Veteran's Health Patient Advocate Leaders Summit Executive Summary

Washington, DC
June 26, 2008

"If we don't do the right thing, and young people lose confidence in their military and confidence in their government, then this will not be the country that was founded on the principles that you and I believe in. So when people ask me, 'Do you believe veterans are entitled to preferential treatment?' 'You bet your life I do.' They shouldn't be in our streets, homeless, jobless, and hopeless. They shouldn't have to ask for healthcare. We should be right there the same way we showed them how to get to the firing line. We should be right there to say thank you."

—Congressman Charles Rangel (D-NY)

Overview

"We've got to share information!" said Robert Wallace, Assistant Adjutant General and Executive Director, Washington Office, Veterans of Foreign Wars (VFW) of the United States, in his opening remarks to the 2008 Veteran's Health Patient Advocate Leaders Summit (PALS). PALS was hosted by VFW with Vietnam Veterans, AMVETS, Disabled American Veterans, American Legion, and Paralyzed Veterans of America. Glenna Crooks, PhD, of Strategic Health Policy International moderated the Summit.

The PALS Planning Committee convened the invitation-only meeting of approximately 100 attendees that represent the interests of more than 30 organizations. The objective of the meeting was to share knowledge among Veteran's Service Organizations, celebrate the contributions of veterans, and discuss important issues facing the care of America's veterans in various undertreated areas. The meeting aimed to inform, enlighten, and empower the leaders of the conference to create new levels of awareness within their own constituencies

Approximately 60% of the meeting was devoted to clinical review of 4 disease areas disproportionately affecting American veterans: traumatic brain injury/blast injury (TBI/BI), diabetes, posttraumatic stress disorder (PTSD), and chronic obstructive pulmonary disease (COPD). The Planning Committee purposefully selected 2 disease areas of importance to older veterans (diabetes, COPD), and 2 injuries predominantly resulting from current conflicts (PTSD, TBI/BI).

The remaining 40% of the meeting was devoted to question-and-answer sessions that afforded attendees the opportunity to discuss issues with the presenters and meeting participants.

PALS Highlights

General

- Many attendees believed that the VA system provides quality healthcare. However, it was recognized that opportunities exist for improving the care and management of veterans with TBI/BI, diabetes, PTSD, or COPD by focusing on prevention and quality
- On closing, attendees were asked to say one word that best described the way they felt after the day's events. Inspired, was most frequently cited. Other sentiments included:
  - Motivated
  - Optimistic
  - Humbled
  - Surprised
- Many attendees were unaware of the access challenges faced by patients with COPD and diabetes, and agreed that formularies and budget restrictions should be reexamined so that veterans can better understand their treatment options and have greater access to those options

TBI/BI

- TBI/BI affects 1 in 5 veterans and has complex sequelae of symptoms. Treatment efforts that address the polytraumatic nature of TBI/BI are optimal to ensure the best care for veterans and their families
- Greater awareness of TBI/BI prevalence through a national campaign may encourage veterans to seek treatment

Diabetes

- Diabetes disproportionately affects veterans and heavily taxes the VA system. Attendees agreed that by empowering veterans through education, improving access to appropriate therapies, and individual/family support, outcomes may improve and inpatient costs may be reduced
- Many attendees were surprised to learn that some FDA-approved diabetes and COPD treatment options are not available to veterans, either because of formulary restrictions or internal restrictions

PTSD

- Supporting families of veterans with PTSD and/or TBI/BI is critical to maintain their quality of life and prevent adverse outcomes such as homelessness or suicide
- A key challenge in the treatment of PTSD is removing the stigma attached to the disorder. Building resiliency among today's veterans is one approach that may help prevent PTSD

COPD

- Attendees believed that the information regarding medication access challenges faced by veterans was new and shocking
- Specific suggestions for improving care for veterans with COPD included:
  - Developing Centers of Excellence for COPD
  - Improving access to state-of-the-art healthcare for veterans with COPD
  - Focusing on prevention and a more proactive approach to COPD diagnosis and management
  - Enabling unrestricted access to proven tools and therapies that improve COPD

"Today we have a huge opportunity to do the right thing, to provide care for our veterans… No matter where one stands on the war; every American wants to make sure that our veterans get the care they deserve."

