

DHB-101509 (2)

UNITED STATES DEPARTMENT OF DEFENSE
DEFENSE HEALTH BOARD

TRAUMATIC BRAIN INJURY FAMILY CAREGIVER PANEL

Bethesda, Maryland

Thursday, October 15, 2009

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- 5 MEG CAMPBELL-KOTLER
- 6 CHERYL LEE CHURCH
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- 8 JONATHAN DODSON
- 9 COMMANDER EDMOND FEEKS
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- 15 SANDY KILADA
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- 17 LIEUTENANT COLONEL RANDY MAUFFRAY
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- 1 PARTICIPANTS (CONT'D):
- 2 GLORIA STABLES
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MIKE WELSH

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P R O C E E D I N G S

(9:33 a.m.)

MS. MOESSNER: Okay, everybody. I think
we'll have you get settled and we'll commence
today's meeting. Thank you.

we -- the agenda, of course, is in your

7 packet. We just heard a couple of people are
8 running behind. I don't know if it's the weather
9 or the traffic. I understand when it rains in
10 Washington, D.C., that adds time onto one's
11 commute. So a couple of people are running a
12 little bit late and we really want them to be here
13 for Lieutenant Colonel Mauffray's presentation on
14 the CEMM.

15 So, perhaps we'll start the day with
16 just some leftover items from yesterday. We have
17 a couple of questions that we may put to the Panel
18 today. And then as soon as the other individuals
19 show up, we'll commence with the CEMM
20 presentation.

21 So, I think how we'll work the morning
22 is, just again, a little discussion on some

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1 miscellaneous items; have the CEMM presentation;
2 have a break. I think a few people still need to
3 check out of their rooms, so there should be some
4 time to do that over break. And then Megumi,
5 Fred, and I will give a little update on the mild
6 TBI -- the so-called Module 5 -- and let you know
7 where that stands and kind of what the future
8 plans are for that and ask for some input on that,
9 as well.

10 Over lunch, a few people have agreed to
11 continue a bit of a discussion about the marketing
12 and dissemination issues that were brought up
13 yesterday -- the report that Shannon had put
14 together. So a few of us are going to meet over
15 lunch and make a plan to update the written
16 proposal and figure out who's going to write the
17 Executive Summary and kind of clean that up a
18 little bit. So we can report on that back to
19 everybody right after lunch.

20 And then I think -- I don't know if
21 other people have miscellaneous items, but then I
22 think we'll be winding down after lunch. You

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1 know, anything else people want to say, certainly
2 a little thank you and celebration is in order, so
3 we'll do that to end the meeting. But I suspect
4 we'll be done a little bit early today, so if you
5 have other items to bring up there should be time.

6 So does that sound all right? Okay.
7 Sounds good. So, I think everyone knows -- do you
8 feel the need for introductions? Does everybody
9 look fairly familiar? I know you've been here
10 most meetings.

11 LTC. MAUFFRAY: No. It hasn't been that
12 long of a process.

DHB-101509 (2)

13 MS. MOESSNER: That's right.
14 SPEAKER: It looks pretty much the same.
15 MS. MOESSNER: Okay. Good. We're no
16 worse for the wear. So, okay, great, thank you.
17 SPEAKER: (inaudible)
18 MS. MOESSNER: Yeah, that's right.
19 Okay. So one of the -- when I met with Meg and
20 Sandy for a few minutes this morning, I think one
21 of the issues we'd like a little bit more input
22 from the Panel on, to bring forward to the DHB and

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1 forward from there to whatever agency is going to
2 house and maintain the curriculum, is what kind of
3 metrics would you suggest? What kind of data be
4 collected about this curriculum? What do you want
5 to know and what could we suggest, again, be
6 collected in terms of whatever you can think of?
7 So we would just like your opinions, your ideas,
8 about metrics.

9 So, let's start with Mike this morning.
10 MR. WELSH: What do I got to do? Am I
11 on? With the metrics, first they should be -- I
12 would think they should be synchronized with the
13 goals that Shannon came up with in the
14 dissemination plan. And then you've got to decide
15 how to use the metrics. A lot of time

16 organizations collect metrics and you start doing
17 metrics for metrics. So, to really make them
18 effective, that guardian that Colonel Fortuin
19 keeps talking about -- the proponent agency --
20 that person has to look at the metrics and be able
21 to interpret them and understand what they mean.
22 so that's another reason to make them aligned with

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1 the goals. And you've got to have a mechanism to
2 update the metrics because if it's hosted on a
3 website, the metrics change daily. So you should
4 always think about a tool that's going to let you
5 update your information without having to manually
6 do it. You know, everybody uses Excel to do their
7 graphs and charts and things, but that data is
8 only good when you update it. So there's things
9 off the shelf you could buy that will keep
10 updating your metrics, like tableau, and you don't
11 have to rebuild them each time you want to present
12 your metrics to a board or somebody.

13 If we start with those goals that would
14 help us frame everything else with the metrics.

15 MS. MOESSNER: Great. Thank you. Yes,
16 please.

17 MS. SARMIENTO: I guess it would really
18 depend on what system is used for the online

19 system. Do you know which programming tools are
20 used? I know that we have Omniture.

21 LTC. MAUFFRAY: For the site?

22 MS. SARMIENTO: For your online system

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1 to check the metrics.

2 SPEAKER: The actual metrics that are
3 used -- as far as tracking the utilization of the
4 site, we do have software. And I don't recall the
5 exact brand -- it's changed several times -- that
6 tracks everything from page views to data amount
7 streamed and things of that nature. And I'm not
8 familiar with what the goals that you guys set
9 were. I guess it was a discussion yesterday. So,
10 I'm not sure how we tie into that.

11 Are what you're looking for ways to
12 improve the curriculum for the future? Is that
13 what the primary thing is? Or to validate that
14 what you did was the right thing to do.

15 MS. SARMIENTO: Yeah. I actually had a
16 similar question because I think metrics is such a
17 broad term.

18 LTC. MAUFFRAY: Right.

19 MS. SARMIENTO: Are you looking at your
20 dissemination efforts? Are you looking at your
21 change in impact measures, such as knowledge,

22 DHB-101509 (2)
attitude, behavior change, or is it just

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1 dissemination metrics?

2 So, for dissemination metrics, if you
3 have -- usually there's some sort of coded system
4 in computers. Like, we have Omniture, and you can
5 actually preprogram it to do, you know, monthly
6 reports or quarterly reports, and it'll show you
7 all the statistics, whether it's the clicks, the
8 downloads, whether someone came from another site
9 or, you know, those sorts of things. Are they
10 going right to your page?

11 And I sent you guys a list of some of
12 the web metrics we collect. And dissemination,
13 it's also good to collect media impressions and
14 there's like clipping services, number of
15 interviews done, those sorts of things. And then
16 social networking, if you have blogs, comment
17 sections. And then with your warehouse, with hard
18 copies, we just collect publications requested;
19 and then questions to our 1-800 number, number of
20 people that ask about our topic areas and then
21 number of inquiries we get. And so I sent you
22 guys a list. I don't have to go through the whole

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1 list now. And you can check to, like, peaks. A
2 lot of the systems, like our Omniture system, will
3 show us, like, if we do an event, it'll track
4 from, like, you can set it up so it's the whole
5 fiscal year; you can set it up, you know, just the
6 first quarter. Let's say you had a big event in
7 February and you see -- you know, hopefully you'll
8 see a peak. Or if you know you did a bunch of
9 media outreach, you can check to see if it had any
10 impact really with number of clicks or orders, and
11 those sorts of things.

12 So, fortunately, with dissemination
13 metrics, it's just preprogramming it.

14 MS. MOESSNER: Right.

15 MS. SARMIENTO: It's not a lot of work.
16 It's just automated systems that will be sent to
17 you. Yeah. So I don't think that would be hard.
18 It's just setting it up beforehand. And I imagine
19 that they already have that system in place, so
20 just taking advantage of that.

21 MS. CAMPBELL-KOTLER: Is there an
22 automated system for hard copy?

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1 MS. SARMIENTO: That would depend on
2 your warehouse. Our warehouse does.

3 MS. CAMPBELL-KOTLER: I'm the warehouse.

4 (Laughter)

5 MS. SARMIENTO: Oh, you're the
6 warehouse?

7 MS. CAMPBELL-KOTLER: I'm so sorry.

8 MS. SARMIENTO: Yeah, I mean, I
9 understand.

10 MS. CAMPBELL-KOTLER: How does that work
11 for print? And I'm the warehouse.

12 MS. SARMIENTO: Yeah. I do, but -- we
13 have small publications or just publications where
14 we only print hard copies for conference
15 dissemination. Yeah, you know, my office is full
16 of those types of things, too, so I understand.

17 That's just -- usually what I look at is
18 the number of -- instead of counting each time I
19 send something out, if I print, you know, 200 of
20 them and then you just count what you have
21 remaining, that you do have to manually track,
22 obviously, because you're the one sending it out.

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1 MS. CAMPBELL-KOTLER: Right.

2 MS. SARMIENTO: With warehouse orders
Page 11

3 you can track -- I mean, through our system we can
4 track how many are disseminated basically on a
5 daily basis. So, you know, actually our warehouse
6 is in D.C.; it's not in Atlanta, so I don't know
7 if you guys share the warehouse with us.

8 MS. CAMPBELL-KOTLER: No, we don't have
9 a warehouse, but we're going to need one soon.

10 SPEAKER: Yeah, really.

11 MS. LLOYD-KOLKIN: You can contract that
12 out.

13 MS. SARMIENTO: Yeah.

14 SPEAKER: There are houses that will do
15 that for you.

16 MS. SARMIENTO: Yeah. Ours is
17 contracted out. There's a company that has the
18 contract for CDC's warehouse and they're in, I
19 think, Annapolis -- no, not Annapolis. What's the
20 --

21 MS. CAMPBELL-KOTLER: Annapolis
22 Junction?

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1 MS. SARMIENTO: I can't think of where
2 it is, but -- maybe that's it.

3 MS. CAMPBELL-KOTLER: I think there's a
4 place called Annapolis Junction that has a lot of,
5 you know, light manufacturing and kind of

6 warehouse stuff, so.

7 MS. SARMIENTO: Okay. Yeah, that sounds
8 familiar. But, yeah. But a lot of it, it's not a
9 lot of work; it's just having it preprogrammed and
10 then it's just pulling off the reports. And then
11 metrics, in terms of impact measures, you know, I
12 think that's very effective and very important to
13 collect, but usually that involves funding and,
14 you know, more formal evaluations, which obviously
15 would be ideal.

16 LTC. MAUFFRAY: So I just pulled up one
17 of our smaller sites here and just the kind of
18 data that you can collect from web usage. And so
19 here it tells you how many unique visitors this
20 site has had over the last -- in October, so in
21 the last 14 days. Number of visits. What it's
22 saying here is that you have 455 unique visitors,

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1 but there were some repeat visitors, people who
2 would come more than once. And it goes on. They
3 looked at 4,410, so that's about 10 pages per
4 visitor.

5 Hits are -- the number is somewhat
6 different. That's the number of individual
7 downloadable items and things that are hit upon,
8 so there can be multiple hits for a single page

9 view. And then how much bandwidth that was used
10 to supply that data.

