components for research, best practices, outcome measures, and education can be developed and refined for the eye trauma wounded and those with TBI vision dysfunction. Critical vision research coordinated with the Defense Veterans Brain Injury Centers (DVBIC) and Defense Centers of Excellence for TBI can facilitate effective eye trauma research between DoD and VA. We predict that the number of TBI-injured will again increase beginning this spring as the troop surge into Afghanistan gets underway.

BVA wishes to clear up false misinformation about VCE that has recently become commonplace: First, VCE is not to be one large clinical eye treatment center for all combat eye injured. It is better understood as “a virtual center with connectivity” to the four major military trauma centers (National Naval Medical Center, Brooke Army Medical Center, Madigan Medical Center, and San Diego Naval Medical Center), the soon-to-be five VA Polytrauma Centers, and the hundreds of other medical centers where the highest proportion of eye-injured and TBI-wounded are already receiving high quality, specialized surgery care and low-vision optometric services.

Second, VCE is not a DoD blind center or rehabilitation facility. It will, however, coordinate its work with the already existing, skilled, multidisciplinary VA Blind Rehabilitation Centers (BRCs) and low-vision clinics with decades of experience treating blinded veterans. The VCE Eye Trauma Registry will track all eye injured and TBI visually impaired, coordinate joint vision research, promote best practices, and develop educational information on vision services for both providers and families.

VA BRS AND LOW-VISION SERVICES

A positive note is that the challenges inherent in the growing number of returning OIF and OEF service members needing screening, diagnosis, treatment, and a coordinated Seamless Transition of services can be met, at least to some extent, by the existence of world-class VA BRCs. The programs provided at such centers now have a 60-year history. In the larger picture of VA programs for blind and visually impaired veterans, BVA began working more than four years ago to ensure

that VA expand its current capacity to serve blinded veterans. Such expansion became necessary as the aging population of veterans with degenerative eye diseases requiring specialized services has continued to increase.

As a result of efforts to broaden and increase services, 54 new outpatient intermediate low-vision and advanced blind rehabilitation outpatient programs already have specialized staffing in place. Many of these new programs are opening with veteran-centered, low-vision specialized teams providing the full range of basic, intermediate, and advanced rehabilitation services. Accompanying these gains is special VA emphasis on outcome measurements and research projects within VHA. The VA approach of coordinated team methods for rehabilitation care has unlocked strategies for new treatments and provided the most updated adaptive technology for blinded veterans. The new, specialized low-vision and blind programs already existing within the VA system must be utilized by DoD through VCE. The eye injured must receive high quality health care with proven outcomes that include constantly emerging vision research.

The mission of each Visual Impairment Services Team (VIST) program is to provide blinded veterans with the highest quality of vision loss services and blind rehabilitation training that truly help them adjust to the major changes they have experienced in their lives. To accomplish this mission, VISTs have established mechanisms to facilitate more completely the identification of blinded veterans and to offer a review of benefits and services for which they are eligible. The VIST concept was created in order to coordinate the delivery of comprehensive medical and rehabilitation services for blinded veterans. VIST Coordinators can assist not only newly blinded veterans with timely and vital information leading to psychosocial adjustment, but can also provide similar assistance to their families.

Seamless Transition from DoD to VA is best achieved through the dedicated work of VIST Coordinators and Blind Rehabilitation Outpatient Specialists (BROS). They are in a unique position to provide comprehensive case management services to returning OIF/OEF service personnel for the remainder of their lives. VIST Coordinators are now following the progress of 135 recently blinded veterans who are being served on an outpatient basis. The VIST system currently employs 112 full-time and 43 part-time Coordinators. There are 39 full-time BROS teams who also manage cases and serve as blind instructors for OIF and OEF blinded veterans.

The VA BROS is a highly qualified professional. Many BROS hold Masters Degrees in both Orientation and Mobility and Rehabilitation Teaching. BROS also receive extensive cross-training at one of the ten BRCs nationwide. The training prepares such individuals to provide, in the veteran's home environment, the full range of mobility, living, adaptive, manual, and other skills essential to blind rehabilitation. VIST/BROS teams are also well equipped to provide excellent local services on a continuing basis when a veteran returns home from an inpatient stay at a BRC.