—Senator Patty Murray (D-WA)

Clinical Overview—Traumatic Brain Injury/Blast Injury (TBI/BI)

Steven G. Scott, DO
James A. Haley Veterans' Hospital, Tampa, Florida

TBI/BI Fast Facts

- 19.5%, or approximately 1 in 5 troops, will experience TBI/BI while deployed
- More than 300,000 may have TBI/BI
- TBI/BI comprises 77% of what is seen in polytrauma centers
- TBI/BI is the leading cause of death in battle, 15% to 20%; 50% of patients will die from their wounds
- The severity of the TBI/BI is related to the amount of time spent unconscious following the blast
- Sport concussions are not the same as blast concussions
- 5 different mechanisms of blast/explosions cause TBI/BI
  - Primary—effects of overpressure
  - Secondary—flying debris, fragments
  - Tertiary—body displacement, wind
  - Quaternary—septic syndromes, burns
  - Quinary—from additives (radiation, bacteria)
- Explosions in closed spaces produce overpressure 5× greater than explosions in open spaces

Impact on the Veteran Community

- TBI/BI is a polytraumatic event with complex sequelae, warranting complex and varied treatments for physical, mental, behavioral, and cognitive effects
- Primary blast injuries comprise an overpressure wave that compresses the whole body and brain. Whole-body trauma results and the physiology of the brain changes as axons are stretched
- Immediate-emerging symptoms of TBI/BI from primary causes include: loss of consciousness, headache, confusion, dizziness, nausea/vomiting, vacant stare, disorientation
- Latent-emerging symptoms of TBI/BI from primary causes include: mood alterations, impairments in vestibular control and visual coordination, headaches, impairments in executive function processes, loss of high-frequency hearing, tinnitus
- Substance abuse is common in those suffering from TBI/BI
- PTSD and TBI/BI have some overlapping sequelae: memory deficit, attention deficit, irritability, and sleep disturbance. However, headache, nausea, dizziness, and balance problems are not similar across the disorders

TBI/BI Q&A

- What should be done to support soldiers with TBI/BI and their families as they transition back to civilian life?
  - Answer: It was suggested that more support for families come in the form of staged transition, similar to transitional care offered at James A. Haley VA, from hospital to civilian life. Many attendees were surprised to learn of the polytraumatic nature of TBI/BI and the varied support structure needed to heal patients and families
- What data exist showing greater incidence of epilepsy in mild TBI/BI?
  - Answer: There is a data gap in mild TBI/BI. We do not presently know the incidence.
- How do you treat TBI/BI and comorbid PTSD? Cognitive deficits are prevalent in TBI/BI, including lack of awareness of one's disorder. But cognitive-behavioral therapy is recommended for PTSD. What protocols are in development to treat both?
  - Answer: This is a problem that many providers struggle with. In the P3 program, the pain of headaches is addressed and this ameliorates some of the irritability. It is important to also try to dissociate how much of the mood disorder is injury related. New coping strategies are introduced in keeping with the altered cognitive capacity that the TBI/BI sufferer may have. There are no protocols, but an interdisciplinary approach is often utilized
- Is it possible to have sensors in helmets to help track possible TBI/BI?
  - Answer: This innovation is being developed at the University of Illinois, but will not detect pressure within the body resulting from blast injuries
- Do you think a national awareness campaign involving all of the parts of the VA community would be a good way to communicate the problems of TBI/BI?
  - Answer: A national awareness campaign could help drive TBI/BI patients to seek care earlier, prevent substance abuse, homelessness, and suicide
- What challenges have you faced with the TriCare system with soldiers returning to combat?
  - Answer: Due to the complex polytraumatic nature of TBI/BI, it is difficult for the system to administratively manage the authorizations required for each problem
- What are you doing to communicate what you've learned about treating TBI/BI?
  - Answer: A grand rounds educational series has been implemented on active military bases to increase awareness among providers. A weekly case study seminar also improves education among providers

Action Steps

- Current *DSM-IV* and *ICD-10* references to concussion do not adequately cover TBI/BI and its sequelae. Revisions to these references are needed that consider the polytraumatic nature of the injuries and varied therapies required for optimal treatment
- Promote development of FDA-approved pharmacologic therapies to treat the psychotic symptoms of TBI/BI
- Create more peer-to-peer communications in the form of testimonials or support groups. These have improved care for many
- Develop ways to provide family support following TBI/BI, which is a critical element of healing the soldier and helping their family better understand and cope
- Integrate substance abuse counseling and prevention into TBI/BI care
- Continue to promote polytrauma rehabilitation care as an integral treatment for veterans with TBI/BI symptomatology to include audiology, vision, pain, physical therapy, PTSD treatment, and TBI/BI rehabilitation

Clinical Overview—Diabetes

Steven V. Edelman, MD
Director, Veterans' Affairs Healthcare System Diabetes Care Clinic, San Diego, California
Professor of Medicine, Division of Endocrinology, Diabetes and Metabolism, UCSD
Founder, Taking Control of Your Diabetes (TCOYD)