11 And then it breaks it down, you can see,
12 over the last 12 months. You can see peaks and
13 valleys of utilization. Here the days of the
14 week, even so you can know, you know, are people
15 going to the site predominately on the weekends?
16 Are they predominately using it during the week?
17 You can use that to target -- for example, if you
18 have newsletter information, things like that,
19 that you want to disseminate, you might know when
20 better to update that information. So if most of
21 the people are hitting the site on a Saturday, so
22 any new information that you want, you want to go

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1 out on a Saturday.

2 You can also see it also tracks where
3 people are originating. So the majority of
4 people, because this is a military site -- that's
5 what this particular site is -- most people are
6 accessing this from dot-mil locations. And then
7 you can see they have commercial dot-com and even
8 down to the country of origin where the sites are
9 being located.

10 MS. CAMPBELL-KOTLER: Fabulous.

11 LTC. MAUFFRAY: And just on and on. How
Page 14

12 are people getting to your sites? If you're going
13 to market a particular area, are they getting
14 there through Google searches? Are they getting
15 there through other links that you might have on
16 other pages? It also goes to show how frequently
17 is your site being indexed and looked at by the
18 search engines? And so if you look at --
19 Googlebot hit the site 625 times, downloaded 7.67
20 megabytes of information, the last time it hit was
21 on the 15th of October. And so just tons and tons
22 of information.

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1 It shows you what file types are being
2 downloaded. You can track individual files. Here
3 are the top URL, top 10 pages that were being
4 viewed, the top 10. And just on and on the amount
5 of data that you can pull out of this information.

6 SPEAKER: And this is what you're used
7 to, huh?

8 LTC. MAUFFRAY: Yeah. And so this is
9 what we track all of our sites with.

10 MS. CAMPBELL-KOTLER: Great.

11 LTC. MAUFFRAY: There's a lot of
12 information that you can have.

13 MS. SARMIENTO: Yeah. That's exactly
14 what we do. Our system is called Omniture. I

15 don't know which -- it looks very similar. I
16 think it's a little bit different, the format, but
17 it's the same thing. And his point is exactly
18 right. And you can tell when you should be
19 uploading. Or if you can tell partner sites, if
20 people are linking off from your partners or from
21 a search engine, and so that helps in terms of
22 where you should focus your outreach strategies.

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1 so there's lots of different things you can take
2 from this information and then see how effective
3 you've been. If you're doing a media event and
4 you don't see a spike in your hits, then it
5 probably wasn't a successful one.

6 LTC. MAUFFRAY: Exactly.

7 MS. SARMIENTO: So you need to rethink
8 how to reach out. So, yeah, that's perfect. And
9 you can downscale those depending on how much
10 detail.

11 LTC. MAUFFRAY: One of the other things
12 that's generally a relatively tightly guarded
13 secret is exactly how particular a search engine
14 analyzes and ranks your particular page. And
15 companies out there all say that they know how to
16 get you, you know, top Google placement and all
17 that. well, the way to get that is you pay for it

18 and, you know, you buy your placement on a Google
19 site these days. But it's not as much -- any
20 more, it's not simple page use or anything. It's
21 a very complex formula where they look at how your
22 site ranks relative to other sites versus views.

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1 How many people outside link into your site? How
2 do their sites rank? So if you have a lot of
3 high-ranking sites linking to your site, your site
4 moves up on the ranking. All kinds of things that
5 intertwine to make these things. So if you did a
6 search for "traumatic brain injury," what's going
7 to pop to the top is very dependent on a lot of
8 factors out there. And so there's a business
9 actually that exists in trying to move your site
10 up on Google searches.

11 MR. WELSH: What's the name of the free
12 tool?

13 LTC. MAUFFRAY: This particular one I
14 don't even see the name on it at the moment. The
15 contractors that run our websites manage the
16 software. I'm not seeing it on here.

17 We could -- it's A.W. Stats, so from
18 Source Fortunate.

19 MS. SARMIENTO: In regards to the Google
20 stuff, I know that's huge. And I think a lot of

21 federal agencies tend to rank fairly high on
22 Google searches. I don't know how that's

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1 happened. I don't think -- but I know that
2 certain agencies do communicate with those search
3 engines because they feel that the information is
4 valid and it is a service, obviously, to the
5 general public that federal agencies tend to rank
6 high. But, you know, I don't -- yeah, I think
7 that's variable. I definitely have seen people
8 also taken advantage if you have a product that's
9 very popular; I know that's happened to us.
10 People will name it after your product or have a
11 book. Like for our Heads Up stuff, a lot of
12 people have taken advantage of that and now they
13 rank higher on the list.

14 SPEAKER: That's a whole other issue.

15 SPEAKER: No control over that. Right.

16 MS. MOESSNER: Go ahead.

17 SPEAKER: I looked at the website. I
18 looked at the backpack website. You know, I
19 thought it was really great.

20 I'm concerned if we have a dot-mil
21 website that people at home are not going to be
22 able to access it. I just didn't -- I don't

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1 recall what the URL was, if it was a dot- mil or
2 not.

3 MS. CAMPBELL-KOTLER: No, dot-com.

4 SPEAKER: Oh, great. Okay.

5 MS. CAMPBELL-KOTLER: It's Traumatic
6 Brain Injury A to Z.

7 LTC. MAUFFRAY: Ours is a dot-org. It
8 can be anything. There are some issues with the
9 government owning dot-com sites. And so we don't
10 actually own our URLs. Our contractor owns our
11 URLs and we pay them to manage it. But it's --
12 there are some issues in how dot-com is related to
13 the government.

14 MS. PRIES: Hi, Rose Mary Pries. I
15 think another population that we shouldn't
16 overlook is evaluating the impact on clinicians.
17 I think that's critically important because
18 certainly we want to impact our end-user, but if
19 we can help out the clinicians in the field,
20 that's an extremely important audience.

21 And I don't know if this is impossible
22 for what we're doing, but another thing that I

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1 always like to collect evaluation data on is has
2 whatever I'm trying to evaluate had any impact on
3 the organization, on either the health care
4 delivery systems or from a management perspective?

5 And I guess, third, I always want to
6 know what the people for whom I'm preparing this
7 evaluation are real interested in. And wherever I
8 can, I try to ensure that I'm feeding them stuff
9 that I know is going to catch their attention.

10 MS. MOESSNER: Excellent. Thank you.

11 MS. CAMPBELL-KOTLER: So, as caregivers
12 or as representatives of military families, what
13 would be important from your perspective that we
14 be capturing?

15 MS. ROCCHIO: I'm real concerned about
16 not the immediate, but the impact further down the
17 line after they're back in a home setting, how
18 things are changing. That kind of data would help
19 in updates because there is a honeymoon period
20 that doesn't last forever. And then things can
21 get very dicey after that. And I think it's
22 important to know how to prepare for that.

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1 MS. CAMPBELL-KOTLER: would that be six
2 months after discharge or a year after discharge
3 do you think?

4 MS. ROCCHIO: It would be nice to have
5 both. And have it all.

6 MS. CAMPBELL-KOTLER: Right.

7 MS. ROCCHIO: Two years down the line.
8 It changes forever.

9 MS. CAMPBELL-KOTLER: It does.

10 MS. ROCCHIO: Yeah.

11 LTC. MAUFFRAY: And when you're -- you
12 know, there are all kinds of electronic mechanisms
13 by which you can reach out and get surveys at set
14 timeframes and things like that if people are
15 willing to provide their contact information at
16 the time of discharge. You know, you can have it
17 set up to where at 30 days, 6 months, 18 months,
18 they would get an automated referral for response
19 to see, you know, how has the curriculum helped
20 them, any suggestions for improvement, things like
21 that. And that may be one way to go about doing
22 it.

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24

1 MS. COHOON: This is Barbara. There's
2 legislation that's been introduced and it came out
3 of the Veterans Affairs on the House-side

4 Committee looking at caregiver issues and wanting
5 to have some research done and some reports. And
6 so a lot of the questions that you guys probably
7 are going to be brought up will, hopefully, be
8 addressed as far as that.

9 I would like us to make sure that we
10 stay focused on the curriculum and make sure --
11 because this is an intervention that we're doing
12 as far as putting it out. And so anytime you do
13 an intervention you want to determine as far as if
14 the intervention made a difference or not. So,
15 again, if we can focus the data that we're
16 collecting back onto the product that we are
17 rolling out.

18 And I think we can make some suggestions
19 as far as maybe what needs to be done outside of
20 the curriculum looking at other aspects that are
21 going on, but no long-term effect.

22 But I think what they talked about

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1 yesterday -- and I think it was Rose Mary brought
2 this up -- that we need feedback back on the
3 curriculum as far as what needs to be added, what
4 needs to be changed. And then we make sure that
5 it's implemented in a timely fashion with that.

6 Our organization, when we did the camps

7 for the kids, we actually did a study with RAND to
8 determine as far as if the camp made a difference,
9 and it's amazing as far as what you pull out of
10 that. And so when we go back and look at the
11 intervention from the curriculum, from there it
12 may lead other questions and answers that you guys
13 want to do down the road. So I don't see that
14 whatever we put forward is going to stop with that
15 data collection, that it will continue from there.
16 And that'll give DVBIC the opportunity to do more
17 research in that particular area. Congress is
18 wanting to have some more research done on
19 caregivers and the impact of being a caregiver.

20 LTC. MAUFFRAY: Is there already a set
21 timeframe for -- there's a set-up date scheduled
22 at any particular point or anything like that?

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1 MS. CAMPBELL-KOTLER: No. No. There is
2 a report that the Department of Defense --
3 secretary of Defense and secretary of the Veterans
4 Administration have to make to Congress a year
5 after the curriculum is disseminated. But that's
6 the only thing. And we don't know who the policy
7 agency will be. Colonel -- sorry, I'm blanking on
8 your name this morning.

9 COL. FORTUIN: Fortuin.

10 MS. CAMPBELL-KOTLER: Fortuin. Excuse
11 me. I can't see that far. Colonel Fortune has
12 been raising that issue that we need to have a
13 policy agency and then an implementation agency.
14 And DVBIC will probably be implementation, but
15 there needs to be another level there.

16 DR. FLYNN: This is Fred Flynn. I have
17 both a question and a comment. One, is there
18 going to be a central database that will have the
19 names and points of contact of all the individuals
20 that we're dispensing the curriculum to?

21 That's number one.

22 MS. CAMPBELL-KOTLER: I think so. I

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27

1 mean, we'll have to maintain records of who -- to
2 whom it has been sent.

3 But the next level down, I mean, I
4 expect that we would be sending large quantities,
5 say, to a federal care recovery coordinator. And
6 then we're going to have to ask them to keep data
7 on who they have given this to. But whether they
8 could share those things back to us, I don't know.

9 DR. FLYNN: well, I think if the data
10 can be entered -- if there is some type of central
11 repository for that data, no matter where the
12 curriculum is dispensed, you know, that would be a

13 great asset. Because when you do send out
14 surveys, if you have e-mail address for people or
15 whatever, no matter what the survey is, you're
16 always going to have a percentage of people that
17 don't respond. And I think in this population it
18 is extremely important that somebody follow up and
19 proactively contact people and find out why they
20 didn't respond. And in many cases my suspicion
21 will be that they are so overwhelmed in the role
22 of caregiver that they don't have time to fill out

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28

1 surveys. But I think that becomes very important
2 for us to know, as well, to see how we can further
3 help those individuals and at least capture some
4 of that feedback from them as to what's working
5 and what's not.

