

**Defense Health Board
Traumatic Brain Injury
Family Caregiver Panel Meeting**

Town Hall Meeting

6:07, p.m., June 17, 2008

Hilton Silver Spring
8727 Colesville Road
Silver Spring, MD 20910

OLENDER REPORTING, INC.
1522 K Street, N.W., Suite 720, Washington, D.C. 20005
Washington: (202) 898-1108 / Baltimore: (410) 752-3376
Toll Free: (888) 445-3376

P R O C E E D I N G S

MS. MOESSNER: Please be seated, everybody. I think we are going to go ahead and call the meeting to order.

Welcome to the Town Meeting of the Traumatic Brain Injury Family Caregiver Panel.

Colonel Gibson will please call this meeting to order.

COL GIBSON: I am acting as the Designated Federal Official for this meeting. Ms. Embrey, who is the Designated Federal Official for the Defense Health Board, couldn't be with us tonight. She is in San Antonio, Texas, actually, at another Traumatic Brain Injury meeting, so as the Acting Designated Federal Office for the Defense Health Board, a Federal Advisory Committee, and continuing Scientific Advisory Body to the Secretary of Defense and the Assistant Secretary of Defense for Health Affairs, I hereby call this meeting of TBI or Traumatic Brain Injury Family Caregiver Panel, Defense Health Board Subcommittee to order.

MS. MOESSNER: Thank you, Colonel.

So we are the Traumatic Brain Injury Family

OLENDER REPORTING, INC.
1522 K Street, N.W., Suite 720, Washington, D.C. 20005
Washington: (202) 898-1108 / Baltimore: (410) 752-3376
Toll Free: (888) 445-3376

Caregiver Panel, and as the Colonel mentioned, a subcommittee of the Defense Health Board, which is a Federal Advisory Committee to the Secretary of Defense.

In 2007, Congress directed the Department of Defense to establish this panel and test it to, and I quote, "develop coordinated uniform and consistent training curriculum to be used in training family members in the provision of care and assistance to members and former members of the Armed Forces with traumatic brain injuries."

Congress was also very specific that the panel members be a mix of health care professionals experienced in caring for individuals with traumatic brain injury, representatives of family caregivers or family caregiver associations, DoD and Department of Veterans Affairs medical professionals, experts in the development of training curricula, and family members of Armed Force service members with traumatic brain injury.

The curricula we are charged to develop will be used by health care professionals who treat or otherwise work with members of the Armed Forces and veterans with TBI and by family members of these victims of traumatic

OLENDER REPORTING, INC.
1522 K Street, N.W., Suite 720, Washington, D.C. 20005
Washington: (202) 898-1108 / Baltimore: (410) 752-3376
Toll Free: (888) 445-3376

brain injury.

After we deliver our report to the Secretary, he will tell Congress how it will be used throughout DoD and the VA. Our purpose today is threefold. It is to listen, to listen, and yes, you guessed it, one more time, to listen.

We are here to hear from you. As you can well imagine, a curricula or training program that doesn't take the student into account cannot be as successful as one that does.

We need to hear from you about the problems you face in dealing with the residuals, the results of traumatic brain injury, how it impacts you and your family, what is working, and what isn't.

Your thoughts and comments will help us to do a better job in meeting your needs, so please be a part of tonight's session. For those who wish to speak during the town hall session, we invite you, and you likely already signed up at the registration desk, to give everyone a chance to speak, statements are limited to five minutes, and you will be asked to come to the microphone at the front of the room facing the panel to deliver your

OLENDER REPORTING, INC.
1522 K Street, N.W., Suite 720, Washington, D.C. 20005
Washington: (202) 898-1108 / Baltimore: (410) 752-3376
Toll Free: (888) 445-3376

comments this evening.

You all should have picked up a handout at the table. I would like to make a quick correction to the information that is in the handout, and that is contact information for those who want to submit comments a little later after tonight, and also for those of you who are listening in by webcast.

The session is being webcast for those who couldn't attend the meeting in person. The panel will not be able to respond or take questions during the webcast interactively for those not physically present here today, but everyone does have the opportunity to submit statements to the panel by one of the following ways, and again, for those of you here today, the updated information to submit comments after tonight would be:

You may contact the 1-800 number for the panel and that is 1-800-870-9244. That number will be in action during business hours. If you call after hours, simply leave a message and your call will be returned.

Again, that number is 1-800-870-9244.

You may also e-mail Maraquita Hollman, who is the project coordinator for the panel, and her e-mail is

OLENDER REPORTING, INC.
1522 K Street, N.W., Suite 720, Washington, D.C. 20005
Washington: (202) 898-1108 / Baltimore: (410) 752-3376
Toll Free: (888) 445-3376

all lower case letters starting with m and then
hollman@dvbic.org. Once again: mhollman@dvbic.org.

The last means for making contact with the panel is via mail, so you may address comments in writing to the TBI Family Caregiver Panel. The address is 8484 Georgia Avenue, Suite 950, and that will be Silver Spring, Maryland 20910. One more time: it's 8484 Georgia Avenue, Suite 950, Silver Spring, and 20910.

Now, carrying on the tradition of our boards, I ask that we stand for one minute of silence to honor those we are here to serve, the men and women who serve our country. Please join me.

[Moment of silence]

MS. MOESSNER: Thank you. Please be seated.

Before we introduce the facilitator for tonight's town hall meeting, we would like to introduce ourselves as panel members of the Board, and we will be doing that one by one. I will start.

My name is Anne Moessner and I work at the Mayo Clinic in Minnesota as the Traumatic Brain Injury Clinical Nurse Specialist and I also do research half-time with the Traumatic Brain Injury Model System program.

OLENDER REPORTING, INC.
1522 K Street, N.W., Suite 720, Washington, D.C. 20005
Washington: (202) 898-1108 / Baltimore: (410) 752-3376
Toll Free: (888) 445-3376

Will the Board members also introduce themselves one at a time starting on my left.

[Pause.]

MS. MOESSNER: I am sorry, apparently we need to use the microphone for those introductions, so that webcast participants can hear your name. Thank you.

CDR MILLER: -- Warrior Regiment out of Quantico, Virginia, and the Bureau of Medicine and Surgery, and I take care of the wounded, injured, and ill, and Marine Reservists returning from the War.

DR. FLYNN: Good evening. I am Dr. Fred Flynn. I am a behavioral neurologist and I am presently the Medical Director of the Traumatic Brain Injury program at Madigan Army Medical Center in Fort Lewis, Washington.

MAJ VOGT: Hi. I am Major Megumi Vogt and I am a neurologist out at Andrews Air Force Base.

MS. ROCCHIO: I am Carolyn Rocchio from Florida. I am a parent of two children with brain injuries and the founder of the Brain Injury Association of Florida.

DR. CHURCH: Hello. I am Cheryl Lee Church. I am the independent living coordinator in the Vocational Rehabilitation and Employment program in VBA.

OLENDER REPORTING, INC.
1522 K Street, N.W., Suite 720, Washington, D.C. 20005
Washington: (202) 898-1108 / Baltimore: (410) 752-3376
Toll Free: (888) 445-3376

CAPT HEPPEL: I am Captain Janie Martin Heppel and I am the Director of the Federal Traumatic Brain Injury program, which is located in the Health Resources and Services Administration.

MR. WELSH: Hello. I am Mike Welsh. I am a retired Sergeant Major from the Army, and I had a TBI injury from Afghanistan. I was treated at Walter Reed and also here at the Washington VA Hospital. Now, I work for the Joint IED Organization.

