



### 2010 Meeting of Minds Summary

When	December 3-5
Where	Gettysburg, PA
Purpose	Lessons Learned/Building Support Network
Who	Wounded, Ill, Injured, Goldstar family members and Supporters
Leads	Tim and Shannon Maxwell
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### **PARTICIPANTS**

- 01 Gold Star representative
- 19 Wounded/Ill/Injured representatives
- 16 Caregiver and other family members
- 07 Supporters

## **OUTCOMES/TESTIMONIALS**

“You meet a need that is not being met by anyone else and the families I spoke with were simply thrilled to be there and to have the support you offer.”

“At first I felt weird being there, but as Sunday morning turned to Sunday afternoon, I didn't want to leave. My family is in New York, but I felt as if I left my family when we all departed Gettysburg. Thank you for all that you continue to do for so many. It means a lot to have someone like yourself and the people there this past weekend in my life. Besides my son, it is what keeps me going.”

“Thank you so much for inviting us to this past event, we truly needed it and I'm SURE (wife) needed to speak with other spouses going through the same adventure we are. She really has NO ONE around here to speak with about our trials and tribulations. I believe this weekend has been an awakening for her as to why I may not act like the man she married - which I desperately want to be, but I feel like a lost soul sometimes.”

“We both learned a lot and feel much more connected to other families that are battling the same issues as us.”

Outcomes ongoing – but, within 3 days:

1 veteran assisted with computer.

1 veteran assisted with job connection.

Caregivers networked.

## LESSONS LEARNED

1. Veterans and Family members feel alone after separation from military. They appreciate group meetings to highlight that they are not alone in the recovery/challenges and to gain insight, support and network.
2. Veterans with TBI, particularly closed head injuries are experiencing seizures and other TBI related symptoms after retirement – lack of follow-up and late detection complicates not only treatment, but access to benefits.

3. Some veterans report strange brain diseases arising. One participant shared a medical theory attributed to depleted uranium contained in shrapnel fragments.



4. There needs to be better **education of community at large and employers** with regard to head injuries and PTSD to demystify diagnosis, decrease perception that folks with PTSD are “sitting time bomb”, improve and adapt work environment so that hires can be productive and purposeful, rather than “case where the employer is trying to do right by the wounded but short expectations and minimal work lead to underutilization of talents and time.



5. Advocacy (self or other) with regard to medical care and benefits is imperative, sometimes the difference between life and death. **Active duty Army participants expressed greater difficulty advocating where medical care believed insubstantial due to command and career repercussions.**

6. Marine Corps District Injured Support Cells are available around the nation to help those Wounded, Ill, or Injured Marines or Sailors attached to Marine Unit who are transitioning out connect to services in their communities: jobs, VFW, VSO's – participants stated advocacy effective and appreciated.

7. **Outreach to TBI and PTSD veteran populations still lacking** and needs to increase with regard to adapted sports and recreation opportunities.

8. TBI and PTSD recovery is a lifetime. Need transition centers nationwide and available, quality counseling for veteran and family.
9. TBI and PTSD veterans are frustrated by lumping of the two diagnoses. On the other extreme Doctors have had the audacity to claim that TBI cancels out PTSD. Veterans and Family request that doctors, therapists and other medical personnel LISTEN to them. They know more about the individual personality/history/etc.
10. There is a huge need for available, highly qualified and skilled neuro-psychiatrists!
11. Pain and medication management is a big concern for families: Patients are discharged with no plan for tapering off pain meds and often on multiple meds from various doctors with no pharmacologic management of interactions and TBI affects. Many families found Dr. Williamson at Bethesda to be successfully working to this end, with positive results at end of treatment. Balboa and Wounded Warrior Battalion West also cited as being successful at pain med weaning.
12. Stigma related to PTSD still impedes productive reintegration.
13. Families wondered why NICOE is empty.
14. Consensus is that everyone coming back from battlefield has PTSD in some form or another.
15. Problem: Lack of uniformity of care within the VA and Army WTUs - NO Consistency.

### **CAREGIVER BREAKOUT LESSONS LEARNED/DISCUSSION**

1. Four top things Caregivers want and need: education, respite, peer support and financial income supplement.
  - a. Forum & Site for Caregivers - My Care Crew : A Community Approach to Caregiving: Through this easy-to-use, private online community powered by Lotsa Helping Hands, caregivers, friends and family have the ability to list needs that can be fulfilled by approved family, friends and community volunteers. My Care Crew utilizes a virtual calendar to enlist and manage help from family and friends in daily caregiving and support tasks. Read more: <http://www.woundedwarriorproject.org/content/view/479/940/#ixzz17Bz6E2>
  - b. Separate TAPS class just for the caregiver to experience ( away from the service members)