6 And I don't know what the answer to this
7 is either, but I suspect that for at least some of
8 the caregivers -- when this is initially
9 distributed, I have the feeling, like anything
10 else, you're excited about it; you open it up; you
11 start to read it or whatever. And then eventually
12 when you get home for long-term rehab and the
13 focus becomes day-to-day care, that winds up going
14 in a closet someplace and it would be interesting
15 to find out, you know, whether or not that's a

16 common behavior.

17 So I think we need to be -- for those
18 that we don't get answers back from in a typical
19 e-mail request-type fashion, I think we need to be
20 proactive and at least, you know, take a random
21 sample at least of that population that don't
22 respond. Call them up and find out, you know,

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29

1 exactly what's going on.

2 LTC. MAUFFRAY: Losing that subset could
3 certainly skew your data.

4 CDR. FEEKS: Yeah.

5 MS. MOESSNER: I know in previous
6 discussions we talked about maybe the FRCs and
7 RCCs, you know, maybe help with some of that
8 evaluation process since they'll be in key roles.
9 So I know there's been some discussion about that
10 as well as they're wrapping up with families or
11 continuing to have interaction with them -- that
12 then maybe they can be key in asking for input,
13 feedback, that sort of thing; or why didn't you
14 give input if you got some online request to do
15 so, that sort of thing. So they might be able to
16 help.

17 MS. COHOON: Again, though, as I
18 mentioned yesterday -- this is Barbara -- the

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19 number of our service members and caregivers
20 assigned an FRC is significantly lower than the
21 numbers that actually have the case managers'
22 three year services. And so, you know, I

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1 understand the reason for going out with FRCs and
2 RCCs, that's important to do that. But we need to
3 be encouraging the services to connect the
4 families with these FRCs. And right now they're
5 reluctant to do that. So until that switches
6 over, you're going to miss out on that population.

7 And so -- and that education piece you
8 all were talking about, too, is going to be key,
9 too, because now you're going to have to educate
10 each one of the services. The AW2s, the WTUs, the
11 Marines, the Safe Harbor and the Air Force group,
12 too. And then also, too, the VA has its own
13 OIF/OEF case managers that are working with them,
14 too. So I think the push with the FRC and RCC is
15 great and, hopefully, maybe the recognition by the
16 Defense Health Board, that the services need to be
17 moving in that direction, will help.

18 MS. MOESSNER: Thank you.

19 LTC. MAUFFRAY: If I could just ask, is
20 the initial dissemination of the curriculum going
21 to be at the time the patients are admitted to the

1 Barbara's comments to springboard into -- one of
2 the other -- as we think about getting to the case
3 managers, FRCs, RCCs, and training them, educating
4 them, getting them excited about the curriculum,
5 we're not quite sure how that's going to happen at
6 this point in time because, again, there's not a
7 large budget to take care of that. So there's
8 been discussion about maybe a couple of webinars
9 or trying to, you know, infuse ourselves into some
10 existing meetings and, you know, trainings that
11 they already have. Are there Panel members who
12 would be interested in or willing to assist with
13 that? To be part of a webinar training? To be
14 part of a so-called speakers or -- bureau or, you
15 know, just a small effort to do an initial blast
16 of training? So if anyone is interested or
17 willing or has some time to do that, we're going
18 to take some names today.

19 MS. CAMPBELL-KOTLER: Yeah, I'm taking
20 names.

21 MS. MOESSNER: Okay, so Mike. Mike
22 sounds like -- and I saw Pam, and Barbara.

1 Sharon? Jonathan?
2 MS. CAMPBELL-KOTLER: Great.
3 MS. MOESSNER: You guys probably feel
4 like you could. I also would be happy to do that.
5 And especially if there are some regional
6 activities, you know, I could certainly do some
7 things in the upper Midwest.
8 Others around the room who may have --
9 Rose Mary?
10 MS. PRIES: No, just a question.
11 MS. MOESSNER: I'm sorry. Other
12 suggestions just about how to get to that group
13 and how that might work, please.
14 MS. PRIES: And to encourage folks to
15 participate in that kind of training, can you
16 offer CEUs? Can you get accreditation from
17 somebody?
18 MS. MOESSNER: That does always help.
19 MS. PRIES: Yeah, exactly.
20 MS. MOESSNER: Good.
21 CDR. FEEKS: This is Commander Feeks.
22 On the issue of continuing education credits, as

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1 inviting as that is, we've looked at that on the
2 Defense Health Board for several of our other
Page 30

3 kinds of meetings because in the days of the Armed
4 Forces Epidemiological Board, which is our
5 ancestral organization -- one of them -- we did
6 accredit parts of our meetings. But the world of
7 continuing education accreditation has changed
8 markedly just in the last couple of years. And
9 it's gone from being something that was fairly
10 easy to do to being something that's enormously
11 difficult and labor-intensive to do. So I just
12 want that to be a part of the thinking if you want
13 to look at trying to accredit something. Thanks.

14 MS. PRIES: Yeah. I guess I just
15 wondered because, you know, you have such a strong
16 education component to a lot of what you do, if
17 you already had those accreditation agreements
18 forged with some of the bodies, but apparently
19 not.

20 CDR. FEEKS: So if the curriculum were
21 accredited once, would it be accredited once and
22 for all?

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1 MS. CAMPBELL-KOTLER: I think it would.
2 We have some relationships with Swank and St.
3 Louis University to offer CMEs and CEUs for like
4 our TBI Military Training Conference. But what we
5 would have to do would be to develop a

6 professional PowerPoint that would be appropriate
7 for credit. I mean, this has been written for
8 families. It's not a clinician document. So if
9 we're offering CEUs, CMEs, we have to develop a
10 presentation that would meet that criteria, which
11 we could give to Swank and then they would certify
12 -- St. Louis University would look at it and
13 could, you know, if we agreed that we'll all
14 present a staying presentation to clinicians --

15 MS. PRIES: Exactly.

16 MS. CAMPBELL-KOTLER: -- whether they're
17 physicians or non-physician groups, it could be
18 done. There's, of course, a cost involved there.

19 MS. PRIES: Let me share this resource
20 with you because it's something we're just going
21 to start pursuing in December. We have monthly
22 conference called for our different constituencies

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36

1 in the field in VA. And we've just created an
2 agreement with the University of North Carolina,
3 who for the grand total of \$150 a year is going to
4 accredit our calls for physicians, for nurses, for
5 -- which we were just blown away. And I mean,
6 sure, we have to do the faculty disclosures and we
7 have to do the creation of objectives and
8 whatever, but, you know, you can't beat the price.

9 SPEAKERS: Wow.
10 MS. PRIES: And we're not even
11 affiliated with UNC. We're affiliated with Duke.
12 So, go figure.
13 MS. CAMPBELL-KOTLER: What part of UNC
14 is doing this?
15 MS. PRIES: Actually, we approached the
16 School of Nursing and School of Medicine, and
17 we're working jointly with them. When I get home
18 I'd be happy to send you the names.
19 MS. CAMPBELL-KOTLER: Okay, thank you.
20 MS. PRIES: But I thought, you know, you
21 can't beat that.
22 MS. MOESSNER: Right. Good.

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37

1 DR. FLYNN: Ann, you mentioned regional
2 level for education and all. One of the things
3 that -- I was told by my wife not to volunteer for
4 too many more things because she rarely gets to
5 see me, but we do have an education branch that's
6 attached to our TBI program. And we have a
7 wonderful, excellent, chief of our education
8 branch who goes out constantly to talk to units,
9 to talk to these family resource groups and what
10 have you. So, I would be happy to work with her
11 to help train her up or even if someone else is

12 doing this at a regional level, maybe perhaps send
13 her on a little trip to, you know, oversee this
14 and I'm sure that she'll carry the ball from there
15 on out.

16 MS. MOESSNER: Terrific.

17 DR. FLYNN: And continue the training.
18 So I think the idea of a regional basis to get
19 more people involved, you know, especially if
20 their field of expertise is education.

21 MS. MOESSNER: Good. Thank you.

22 COL. FORTUIN: And I'd certainly be

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38

1 willing to go down to Fort Carson to talk to
2 anybody.

3 MS. CAMPBELL-KOTLER: Well, we have an
4 excellent education coordinator at Fort Carson.

5 COL. FORTUIN: I'm sure. Well, they've
6 got a huge program down there.

7 MS. CAMPBELL-KOTLER: So I think in the
8 regional approach we can utilize DVBIC education
9 coordinators to kind of create a framework,
10 anyway, or process --

11 MS. MOESSNER: And then if any of us --
12 you know, I would certainly be happy to do
13 anything at the Minneapolis VA if they're pulling
14 people into that area because that's only an hour

15 away from me. So, I wonder, too -- and I know,
16 you know, you're planted in Richmond -- so, yeah.
17 Okay. Well, as we develop a strategy,
18 we just wondered about how that might look. And
19 you know, we need -- you hate to get the
20 curriculum approved and, you know, maybe there's
21 not a lot of time and money that attaches to it
22 right away. But if it's able to be rolled out in

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39

1 a fairly timely manner, we need to do some sort of
2 blast of initial training notification, you know,
3 getting the folks fired up, knowing what they're
4 handing out. So, that can build over time, but at
5 least some sort of initial round of training.

6 COL. FORTUIN: I think that just part of
7 our discussion this morning on the metrics and
8 evaluation, I mean, it really begs for a robust
9 evaluation plan of sorts. And I don't know that
10 that was ever the -- one of the objectives of this
11 group necessarily, but I think any input we can
12 get -- because, you know, I always get metrics and
13 measurements confused. And, you know, process and
14 impact, da-da-da-da-da. But every basic -- as a
15 bean counter, one of the things that I'd be
16 looking for is we pretty much know how many
17 moderate and severe TBIs are coming through the

18 military -- coming out of this war. And so you
19 can just very basically look at that, you know,
20 assign -- since we generally work in very large
21 numbers, assign a book to them.

22 How much does that cost per book? And

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40

1 then add in the cost of the webpage as well. And
2 just a cost per person is something that you're
3 going to be looking for.

4 But there are so many -- so many things
5 that have been discussed this morning. And then,
6 of course, whatever metrics or measurements they
7 are you decide upon drives your data collection
8 plan, which can get very, very convoluted and
9 complex as well. So I think this is just a huge
10 undertaking, but very important.

11 MS. MOESSNER: It is important. I know
12 the DHB brings this up every time I go there.

13 COL. FORTUIN: Congress -- it's got to
14 -- you've got to put something in your report back
15 to Congress.

16 MS. MOESSNER: Right.

17 MS. BENEDICT: While we do know the
18 numbers of the combat injured that are coming back
19 at the four polytrauma centers, we're also
20 treating polytrauma TBI folks stateside, you know,

21 OCONUS that had accidents in Germany and whatnot.
22 So we want to make sure that we -- and that, on

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41

1 occasion, is a large number of the folks that we
2 have on the unit depending on what's going on
3 overseas.