DR. BENEDICT: I am Dr. Sharon Benedict. I am from the Department of Veterans Affairs. I am a rehabilitation psychologist at the Polytrauma Rehab Center in Richmond, Virginia.

DR. LANGLOIS: I am Dr. Jean Langlois. I am a researcher in traumatic brain injury at the Centers for Disease Control and Prevention in Atlantic, and I am a member of the TBI Advisory Subcommittee of the Defense Health Board and will be following up on the work of the Caregiver Panel after they stand down.

MR. DODSON: I am Jon Dodson and I am a retired Army officer. I am a severe penetrating TBI survivor from Vietnam. I went through the system when it wasn't a

OLENDER REPORTING, INC.
1522 K Street, N.W., Suite 720, Washington, D.C. 20005
Washington: (202) 898-1108 / Baltimore: (410) 752-3376
Toll Free: (888) 445-3376

system, so I am here. I work now as a volunteer with the Walter Reed Army Medical Center Wounded Warrior Mentor program, mentoring SPTBI patients, helping them

Thank you.

MS. COLLINS: Good evening. I am Patricia Collins from the Office of the Chief Medical Officer at Tri-Care Management Activity, and that office oversees clinical quality, population health, behavioral medicine, and patient safety. I want to thank you for coming.

DR. PRIES: Hello. I am Dr. Rose Mary Pries. I head the Department of Veterans Affairs, Office of Veterans Health Education and Information. Thanks for joining us.

MS. SARMIENTO: I am Kelly Sarmiento, Health Communication Specialist at the Centers for Disease Control and Prevention, CDC Division of Injury Response.

REV. CERTAIN: I am Robert Certain. I am an Episcopal priest. I started life as a Vietnam veteran, an ex-prisoner of war, and I do networking with faith communities and mental health care providers in North Georgia. I serve on the full board, but not on this panel.

OLENDER REPORTING, INC.
1522 K Street, N.W., Suite 720, Washington, D.C. 20005
Washington: (202) 898-1108 / Baltimore: (410) 752-3376
Toll Free: (888) 445-3376

MS. STEPHENS: Good evening. I am Gretchen Stephens and I work for the VA in the National Physical Medicine and Rehabilitation Services program office. Welcome.

MS. KEBE: Good evening, everyone. I am Melody Kebe, National President of the Society of Government Meeting Professionals, and I was called to help at the last minute, so I am here to help you.

I know each of you have had a long day and Anne tells me we have until 8 o'clock to meet, so I think if we can get through your questions quickly, so the panel members can answer your questions, we will be out of here at 8 o'clock. Agree? All right.

Who is the first one who would like to pose a question for the panel? Not all at once.

You would. Please step to the mike.

MS. WILEY: Hi. My name is Therese Wiley. I am a survivor of a traumatic brain injury from 1985. I survived a massive cerebral brain hemorrhage, two-month coma, learned everything you have learned in life twice, and why I wanted to address this panel is I am also currently a policy analyst for the Department of Health

and Human Services Office on Disability and here is my boss.

What I want to makes sure you guys take into consideration is my previous job, I was at the Department of Agriculture as the Disability Employment Program Manager, so between that function and surviving a TBI, I think one of the number one things that is neglected in survivors is getting people back to work, and don't get people get back to work in mail rooms.

I know it's the number one high demand job for people who survive a TBI. There is nothing wrong with that job, the majority of my friends have that job. I love them, every one of these hard-working, dedicated employees.

They go to work 40-hour weeks, they have pride in their jobs. All right. But the mind can learn so much more and when you are pigeonholed into one type job, that's a shame.

I just think it's something that, you know, I had to learn, I will freely admit to everybody everything, walking, talking, swallowing, reading, everything, but I have since having my TBI, I got a Master's in IT from

George Washington University. I have a 20-year Federal job that I have completed successfully.

There is hope for all of these people. Don't pigeonhole them. So, I just hope in your plans, you have high goals for putting education on your work plans.

Thank you. No questions, just a comment.

[Applause.]

MS. KEBE: So, meaningful jobs. Next question or input to help them build a curriculum for you? Anyone? Anyone on Webcast who would like to pose a question? Yes, please, step up. Would you like to read that? Okay.

Being a caregiver to both our oldest daughter, my husband, and other children is totally exhausting. I am afraid my health will fail me. Sometimes I have such chest pains and pains in my back between my shoulder blade that I feel like there is a knife in my back.

I am sure I have depression issues now. I do not know how to laugh and rarely laugh. I feel like everything is work. Even fun is too much work. I don't even remember what I used to do for fun. I have little interest in most things as it all feels like work.

I live on very little sleep. I live on very

little sleep each night as I stay up late to work when Hugh is asleep and get up early before the kids are up. Almost all house care is left to me and I mean repair, yard work, cooking, cleaning, plumbing issues, electrical issues, peacekeeper, et cetera.

I mow the lawns, spray for weeds, and spiders, whack weeds, plant and weed the garden, change light fixtures that are bad, make updates on our house, all paperwork. There is just not enough time for me.

Thank you to the individual that provided comments, but we need some real input here for them to help build a curriculum. What are your needs? Anyone? Yes. We do have a webcast question for the panel.

The question to the panel: How do you plan to incorporate full support to family members while you are training them to care for their loved one?

Is there anyone who could address that quickly?

We are on our second meeting today. We met in January for the first time, and met again today as a panel, and that particular issue is being discussed and was discussed today and we will be taking tonight's feedback and incorporating it into our discussions

OLENDER REPORTING, INC.
1522 K Street, N.W., Suite 720, Washington, D.C. 20005
Washington: (202) 898-1108 / Baltimore: (410) 752-3376
Toll Free: (888) 445-3376

tomorrow, but I will let you know that in the various subgroups that broke up and met today, the logistics of conducting family training is something we are mindful of, you know, multi-media approaches to doing the training, but also the logistics of providing the training, how does that look, and I think that is an extra point that we will consider in more depth tomorrow is while you are experiencing training and at training sessions and programs, you know, what is happening to the person you are to be caring for.

Other comments from the panel?

MR. DODSON: In our sessions, we are very sensitive to caring for the caregiver. The one webcast talked about being exhausted and burned out. That is a very serious issue, because if you burn out the caregiver, then, you lose everything.

The people that I am working with at Walter Reed are severe TBI people. We are starting to see some burnout with the caregivers and we have instituted practices where we can get them help to work with themselves and to take care of their husband or wife.

Thank you.

OLENDER REPORTING, INC.
1522 K Street, N.W., Suite 720, Washington, D.C. 20005
Washington: (202) 898-1108 / Baltimore: (410) 752-3376
Toll Free: (888) 445-3376

MS. KEBE: Are there any more comments from the panel? From the audience? Please.

AUDIENCE: Hi. I would like to know if the education curriculum is going to include ways to train the family members, not only on how to care for their service member, but also how to access sources and resources that are there to care for themselves, to access things like respite care or non-profit organization care.

There is a world of resources out there, but it is hard to get to it, the curriculum includes some of that.

Thank you.

MS. MOESSNER: Actually, one of our subgroups today particularly dealt with the needs of the caregivers along that line. Perhaps one member from that subgroup would be willing to field this question.

Right. Caregivers access to resources, so the subgroup specifically talked about the caregiver, the needs of the caregiver, and access to services and resources.

MS. FRIEL: Hello. My name is Veronica Friel. I am on the staff of the Agency for Healthcare Research

and Quality, which is an agency within the Department of Health and Human Services, and I just happened to have something. It's an announcement that was distributed today throughout HHS about a satellite broadcast that is being held on Wednesday, June 25th. I made 50 copies of this.