Advanced Outpatient Rehabilitation Programs occur in "Hoptel" settings, as VA calls them. Hoptel sleeping arrangements function perhaps more like hotels than hospitals. Such programs offer Skills Training, Orientation and Mobility, and Low-Vision Therapy for veterans who need treatment with prescribed eye wear, magnification devices, and adaptive technology to enhance remaining vision. Those returning from blind centers benefit from these outpatient services when they require additional training. A VIST Coordinator with low-vision credentials manages the program with other key staff consisting of certified BROS, Rehabilitation Teachers, Low-Vision Therapists, and a part-time Low-Vision Ophthalmologist or Optometrist. Medical, surgery, psychiatry, neurology,

rehabilitative medicine, pharmacy, physical therapy, and prosthetics services can all be consulted as needed within the VA Medical Center, effectively providing the full continuum of care for the OIF and OEF veterans. DoD and VA are in the process of developing a bi-directional electronic health care record that exchanges medical records and clinical eye trauma surgery information. Private agencies that offer blind rehabilitation would rarely have full medical services, surgical subspecialties, and psychiatry all co-located within one facility, meaning veterans and families would have to travel additional distances to obtain needed outpatient care for other conditions, adding to wait times for consultants, delays in obtaining prescribed medications, or waiting on new treatment plans. BVA strongly recommends that private agencies utilized for services provide outcome studies. We also recommend that they be accredited by the Commission on Accreditation of Rehabilitation Facilities, that they be required to utilize VA electronic health care records for clinical care, and that they meet specific outcome measures for future contracts.

Another important model of service delivery that does not fall under VA BRS is the VICTORS program, or the Visual Impairment Center to Optimize Remaining Sight. VICTORS is an innovative program that has been operated by VA Optometry Service for more than 18 years. The program consists of specialized services to low-vision veterans who, though not legally blind, suffer from visual impairments. Veterans must generally have a visual acuity of 20/70 through 20/200 to be considered for VICTORS. The program, entirely outpatient, typically lasts 3-5 days. Veterans undergo a comprehensive, low-vision optometric evaluation. They receive prescribed low-vision devices and are trained in the use of adaptive technology to optimize functional independence.

The Low-Vision Optometrists employed in the Intermediate Low-Vision programs are ideal for the highly specialized skills necessary for the assessment, diagnosis, treatment, and coordination of services for Iraq and Afghanistan returnees with TBI visual symptoms. This is because such veterans often require long-term follow-up services. The programs also assist the aging population of veterans with degenerative eye diseases. Such programs often enable working individuals to maintain their employment and retain full independence in their lives. They also provide testing for and research into the effectiveness of adaptive low-vision technology aids that have recently become available through training, review, and research. In conjunction with a wide network of VA eye care clinics existing in VA medical centers nationwide, combined VIST/BROS teams and Intermediate/Advanced Outpatient programs can provide a wide network of specialized services for veterans and their families in .

All of these programs test the effectiveness of new adaptive low-vision technology aids through training, review, and research. Programs requiring long-term follow-up services, such as the new Advanced and Intermediate programs, are cost effective for high-need, low-vision OIF/OEF veterans with residual vision from TBI. Combined VIST/BROS teams and Intermediate/Advanced Outpatient programs can provide a wide network of specialized services for service members and their families in coordination with existing VA Eye Care clinics within VA medical centers. VCE is critical to the success of all of the aforementioned specialized VA services.

CONCLUSIONS

Serious combat eye trauma and visual dysfunction associated with TBI among OIF and OEF service personnel have become the second most common injury resulting from the two conflicts. More than

9,940 visual injuries have occurred and thousands more have visual dysfunction stemming from TBI. We urge members of the full House Committee to demand compliance with the existing NDAA requirements. Both DoD and VA should provide the \$5 million funding for the remainder of FY 2009 for joint professional and administrative staffing, joint office space for no fewer than 12 staff members, construction, information technology, and funding oversight of all activities of the Vision Center of Excellence and Eye Trauma Registry. Congress indeed expected compliance 13 months ago. The establishment of the Defense Intrepid Center of Excellence for Mental Health and the TBI Center of Excellence, along with VCE, would substantially improve the multidisciplinary coordination, treatment, rehabilitation, and research into eye trauma and TBI-related visual impairment experienced by service members and veterans throughout the DoD and VA systems.

BVA again expresses sincere gratitude to this Subcommittee for the opportunity to present our testimony. We hope that you understand the deep sense of frustration we have felt over the course of the 13 months since NDAA established VCE. Simply put, the time for DoD and VA to implement VCE, as intended by the 110th Congress, is now. With the large numbers of veterans suffering direct eye injury from battle and TBI visual dysfunction, further delay is unacceptable. Because the population of war wounded service members and veterans is widely diverse geographically, it is not appropriate or reasonable that one military or VA medical treatment facility become a clinical center for all eye-wounded service members or for TBI patients with visual dysfunction. Depending on such an idea would be cost prohibitive and delay care for literally thousands of men and women.