4 COL. FORTUIN: We have more TBIs in
5 country --

6 MS. BENEDICT: Right.

7 COL. FORTUIN: -- from the war anyway.
8 So that's a critical component. Except that I
9 think Congress directed this at this point more
10 for the combat wounded. But it'll grow. It'll
11 grow from there.

12 MS. MOESSNER: Yeah.

13 MS. CAMPBELL-KOTLER: There was not any
14 mention of evaluation in the mandate from
15 Congress.

16 COL. FORTUIN: But it's implied in the
17 report.

18 MS. CAMPBELL-KOTLER: Yes.

19 COL. FORTUIN: It's implied -- if we
20 have to do a report, you've got --

21 MS. CAMPBELL-KOTLER: It's implied that
22 there would be evaluation. Right.

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1 COL. FORTUIN: You've got to report on
2 something.

3 MS. CAMPBELL-KOTLER: Exactly. But my
4 concern is that the report is not coming from the
5 Panel; it's coming from the secretary of Defense,
6 secretary of Veterans Affairs.

7 COL. FORTUIN: Exactly.

8 MS. CAMPBELL-KOTLER: And how long will
9 it take for them to gear up to be able to have an
10 evaluative component to this? And do we have to
11 wait until that's in place before we start
12 distributing the curriculum?

13 COL. FORTUIN: I hope not. I think that
14 would be a huge mistake.

15 MS. CAMPBELL-KOTLER: Right. I do, too.
16 I don't know. I mean, I want to get it out, but
17 then the evaluation is going to be, I guess, maybe
18 retrospective, at least for the people that
19 received it. I don't know how this is going to
20 work. I don't know. I don't have any experience
21 with how these things are done in the military.

22 SPEAKER: Sometimes the secretaries

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1 delegate it down to the -- you know, whoever the
2 undersecretary for Health is. Or, I mean, I've
3 done 26 Reports to Congress, and some of them were
4 signed by the secretary, some by the DEPSEC, some
5 by the ASD. But I think we're going to need
6 qualitative information that Rose Mary suggested
7 with those tear-off cards before you can get into
8 the quantitative. Because I think that's -- we
9 just need to see what we get. You know, was this
10 useful? How was it useful? The comments, that
11 kind of thing.

12 MS. BENEDICT: Are we having to collect
13 data to justify further funding for the cost? No?

14 MS. CAMPBELL-KOTLER: No.

15 MS. BENEDICT: So years down the line --

16 MS. CAMPBELL-KOTLER: We always have to
17 justify.

18 COL. FORTUIN: You will have to collect
19 that sort of information to program funds for the
20 future.

21 MS. BENEDICT: Right. That's what I'm
22 asking.

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1 MS. CAMPBELL-KOTLER: Yes.

2 MS. SARMIENTO: I think it's a big trend
3 with all communication, education initiatives, is
4 any time you're going -- even before you start
5 launching it they're going to ask you what's the
6 impact, and so thinking about things just helps
7 you be prepared for the questions. You will get
8 them.

9 Because it's like why are we putting all
10 this work together? why are we putting this out
11 and just disseminating it? They don't want to
12 hear process numbers anymore. I mean, those
13 metrics are very important, like the dissemination
14 numbers, the web hits, but the -- I mean, I hear
15 it over and over again. Okay, great, thanks for
16 the process numbers, but what sort of impact are
17 you having?

18 And the evaluation plan, I think, is
19 key. And really -- but first you need to have
20 your dissemination communication plan in place
21 because if you identify who your primary and
22 secondary audiences are, your evaluations are

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45

1 going to be targeted to those separately. You're
2 not going to use the same survey or survey
3 channels to do that.

4 And what we actually do is do a
5 quantitative and qualitative evaluation. And
6 honestly, you generally need funding to do these
7 things. So I don't know if there is an
8 opportunity to go back and say this is something
9 we want to do and get that funding or if an
10 outside agency is willing to take this on
11 independently. But, you know, actually, it's nice
12 when a separate agency that didn't develop the
13 material actually evaluates it. It's less biased.

14 MS. CAMPBELL-KOTLER: Yes.

15 MS. SARMIENTO: But we have -- the same
16 I sent you last night, it shows that we did a
17 quantitative survey and then follow-up focus
18 groups to get some qualitative data as well. So,
19 we kind of used that format because you can tease
20 out certain things depending on -- you know,
21 surveys can tell you so much when they're
22 quantitative, but you can't really get a lot of

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46

1 the details. And from those findings we've really
2 built and expanded on, you know, those
3 initiatives. So I have a few types of examples.
4 I just sent you one and then in terms of report
5 out, we do activity reports on all of our
6 initiatives. And if we have evaluation findings

7 we put those in there, obviously. But we also
8 collect partnership activities -- how many
9 materials partners are disseminating, their
10 outreach. You know, if it's including the number
11 of people that are doing education trainings,
12 those type of things are also good to include.

13 So I can send a sample of that type of
14 report, as well.

15 MS. MOESSNER: All samples welcome.

16 MS. CAMPBELL-KOTLER: That's right.

17 MS. SARMIENTO: Thank you.

18 MS. COHOON: Meg, going to an earlier
19 question you had as far as the family impact, one
20 of the things that we've been seeing is that the
21 main caregiver becomes the gatekeeper of the
22 information. And sometimes the children don't

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47

1 necessarily get this particular information,
2 especially as far as the sound. And when we were
3 developing this, I remember telling you all that
4 it's very important for the kinds to understand
5 where the injury took place and then what sort of
6 signs and symptoms are we seeing in our parent.

7 So, again, when we're looking at
8 dissemination and we're looking at as far as the
9 impact, if somehow we can look to see if the kids

10 ever got this information -- because we do put
11 some pieces in there for them, but that will then
12 outline if maybe something needs to be built
13 specially for the children. And I know that the
14 services now are paying more attention and having
15 breakout groups at Walter Reed and Bethesda and
16 Down and BMC. So, again, having -- using this as
17 an opportunity to see if the kids are actually
18 gaining anything from this, too, would be helpful.

19 MS. KILADA: This is Sandy. Just to
20 follow up on that comment, I'm wondering if we
21 should put something in the curriculum, maybe in
22 the Introduction, just saying, you know, something

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48

1 about sharing it with your children -- the
2 importance of them sort of understanding what's
3 happening and how that affects them positively, or
4 some language. Is that something we can whip up?

5 MS. COHOON: We're not sure why the
6 gatekeeping is going on and if it's actually
7 intentional or not. When Dr. -- his last name is
8 escaping me now -- Sarcozo from USHU -- he
9 actually came to our wounded camp and was using
10 them as participants for a study. And when he
11 had -- others that run in the same field with him
12 just came out with a report -- in there talked

13 about the fact that they do find when they talk
14 with the caregiver, they don't talk about the kids
15 at all. And it's lacking so much that it's almost
16 like, you know, it stands out on its own.

17 So, the conversation he and I had was
18 that -- because he was going to do focus groups
19 while he was doing our camp -- was if that was an
20 opportunity to ask at that time to find out why
21 the lack of discussion as far as around the kids.
22 so -- and he was going to talk with us when --

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49

1 after they started doing their analysis with that.
2 But it's fairly stark that they don't do that.
3 And we don't know if it's deliberate or not.

4 MS. LLOYD-KOLKIN: This is Donna
5 Lloyd-kolkin. We do have a section in Module 3
6 about how to talk to your children. And we don't
7 specifically suggest there that they talk -- that
8 they look at the diagrams, for example, and
9 explain how it happened. But we could certainly
10 add a bullet to that -- a specific suggestion.

11 MS. COHOON: It's not so much about
12 adding into the curriculum. It's to see if the
13 curriculum -- any information in the curriculum
14 got to the kids. Because one of the focus groups
15 --

16 MS. LLOYD-KOLKIN: Encourage the
17 caregivers to actually do that in order for that
18 to happen.

19 MS. COHOON: well, maybe if the kids are
20 present when they're talking to the caregiver,
21 encourage the kids to be looking at the book on
22 top of it all. Because if it's given to the

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50

1 caregiver, we're not sure if they're even going to
2 share it with the kids. That's the --

3 SPEAKER: That's their choice.

4 MS. CAMPBELL-KOTLER: The focus group
5 caregivers did say that they would use this to
6 share with other family members. It didn't say
7 children specifically, but they did at least have
8 the concept that this was going to be a tool that
9 would be helpful in communicating with others
10 about the TBI. So, maybe.

11 MS. COHOON: But we did have one
12 actually say that they didn't like that part in
13 there with the children. Remember?

14 MS. CAMPBELL-KOTLER: You're right.

15 MS. COHOON: They thought that they were
16 being told that that's what they have to do.

17 MS. CAMPBELL-KOTLER: Had to do. You're
18 right.

DHB-101509 (2)

19 MS. COHOON: But again, that was
20 probably one person.

21 MS. BENEDICT: You know, back to
22 evaluation and what we need to look at, I think

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51

1 sort of one of the unintended benefits or usages
2 -- when this starts to get out there, there's
3 going to be a great demand for this material for
4 training purposes.

5 MS. MOESSNER: I know.

6 MS. BENEDICT: And I think -- so we're
7 going to be sending out a fair amount of
8 curriculums, I guess, curricula, to sites that are
9 going to want to be using it to train TBI
10 caregivers and new people coming onboard. And I
11 think we need to track those numbers as well.

12 And it might be really good to get some
13 feedback from them as to what they think of it as
14 a training tool. Because I know I've shown a
15 couple of people this. They're like, oh, my god.

16 MS. MOESSNER: I know.

17 MS. BENEDICT: Yeah. We need this for
18 -- the benefits piece, all the social workers are
19 interested in looking at the benefits piece. So I
20 think we need to think about that, too.

21 MS. MOESSNER: Yeah. I've actually had

22 DHB-101509 (2)
calls from some of the VAs around the country

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52

1 saying we heard it's almost done. We have such
2 high staff turnover and can we use this as a
3 training tool for our new staff?

4 MS. BENEDICT: There's a little bit of a
5 buzz out there. They kind of know something's
6 coming; they don't exactly know what it is.

7 MS. MOESSNER: Right.

8 MS. BENEDICT: But it's out there, so.

9 MS. KILADA: Can I just say something
10 quick? This is Sandy. Just based on something
11 Kelly said yesterday, it seems -- because of the
12 price of this piece, we may want to direct people
13 more and more to the online electronic curriculum.
14 And I just wonder if once we start doing that
15 there should be a different evaluative piece.
16 Maybe something right on that is connected to it
17 that they can tap into it and evaluate it that
18 way.

19 LTC. MAUFFRAY: The other thing that's
20 very easy to do right up front is -- the
21 electronic version -- is the PDF version of this
22 can be made available this afternoon. I mean,

1 when it's ready to go it can be that fast. And
2 from a distribution standpoint, from a cost
3 standpoint of supplying the information, it
4 becomes then just a matter of bandwidth.

5 And that's really a very efficient,
6 cost-effective way to be able to distribute the
7 product in its exactly as you see it form.

8 MS. BENEDICT: People can print off what
9 it is that they're really looking for.

10 LTC. MAUFFRAY: True.

11 MS. BENEDICT: Instead of us having to
12 send the entire product and maybe what they really
13 want is Module 4.

14 MS. MOESSNER: Right.

15 LTC. MAUFFRAY: Exactly.

16 MS. SARMIENTO: I think that a huge
17 trend anyway. Most of the things we do now we
18 focus on electronic distribution. We just find
19 that that's how people search now and really don't
20 want that many bulky things.