It is a satellite broadcast. It will be from 1:00 to 2:30 p.m. Eastern Time, and it's about the health implications of caregiving, and it is sponsored by the Centers for Medicare and Medicaid Services and the National Alliance for Caregiving.

If you check the website, there are all kinds of -- I have samples with me -- of information about websites, Federal Government agencies, and specifically, directed towards caregivers, because being a caregiver means that there is a lot that is coming out of you, and please get one of these, and as I said, I have samples of the other materials that are available.

MS. MOESSNER: Thank you kindly for that resource.

Again, to go back to addressing the question about caregiver access to resources, that there are a lot

OLENDER REPORTING, INC.
1522 K Street, N.W., Suite 720, Washington, D.C. 20005
Washington: (202) 898-1108 / Baltimore: (410) 752-3376
Toll Free: (888) 445-3376

of existing resources, but how do you keep track of that and navigate the system, and what do we have planned for that?

DR. BENEDICT: Some of the discussion that happened today was particularly about caregiver issues specifically. There are certain things that the group is looking at, in particular, wellness and self-care, and we believe that in order for you to be an effective caregiver, you have to be able to take care of yourself.

So, I think the intention is throughout this whole product that we are going to be putting together, there will be access to all kinds of resources, websites, and information sources that will help caregivers, but we are particularly interested in doing a specific section on wellness and self-care.

As a subpart of that, being able to somehow manage the information flow that you are getting, which tends to be overwhelming and all at once.

So, yes, that is a definite goal of at least this subcommittee.

MS. MOESSNER: And I will add that all the groups that met today without discussion amongst each

other really came up with the issue of self-advocacy, advocacy for your loved one, and learning communication skills as you are trying to navigate the system, so that will be incorporated into the curriculum in several ways.

MS. KEBE: I was instructed that if you have a question, please, you have to use the mike. I am sure many of you have a reason for being here this evening, and you want your message to be heard, so are there any other questions for the panel this evening?

Yes, please.

MS. KANT: I am Susanne Kant. I am the Assistant Director of the Brain Injury Association of Maryland, and I am glad that Ms. Rocchio is here to emphasize the fact that there is an existing network of resources available to make sure that people are made aware of the fact that there are brain injury associations. We have many of these resources. We have information for caregivers. We have information for survivors.

I understand that there are specifics to this population, but I don't know that everything needs to be rebuilt from scratch because there are many pieces out

there already.

Thank you.

MS. KEBE: Thank you.

How many of you are using the resources available to you? Does it work, those resources are available, readily available? Please.

MS. WILEY: My mind is whirling as you are coming up with these topics, because like any situation in life, you have to know what time of the recovery process you need what and the Brain Injury Association is an excellent resource.

However, as the last woman was speaking, I really respect and rely on the Brain Injury Association, all of the support groups, but there was a time when my family was ready, but I wasn't, and now I am ready, and they are not. You know, things change, and so you need to -- you can't have a set plan for everybody. Every family is different, needs are different, and just give one personal anecdote, my mother to this day who was my caregiver full time for a decade, more so, maybe 15 years after I recovered, cannot talk about brain injury today to anybody. She weeps, you know, and so I am just saying

OLENDER REPORTING, INC.

1522 K Street, N.W., Suite 720, Washington, D.C. 20005
Washington: (202) 898-1108 / Baltimore: (410) 752-3376
Toll Free: (888) 445-3376

there is a readiness level, that's what I am trying to get across. You have to have a readiness level. The person who has the need, has to know when they need something, but you all, as planners, have to be cognizant that, you know, people are human, so just keep that in mind is what I am trying to say.

MS. KEBE: Thank you. Now, certainly before you can be ready, one needs to be educated, right? Do you think you have been educated in terms of the resources available, what it all takes? This panel needs your input to help build that curriculum, the caregiver curriculum.

MS. FOREST: I would like to go backwards. I am Anne Forest, a survivor of mild brain injury. I just finished my 11th anniversary -- or my 11th anniversary was this weekend. I am still making progress.

Just a couple of things. One of the things with a mild injury, the whole concept of caregiving is very strange, because I didn't have a caregiver, and I always wonder how that works, where -- I know that I looked at a lot of information and said, wait a second, I don't have a caregiver, and so information that was targeted to caregivers I didn't know how to understand that

information given that I was my caregiver.

You asked that question earlier about information resources and I find that a lot of the literature about brain injury is often severe brain injury, means severe brain injury, and for people with mild injury, you need very targeted information.

We have a difficult time -- many of us have a difficult time with information processing, so we need very specific information that is addressed to a mild caregiver or a mild brain injury, and a lot of the terminology in brain injury doesn't apply to mild.

I wasn't hospitalized acutely, and so there was no post-hospitalization period. Community re-entry, I never left the community. I know earlier on, I would look at these words, I wasn't processing the information very well, and I said this information just doesn't apply to me.

Later on, as I processed information better, I can see okay, the title is wrong, but there is useful stuff in here, so I guess the point that I want to say is just I think different information has to be developed for people with mild injury taking into account that they need

care, and yet they are in a different situation and often don't have caregivers, some people do, and I hope that that will be addressed, and I didn't come prepared.

MS. KEBE: Thank you.

Are there any TBI caregivers in the audience? Yes, sir. I knew there was something about you. Could you please share with us the most critical need of a caregiver?

DR. SITAR: Well, I think I am in a unique situation. I am a psychologist and I do neurobiofeedback, otherwise known as EEG biofeedback or neurofeedback. Is anybody aware of it? Can I see a show of hands? Okay, good. Anybody else out here? I thought I saw two familiar faces.

Anyway, I was trying to figure out -- a friend told me about this meeting, and I thought I would come and network. Then, I realized it is for the families, and then I had to sort of figure out where I fit in, but I guess encouraging you to go on line, read about it, and see where it might fit into your treatment plans.

I guess I will say it. If your program and you are offering care for people with head injuries, and you

are not offering neurofeedback, I think you are offering substandard care.

The original research that got me into the field was done by a psychologist at a VA hospital in Southern Colorado. His was to get reassigned to a desk job for his brilliant work. There is research done at a VA hospital in Florida that has been going on for years on brain mapping EEG for closed head injury, and there is a database, but it just isn't getting disseminated.

I know there is funding coming down the pike, I was at the NARSAT [ph] meeting and we are hopeful that some things will happen from there. The word is getting out. It has been for me a 20-year kind of slow, painful watching the word get out and the funding not come time after time.

So, find out about it, advocate for it, it is not the be all-end all, but it can be an important contribution to recovery.

MS. KEBE: Thank you. Would you like to answer that?

DR. FLYNN: Actually, I don't have an answer per se. I came to listen and to learn from you, but I wanted

to know who are your most responsive patients, and do you feel that they fall into a category of severity of brain injury. In other words, are milds more likely to respond to neurobiofeedback or is it that moderate to severes can also benefit?

DR. SITAR: Most of the literature talks about closed head injury or mild traumatic brain injury, but I think it is wide open as to who you can help and how much. Some of the earliest work -- and it goes back to the '70s and '80s -- was on seizure disorders and certainly people can come out of a head injury with an ongoing seizure problem.

I think the research needs to be done. People have been brought out of comas with it, but it is not kind of patentable process and you can't -- we need more research and we need more people aware of it.

There are a couple of organizations that have links to various psychologists, social workers, therapists around the country that do this work, and that have volunteered to treat veterans, so getting the word out on that, and I can supply some information later.

MS. KEBE: Okay. The question I have for you is

as a caregiver, it often takes its toll on you, burnout. How do you recognize it?

