



**Defense and Veterans Brain Injury Center**  
**“The TBI Family” Podcast**  
“Caregiver Study and Brain Injury Awareness Month”  
Episode 106, Transcript  
**TRT: 20:44 min**  
**Host: Dr. Scott Livingston**

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**Producer:** So can I get just your first name?

**Chuck:** Chuck.

**Denise:** Denise.

**Producer:** Do you use social media yourself, sir?

**Chuck:** I do.

**Producer:** What kind of accounts do you use?

**Chuck:** I rarely use Facebook that's really about it as far as social media.

**Denise:** Probably really just Facebook.

**Producer:** Okay. No Twitter?

**Denise:** I'm not on Twitter. Sometimes I'll go on to read things, but I don't have my own personal account.

I think it's a good thing definitely. I mean primarily the purpose I think was to stay in touch with people or find people, connect with people. I think it's a good thing in general.

**Chuck:** It has, I guess, it's strong points.

**Producer:** So we have a campaign that we run every March, it's Brain Injury Awareness Month, that is trying to get people to think ahead. If we could use social media to let people know about traumatic brain injury, how to prevent it, how to know when they have one and how to get it treated, would you say that'd be a good thing?

**Chuck:** Of course. It's definitely a good thing to help get the word out there if you can do that.

**Denise:** I'd be happy to help [music].

**Livingston:** Hello and welcome to the TBI family, a bi-weekly podcast for caregivers of service members and veterans who have experienced traumatic brain injuries. This program is produced by the Defense and Veterans Brain Injury Center, otherwise known as DVBIC. I'm your new host, Dr. Scott Livingston. In this episode, we'll talk about Brain Injury Awareness Month and how you can use your personal social media to spread the word about traumatic brain injury. But first DVBIC and the Walter Reed National Military Medical Centers, National Intrepid Center of Excellence, also known as NICoE, are trying to learn about well you. A study called “Health Related Quality of Life in Caregivers of Service Members with Military Related Traumatic Brain Injury” has been underway since 2012. The TBI Family's producer, Terry Welch, spoke with Dr. Louis French, deputy director of Operations at NICoE and the principal

investigator on the study about this 15-year-long investigation into how the act of caregiving can affect caregivers and their families.

**Welch:** Could you tell me a little bit first about how the 15-year caregiver study came about, how it was started, who mandated it?

**French:** Sure. A number of years ago, Congress made a very wise decision in that it made sense to investigate the outcomes of people that suffer traumatic brain injury in the military, and they realized that when they made that mandate for a research study like that, that they needed to look at a multitude of aspects around outcome, and they realized that one of the important things that had unfortunately been too little studied was the impact of the injury on the family. So it specifically said in the congressional language that they wanted to have part of the study look at the impact on the family. We decided that that would be one of the key parts of what we are doing in this overall study and so out of the really four aspects of the study that has a prominent part. That caregiver study also bleeds over into our work with the VA because we, like with all of the portions to this, we realized that our partners [inaudible] are going to be the ones that are providing care for many of these people over the rest of their lifespan, and we want to make sure that as they transition from one part of their care system to another that we are capturing the needs that they perceive, how things change as they age or as they go into a different care system what their needs are and how they're different.

**Welch:** You have a report to Congress that's coming up soon; it's kind of a half-way point report is that what you'd call it?

**French:** Yes. Yes.

**Welch:** So I know that lot's already come out of this study. There have been some publications. What have you learned so far?

**French:** So the good news about this is that for many individuals, they are getting the services and things that they need. The unfortunate part of this story is many people still feel an unmet need. And as you would expect for some of the people that have an unmet need it's not that the system doesn't have what they want, but in some cases, they don't know how to access that particular service, so it becomes really a question of education in terms of making sure that the people that need something are expressing that to the people who can help provide that and get those two sides connected. We know that the process of being a caregiver is an immense burden for many people. Sometimes patients, depending on what their needs are, those needs can span the physical, the behavioral, the emotional parts of the spectrum. And having a great number of needs has a great impact on the family. There's no doubt about that. We shouldn't be surprised about this because I think if you look at caregivers of individuals with any kind of chronic illness, we see those things, too. People who are caregiving people with chronic medical illnesses, people who have a loved one with dementia or other sorts of problems as they age, all of those things require an immense amount of energy, and time, and emotional energy to make sure that our loved one's needs are met. So that's, I think, one of the big parts that we've learned from this, and as I said, it's not a big surprise about this.