Diabetes Fast Facts

- Two types of diabetes exist, type 1 and type 2
  - Type 1 phenotype is thin, diagnosed young, where the pancreas no longer makes insulin
    - 10% to 15% of patients with diabetes
  - Type 2 phenotype is usually overweight and heavy, diagnosed after the age of 35
    - Resistant to insulin
    - Rely on prescription medications and insulin for control
- 85% of patients with diabetes have heart disease
- Symptoms of high blood glucose include thirst, frequent urination, blurred vision, slow wound healing
- When patients measure their HbA1c level, the goal is less than 7%
- By 2025, an estimated 333 million Americans will have diabetes
- Currently, 8% of Americans have diabetes

Impact on the Veteran Community

- 20% of veterans have been diagnosed with diabetes
- 80% of veteran deaths occur from heart disease (a factor in type 2 diabetes)
- The average annual cost of care for a veteran with diabetes is $11,157
  - Inpatient costs are 64.1% of the diabetes budget and are associated with amputations, heart disease, and kidney disease
  - By empowering veterans to control diabetes, inpatient procedures may be minimized
  - Outpatient costs make up 11% of the budget

Diabetes Q&A

- Why do veterans have limited access to medications, injections, and monitoring systems?
  - Answer: These items are not on formulary. Therefore, medication that is available to the general public is not available to veterans unless they also have managed healthcare
- How do we, as a group of organizations, get a variety of medications and monitoring systems on formulary?
  - Answer: A team should be formed of diabetes specialists, nutritionists, pharmacists, and caregivers to discuss best options for veterans being served by the VA
- Should there be a marketing/publicity campaign to make sure that veterans are aware of the services they could receive through the VA?
  - Answer: It is a great idea to better educate veterans and raise awareness of the diagnostic and treatment options that may be available

- When is it determined what treatment is necessary?
  - Clinical guidelines state that by examining eyes, kidneys, nerves (feet), heart, and brain, the physician can determine the necessary treatment
- Could there be a reallocation of budget items?
  - Answer: To empower veterans to take more control of their diabetes could reduce spending for inpatient services such as amputations and heart disease and potentially reduce formulary expenditures
- What medications/injections would you recommend become available on formulary?
  - Answer:
    - Long-acting insulin pens
      - Provide accurate dosing
      - Less painful
      - Improved social acceptability
    - Prescription medications/injections that
      - Improve glycemic control
      - Reduce HbA1c
      - Reduce glucose fluctuations
    - Continuous glucose monitoring
      - Identifies glucose excursions
      - Educates and motivates patients
      - Provides reliable and accurate data
- Why do some veterans not treat their diabetes?
  - Answer: There are many reasons for the lack of treatment that may include lack of disease awareness as well as emotional issues and/or homelessness
- How do we make sure veterans are motivated to control their diabetes?
  - Answer: Veterans and their care administrators may begin to:
    - Form teams that include diabetes specialists, nutritionists, pharmacists, and other caregivers
    - Communicate best practices among VA diabetes specialists
    - Encourage participation in education and empowerment programs that promote:
      - Increased screening
      - Prescribed medication use
      - Taking aspirin
      - Lifestyle modifications (eg, diet, exercise)
      - Foot care
      - Family member support

Action Steps

- Continued information sharing on diabetes was encouraged
- Create greater collaboration to ensure that veterans have access to optimal treatments and education for improved diabetes outcomes
- Examine VA budgets and reconsider formulary choices
- Promote publicity campaigns to inform veterans of the services that the VA offers for diabetes care

Clinical Overview—PTSD

Gregory A. Leskin, PhD
Military Family Liaison, National Center for Child Traumatic Stress, UCLA

PTSD Fast Facts

- Traumas such as combat, rape, or natural disaster can cause PTSD
  - PTSD is a chronic anxiety disorder with relapses and recurrences
    - 3 conditions must be present in PTSD: a significant stressor, an intense fear response to the stressor, and a resultant significant change in global functioning
- Approximately 7.8% of Americans suffer from PTSD
- Untreated PTSD causes significant disability and increases medical utilization substantially
- Secondary and associated responses may include: depression, aggression, lowered self-esteem, identity disturbance, poor interpersonal relationships, guilt, physical illness, substance abuse
- Risk factors for PTSD include gender, low socioeconomic status, low education level, low intelligence, racial status, psychiatric history, childhood abuse, previous trauma, adverse childhood, family psychiatric history, trauma severity, lack of social support, general life stress
- Chronic anxiety can result in insomnia, decreased libido, hippocampal damage, and hypertension