DR. SITAR: For me, the burnout isn't so much dealing with the patients, it is dealing with the system, the insurance companies don't cover it. I would not want to fight CHAMPUS to get coverage or whatever it is called these days.

On the other hand they are constantly keeping up with the literature and going over the listservs each night, and keeping up with the research and deciding what equipment to buy next. At least at this point I am not married and I don't have a spouse who is complaining about me spending more money on more equipment each year and more databases, and things like that.

MS. KEBE: Do you know of any other caregivers who may go through the same experience?

DR. SITAR: Yes, I know caregivers, well, again, the frustration is you put together a research proposal and it gets turned down in favor of yoga, and then you don't get results from that study, and you go okay, you missed that boat, but you put another research proposal in and hope to get some funding and do some more research.

So, there is specialized issues I am talking about here, because it's a relatively new science and it hasn't been as widely embraced as we would like it to be.

MS. KEBE: Thank you.

Are there any others?

From what you have heard so far, any comments.

Yes.

MS. MUNOZ: I am not a caregiver, but I do work for a foundation who is trying to look at family caregivers and the family support that is offered to these wives, husbands, mothers, who are taking care of their severely wounded.

One of the things that we keep hearing is it is so hard for them to navigate the benefit system as they are trying to get the benefits for their service member. Maybe some of the training could incorporate how they can do that. I don't advocate that they should have to become experts in the benefits administration system, but it seems like they have to.

The benefits are wonderful if you can access them. So, will some of the training address that, how to help the families, how to make it easier for them to

access those benefits, because right now some of them are so worn out with just the caregiving, they don't have it in them to fight the system, and what is being done to make that an easier navigation.

COL GIBSON: That is a very, very good question. It is something that this panel talked about earlier today. As a matter of fact, they are going to get a briefing from the Walter Reed Warrior Transition folks who have that type of support for wounded warriors as they come back.

This is not new for just this group. As you remember back to last February at Walter Reed, this was an ongoing problem at that time. There has been a lot of work done to improve that process, but we are still a long ways from it being seamless and ensuring that every family member of every service member who comes with a wound, with a medical problem, understands and knows how to, and gets the help to engage with the system.

So, yes, it will be part of it. I don't think that is going to be enough. I think that we need more and we need to ensure that every wounded veteran, soldier, has somebody on his side as that whole process starts.

I had one other follow-up. Would you like to comment before I ask a question?

MR. DODSON: The issue is not are there benefits out there, the issue is how do you tell the 18-year-old spouse of a seriously wounded TBI patient how to get to them. In our group here, we are looking at how can you make a resource accessibility easy for those people to grab it and read it in what I call English, and not either military jargon or DA jargon or whatever.

A lot of the leverage is on some of the service organizations, the DAV, the VFW, the American Legion, those organizations are fantastic in what they are doing, but to get the young wife or the husband to that resource is a challenge, and so we need to figure out -- and we are addressing -- how to make that very easy, make it user friendly.

COL GIBSON: I had a follow-up. Ma'am, you were talking about mild traumatic brain injury. This is something that the group talked about a little bit today, but, you know, we tend to think about traumatic brain injury as sort of a spectrum from mild to moderate, severe, and that the intervention, if you will, is more or

less intense, but it's the same intervention over the spectrum.

My question to you is do you think that is the right model, or should we be talking about developing curricula, developing approaches for caregivers unique to each of our basic categories of TBI, or is it the spectrum that we really need to be working on, it's the same model just more intense or less?

MS. FOREST: I would like to think about that question, but, you know, a lot of people with mild injury are fine in three months, six months, and it seems to me that a lot of the civilian literature is based on for the people who get better in three to six months, and it seems to me it's the people that don't, the 20 percent or the 30 percent actually believe from living in the community and learning that I don't believe the number, that 80 percent are getting well.

I mean I think the literature says one thing and in reality you see that there are a lot of people with lingering symptoms from mild injury that have either fallen out of the system and are not getting care, or have been treated a little bit and are not getting care.

It seems to me if we are trying to get people well or back to work, that the literature needs to be targeted to what happens if you don't recover from mild injury and what are you looking for. If you are failing, that should tell you. You shouldn't have to fail for years in order for people to be helping you.

So, I do think that literature targeted specifically for the group of people that don't get better from mild injury is necessary. In terms of a continuum, isn't it an open question whether it's a continuum or not?

COL GIBSON: I just wanted your opinion.

MS. FOREST: Let me think about that, but I know that the name just really creates a lot of problems from the inside of a mild injury you think, well, this is mild, so tomorrow I will be well, tomorrow I am going to be able to do all these things I couldn't do.

I think I went for four years, maybe six, thinking that tomorrow I was going to wake up fine and without a lot of support and finding out what is a mild injury, you know, I self-limited services that were also being limited by my caregivers or the medical system that wasn't seeing my injury as major.

So, I think that you start out with this bias of mild injury, and then when there is not information talking about what happens when you don't get well, you begin to believe that the system doesn't really want you well, which is not where we want people, especially people who serve our country, we want them to be as best as they can be. So, that's my partial answer. I will think about your question.

MS. MOESSNER: Thank you very much. We did talk about the mild injury again this morning. I work in the civilian sector, and you are right, this is an issue that has been discussed for some number of years.

I think we were toying this morning with the idea of making sure in any introductory curriculum that we put together that this all is discussed, that there is severity of initial injury, which is a lot of medical indicators that are looked at and examined and documented, but it is really the residuals, again in my experience and in some other panel members, it is the residuals that you are facing and coping with, and the ongoing recovery process which again for most people can take years and be life long that we seem to -- that's where we wanted to put

a lot of attention is on what are the leftover changes in you and what are the practical suggestions we can come up with to tackle those aside from the initial injury severity information.

So, again, you know, if anyone has more feedback for us on the best approach to take, again, we were sort of toying with separate modules looking at cognitive effects, physical effects, you know, system issues, that sort of thing, but also addressing these more complicated issues and introductory materials.

MR. MOOTSIALEIS: Hello and thank you for letting me speak. I will say who I am in a moment. For now I just want to say I am going to talk about an issue that is dear to me, having had a head injury myself as several others.

It is unfortunately the disincentive to work. It is very powerful, because what we have right now in the care system is a, for lack of a better word, it is important that work that gives you just enough to keep you alive, not enough to do anything substantial, and what the disincentive is, the knowledge that if I go back to work, or when I go back to work, they will stop giving money,

OLENDER REPORTING, INC.
1522 K Street, N.W., Suite 720, Washington, D.C. 20005
Washington: (202) 898-1108 / Baltimore: (410) 752-3376
Toll Free: (888) 445-3376

and then [inaudible].

In 2000, I had a head injury in 1991. I was in my third year of medical school. I was in a bicycle accident and in a coma for two months and in rehab for 11 inpatient, two years outpatient.

I got back to school. I still have a problem with my speech. It sounds rather nasal and is very hard for me to remember to breathe, but I got back. I got my M.D. and my internship in medicine. I started my residency, so I told them at the VA, not the VA, at the Security I am okay now, you can stop paying me, I really didn't need this money, I am fine.

[Inaudible], by the way, you owe us \$27,000 [inaudible], just finished med school, student loans, that was a lot of money and to pay back, it seemed a little hard, but I am paying them off, got unemployed for a year, back on Social Security, then, I got my residency at the University of Buffalo. It is now 2006, so 2007 came around, and they started paying me again.