One of the other things that we quickly learned about this is that the existing instruments out there in order to assess a person's needs were not really available. We had a fortunate partnership with some folks at the University of Michigan who are real experts in developing questionnaires to assess needs of people of all sorts. And so we, using some very sophisticated techniques, have worked with them on developing some questionnaires to better assess the needs of caregivers. The most important first step in that was to get some focus groups together. To get groups of caregivers together and for us to sit there and talk to them and listen to them and just hear their stories and what they thought their needs were and what the needs of their loved ones were. So we could develop banks of items, questionnaires that we could use for this. And once we were able to do that and get things psychometrically sound, we were then able to go back to these groups again and show them to them and actually test them out and make sure that what we developed was really useful in terms of what their needs were.

**Welch:** Were you part of the focus group project yourself or--?

**French:** As the principal investigator on that, I was not personally attending most of those focus groups. We had

some of them, they were held locally in the DC area. We had some that were held up at University of Michigan, but I did not sit in on many of those. Although I very eagerly followed the results of those and looked at the transcripts. It was actually quite an emotional experience for me in hearing some of the sad stories out there. Unfortunately, there are a lot of people who are in real distress.

**Welch:** I'm guessing that most of the folks that we've talked to are people with moderate to severe TBI then, or people who consider themselves caregivers in this aspect.

**French:** So, it's a mix. The majority of people that have been hurt in the conflicts in Iraq and Afghanistan and related kinds of conflicts have been hurt through blast explosion. And the sad reality is, is that when you're close to something that blows up, there's lots of ways that you can get hurt. And so besides the traumatic brain injury aspects of things, people often have comorbid physical injuries. Sometimes injuries to their face, their sensory organs, their eyes, their ears. And it's very likely that the people that experience this also had some emotional reaction to what happened to them. I don't think that anyone can see horrible things or get hurt and having a serious injury without having some emotional response to that. So the people that we see in these groups are a mix. Some of them have the traumatic brain injury that they have may be driving their clinical need. In other cases, it may be the physical or mobility issues that are making things more difficult for people. It may be cognitive or emotional. All these things interact to cause function or dysfunction in people. So in some cases, the people with the milder traumatic brain injuries may have other symptoms that are causing them, requiring them to have assistance. So I would say it's a real mix of people in the study.

**Welch:** On a personal level, I mean in your personal opinion, what would you like to see be the outcome of this study? What would you like to see change as the outcome of this study? Or what would you like to see happen for caregivers at the outcome of this study?

**French:** You know, I said a couple of minutes ago that I think one of the really unfortunate things is what's probably a gap in communication or advertising. I think that's something that the DOD and VA needs to work on if people are not getting the message it's a shame if we have a really good program in place to address the needs which in many cases we do, but people are not finding out about it or not accessing it in the way that they need to, and I think one of the best things that could happen is there would be a way of making sure that everyone who feels like they need something like that is getting access to the programs that they want or someone is paying attention to what their particular needs are. I think one of the difficult transitions for both patients and family members is when people make the transition from being in the military to moving to care outside the military care system. Any time there is a transition like that there is the possibility that there's going to be a gap there and what we don't want to see is people falling into that gap because that's a vulnerable time right then, and we don't want people to be getting excellent care in the DOD and have the possibility of getting excellent care in the VA, but not being able to make that leap. So I think we have to build that bridge over that gap a little stronger, and I think we really need to enforce the educational piece of this to make sure that people can access the services that are available.