- c. Educational Classes to deal with injuries/understand affects of brain injury and PTSD.
  - d. Respite/Income Supplement – mom shared as single parent, she is trying to hold down a fulltime job to support she and veteran, but he cannot be left alone due to impulsivity of TBI – needs help to monitor him and/or income so she can better care for him, as well as, break time for self.
2. There is concern about effects on the children
- a. Counseling Services limited
  - b. Camp COPE: <http://campcope.org/home.html>
  - c. Operation Purple Camps: <http://www.militaryfamily.org/our-programs/operation-purple/media.html>
  - d. Focus Project: Family Resiliency Training: Come to home and build a resiliency plan. They can telecommunicate via computer ( Skype)
3. Hardest thing to face: Isolation
- a. There's an emotional void on so many levels: intimacy and friendship changes
  - b. Pull away from those who judge.
  - c. You avoid help: You do not want to trouble others when they have troubles.
  - d. Lack of Support Groups: Much judgment from the outside community that does not understand the warrior culture – even experience “War Envy” from spouses of those who did not deploy and are angry at those who have experienced the warzone.
  - e. Family Unit/ Outward Support VITAL for recovery
4. Worry of a mother- Who is going to advocate for my son when I am gone?
- a. Thomas Jerome House: Modified Group home for wounded warriors with severe injuries that need assisted living. It is a community where servicemen with traumatic brain injuries and their assistants, live together as family, respecting the dignity of the human person. Thomas Jerome House is committed to enhancing the quality of their lives by providing them with a sense of purpose and supporting them to maintain an active role in society. <http://www.thomasjeromehouse.org/>

- b. For son severely impaired and unable to communicate for self in nursing home, mom's advocacy meant the difference between him receiving any therapies and specialized treatments and his being allowed to waste away, forgotten and cut off by the VA.

5. Suggestions:

- a. Wounded Warrior Community Basis- Living Quarters to form a community for ones to lean on one another.
- b. Include Wounded Warrior process/possibility as part of Pre-Deployment Briefs. Knowledge is power – family can be prepared with passports and general understanding, plus take comfort in knowing there are people out there to help.

**Message to Caregivers From a Warrior's Perspective**

1. Warriors communicate themselves in different ways – look for subtle signs.
2. Lack of information/details of cause of injury leaves the service member in great frustration as to where they are in life and what route they must take
3. Do not approach warrior as an authoritative or mother/father figure but as a partner/friend figure. Point out difficulties on a peer level. Be open and research and suggest options for your loved one.
4. Listen, do not mimic actions, become mutually aggressive, or take things too personally (by countering instead of “meeting” the loved one).

**SOME SUPPORT AVENUES**

1. National Resource Directory
2. Navy Marine Corps Relief Society: Visiting Nurse Program: Non-invasive, open/caring listeners, go into situation with no agenda and no predisposition.
3. Chance Phelps Foundation: Gold Star Mom-Gretchen Mack hosts up to 16 people/week to stay at Cabin in Wyoming during the summer.
4. NEADS trains and provide dogs, free to veterans, to be an extension of a person's life. They train “Trauma Alert” dogs that can sense seizures and PTSD triggers and will provide comfort to the veteran, a distraction until situation calms.

5. Ed Beesley, Author of *Lucky Enough*, is spokesperson for IBOT. In collaboration with Huey 091 Foundation looking for a veteran to provide, free of charge, an IBOT in the Detroit, Michigan Area.
  6. Several participants touted Compass Course hosted by Veteran Employment Transition Foundation at General Jones' Outdoor Odyssey as an impactful and successful 1 week long course that helps medically retired transition back to work.
  7. In response to request for information at Tampa Meeting of the Minds, a power point brief highlighted several adapted sports and recreation options for those with TBI and PTSD – brief was provided and is available on the SEMPERMAX website.
  8. <http://www.woundedwarriorproject.org/content/view/942/#ixzz17BBOPyZ4> RESTORE: WWP Restore is an online, multi-media tool that offers warriors and caregivers the chance to learn about readjustment challenges. Warriors can take self-assessments and participate in interactive skill-building exercises that provide practical ways to deal with combat stress.
  9. HBOT – Hyperbaric Oxygen Therapy proposed as highly recommended treatment option by participant. Long-term maintenance of therapy was required. Still much unknown – effectiveness dependant upon element present in brain; more successful treatment of acute head injury in first 72 hours cited; further research necessary to gain global acceptance as viable treatment for TBI. Dr. Paul Harsh one proponent, offering treatment. Reported that some families have received support for medically prescribed treatment from Tricare and Injured Marine Semper Fi Fund.
10. Job Opportunities:
- a. veteransgreenjobs.org– Employ OIF/OEF/even some Vietnam Vets
  - b. Wounded Warrior Program thru House of Representatives: Washington Capitol [www.cao.house.hsc.gov](http://www.cao.house.hsc.gov)- Disability Rating of 30% and OIF/OEF (35/50 positions filled) - 2 year fellowship: Opportunity to be hired on as full staff member or be introduced to a new career choice

**Next Meeting of the Minds Conference will be in California in 2011**

**NOTE**

Above is a summary of discussion points and input from participants. Additional research and information will be posted on the SEMPERMAX website as accumulated. Action items for advocacy will be sent forward.