They told me I had one year [inaudible], hey, stop paying me. By the way, I owe them now \$30,000. This can be very frustrating, so my suggestion might be beside

OLENDER REPORTING, INC.
1522 K Street, N.W., Suite 720, Washington, D.C. 20005
Washington: (202) 898-1108 / Baltimore: (410) 752-3376
Toll Free: (888) 445-3376

the fact that I am now a physician a little under two months of getting my residency training in preventive medicine, I would like to know what can be done to make Social Security (a) more user friendly, (b) more I will say in a type of situation again, a little more magnanimous than simply saying, oh, by the way, ha-ha-ha, you owe us \$30,000. I would like to see what can be done to try to remove the disincentives to work by allowing a little bit of bridge money to cover the transition phase from disabled to being able.

Thank you.

MS. KEBE: Thank you.

MS. MOESSNER: Thank you very much for your comments.

MS. KEBE: Speaking of training, some of the caregivers are saying that the training process needs to be a "train as you go," that offers a road map towards recovery, and some feel that their suggestions are not being heard, so they are reaching out again saying they need that training manual, if you will, to help them to get through the processes.

Now, I do have another question for the panel,

OLENDER REPORTING, INC.
1522 K Street, N.W., Suite 720, Washington, D.C. 20005
Washington: (202) 898-1108 / Baltimore: (410) 752-3376
Toll Free: (888) 445-3376

but you have to listen to the introduction to the question.

There has been a great deal of focus placed on the screening and diagnosing of TBI over the last couple of years, however, it seems as though the treatment of TBI, i.e., cognitive therapy, SLPs, OTs, and education for both the individual and the family support system regarding compensation and living with TBI is lacking.

The services available to service members vary by location at MTFs and military installations, so the question is what is being done to ensure that all service treatment and education regardless of their location.

Would anyone like to address that? I guess that's you.

COL GIBSON: I guess that's me. I guess I am speaking for DoD tonight, so a very good point, the standardization, state of the art of ensuring that we communicate advancements in delivery of care is an important issue.

There is a gal by the name of Lori Sutton that is the Director of the Department's Psychological Health and Traumatic Brain Injury Center of Excellence.

OLENDER REPORTING, INC.
1522 K Street, N.W., Suite 720, Washington, D.C. 20005
Washington: (202) 898-1108 / Baltimore: (410) 752-3376
Toll Free: (888) 445-3376

Part of her job and part of her staff's job is to do exactly what was mentioned here, ensure that we are providing proper training across the entire system, ensure that we capture those best practices as they occur, and communicate those best practices across the spectrum of care, and in addition, validate through research these approaches to ensure that they are effective.

As you know, in medicine, et cetera, we talk about things being anecdotally -- they work well for this provider, they work well in this situation, may not work that way across the spectrum.

To do the research, to ensure that we are headed in the right direction, and making advancements is a big part of our job. She is at that meeting in San Antonio this week that I mentioned earlier today, and working specifically on strategic plans for that entire portfolio of work.

Does that answer the question?

MS. KEBE: Okay. You have heard the comments from the panel members this evening, and you have heard from a caregiver. Are there any more questions? Please.

MS. ELMORE: Thank you. I am Diane Elmore with

the American Psychological Association, and many of our members provide care for individuals with TBI and their caregivers, both in DoD and VA, as well as in the community, and we commend you for your efforts. We think this is a very important task that you are undertaking.

We look forward to working with you all on this. I am wondering if you can tell us, it sounds like the physical and mental health issues related to caregiving are being handled in some of the subgroups, and I am wondering if you can tell us a little bit more about the subgroups and what their specific efforts are.

MS. MOESSNER: Well, today, again, as we are developing the curriculum, you know, there are a lot of curricula that exist in various areas around the country through various service providers, so we are looking to again access information that already exists, but today, we broke into subgroups to talk about one group looked specifically at possible potential common effects of traumatic brain injury in the various domains, physical, cognitive, neurobehavioral, emotional, and then just the life-long, longer term components of recovery that people may face.

So, one group specifically is looking to take the lead on module development, looking at existing materials, and tweaking it for this particular population and for the needs and to meet the goals of the panel.

The other two groups -- I happened to be in the effect group -- so help me out, those of you in the other groups. One of them again was looking at needs of the caregiver across the spectrum, system navigation, personal health needs, and we have talked a little about that today.

The third group - somebody might remind me -- the systems, right, and so the third group was looking specifically at systems of care, you know, funding issues, access issues, education, because we know that is an enormous burden for caregivers, again, learning the system, navigating the system, learning how to become advocates.

So, those were sort of the umbrella areas that the subgroups were looking at, tackling, and please let us know if there are gaps, you know, as the meeting continues on, in those broad categories, again, documents and pages of information were developed by each group today, and we

will be spending considerable time tomorrow reviewing the comments from tonight and just reviewing the brainstorming that was done for a couple of hours today in those various groups.

I will tell you based on some earlier questions and comments that have been made at the meeting, that we are being mindful and the following things did come up across the board today in several discussions.

We are looking to develop a curriculum that is flexible, that does consider different levels of difficulty in terms of cognitive ability or issues, emotional adjustment, you know, what have you, that really we are trying to think in terms of a flexible curriculum.

If you want a little information on a topic, that that is readily available, but if you want more in-depth information, that, too, would be available, that perhaps there would be some introductory material that would be beneficial for anybody accessing the curriculum, to go ahead and take a look at.

But then after that, there is a lot of free choice in navigating the system, so when you are ready to learn more about a particular topic, that you can go into

OLENDER REPORTING, INC.
1522 K Street, N.W., Suite 720, Washington, D.C. 20005
Washington: (202) 898-1108 / Baltimore: (410) 752-3376
Toll Free: (888) 445-3376

that section and maybe some areas you won't access for some number of months or years, but that's okay.

You know, it really is designed to be flexible, and that it is designed to consider all aspects of the continuum of care, so from acute care onset of injury, all of those early medical issues, those early rehabilitation issues, but also extending out into months and years post-injury, again more of the long-term, community re-entry, returning to life, whatever you want to call those sorts of issues.

So, all of those were definitely discussed today. There was other discussion about needs assessment, readiness to learn, so be assured that those issues were brought up as well. If you have ideas for the panel on how to conduct a needs assessment and looking at identifying readiness for information, please do let us know, because those are difficult and challenging situations to try to determine an efficient way to detect readiness to learn, who does that, and so on.

So, please, again, we will be happy to take extra information and guidance on those particular areas.

MS. KEBE: So, of the subgroups that you heard

Anne mention, are there any that have special interest to you, that you would like to address to the panel?

Okay. I think they have got a lot of work to do. Yes, please.

MS. MUNOZ: I just have one more question. I am assuming that the part of the curriculum that will be helping the caregiver know how to literally and physically be able to provide care to that injured service member, will there be some type of assessment of how well they learned that, like a certification, and will that certification be able to put them at a level where the VA could actually compensate them for the caregiving activities that they undertake for their family.

Right now there is aide and attendants available through the VA. Could these family caregivers be positioned to receive compensation for that via this training that you are doing? Thank you.

MS. KEBE: I would also ask the panel if they can share some of the criteria.

MS. MOESSNER: I will tell you that again this is a little out of my league, so I will just address that competencies and demonstrating that the material is

grasped in some manner, or learned, was discussed.

There was a little discussion about the definition, for example, of family caregiver that we looked at and developed today about paid versus unpaid, and so those discussions did come up.

I will defer the rest of the answer to somebody who maybe works in the VA system that could maybe speak more than I can about the possibility of training people to actually be paid caregivers.

MS. STEPHENS: Thank you. We are looking at that. There hasn't been resolution and they may require additional legislation in order to allow us to do that, but it is on the table in terms of the paid caregiver.

MS. MUNOZ: But it's not part of this?

MS. STEPHENS: No.