21 I think this has been brought up before
22 and I know we were talking about it a little bit

1 yesterday, but I imagine that your site is already
2 tagged for 508 and those sorts of things?

3 LTC. MAUFFRAY: 508 compliance is one of
4 the requirements. Yes.

5 MS. SARMIENTO: Great. Because any time
6 a price release, they're going to check your site.
7 And they'll block any launch, so make all the
8 PDFs. That's great.

9 And then in terms of planning for your
10 evaluation, even before you have funding in place
11 you may want to start your OMB and IRB process
12 because it can take about a year.

13 MS. MOESSNER: Seriously?

14 MS. SARMIENTO: And ideally you can --
15 yeah, unfortunately.

16 MS. MOESSNER: Wow.

17 MS. SARMIENTO: That's pretty -- yeah, I
18 mean, that's not an overestimate. That's pretty
19 -- sometimes a year and a half, but they have new
20 OMB people and it's been -- the last one took me
21 about eight, nine months, which was very exciting.

22 But so what we do is we actually start

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1 the evaluation paperwork way before the launch
2 because ideally what you would do is do a

3 pre-test/post-test. But, again, it depends on
4 your funding and usually we don't have funding to
5 do that either. But -- so you would need the
6 pre-test obviously approved before you have a
7 launch or else you can't pre-test it. But if you
8 can't get that in place and don't have the
9 funding, which is very common, you can just do the
10 post-test. And it's nice to do it six months and
11 then a follow-up at least a year. Like a
12 six-month and a year or at least just a year out.

13 And then you can also do, you know,
14 various things as I mentioned before. Online is
15 obviously less expensive, but it will still have
16 to be through the OMB process, so.

17 SPEAKER: It would be a great
18 dissertation project.

19 MS. MOESSNER: Yoo-hoo. Any grad
20 students in the room?

21 MS. SARMIENTO: We get requests from
22 students -- oh, my gosh -- all the time that want

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1 to do dissertations or their master's thesis using
2 our information. And we've had some that have
3 gone out and taken a lot of our sports materials
4 that they're really interested in. And so they
5 actually will go and say I'm getting -- I'm going

6 to my local community club and I'm going to do
7 training on coaches; I'm doing a pre- and
8 post-test, and they send us their results, which
9 is great. You know, it's small scale, but if you
10 have someone that's very active and motivated.

11 But, again, you know, we've been
12 fortunate in some cases to have outside
13 universities or outside agencies that have great
14 contacts with the target audience that have taken
15 on the evaluation on their own and then showed us,
16 you know, here's what we found. And then they
17 publish the data. So, you know, sometimes you can
18 get partnership evaluation, as well.

19 MS. MOESSNER: Okay.

20 MS. BENEDICT: I think it points out the
21 bigger issue in that when you brief in November is
22 --

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57

1 MS. MOESSNER: I don't want to.

2 MS. BENEDICT: Is it possible to say
3 then that the committee is recommending that we
4 put together an evaluation piece for this -- a
5 formal evaluation piece -- and that we're going to
6 need some funding to do that because it's onerous
7 and it's expensive. And it takes time to do.
8 Instead of sort of shooting from the hip.

9 MS. MOESSNER: Right.
10 MS. BENEDICT: And they've already spent
11 a ton of money on this thing.
12 MS. MOESSNER: Right.
13 MS. BENEDICT: So, you know.
14 MS. STABLES: Do you think that USIS
15 would be interested in this?
16 LCDR. HERBIG: Do I think so?
17 SPEAKERS: Yeah.
18 LCDR. HERBIG: Who asked me that?
19 MS. STABLES: I did. Over here.
20 SPEAKER: Gloria.
21 MS. STABLES: Ma Stables. Don't they
22 have students? would they be able to (inaudible).

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58

1 LCDR. HERBIG: You know what? Actually
2 -- sorry, I know I'm supposed to speak through the
3 microphone. This is Herbig.
4 The graduate nursing students do
5 secondary data analysis, so it's feasible that we
6 could work with them doing the evaluation piece of
7 this. Yes.
8 MS. STABLES: Have the professors plan
9 the whole strategy and then have the students --
10 LCDR. HERBIG: Yeah, I could talk to Dr.
11 Kearney Littleton about it.

12 MS. STABLES: Don't they do qualitative?
13 Don't they have a quantitative and a qualitative
14 for their master's?

15 LCDR. HERBIG: But it's -- master's is
16 usually secondary data analysis.

17 MS. STABLES: Oh, is it? We didn't.
18 Because you could do qualitative as far as, you
19 know, where you could hold the focus groups, those
20 that have already gotten it, and then get them
21 together.

22 LCDR. HERBIG: It would a good project

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59

1 for our PhD students.

2 MS. KILADA: I was also thinking the
3 master's in public health students, that might be
4 another group that would --

5 MS. STABLES: But you need a group
6 that's going to plan it. You know? Someone who
7 has done it before you bring in the students.

8 SPEAKER: And we need funding.

9 SPEAKER: Yeah, I have to do primary for
10 my master's.

11 MS. MOESSNER: Anything else on this
12 topic of -- thank you for the good suggestions.

13 Mike?

14 MR. WELSH: Mike welsh. Since this is
Page 53

15 our final hour just about, there's a lot of work
16 still to accomplish. Maybe what the Panel should
17 start leaning towards is at this point writing the
18 Executive Summary of creating a list of
19 recommendations to the Health Board with, you
20 know, with all the issues about metrics and so
21 forth, creating a need for certain talent to be
22 onboard to have a proponent agency, such as the

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60

1 Center of Excellence for Mental Health -- whatever
2 they call it at General Sutton's organization.

3 COL. FORTUIN: DCoE.

4 MR. WELSH: DCoE. Get them to be the --
5 recommend them as the owner to have the
6 responsibility for maintaining with the
7 establishment of analytic analysts and a
8 combination of, you know, coordinator, public
9 affairs-type officer on the staff. And those guys
10 would take care of this and keep it alive and keep
11 it growing. Because there's so much that has to
12 be done to keep this alive. And this Panel is
13 getting ready to go away and the best we can do is
14 make recommendations to the Health Board and ask
15 the Health Board to maintain these Panel members
16 as a reach-back resource for DVBIC.

17 I'm off.

18 MS. MOESSNER: Thank you. Good. Anyone
19 else? Commander Feeks?

20 CDR. FEEKS: Yeah, this is Commander
21 Feeks. The Panel, as you know, is scheduled to be
22 disbanded 60 days after the product is delivered

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61

1 to the secretary. I'm not sure what the hurry for
2 that is because your appointments, otherwise,
3 wouldn't expire until next summer. But I think
4 that there is a general desire in the Committee
5 Management Office of Washington Headquarter
6 Service that oversees all the federal advisory
7 committees in the DOD to make sure that things
8 that are supposed to disband actually do. So, I
9 have made the suggestion why don't you just kind
10 of keep them around until the summertime in case
11 there's a need to reach back? And the response
12 that I got was, no, we're going to go with the 60
13 days thing.

14 As I've mentioned on other occasions, I
15 still expect that the TBI Subcommittee of the
16 Defense Health Board will be reappointed, or at
17 least it will be populated, whether it be by
18 reappointing the people that were on it or new
19 appointments, and that they will be the external
20 advisory body to oversee the curriculum and its

21 periodic review and revision. I don't know if
22 that's an answer to your question or not.

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62

1 MS. MOESSNER: Does anybody -- just out
2 of curiosity, anybody in the room sit on the TBI
3 Subcommittee? I know, Barbara, you have some link
4 to the DHB, but you'll have to remind me. So
5 you're on that particular subcommittee?

6 MS. COHOON: Yeah. And then I also sit
7 on the -- the TBI and Psychological Health have a
8 joint one. I sit on the TBI and then the TBI and
9 Psychological Health pulled some people together
10 to sit on a joint.

11 MS. MOESSNER: Okay.

12 MS. COHOON: But they haven't met except
13 for that once. And the TBI hasn't met for quite
14 some time.

15 CDR. FEEKS: Well, the issue with that
16 subcommittee is that most of their appointments
17 expired in March. And with the transition of
18 administrations, I mean, think about the process
19 of appointing an entire government. That's a big
20 thing. That's a big process and we are affected
21 by that. So that's why the TBI Subcommittee
22 hasn't gotten together.

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1 And the ad hoc working group that you
2 refer to that consists of some members of the TBI
3 Subcommittee and some members of the Psych Health
4 Subcommittee that were assigned to work on a
5 question that was put to both subcommittees, is
6 affected by that. Only the Psych Health
7 Subcommittee is whole right now and the TBI
8 members of that working group are awaiting
9 reappointment.

10 MS. MOESSNER: Okay.

11 MS. CAMPBELL-KOTLER: Is it possible to
12 add members from this Panel to the TBI
13 Subcommittee?

14 CDR. FEEKS: It is certainly possible.
15 It's not up to me, but it sounds like a great idea
16 to me. And at the same time, that would
17 constitute a new appointment rather than a
18 reappointment. And as you can imagine, you know,
19 the new administration wants to be fully engaged
20 in the appointment of new people to whatever
21 offices they're supposed to be appointing people
22 to. And that includes the federal advisory

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1 committees, even though their existence is to give
2 advice and not to make policy.

3 So, but it's always a lengthy process to
4 bring in a new administration. For instance, I'm
5 told -- and maybe some here who have memory of
6 this -- when the Bush Administration came in, in
7 January of 2001, I think it was not until at least
8 November that the assistant secretary of Defense
9 for Health Affairs was confirmed. Does that sound
10 right?

11 SPEAKER: October.

12 CDR. FEEKS: It was October? Okay.

13 SPEAKER: That's the fastest I've ever
14 seen since 1990.

15 CDR. FEEKS: Okay. So there it is. It
16 takes a while; it just does. Once they're in
17 place, then things, you know, acquire a rhythm and
18 a speed that's more -- well, they acquire the
19 rhythm and the speed that you'd expect them to
20 have when everything is up and running. But we're
21 not there yet.

22 MS. BENEDICT: Commander, I have a

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1 question. On the TBI Subcommittee, is there a
2 subcommittee of the subcommittee or whatever that
3 deals with caregiver issues? Because with all
4 this pending legislation and all this interest in
5 caregiver support, it would seem like that would
6 make some sense. But I don't know. Are there
7 subject matter experts on the TBI Committee that
8 are caregiver SMEs?

9 CDR. FEEKS: I'm going to put Barbara on
10 the spot and ask her to help me with this question
11 because, frankly, I know that there are
12 neurologists. The chairman is a brain surgeon and
13 that there are also, you know, neuroscience PhD-
14 types. But I don't know if there's a caregiver.

15 MS. COHOON: When we met the first time
16 that I came, it was joint with the Psychological
17 Health. And so, you know, it's not -- and
18 everyone didn't talk about as far as necessarily
19 what their background -- and the reason for me
20 being asked as far as to join was to bring a
21 family voice onto the piece. But most of the
22 subcommittees that I have seen, they tend to be

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66

1 more of your resident experts in the area in which
2 the committee was stood up. Health care is the
3 same way. And I found the same thing with

4 psychological health, although there is a chaplain
5 and an ethicist that's on that particular piece,
6 too. But that's the only time that we met.