Impact on the Veteran Community

- 26% of returning troops may have some type of mental health issue
- Troops who are repeatedly deployed and experience multiple traumatic events are at risk
- With the overwhelming amount of soldiers returning from war with PTSD and severe depression, the United States could be spending up to $6 billion on treatment
- Annual costs to treat PTSD and related comorbidities range from $6,000 to $25,000 per veteran

PTSD Q&A

- Is PTSD hard to diagnose?
  - Answer: At times veterans suffer from depression or substance abuse and it can be difficult to determine if it is severe depression, TBI/BI, or PTSD
- Are there strategies that could be employed prior to a soldier ever seeing combat to prevent or reduce PTSD?
  - Answer: Yes, if new soldiers had initial resiliency training, they may be better prepared to cope with traumatic combat situations. Project Focus is a program that is available to help veterans receive resiliency training
- Why is it that veterans have access challenges to cognitive behavioral training (CBT)?
  - Answer: The treatment is expensive and time-consuming as well as:
    - Provider issues (providers are not trained)
    - System issues (hours are not convenient for those who are employed and need treatment)
    - Clinical issues (many veterans have to be treated for substance abuse prior to being treated for PTSD)

- Are the PTSD treatments veterans receive comparable to CBT?
  - Answer: CBT is the only theoretically based and validated treatment for PTSD that is currently available. Veterans do not have access to this treatment
- When will Combat2College become disseminated in more areas?
  - Answer: The Combat2College Program must be further assessed for its level of success. If it is a successful program, then more of these programs will be started
- How do we eliminate the stigma surrounding PTSD?
  - Answer: Educational tools such as, *PTSD does not mean you are crazy*, published by the VVA are a good start to eliminating the stigma
- How do veterans know about the services the VA provides?
  - Answer: Pamphlets outlining the VA services are available, but more would be helpful for veterans
- Does anyone follow-up on the veterans who do receive treatment?
  - Answer: There is no formalized follow-up program, but there is a definite need for monitoring and outcomes research

Action Steps

- Veteran's organizations should collaborate to develop programs that will focus on prevention, evidenced-based clinical treatment, the combat stressors faced by the new generation of soldiers, and outcomes monitoring
- Create and publish information on the treatment of PTSD with an emphasis on reducing stigma so that more veterans seek treatment
- Seek additional funding for PTSD research to advance the diagnosis and treatment for veterans

Clinical Overview—COPD

Claudia G. Cote, MD, FCCP
Associate Professor of Medicine, Division of Pulmonary, Critical Care and Occupational Medicine, University of South Florida College of Medicine, Tampa, Florida
Staff Physician, Division of Pulmonary and Critical Care, Bay Pines VA Medical Center

COPD Fast Facts

- COPD comprises mucus hypersecretion (luminal obstruction), disrupted alveolar attachments (emphysema), mucosal and peribronchial inflammation, and fibrosis (obliterative bronchitis)
- The phenotype of COPD is evolving to include more women
  - In 2004, 63% of reported cases were women
- 16 million people in the United States have COPD and another 15 million have spirometric evidence of impaired lung function but remain undiagnosed
- COPD symptoms do not manifest until 50% of lung capacity is lost
- By the year 2020, COPD is estimated to be the third leading cause of death worldwide

Impact on the Veteran Community

- COPD disproportionately affects veterans
  - 19% to 20% prevalence vs 6.6% prevalence in civilian population
  - Is the leading cause of disability among veterans
  - Is the fourth most common diagnosis among hospitalized veterans and first among veterans aged 65 to 74
  - Veterans have a higher likelihood of smoking history (74%) vs nonveterans (48%)
  - More veterans smoke—34% vs 28% nonveterans
- COPD exacts a heavy economic burden
  - COPD is the most expensive chronic disease among veterans
  - COPD accounts for 16% of VA bed occupancy
  - Median hospital length of stay (LOS) for a veteran with COPD is 12 to 13 days vs 6 days for non-COPD veterans
- COPD costs $10,618 annually per veteran
- Breakdown of VA national healthcare expenditures for COPD
  - 67.2% hospitalizations
  - 24.3% outpatient care
  - 8.4% prescription drugs

COPD Q&A

- COPD is confirmed with spirometry, and spirometry can be used to screen for COPD. What can be done to encourage routine use of spirometry like blood pressure measurements?
  - Answer: The VA is more likely to implement screening and confirmatory spirometry than the private sector. However, it is not widely implemented because of reimbursement issues
- When should spirometric tests be performed?
  - Answer: Clinical guidelines suggest everyone aged 40+ should receive testing. If lung function is <80%, COPD treatment should be initiated irrespective of symptom presence