MS. LEE: Hi. I am Elizabeth. I am actually with Senator Clinton. I have a question, but first, Senator Clinton actually has legislation, it is called, the Caring for Wounded Warriors Act, suggesting exactly what you just said.

It is S.23-971, and I can leave material about it outside, but it is a great idea and thank you for

bringing it up.

Also, Senator Clinton sends her regards and her encouragement, and keep up all the great work. I have two questions for you guys.

First of all, what is your timeline in terms of development and when can we expect to see your report? Second of all, what kind of providers do you think we will be working with? Is this more in a social work setting, in a primary care provider, and who will be sort of interfacing most with the caregivers?

MS. MOESSNER: I don't know if any panel members have a copy of the timeline that was discussed with them.

I did not bring one. I can tell you that there was a preliminary timeline put together by Maraquita and her staff, and the panel's immediately response was can we try to be a little bit more aggressive and move some of those timeline dates up.

So, it looks like by -- I am reminding myself here -- the first draft of the curriculum, we would like to have in place by mid-July, the second draft in August.

Initially, the idea was that the panel would have a month between drafts to mull over the information,

OLENDER REPORTING, INC.
1522 K Street, N.W., Suite 720, Washington, D.C. 20005
Washington: (202) 898-1108 / Baltimore: (410) 752-3376
Toll Free: (888) 445-3376

offer feedback. Everybody in the room agreed we would like to reduce that to two weeks between drafts in order to be more ambitious and to move the process along with the understanding there are people who need this information now, and we need to ramp it up a little bit.

So, everyone agreed to two weeks in between. By the end of the year, it looks like the curriculum, probably the first week in December I think if that's right, Colonel Gibson, presentation of the curriculum to the Defense Health Board is the goal at this point in time, and then a distribution plan and some piloting to take place after that.

I believe the non-negotiable date in the timeline is that the report is to be submitted to Congress by August 1st of 2009, but it looks like a curriculum should be in place and in pilot testing by the end of the year and early into 2009.

MS. ROCCHIO: Should the VA approve funding for family caregivers, there is currently in the works, under the aegis of the Brain Injury Association of America, the American Academy of Certification of Brain Injury Specialists, that currently now do certify those people

working at a skills level with people with brain injury that are not subject to licensure.

They are, at this time, preparing a family component that would address that need. So, if somebody will pay for those caregivers, there is a way that they could be certified by meeting certain training criteria and testing.

COL GIBSON: I just wanted to add that -- and I am sure you all know this and understand it -- but a curricula is a living thing, it evolves, it is never done, and I hope this one is never done.

We hope to be able to learn by using this curricula within the Department of Defense, and continue to tweak it, make it better, find out, do the assessments, ask the patients, ask the family members, do the science to make sure that it continues and continues and continues, and it isn't just something that we did it and we put it on the shelf, and now we are deploying it regardless of whether it is effective or not.

So, it is an iterative product.

MS. MOESSNER: We have a question that I have had in front of me for just a few minutes. Let me bring

this one up. The question is: I find it very interesting that you have a panel full of professionals without the benefit of any family caregivers. Why is that you have not brought together a full think tank of numerous family caregivers that may offer some of the real life situations?

We were directed by Congress to specifically have certain representatives on the Committee, and the list that I read earlier, again as just a quick reminder, included health care professionals experienced in caring for and assisting individuals with traumatic brain injury, representatives of family caregivers or family caregiver associations, DoD and VA professionals, experts in the development of training curricula, and then family members of service members with traumatic brain injury.

We do have -- the full panel is not represented here today -- have one individual who has been in a caregiving role that is here today and been active in all panel discussions.

We have two additional in my recollection that are indeed an active member of the panel. They were unable to be here this evening and to be at this meeting.

So, I think in terms of percentages and representation, there are at least three, and I might be missing somebody that are part of the panel.

Further, there will be focus groups conducted with family caregivers, and we spoke at length about that during the meeting this morning, about how those might look, and should we have family members that we are working with to give us feedback on draft forms of the curriculum who currently have their loved ones in acute care or in patient rehabilitation, or should we go for families, you know, specifically focus on families whose loved ones were injured some time ago and who are through more that early crisis stage, and they may be able to give us feedback that would be useful.

So, if you have any input for us on that situation, we were sort of leaning towards people who had been injured maybe within the past year or greater. I don't want to use chronic in a bad way, but just people who have been at this a little while, who might be able to give us feedback.

But I think we are open to more input on where do we get to these current family caregivers to give us

OLENDER REPORTING, INC.
1522 K Street, N.W., Suite 720, Washington, D.C. 20005
Washington: (202) 898-1108 / Baltimore: (410) 752-3376
Toll Free: (888) 445-3376

input into the curriculum as we move forward.

MS. KEBE: I have a question I believe has already been answered. How many of the subgroups have family caregivers in them?

MS. MOESSNER: I think one today was actively in the discussion, and then there are other members on the panel who will be pulled in to participate in those subgroups and offer feedback and input.

MS. KEBE: Thank you.

Sir, I believe you have a question.

MR. HARRIS: Good evening. I had two questions for the panel in general, but I heard the Colonel address part of it, and I also was interested to know from a priest if in addition to the medical and psychological pieces of TBI, what are the spiritual components that are involved in wellness or movement toward wellness.

The question you mentioned, Colonel, the topic you touched on about seamless transition, what are some of the challenges that a team's approach faces, for example, like with the VA, in the seamless transition, how could the VA move toward or navigate some of those challenges in a team's approach to meeting with the veterans at a point,

and their family members, at a point that it could be more user friendly?

REV. CERTAIN: To address your first question about spiritual approaches, the legislation was not written to include clergy or representatives of faith communities in America, and one reason I am here, not as a member of the panel, but as a member of the full board, is because I represent that aspect on that full board, and was here to remind this very august panel that the Greek word psyche gets translated into English as soul, and we are talking about, not just wounds of the brain, but wounds of the soul when our troops come home.

The other thing that I was here to remind the panel about was that the largest network of community-based care for caregivers, the spiritual support, funding, housing, clothing, food, relief is in the faith communities of the country, and while it may not be politically correct to write that in the legislation, the reality of the matter is that, at least in my experience, the experience in the places I have lived from the East Coast to the West and back, is that the faith communities provide the support for the family caregivers,

not exclusively, but in a very important way to a great number of people.

So, I am encouraging the panel to, when they report to Congress, to remind the Congress that this panel and the Defense Health Board, Department of the Army and the Department of Veterans Affairs, are not the be-all and end-all of how we care for one another.

We have heard testimony to that effect from so many of you tonight that a lot of folks out in the field have already put together programs that are very workable, and we are not here, I hope, to reinvent a wheel and say we have done it right, but to rather provide the proper network that includes a whole approach to the fullness of people's being, which does include the faith communities of America.

COL GIBSON: You raised very good points. Thank you for that question. I think about it from the standpoint of, as you mentioned, teams, and I can't really speak for VA. I do know some of the things that are going on within VA with respect to a team's approach clinically, managing a patient, managing a veteran with a team's approach within the VA.

We are seeing the same thing in the Department of Defense. You can look to Brooke Army Medical Center or Walter Reed here where we now have a health care coordinator physician, who is bringing together teams of providers to address the specific issue issues of the wounded service member.

In addition, we have got a pilot project going on within the Department of Defense and the VA have a pilot program on here in the National Capital region that helps with that seamless transition, or hopefully, someday, seamless transition between being an active duty service member and being a veteran drawing care benefits from the Department of Veterans Affairs.