We request that the House VA Committee require that both Secretary Gates and Secretary Shinseki get VCE on track again. The Defense Appropriations War Supplemental in April should present the next feasible and excellent opportunity to add additional directed funding.

RECOMMENDATIONS

- The Secretary of Defense and Secretary of Veterans Affairs must immediately direct the Senior Oversight Committee Executive Director to approve the organizational structure and charter for VCE and provide DoD/VA clinical/administrative staff teams. He must oversee the securing of temporary office space for at least 12 staff members and see that financial resources are in place to begin to begin full implementation of the operations of VCE. He should then report back to this Committee within 30 days. VHA was directed to spend \$6.9 million in FY 2009 for VCE. These funds should be utilized now for at least some of the expenses associated with VCE's establishment.
- The military director of VCE, Colonel Gagliano, and VA Deputy Director Dr. Cowan need immediate administrative and information technology staff support, office equipment, travel funding, and educational support resources from both DoD and VHA to implement the new VCE joint program, with no less than \$5 million to cover FY 2009.

- Congressional oversight should ensure that MILCON/VA and Defense Appropriations Chairmen and Ranking Members review budgets for FY 2010 to ensure that they provide no less than \$6.5 million for staffing, \$10 million for FY 2010 vision research, and no less than \$2 million for information technology. Some \$6 million is urgently needed at present to fund a Navy construction project that will renovate office space and other facilities at National Naval Medical Center in Bethesda, Maryland, where VCE Headquarters is to be located. All Program Operational Management initiatives should then be funded for FY 2011, FY 2012, and FY 2013 as mandated by the reporting clause in the National Defense Authorization Act of 2009.
- VCE must be patient and family centered, comprehensively coordinated, and compassionate. It should be a virtual center providing real Seamless Transition that ensures electronic bi-directional registry exchange of both inpatient and outpatient eye care clinical records that both DoD and VA eye care staff can update and share with the Veterans Benefits Administration so that benefits for service-connected injuries can be assessed.
- All DoD/VA case managers need educational updates on the various VA specialized vision programs for eye trauma and TBI visual dysfunction. Veterans and family members need information on locations of vision services within DoD and VA. VIST/BROS teams must be notified early in the treatment process of transfers to their local area of any eye-injured service member. All DVBIC and VA TBI Centers must report data to VHA on eye trauma or TBI vision dysfunction cases.
- Private agency involvement in the treatment and rehabilitation process should be narrowly limited to those meeting strict accreditation, certification, educational, and university peer-reviewed research criteria. Such agencies should be equipped with multidisciplinary staff support and meet all Health Insurance Portability and Accountability (HIPPA) requirements.
- VCE should become involved in the DoD peer-reviewed Congressionally Directed Medical Research Program (CDMRP) in order to encourage additional TBI visual dysfunction research. More eye trauma research in conjunction with DoD, VA, NIH, and universities with VA academic affiliations is desperately needed now. Potential long-term consequences of mild-to-moderate TBI in OIF/OEF veterans are still unknown. Discoveries of such consequences will require new technology and diagnostic research support. BVA, supported by the current Veterans Service Organization Independent Budget, requests \$10 million for CDMRP in FY 2010 as directed vision research.

DISCLOSURE OF FEDERAL GRANTS OR CONTRACTS

Blinded Veterans Association

The Blinded Veterans Association (BVA) does not currently receive any money from a federal contract or grant. During the past two years, BVA has not entered into federal contracts or grants for any federal services or governmental programs.

BVA is a 501c(3) Congressionally chartered, nonprofit membership organization.

THOMAS ZAMPIERI BIOGRAPHY

Dr. Thomas Zampieri is a graduate of the Hahnemann University Physician Assistant Program (June 1978). He obtained a Bachelor of Science degree from State University of New York and worked as a Surgical Physician Assistant within the Department of Veterans Affairs for 19 years. He graduated with a Masters Degree in Political Science from the University of St. Thomas in Houston, Texas, in May 2003. Dr. Zampieri completed his Political Science Ph.D. through Lacrosse University in December 2005. He was employed in April 2004 as the Director of Government Relations at the National Headquarters of the Blinded Veterans Association (BVA), a Congressionally chartered Veterans Service Organization founded in 1945.

Dr. Zampieri served on active duty as a Medic in the United States Army from 1972 to 1975. Upon completing Physician Assistant training, he served from September 1978 to August 2000 as an Army National Guard Physician Assistant, retiring as a Major. During this time, he was involved in several military medical training programs and schools, successfully completing the Army Flight Surgeon Aeromedical Course at Fort Rucker in 1989 and the U.S. Army Medical Department's Advanced Officer Course at Fort Sam Houston, Texas, in 1992.