- Can lung function be improved in patients with COPD?
  - Answer: Yes, lung function can be improved in some patients and long-acting agents and lung transplantation are the most likely treatments to improve lung function
- Has there been a gene isolated to help identify at-risk people?
  - Answer: Yes, it is linked to the same gene that plays a role in the development of lung cancer. Gene isolation is believed to be a promising advancement
- What percentage of patients with COPD has no history of smoking?
  - Answer: Although smoking commonly causes COPD, approximately 10% of patients in the Bay Pines VA have no history of smoking. But, all have been exposed to second-hand smoke
- Why is there a disconnect between the way the VA treats COPD and other chronic diseases?
  - Answer: The VA has established Centers for Excellence for other chronic diseases and patients who need specialized care have access to it. Four percent to 5% of veterans with advanced COPD need the care of a specialist, but not all veterans have access to the care of pulmonary specialists
- Is it possible to raise the standard of care without significant financial investment?
  - Answer: Examples exist in other disease areas where medications are prescribed to avoid complications (eg, in hypercholesterolemia). A small increase in spending on medications may reduce the money spent on acute incidents (eg, hospitalizations)
- Are there examples outside the VA that represent higher quality of care?
  - Answer: Many of the larger hospital systems outside of the VA system (eg, Mount Sinai) have established Centers of Excellence to treat COPD
- What could be done to promote further awareness of COPD in the veteran community?
  - Answer: First, educate the patients and confront the complex dynamics and challenges of smoking cessation. As well, providers must confront their own biases and treat with urgency and compassion. Proactive screening for COPD must become standard practice, as seen in other chronic diseases such as hypertension and hyperlipidemia

Action Steps

- Spirometry screening is an actionable solution that may identify COPD early and reduce the human and economic costs of exacerbations
- A COPD treatment paradigm that emphasizes treatment of acute events in the hospital and not prevention and minimizing exacerbations was described as "penny-wise and pound-foolish" and requires a shift in thinking to optimize treatment for veterans
- Opportunities exist to improve awareness among legislators about the prevalence, treatment gaps, and medication access challenges for veterans
- Methods to prevent and manage the cost of COPD hospitalizations without sacrificing quality of care should be explored
- Promote prevention and expanded treatment options as a means to positively impact the management of COPD

Appendix

Veteran's Health Patient Advocate Leaders Summit

June 26, 2008

Hyatt Regency Capitol Hill
400 New Jersey, NW
Washington, DC

Schedule of Events

Thursday, June 26, 2008		**Room Names**
7:30–8:30 AM	Registration Continental Breakfast	Ticonderoga Foyer Ticonderoga
8:30 AM–5:00 PM	General Session	Yorktown
8:30–9:15 AM	Welcome/Opening Remarks	
9:15–9:30 AM	Remarks by US Congressman Charles Rangel	
9:30–10:00 AM	Networking Break	Yorktown Foyer
10:00 AM–NOON	First Breakout Segment TBI/BI Diabetes	 Yorktown Valley Forge
NOON–1:30 PM	Lunch	Ticonderoga
1:30–3:30 PM	Second Breakout Segment PTSD COPD	 Yorktown Valley Forge
3:30–4:00 PM	Networking Break	Yorktown Foyer
4:00–4:15 PM	Remarks by US Senator Patty Murray	
5:00 PM	General Session Concludes	
5:00–7:00 PM	Reception	Congressional A

Organizations in Attendance

A complete contact list was available to all attendees. VSO representation included:
42nd Engineers
AFGE, Legislative Department
AMVETS
The American Legion
American Psychiatric Association
American Psychological Association
American Public Health Association
Association of American Medical Colleges
Blinded Veteran's Association
Brain Injury Association of America
Center for Health Care Policy and Research
Commission of the Future of America's Veterans
Disabled American Veterans
Easter Seals
GlaxoSmithKline
House Committee on Veterans' Affairs
IAVA
Intelligent Concepts, Inc.
NGB
MOAA
Men's Health Network
Military Officers Association of America
National Alliance on Mental Illness
National Association of State Directors of Veteran Affairs
National Coalition of Homeless Veterans
National Military Family Association
National Multiple Sclerosis Society
Oak Grove Technologies
Office of Senator Hillary Clinton
Paralyzed Veterans of America
Sanofi-Aventis Pharmaceuticals, Inc.
UCLA/National Center for Child Traumatic Stress
US Department of Veterans Affairs
Veterans Coalition
Veterans Innovation Center
Veterans of Foreign Wars
Veterans of Modern Warfare
Vietnam Veterans of America
Wishing Well, Inc.
Witness Justice