The whole goal of that is to make it seamless. What I am not sure of, and I am speaking for myself here, is that overarching team's approach where we are communicating as an entire unit across the DoD-VA spectrum from a clinical standpoint, from a benefits standpoint.

I think we have a ways to go there in my view. I think it's an admirable goal and I think that with the folks that are working on that sort of thing right now, that we are making pretty good headway, but would someone

from Veterans Affairs like to follow up on this question?

DR. PRIES: Thank you. I would like to add just one more comment to that. One of the things that we spent a lot of time discussing today is the importance of family members as true partners of the health care team, and how do we facilitate that dialogue, those communications to really engage family members in the health care process, so that we can obtain their input, to ensure that the care and the rehabilitation that we are trying to provide will really be targeted to their needs and to get them really engaged as our full and active partners.

COL GIBSON: Does that answer your question?

MR. HARRIS: Yes, it does.

DR. FLYNN: One of the things I will let you know that we are doing out at Fort Lewis, Washington, out at Madigan, and again, this is more on a regional basis, not a national basis, but I think many of the regional centers are trying to do this, too, in terms of networking active duty military with the VA system.

We are an active duty tertiary care medical center and we have a VA liaison right on-board with us. We also have case managers within our TBI program who

OLENDER REPORTING, INC.
1522 K Street, N.W., Suite 720, Washington, D.C. 20005
Washington: (202) 898-1108 / Baltimore: (410) 752-3376
Toll Free: (888) 445-3376

network with the VA liaison on a regular basis.

We do two things. One, we go to the VA liaison, we introduce the soldier and their family members to the VA liaison and basically if this is a soldier who is going to be medically boarded or is going to be leaving the service soon and needs follow-up VA care, all of this is orchestrated before that individual ever gets out of uniform rather than after the fact.

In addition to that, we also have an active network program going on for ongoing active duty troops that need certain types of rehabilitation that we may not offer at Madigan. Again, our case managers are in constant contact with the VA liaisons.

I work very closely with Dr. J. Umamoto [ph], who is the Director of the Puget Sound VA system, Polytrauma Clinic and TBI Clinic. They come down and visit us, we go up and visit them, and we coordinate care of our soldiers. While our soldiers are in the VA system, we are in constant communication with them for what they are doing at the present time, what their needs are, and what they will need when they get back to us.

Often they will come back to us with a treatment

OLENDER REPORTING, INC.
1522 K Street, N.W., Suite 720, Washington, D.C. 20005
Washington: (202) 898-1108 / Baltimore: (410) 752-3376
Toll Free: (888) 445-3376

plan in place for follow-up while they are still in uniform. So, the old notion that the VA takes care of soldiers after they get out of active duty and somewhere in between that gap they leave the Army, and then there is this big gap of where am I in limbo, and then all of a sudden they are in the VA, we are closing that seam and I am sure there are a lot of other centers who are doing the same thing.

COL GIBSON: Thank you. That actually helped answer the second part of what I was going to talk about. We are talking about the soldier who becomes a veteran, who becomes a soldier. We also have folks who get medically retired from active duty, who are not only eligible for VA care, they are eligible for DoD care, and can be seen in our medical treatment facilities or Tri-Care.

This type of model where we are coming together as a group for a continuum of care is an important step forward.

MR. HARRIS: Could you just say a little bit more about what it is you are doing with the families and the veterans from the VA point of view? What initiatives

would be important? You mentioned something about including the family --

DR. PRIES: I am a health educator by training and I am not a clinician, so let me preface my remarks with that, and I work very closely with my colleagues who provide the clinical care to patients with traumatic brain injury.

However, as a health educator, one of the things that we really strive to do is to design education. We make assumptions as members of the health care team that we assume that either patients or their families understand the medical model, understand the kind of information that will help us guide the development of their treatment plan.

We think they know how to ask questions, we think they know how to interface with us, to provide us the input that will help us help them, and I think that is unfortunately, an incorrect assumption, that for the average lay person who has to interface especially under conditions like this, where you could have a very serious injury with potentially long-term outcomes of a very serious nature.

These people are stressed, and if we can help them communicate with us in some very simple ways, I will give you an example.

One of the things that we encourage in the VA people to do is to prepare for a clinical encounter, write a list of maybe no more than two or three or four things that are of prime concern to you, bring those up with your physician or with your provider at the beginning of the visit, so that that person knows what is a hot button item for you right then and there, so that as they are designing your treatment plan that day, or modifying your regimen, or whatever, they can address your needs and your concerns and your questions, so it isn't like, you know, the doctor is on his way or her way out the door and you say, oh, by the way, I forgot to ask you this.

It comes up, upfront, and the physician can build it right in, in the dialogue process. That is a very concrete and simple example, but it is one of the things that we can do to really help patients and family members interact with the health care team.

So, it is a whole bunch of prompt tips on both sides of that coin, both for the provider as well as for

the family member of the patient. I don't know if I am really answering your question.

MR. HARRIS: Yes, you did.

DR. PRIES: Okay. Thank you.

MS. STEPHENS: I just wanted to add a little bit to this in making you aware that we do have an integrated system of care for veterans and active duty service members with traumatic brain injury.

We have our four polytrauma centers. Every VISN has a polytrauma network site, and we also have eight polytrauma support clinic teams, and these are all staffed with individuals with expertise in TBI and help support the families as well as the veteran and servicemen.

DR. BENEDICT: Well, I am a clinician, so I can speak to that part of it, and being a member of an interdisciplinary team at Richmond, who is tasked with providing acute rehabilitation, I can tell you that it has been a primary focus since I started working at the VA two and a half years ago, and before that even, to incorporate the families into building the treatment plan, into educating them, and not just by having little meetings here and there.

They get the message from the get-go and even before they come down from the military treatment facilities, we have got tools in place, for example, the family education manual that gives them information about the rehabilitation process, the VA rehabilitation process, who the team is, the team members, what their roles are, a little bit of how to take care of themselves while they are taking care of their loved one.

The VA polytrauma system of care has adopted family-centered care and recently in April of this year, rolled out as a six-month pilot, a family care map, a web-based interactive tool, which takes the families through the rehabilitation process before they get to VA polytrauma and then after they have left, and this is a tool that they can navigate through, and talks about potentially better practices at each one of the steps through the rehabilitation process and has content and suggestions and tips for the families to interact with the team and to get the information and encourages them to be a member of the team and an active member of the team.

COL GIBSON: Let me add one thing and since we have a representative from Congress here, VA at the

OLENDER REPORTING, INC.
1522 K Street, N.W., Suite 720, Washington, D.C. 20005
Washington: (202) 898-1108 / Baltimore: (410) 752-3376
Toll Free: (888) 445-3376

present time is restricted in providing care to family members of veterans. They can only provide care to veterans.

While they are part of the team in building the curricula, building the care plan for a veteran with traumatic brain injury, they themselves, as they have to deal with the emotional issues, are not eligible for care. I just wondered, is that part of this new legislation, as well?

MS. LEE: It is not. [Off mike.]

COL GIBSON: Thank you, ma'am.

MS. KEBE: Good question. I have a comment from a webcast attendee, who is a transition patient advocate and has said I have found the spouses and families who have been caregivers of service members who were injured sometime ago are extremely knowledgeable and would be able to provide the greatest insight for this training.

So, you have those that you reach out and ask for input.

Any more questions for the panel?

Okay.

MS. FOREST: I could make a couple more comments

on resources I would like to see. A lot of people come to me who are caregivers and I guess in a sense I am a caregiver to myself, but I am learning about neuroplasticity and what neuroplasticity has to offer us in terms of getting better.