7 And I -- who ended up becoming the
8 chairman for the TBI Subcommittee because it was a
9 vote on the e-mail? Was it the woman who became
10 -- who became the chairman of the TBI?

11 CDR. FEEKS: Russ Bullock. He's the
12 brain surgeon from Miami.

13 MS. COHOON: Okay.

14 CDR. FEEKS: And, in fact, let me just
15 -- it's not a very --

16 MS. COHOON: Because Dr. Kelly had to
17 step down.

18 CDR. FEEKS: Right.

19 MS. COHOON: And so -- and again, I know
20 there's been some talk about us meeting sometime
21 in the fall and then that got changed, so it's the
22 appointment issue.

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1 CDR. FEEKS: Right. That is the issue.

2 MS. COHOON: Okay. All right. But, I
3 mean, everyone is having to be reappointed, no
4 matter what, not just the Defense Health Board.
5 The Beneficiary Advisory Panel, which many of us
6 sit on, same thing, had to go through a

7 reappointment process. So there's a lot of
8 paperwork being funneled through. So it's -- time
9 is slow.

10 CDR. FEEKS: That's right.

11 COL. FORTUIN: If I could -- this is
12 Nancy -- these things don't have to reside in the
13 Defense Health Board. There's, you know, there's
14 a lot that -- between VA and DOD, they do work
15 together a lot. So I don't think that we have to
16 be -- I think there's valid concern, but I think
17 that, you know, DOD and VA can be responsible and
18 carry these things on without an advisory
19 committee, as well. So I don't think that the
20 future of this is dependent upon an advisory
21 committee to continue.

22 MS. MOESSNER: Good. All right.

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68

1 All right, thank you, everybody. I
2 think we're going to let Colonel Mauffray give his
3 presentation on the CEMM and what's been happening
4 on their website and what their plans are.

5 LTC. MAUFFRAY: All right. Well, good
6 afternoon. I'm Dr. Randy Mauffray. I'm the
7 director of the Center of Excellence Medical
8 Multimedia out in Colorado Springs at the Air
9 Force Academy.

10 And as most of you are aware, we've kind
11 of been simultaneously, I guess, working on
12 traumatic brain injury and trying to disseminate
13 information to folks about traumatic brain injury.
14 So this is the Traumatic Brain Injury: The
15 Journey Home Project that we've been working on in
16 cooperation with DVBIC, as well.

17 So, what I'd like to do is just show you
18 a little bit about this particular site and then
19 discuss with you some of our plans to try to
20 incorporate the Defense Health Board- Family
21 Caregiver curriculum information into this site,
22 which I think will be a nice pairing and really

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1 provide a very robust single point of information
2 for patients and family members to have access to.

3 As you guys may recall, the original
4 organization of the site basically goes through
5 the basic anatomy and physiology of the brain. We
6 do have some content on mild TBI, followed by
7 moderate. And then the caregiver journey piece,
8 which we have laid out here, is the location that
9 will predominantly be the repository for your
10 Module 3 information. Most of Modules 1 and 2 are
11 contained in these preceding three pieces. And
12 then Module 4 will be sort of a -- brought in as

13 more of a text-base. That's a very volatile-type
14 information. The information on benefits and
15 things of that nature that needs to be updated
16 will exist more as a text-based, searchable piece
17 that's part of the site as well.

18 Our initial plans were to take what is
19 Module 3 and using it kind of as a source
20 document. What we're looking at creating is six
21 sessions. It would be sort of like support group
22 sessions. And this is kind of going through

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70

1 incidental learning-type techniques where what
2 we're going to do is have three families. The one
3 family consists of sort of -- it's a newlywed
4 family with a younger wife, injured husband. The
5 second family was an older husband who had been
6 injured with a wife possibly in her 40's with an
7 older teenage son that consists of the second
8 family. And then the third family was a parent --
9 mother-father family with an injured son. So
10 those were the three groups that would be
11 interacting with what had gone on with their
12 traumatic brain injury.

13 And those sessions would be guided by an
14 expert. And the content that is Module 3 is kind
15 of providing the basis of that script. The quotes

16 that have been developed throughout the curriculum
17 actually are being incorporated and rolled in to
18 provide that kind of same connection and personal
19 interaction that folks have seen in that.

20 One area that we're having to pull from
21 Modules 1 and 2 is you guys did quite a bit of
22 effort in the -- what you see, what can I do part

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71

1 of the symptoms and affects of traumatic brain
2 injury. So what we're looking at there is we're
3 scrubbing through those two modules and actually
4 taking that content and bringing it into the
5 sections where they're appropriate. So that
6 information will also be available as you're
7 making your way through the various parts of the
8 website. So I'll just show you a little bit about
9 what we have here.

10 And just as a note for those of you that
11 weren't at the military TBI meeting that we just
12 recently had, the site was just recognized with a
13 FREDDIE International Health Media Award, which is
14 one of the -- or is the top honor, really, in
15 health information and health media -- this kind
16 of environment.

17 One of the areas -- we're bringing that
18 other information from Modules 1 and 2 -- one of

19 the places that kind of information will tend to
20 reside is here where it says Related Information.
21 So when you get the overview information that's
22 here in the main column, you'll be able to bring

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72

1 up those cross linked pieces. And this provides
2 us the opportunity to take various different
3 aspects of the curriculum and tie them together.
4 So as somebody is going through the site they can,
5 you know, jump immediately to another piece that
6 gives them direct access to those other things
7 that we were talking about.

8 So, for example, if you're looking at
9 one of the symptoms, Related Information may be
10 the "what will I see, how can I treat it, what can
11 I do" part. And those will be linked in there.

12 One of the other things I had shown
13 earlier at one of the other sites was the
14 interactive brain piece. And this has continued
15 to grow out as well. This particular piece allows
16 someone to sit here and actually explore various
17 aspects of the brain. You can move the brain;
18 choose any particular area that you want to look
19 at. It gives you the overview of what that
20 particular area of the brain is. It tells you
21 what that area of the brain does, and it also

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tells you what happens if that part of the brain

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73

1 is injured. And all this is also voiced-over so
2 it can be read to you, as well.

3 And so we have a basic side view of the
4 brain. We have a sagittal view of the brain. It
5 remembers where you were, brings it in. Also, for
6 example, you have the basic lobes, which are here,
7 the red dots. It also brings up functional areas,
8 like Wernicke's area, Broca's area, the sensory
9 cortex. So you can get an idea. At least if you
10 know where the injury may have taken place, that
11 these are some of the symptoms and some of the
12 effects that you might expect to see. So, those
13 are just some of the additional changes and
14 additions we've been making to this little
15 interactive brain piece.

16 It also brings up a vision piece. And
17 here we just have basic visual anatomy describing
18 everything from eyes through to chiasm nerves,
19 optic radiations, and what have you. It brings up
20 visual fields. And what this part actually does
21 is allow you to see what normal visual field --
22 you can see what both visual fields would look

1 like. And then if you click on a particular area
2 it shows what happens if there's damage. So in
3 this case, damage to the left optic nerve. You
4 actually lose all vision in the left eye,
5 maintaining vision in the other side. As you push
6 back into, like, the optic tract, optic
7 radiations, it shows you what kind of visual
8 deficit you might see. And in this case you have
9 this kind of pie-in-the-sky deficit when you end
10 up on the optic radiations. Or if you actually
11 lose an occipital lobe where you have this
12 homonymous hemianopsia that would develop.

13 And you also drop in some motility
14 issues. And you can actually see the various
15 pieces of -- so just normal motility. And then
16 you can bring out, you know, what happens if you
17 have a cranial nerve deficit. And so here it's a
18 right third cranial nerve. You can see there's
19 very little movement on the right eye. So just
20 some other pieces and then just some basic left
21 brain-right brain-type stuff.

22 So trying to provide a way for an

1 individual to kind of go through and look at what
2 might have happened to the brain and why they're
3 seeing a particular aspect or symptoms in their
4 loved one.

5 And then all those menu items that you
6 saw up on the home page are carried through as you
7 break out the various sections. We also had
8 worked with DVBIC and Henry Jackson to try to
9 match some of the coloring that was being used in
10 the caregiver curriculum so that that was brought
11 forward. And then also there's a Resource Center
12 piece here that's pulled up and has everything
13 from related links to FAQs.

14 One of the things that I mentioned
15 earlier is that there -- and it can be human
16 resources, it can be there in the Related
17 Information piece -- but it's very easy for the
18 curriculum to immediately be available just simply
19 uploaded and it could be completely available for
20 download tomorrow, which is, you know, provides
21 access to that information very, very quickly.
22 And I think it will be a very good way to move

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1 forward.

2 That's sort of just a quick overview and
Page 68

3 you guys have already seen some of the video and
4 animation pieces to it so I'm not going to take a
5 lot of your time in showing that kind of
6 information again. I'd like to -- if there are
7 any questions or comments on what we had discussed
8 as sort of how we were planning to move forward in
9 incorporating the curriculum, I'd certainly like
10 to hear any comments on that.

11 Mike?

12 MR. WELSH: I didn't catch in the
13 beginning -- is this your test site or is this
14 public now?

15 LTC. MAUFFRAY: This is live. This is a
16 live site.

17 MR. WELSH: Okay.

18 LTC. MAUFFRAY: And I didn't click on
19 this. You guys have seen some of the personal
20 journeys as well. And one of your esteemed Panel
21 members agreed to be on this particular piece.
22 But these are stories about people who have

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77

1 recovered or are recovering from traumatic brain
2 injury.

3 And some have recovered more than
4 others.

5 CDR. FEEKS: Christina?

6 LTC. MAUFFRAY: And this is Scott
7 Lilley, who was an Air Force member that suffered
8 a traumatic brain injury.

9 (Video plays)

10 SPEAKER: "April 15, 2007, we were
11 traveling home from the middle of Baghdad where we
12 were working on a JSS. As we were coming home,
13 about a mile from base, coming around a curve, an
14 EFP went off. A piece of shrapnel somehow got
15 inside the turret where I was manning the 240 and
16 it hit me in the left side of the head. So they
17 put me on a helicopter and flew me to Balad. Once
18 I got to Balad is when they did all the surgeries
19 and everything and took out about a fourth of my
20 skull."

21 SPEAKER: "It was a Sunday morning.
22 Jolene and I were getting ready for church and we

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1 got a phone call."

2 SPEAKER: "When Frank answered the phone
3 he said, 'Oh, good morning, Staff Sergeant Scott
4 Lilley,' because he saw that it came from Minot
5 Air Force Base, so we thought maybe it was just
6 coming through."

7 SPEAKER: "But it turned out it was his
8 commander from Minot. And he told us that Scottie

9 had been wounded."

10 SPEAKER: "Then I heard silence from
11 Frank and I thought what's going on? And all of a
12 sudden he came into the bedroom and he was writing
13 stuff down on a piece of paper and it said 'head
14 wound, shrapnel to the head.'"

15 SPEAKER: "He was to be airlifted as
16 soon as possible from Balad to Landstuhl in
17 Germany."

18 LTC. MAUFFRAY: Those are available on
19 the site, obviously, if anyone would like to go
20 and see those. There are five of those on there
21 currently. These focus predominantly on the story
22 of the individual that was injured and focuses on

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79

1 their story. What we also plan to do is bring in
2 the caregiver piece and focusing on the caregiver.