**Welch:** So is the study still recruiting and how would people get involved if they were interested in that?

**French:** Absolutely. So the study is still in place. We have an email address that people can access. We have some telephone numbers, and we can certainly publicize all of those because we want to make sure that people are interested can participate. We get requests from a number of people who their situation may be slightly different and in some circumstances, there may be an injury that falls outside of the scope of what we've been mandated to do. We can't include those caregivers in the study, but we nonetheless like hearing about their experiences and what's going on, even if they may not be able to participate directly. We realize that the commitment to doing this, although we're not asking a ton of people, is a burden for some people. And under those circumstances, too, we may be interested in talking with you about a way to sort of modify what people can do. The last thing I would point out is that while we worry about people and their access to services, the study itself cannot be a method of treatment for people. So we don't want people to come into the study with the expectation that by being there and being with, potentially with peers or talking about the situations that they have, that it's going to provide treatment or care for them in terms of that. There may be some indirect benefit for people in participating, but the study wasn't designed to provide direct care for individuals that may want to access something. That being

said, we can often point people in the direction of things if they don't know how to get the care that they want.

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**Livingston:** If you are interested in taking part in the study, feel free to call 855-821-1469 or email [caregiver.study@dvbic.org](mailto:caregiver.study@dvbic.org). That number and email address, as well as links for more information, can be found in the description of this podcast.

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**Livingston:** Every year, DVBIC and other brain injury organizations observe Brain Injury Awareness Month in March. This year we're asking others to help share the word about the month through their social media accounts. DVBIC works 12 months out of the year to conduct research, to provide clinical support, and to educate and train service members, veterans, family members, health care providers about traumatic brain injury, which includes ways to prevent TBI, ways to recognize it if an injury does occur, promoting efforts for patients who've sustained a brain injury to get help, as well as conducting research on what are the most effective ways to treat it. Brain Injury Awareness Month really gives us an opportunity to focus that message on service members and veterans and their family members who support them to really translate that knowledge, translate that research that's being done throughout the year, showcase what DVBIC is doing to support those individuals. So the theme for Brain Injury Awareness Month this year is "Think ahead, Be safe, know the signs, and get help." Our main focus of that messaging is for service members and veterans. As caregivers and family members, you already know about traumatic brain injury. You already know that message to think ahead. Our ask of you this month, in particular, is to help us to spread that word. Help us to increase awareness to get more recognition for the scope of traumatic brain injuries, what services are available to support caregivers like yourselves and the individuals with TBI that you care for. So it's easy for you to be involved in Brain Injury Awareness Month. The most direct way that you can help support the effort is by taking part in our social media efforts which you can download our hashtag card for Brain Injury Awareness Month, put a personalized message about brain injury, what brain injury means to you, what role you play as a caregiver in supporting a service member or veteran with TBI, take a photo of yourself with that hashtag card, put it on your own social media, or post it back to DVBIC's A Head for the Future social media campaign efforts. So be sure to use the hashtag B-I-A month, that's B-I-A month and #ThinkAhead. We hope you'll consider helping us spread the word about brain injuries to your friends and family. For more information, please visit [dvbic.dcoe.mil](http://dvbic.dcoe.mil). [music]

And that's the show. As always, if you have any questions about the podcast, about DVBIC products or programs, or are interested in telling us your story, please feel free to email us at [info@dvbic.org](mailto:info@dvbic.org). On the next episode, we'll talk, about how art is helping to ease the burden for some caregivers.

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**Livingston:** The TBI Family is produced and edited by Terry Welch and is hosted by me, Dr. Scott Livingston. It is a product of the Defense and Veterans Brain Injury Center, commanded by Army Colonel Geoffrey Grammer and the Defense Centers of Excellence for Psychological Health and Traumatic Brain Injury, commanded by Navy Captain Mike Colston. Thanks this week to the Walter Reed National Military Medical Center Public Affairs team, especially Megan Garcia. Thanks also to the National Intrepid Center of Excellence, Miki Gilloon and Dr. Lou French. And finally, thanks to Spencer Burgos who helped us out with the Brain Injury Awareness Month story and leads the social media effort for DVBIC's A Head for the Future campaign. As always, thank you for listening, and we'll see you in two weeks.

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