A lot of rehab happens at home, it doesn't happen just because -- I mean if you are practicing rehab an hour a day, you are not going to make a lot of accomplishments that you will if you realize that you can practice at home, that practice, practice, practice will get you there, that it is error by trial and not trial by error, but that you have to constantly be doing things over and over.

I think that helping people understand that they can help their loved ones by doing rehab at home and realizing that everything that you do in your day makes a difference, positive, how did people who made successful recoveries, how did they do it? What was it that helped them do it? How did they get there?

That is what I wanted to know, I wanted to know the path, I wanted to know who got there. Tracy here has gotten back to work full time, I want to know how to do

OLENDER REPORTING, INC.
1522 K Street, N.W., Suite 720, Washington, D.C. 20005
Washington: (202) 898-1108 / Baltimore: (410) 752-3376
Toll Free: (888) 445-3376

that.

I have heard that having models is hugely important for people recovering, just knowing that somebody else can do it helps inspire other people, if they can do it, I am going to do it. Even if you are motivated, that is really helpful.

The last thing is that I know a piece of my recovery that I was told after two years nothing could get better, that I was going to be a stone as what I thought, that I couldn't get better.

I am 11 years out, I am about to be able to get my driver's license, I am still gaining very obviously improvements, and I think that in the training manual, there should be information about people who are still recovering further out from the one or two years that a lot of people are told in acute settings, and just information about those kinds of people who have gotten better, what they have done 11 years out and 20 years out or whatever.

MS. KEBE: So, a step-by-step guide would help also.

MS. FOREST: A step-by-step, but hope that even

if you are not, you know, recovery is very slow in the beginning, it is very, very slow, and you are not seen that you are getting better, and so it makes it harder to keep doing it, because there is no feedback loop there.

Caregivers need to know how slow it can be in the beginning, and in my experience it picks up. The more neurons you have got firing, the more you can build on, so hope and information about how that process can build on itself.

As you start seeing that you are getting better later out, you get that much. It's like exercising, you see, wow, this is worth doing. So, information about what happens further out that is self-motivating and moving forward.

MS. KEBE: And I think everyone in this room would agree with you.

MR. DODSON: Jon Dodson. I am the 38-year recovering SPTBI, four craniotomies, it was a lot of fun. What we have found and what I have found, I was a self-caregiver because in 1969, nobody knew about this stuff.

The neurosurgeons put a bandage on my head where

a hole was. Okay. That works. But what we have found is that there is a TBI comes in, and then there is a stage where it will get worse, right after they come into the system, and so what I do, I do two things.

First of all, I am the hope guy to the TBI kids because I walk up to them and say 38 years ago I was where you are, I couldn't talk, I couldn't walk, and I said here I am now. I said you can make it. And what I found is, is it is not necessarily the patient that gets enthused about that, but it's the spouse in the room, or the brother, or the sister, or the father, or the mother, that all of a sudden they say, wow, you know, okay, and they feel my hole and all that other stuff.

I wear long hair, so you can't see my scars, but anyway there is a stage there where it regresses, and we are very careful to tell the family caregivers at Walter Reed just be aware that that is going to happen, and when that happens, give us a call. Okay? Thank you.

MS. KEBE: Thank you.

Are there any last questions or comments?
Please.

DR. PRIES: I will share a little bit of a

personal story. My sister has a daughter who had a very serious head injury. One of the things I did with here to get it exactly what you were talking about, about modeling and hope, and seeing where you have been and where you are today.

Early in the recovery process I gave her a journal and I said, Theresa, write things down, put in there what you are observing, how you are feeling, how Angie is doing, and in the recovery process on the days when it seemed like, you know, Angie had slipped or whatever, I said go back and read your journal, look at where she has come from.

You know, you may think you have plateaued right now or she is in a not so good place right now, but look at the progress that she has made, and it really, it was a tip that really helped my sister, so again, those things that we can share with family members, that may show them the progress and where they have come from, and again, to give them hope.

And modeling is a very important experience, and the more models we can offer, that are like a lot of different people, to be really effective, people have to

relate to the model.

So, the more success stories that you can offer people, of people who are different, but who yet have achieved positive outcomes and success, the more likely people can relate to those and really say I could that, too.

MS. KEBE: Thank you.

MS. FRIEL: I have got to tell my story. I, too, am a survivor of a traumatic brain injury on a motorcycle that I was driving without a helmet 30 years ago, and I had a severe concussion, absolutely no physical injury, but I was in a coma for three months, and when I came out of it, I had amnesia from just before the accident until two weeks after regaining consciousness I am told.

There was nothing available in those days, and I remember it took me about 18 months to fully recover physically. I had to go to physical therapy to learn how to walk again. You know, you don't realize that walking is a learned behavior. Little children learn to walk. I had to learn to walk again.

I remember going back to the University, I am a

graduate of Washington University in St. Louis, and I had to think for the longest time about how to walk, you know, left foot forward, right foot forward, left foot, right foot, and I remember crossing the quadrangle at Wash U. and feeling so good that I was back at school, I was taking one course that semester.

Somebody said excuse me, and I was passed by a fellow on crutches with a cast above his knee. I was walking that slowly, but I was walking.

I received by Bachelor's Degree from Washington University in St. Louis, and I went on to earn my Master's and my Ph.D. from the American University here in Washington, which is why I am here.

So, neurologists have done thorough exams of me and there is a part of my brain that is dead from the concussion, and there are things that a neurologist can show that I have motor skills that are deficient, and I kind of wonder sometimes who I would be if that part of my brain wasn't dead.

But there is hope if you keep at it.

MS. KEBE: And with hope, anything is possible.

Thank you.

OLENDER REPORTING, INC.
1522 K Street, N.W., Suite 720, Washington, D.C. 20005
Washington: (202) 898-1108 / Baltimore: (410) 752-3376
Toll Free: (888) 445-3376

There are no more questions from the webcast, and I believe you have a question for the panel?

MS. WILEY: I just have one more question. How much has been looked into examining rehab hospitals particularly TBI rehab units throughout our country for planning what you are working on, and in more detail, have you looked at what psychiatrists are doing in this country, because they are integral people for bringing together what is happening in the civilian in the civilian world?

MS. STEPHENS: Well, we do communicate regularly with private sector psychiatry community, and we recently had a state of science conference and brought in all kinds of experts from the field, so we are discussing with our contemporaries out there what the latest and the most recent technology is to incorporate that into our programs.

MS. KEBE: Thank you. I believe we are almost at that time. If there are no more questions from the audience, I would like to thank you very much for participating, coming out this evening, and to the panel members. Are there any last comments that you would like to share? Thank you. I will turn it over to Anne.

OLENDER REPORTING, INC.
1522 K Street, N.W., Suite 720, Washington, D.C. 20005
Washington: (202) 898-1108 / Baltimore: (410) 752-3376
Toll Free: (888) 445-3376

MS. MOESSNER: Thank you very much for coming and even more for your open and personal comments, both from the webcast participants and for those of you hear in the room today.

The panel will be meeting repeatedly over the next months, as I mentioned the timeline earlier, to finalize the curriculum, and when completed, it will be presented to the Defense Health Board at a meeting that is open to the public.

So, at that time, the public will again be able to provide comments before the curriculum is delivered to the Secretary of Defense.

With those words, I will say this Town Hall session of the TBI Family Caregiver Panel is now closed. Than you for coming.

[Town Hall meeting concluded 7:47 p.m.]

- - -

OLENDER REPORTING, INC.
1522 K Street, N.W., Suite 720, Washington, D.C. 20005
Washington: (202) 898-1108 / Baltimore: (410) 752-3376
Toll Free: (888) 445-3376