3 what we are currently discussing is
4 whether or not to go back and revisit some of the
5 people that we interviewed now nearly almost a
6 year and a half ago to get their follow- on
7 information and see -- and compare, and that way
8 you actually have the two things on there, on how
9 things have gone for them. But I think having
10 that caregiver-specific piece where they're
11 talking about their own journey -- and that's the

12 title of that section, The Caregiver's Journey --
13 I think will be very important in how it's
14 affected their lives and how they're moving
15 forward.

16 Yes?

17 LCDR. HERBIG: This is Herbig. I have a
18 question. If they want to download this
19 curriculum exactly as it is, where are you going
20 to locate that on the website?

21 LTC. MAUFFRAY: It can be located any
22 number of places. The first place that comes to

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80

1 mind is as a resource right here. The Related
2 Information piece that I showed a second ago, it
3 could actually be listed here as the curriculum.
4 Right there. So it can -- that's one thing that's
5 wonderful about the web. It can physically live
6 in one location, but you can have links to it from
7 any place that's appropriate. So I think there
8 are a lot of ways we can connect into it.

9 One of the discussions we were having
10 with the developer -- it's easier to do in a
11 fixed-media product; a little harder to do in the
12 web-based product -- was actually bookmarking
13 directly into the curriculum. So if there was a
14 particular piece where you were reading something

15 and you clicked on Related Information, it would
16 actually pop that PDF and then go to that page of
17 the document. So that's one sort of advanced way
18 to linking into it.

19 LCDR. HERBIG: Thank you.

20 MS. ROCCHIO: Carolyn, I'd like to make
21 a suggestion. When you do The Caregivers'
22 Journeys, if you could include at least one child

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81

1 of an injured person.

2 LTC. MAUFFRAY: Sure.

3 MS. ROCCHIO: That would be very
4 important. That would address the issue that
5 Barbara is concerned about, and I too, because it
6 doesn't affect just the caregiver. The entire
7 family.

8 LTC. MAUFFRAY: I agree. And that's one
9 of the reasons that when we were doing the initial
10 laydown -- we've actually already done some of the
11 script development for two of the sessions that we
12 were talking about. There would be 6 of these for
13 about an hour, hour and 15 minutes of a total
14 additional video time on it. And as we were
15 laying down who that would be, having that little
16 older teenage-kind of son became important. And
17 what you see is this interaction goes on.

18 And like I said, this is sort of -- you
19 have the, you know, didactic piece of learning.
20 This is more incidental learning. So you learn
21 from their interaction that's happening in this
22 group -- is that you actually see how it impacts

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82

1 that teenage son and how he's really having to
2 struggle with the changes that have happened to
3 his dad.

4 And then in this script it also -- sort
5 of interesting what you guys had said; we were
6 doing this development already -- the mother's
7 sort of lack of information to him, how he was
8 becoming frustrated with not knowing why this
9 stuff was going on and not having the information.
10 And so that, hopefully, will be a part that ties
11 the kids into it, as well.

12 MS. ROCCHIO: Yeah. The kids are really
13 forgotten in this. Thank you.

14 LTC. MAUFFRAY: Yes, ma'am?

15 MS. PRIES: Rose Mary. I hope that when
16 we do the caregiver component, that we'll be able
17 to do two things. Number one is to include an
18 African-American family, and maybe include family
19 members of a female veteran since our veteran
20 stories were all male, just so we've got a nice

21 representation of the populations.

22 LTC. MAUFFRAY: We try to get the racial

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83

1 cultural diversity in all the programs that we do.

2 That doesn't mean we're always successful --

3 MS. ROCCHIO: I understand the
4 difficulty doing that.

5 LTC. MAUFFRAY: -- in trying to recruit
6 people in doing it. And maybe this is a topic to
7 bring up now as we're looking at putting these
8 people in. We had -- initially our plan was to
9 have a husband who was caring for a traumatic
10 brain-injured wife. That was one of our thoughts.
11 But as you look at the statistics, they're skewed
12 so far the other way. Is that the right approach?
13 Should we dedicate a third of the characters who
14 are part of this to -- I think I was just reading
15 here it was 10 percent, 10 percent of the
16 caregivers were male. So that's just a matter of
17 discussion.

18 I would like to see what your opinion
19 is. Anyone?

20 MS. KILADA: I'll just say -- this is
21 Sandy -- I mean, I think it's still 10 percent.
22 That's still a high percentage. We just don't

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1 want to leave anybody out, especially because
2 they're already -- I think because it's such a
3 small percentage being left out of many other
4 things.

5 LTC. MAUFFRAY: Well, we did bring in --
6 the way the current laydown was, we do have the
7 father of the one individual and we did have a
8 son. And so as we were looking at the
9 distribution in where the caregiving is
10 predominately coming from, we said, okay, we have
11 two male characters who are participating in the
12 caregiving. And did that provide a sufficient
13 coverage there?

14 MS. COHOON: I know when I was just at
15 -- this is Barbara -- when I was at the VA
16 Conference a couple of weeks ago, one of the
17 things they kept bringing up to the caregivers of
18 the veterans was that it's not usually -- if it's
19 a spouse, the female that's injured, that it's --
20 the male caregiver tends to be active duty
21 themselves, too, and have also dealt with other
22 issues, like forward deployments.

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1 So not only taking care of the home, but
2 also they themselves have deployed, and don't lose
3 sight of that. So that was something that, you
4 know, I hadn't really thought about either.

5 You're thinking about the male spouse
6 that's staying home and has a civilian job. And
7 what they were bringing out is that that's not the
8 norm; it's dual active duty and that there's other
9 idiosyncrasies going on here on top of all of
10 that. So when you're looking at a male spouse,
11 maybe looking more that's active duty, not just
12 necessarily a civilian.

13 LTC. MAUFFRAY: That's a good point.
14 Yes, sir?

15 DR. FLYNN: Randy, one of the issues
16 that I think was brought up at the very first
17 meeting -- and Liza, you can speak to this better
18 than anybody -- is the element of a relative who
19 is the caregiver, but a non-beneficiary caregiver.
20 And I still recall some of the issues that were
21 brought up regarding the lack of either concern or
22 the lack of intent to serve that non-beneficiary

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1 caregiver. And I think from everything from
2 security getting on post to using the PX -- other
3 things like this, you know -- very important
4 issues for that individual that only, I think,
5 retards their progress through the state of acute
6 care. I don't know if you want to mention
7 anything about that, Liza, but that always stuck
8 in my head when you brought that up.

9 MS. BIGGERS: I think if, like, I mean,
10 I was just a sister. And even sometimes with
11 parents, if it's not a spouse then, you know, it
12 depends. As long as the caregiver can, you know,
13 be there and is funded to be there -- I'm just
14 really adamant about the whole definition of
15 caregiver being pretty open because you don't know
16 the family dynamics and you don't know who's going
17 to be that person.

18 LTC. MAUFFRAY: In this scenario that
19 we're laying out, the parent group -- the
20 mother-father group -- were non- beneficiaries.
21 So that certainly was -- that could bring them
22 into some of those issues.

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1 MS. MAXWELL: Have you also considered
2 -- this is Shannon. Have you also considered at
3 all, we've got some families with the service

4 member being wounded, but they already have an
5 EFM, special needs child --
6 MS. COHOON: Special needs.
7 LTC. MAUFFRAY: Special needs child.
8 MS. MAXWELL: -- in the household, so
9 your caregiver is now dealing with two issues?
10 LTC. MAUFFRAY: Not as a separate group.
11 And I guess I can certainly see how that would be
12 an additional challenge. The one thing we do have
13 to look at is our capacity to bring in character
14 development, which is what -- this is sort of
15 limited. And you have a fixed amount of time that
16 will provide in the video piece. And so you want
17 to develop some emotional connection to these
18 individuals, but then you also want them to be
19 providing some of this incidental learning. And
20 so when -- it's, you know, a zero- sum game as you
21 shift from one side to the other. And so if we --
22 certainly, a huge issue, the Exceptional Family

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88

1 Member program. In fact, we were just having a
2 discussion on it yesterday in San Antonio. That's
3 not something that we currently have in the plan,
4 though.
5 MS. COHOON: This is Barbara. Carolyn
6 had brought up a good point last night. Maybe

7 with your dad that you're talking about, you know,
8 when you're the parent and you have to start
9 looking at long-term plans, that you're not going
10 to be around forever.

11 LTC. MAUFFRAY: Sure.

12 MS. COHOON: Is that talked about?
13 Because I know we talk about that in the
14 curriculum as far as, you know, you may decide at
15 some point that I just can't be a caregiver
16 anymore and you need to make a plan. But, you
17 know, I thought what Carolyn brought up was very
18 moving and something that sometimes we lose sight
19 of.

20 LTC. MAUFFRAY: What we're currently
21 developing is very tied to the curriculum. So if
22 it's something that's covered in the curriculum --

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89

1 and I'm seeing nods yes -- then the intention is
2 for it to be covered as a topic because we're very
3 tightly developing it based on the curriculum. In
4 fact, like I said earlier, incorporating the
5 quotes that are dispersed throughout the
6 curriculum, trying to tie it fairly closely. So
7 if you're going through the curriculum, we don't
8 want it to be an exact duplication or anything of
9 that nature, but certainly a translation of that

10 into a video world in developing these characters.
11 So the intent is if it's in the curriculum, that
12 it'll at least be covered in there.

13 MS. COHOON: well, I know with the focus
14 group, too, the thought was that some people
15 didn't feel that recovery was necessarily going to
16 occur. And so part of the discussion again we had
17 in the curriculum is, you know, we're not
18 expecting the take home parent or the spouse that,
19 you know, there are other alternatives that are
20 out there. So, I think it would be good to make
21 sure that they know that they have alternatives.

22 LTC. MAUFFRAY: Sure. And the other

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90

1 thing was the distribution of recovery as we were
2 looking at these particular characters. We've
3 previously had discussions and one of the comments
4 that Liza had made was, you know, we don't --
5 don't take our hope as the first thing you do.
6 And so as you look at the development of these
7 things and providing information really very front
8 loaded to people, we don't want to paint a picture
9 that's, you know, too hopeful, but we also don't
10 want to take that one thing that they're holding
11 onto. As she told me then, we'll come to the
12 realization. We understand where this can go,

13 but, you know, we need something to hold onto as
14 we're trying to work through this recovery
15 process. So that -- as we were looking at these
16 individuals and how these characters were being
17 developed, it was certainly one of the things that
18 stuck into my mind.

19 we do have one of the individuals -- and
20 currently it's paired with the parents in somebody
21 that doesn't recover to the level of, for example,
22 what you were seeing in the video pieces there.

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91

1 Somebody that does require more care, is less
2 independent, and we have not made the decision to
3 have somebody that's like in a semi-conscious
4 state or anything like that as one of the primary
5 pieces that we're looking at because then you're
6 really focused more on the long-term care-type
7 situation and nursing care versus the caregiver
8 piece of actually managing the patient at home.
9 And so that particular aspect of it wasn't
10 something that we were currently planning to cover
11 in this phase of it.

12 Am I right, Liza?

13 MS. BIGGERS: I think the doctors do a
14 good enough job of keeping you in reality. I
15 think that, you know, I always thought it was

16 better to think positive, even if you knew it
17 might not turn out the way you want. At least
18 you're working towards that. Because if you're
19 not thinking like that, then what's the point of
20 you being there? So, I like the tone. I like the
21 tone of the website. I think it's right on.

22 LTC. MAUFFRAY: And like I said, the one

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92

1 quote was "Don't take our hope." I remember that
2 very distinctly from that conversation.

3 MS. ROCCHIO: This is Carolyn. Oh,
4 excuse me, Meg.

5 And a recovery, too, on a patient chart,
6 is not recovery to a family because recovery
7 occurs over such a long period of time. And when
8 you talk about the long-term care of people being
9 in nursing homes, no. I'm at the 27-year mark and
10 my son requires 24/7. He walks, he talks, he can
11 take care of himself. His brain just doesn't
12 work. It doesn't think for him. So you're going
13 to have a large majority.

14 And Barbara and I are, you know, really
15 concerned about the housing options. Some of the
16 VA's have some ancillary programs. They don't
17 necessarily work when they have that severe
18 cognitive and particularly behavioral aspect.

19 DHB-101509 (2)
LTC. MAUFFRAY: And by long-term I
20 wasn't talking about timeframe; I was talking
21 about long-term skilled nursing care where you
22 have a semi-conscious or --

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93

1 MS. ROCCHIO: And some will need that as
2 well.

3 LTC. MAUFFRAY: That's what I was
4 referring to there.

5 MS. ROCCHIO: Yes. Absolutely.

6 LTC. MAUFFRAY: But, no, I agree. The
7 fact that this is really a lifelong commitment
8 that you're being asked to make is something that
9 we need to cover. And I think part of that -- we
10 have the opportunity with the parent group to
11 provide what you were talking about, which is the
12 what happens if I'm not here. I'm no longer able
13 or capable from my own health standpoint to
14 provide this care. And then we have from the
15 relatively newly married couple, the opportunity
16 to discuss, you know, this is forever. And how do
17 I deal with that? And this is my reality today.
18 And so I think there's really a lot of good
19 opportunity there to get some of this information
20 out.

21 MS. STABLES: In terms of the

22 DHB-101509 (2)
populations that you're going to feature on here,

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94

1 do you have any Hispanics or Latinos?
2 LTC. MAUFFRAY: We haven't cast the
3 group at all yet, so all we have right now are
4 character types, not specific characters yet. And
5 so we actually have a casting call that will be
6 coming up fairly soon, in a week or two, where we
7 actually will have hundreds of different people
8 coming through reading for the parts and trying to
9 find out who is the best characters for a
10 particular area. And at that point it's a call
11 for all cultural areas, and we usually ask, you
12 know, could you provide us an emphasis for this or
13 that or another. But right now there's not an
14 individual that's set for any particular role.
15 MS. STABLES: And these are all
16 real-life families with TBI or --
17 LTC. MAUFFRAY: These will be characters
18 based on real --
19 MS. STABLES: Actors/actresses?
20 LTC. MAUFFRAY: Actors/actresses based
21 on what we're pulling from real life. And so what
22 we're trying to do -- when you -- you try to do

1 this kind of thing, when you're dealing with real
2 people, we like to keep them as real people. And
3 so you saw personal journeys, caregiver journeys,
4 and so they'll be there as the real part. But
5 when you get into the technical aspects of trying
6 to make sure that things are delivered in a
7 certain way and the information is put out there
8 concisely and reproducibly when you're trying to
9 edit and things like that, what we're trying to do
10 is develop characters that are based off of an
11 amalgamation of other information that we have.
12 So it's not necessarily this one family is
13 representative of everything that transpired in a
14 particular person, but rather using those people
15 to convey that information that we got from real
16 people. And then there will be a separate piece
17 where we have real people talk about their real
18 stories.

19 MR. WELSH: This is Mike. I don't know
20 if this will help you with your demographics, but
21 I was born in Venezuela in Maracay -- if that will
22 help out.

1 LTC. MAUFFRAY: That sounds great. I'll
2 mark that one down.

3 SPEAKER: You were born in Venezuela.
4 Was your father with the State Department or?

5 LTC. MAUFFRAY: And what I hope is that
6 as we bring the caregiver curriculum content in,
7 what we really have is a very robust, very useful
8 tool for people to be able to go to and get just,
9 you know, really get tons and tons of information
10 that's very helpful to them and in a way that they
11 can use and feel comfortable with the presentation
12 of it.

13 Oftentimes, if you get into pure
14 didactics where you have somebody up there
15 lecturing to somebody, then there's sort of a
16 turnoff. But through the incidental learning-type
17 stuff where you as a kind of reality TV-type thing
18 when you think about it, you sit there and you
19 watch somebody discuss something and you're just
20 learning from their experience. It doesn't always
21 seem quite as threatening or quite as intrusive as
22 if somebody is up there telling you what to do.

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1 COL. FORTUIN: How will you ensure the
2 consistency between the information that is not

3 directly in the curriculum and your website? For
4 instance, whenever I see TBI and PTSD together, I
5 get nervous because there are huge professional
6 points of view.

7 MR. WELSH: Thank you.

8 COL. FORTUIN: Say it again?

9 MR. WELSH: Thank you very much.

10 MR. DODSON: Yes, thank you.

11 LTC. MAUFFRAY: That particular piece
12 basically was actually brought up as a -- because
13 of that controversy.

14 we don't delve into it in great depths.
15 we basically just put out that there's this
16 potential for overlap. And that it's something
17 that needs to be aware of and things like that.
18 So we don't get into it from a standpoint in
19 advocating one way or another; just that it's
20 something to be aware of and you can see what's
21 already on the site. So, this was information
22 that came -- we ran through DVBIC and the SMEs and

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1 the development. It's not something we just come
2 up with.

3 So, the other goal is to -- and I
4 mentioned looking at Modules 1 and 2 -- we have
5 the four modules. The fourth module, really, with

6 the benefits, is heavily text- based. Module 3 is
7 that primary development piece with the caregiver
8 module. And then Modules 1 and 2, which kind of
9 provide that background information -- what
10 traumatic brain injury is, what to expect -- those
11 two are the ones that actually are requiring us to
12 kind of go through and scrub a little more in
13 detail, trying to pull out the content that we
14 don't necessarily have in a way that we can put it
15 on the site. Our intention is not to redo the
16 site to be the caregiver curriculum; the idea is
17 to mold the two and make sure that the content is
18 presented there. And that's basically the goal of
19 what we're working on.

20 COL. FORTUIN: So, who is the final
21 authority for what is on the site? Is it your
22 organization or -- is it DVBIC? Is everything run

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1 through DVBIC? How is there one voice on this
2 topic to ensure that DOD -- everyone within DOD is
3 putting out a consistent message?

4 LTC. MAUFFRAY: I can't speak for DOD.

5 COL. FORTUIN: well --

6 LTC. MAUFFRAY: That's a little above
7 me.

8 COL. FORTUIN: Since you guys are part

9 of DOD.
10 LTC. MAUFFRAY: What I was saying
11 earlier is that the development we're doing -- the
12 new development we're doing is very tightly tied
13 to the curriculum, and so it's the source document
14 that we're using for the development. So if
15 there's something you don't like in the
16 curriculum, then there's a very good chance there
17 will be something on the site --
18 COL. FORTUIN: I love the curriculum.
19 LTC. MAUFFRAY: Okay. That's our source
20 document.
21 COL. FORTUIN: And I love your website.
22 LTC. MAUFFRAY: Okay.

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100

1 COL. FORTUIN: I just, you know, it's
2 just a -- if we've got the curriculum owned by one
3 organization and the website owned by another
4 organization, how are we going to ensure that they
5 remain consistent in their messaging and so on?
6 LTC. MAUFFRAY: Yeah. You're talking
7 about the future then?
8 COL. FORTUIN: The future. Yes, sorry.
9 LTC. MAUFFRAY: Well -- and that's one
10 of the things that we'll have to address. And
11 that part of this goes into the whole policy

12 issues you guys were discussing, I guess, a fair
13 amount yesterday with how do you pass this
14 curriculum off. And maybe it goes to the Defense
15 Center of Excellence or however that happens. But
16 whenever that happens, then we will need some kind
17 of agreements in place with that organization to
18 ensure that things remain consistent because
19 clearly when there's an update to the curriculum,
20 we would like to know about that. The one thing
21 that we don't want to have is have conflicting
22 information being presented.

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101

1 Normally, the website provides the
2 opportunity to very quickly provide the update,
3 and it's actually the printed document that's
4 trailing. And so coordinating that can also be a
5 challenge as well because then even though your
6 intent is to have them simultaneously, you have an
7 investment in this printed document and so do you
8 not update the website until you have new versions
9 of the curriculum ready to go to print? Or do you
10 say, no, this information is so important that it
11 needs to go out now?

12 And the way we generally manage our
13 other sites is we have a review process that goes
14 on, and in that review process things are tagged

15 as either -- as an update for the future as an
16 urgent update or as a critical update that if you
17 can't make this update, you need to pull down the
18 information because it's so wrong that we can't
19 even disseminate it. And until you can update it,
20 it needs to come down. And so we kind of
21 categorize things in that way.

22 So, minor, technical updates go in a

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102

1 regular cycle. Major updates happen largely based
2 on funding. And then those critical updates,
3 obviously, can push unfunded requests and sort of
4 urgent demands for updates. And so that kind of
5 agreement, we need to know who the controlling
6 body is going to be.

7 COL. FORTUIN: Okay. And that's my
8 question. So, currently, the Air Force owns -- is
9 the authority for the website.

10 LTC. MAUFFRAY: Correct.

11 COL. FORTUIN: But through a Memorandum
12 of Agreement or whatever --

13 LTC. MAUFFRAY: We have a contract in
14 place for -- and a MOU in place with DVBIC,
15 correct.

16 COL. FORTUIN: Okay. Great.

17 LTC. MAUFFRAY: And the Henry Jackson

18 Foundation.

19 COL. FORTUIN: Thanks.

20 MS. COHOON: Just to use an example, we
21 just this morning change -- or was it yesterday --
22 added "post- traumatic stress/post-traumatic

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103

1 stress disorder" because Admiral Mullen has been
2 using "post-traumatic stress" on a regular basis.
3 So to reflect that -- so, again, bringing up
4 Nancy's point about staying on message with, you
5 know, you have PTSD -- anyway, could you have
6 both? Could you have post-traumatic stress and
7 TBI? Because I know there can be co-morbidity
8 going on at the same time, but that's not my area
9 of expertise. So would he need to add
10 post-traumatic stress on this piece -- on this
11 website or not?

12 COL. FORTUIN: We talked about piecing
13 it: Post- traumatic stress disorder, PTSD, and
14 whatever. Right? Yeah.

15 LTC. MAUFFRAY: You're asking whether or
16 not to add post-traumatic stress as an
17 intermediary kind of diagnosis before
18 post-traumatic stress disorder.

19 MS. COHOON: That's not my area of
20 expertise. I'm asking those, you know, that TBI

21 is their area.

22 DR. FLYNN: This is Fred. I think it's

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104

1 imperative, especially when I know we're going to
2 get into mild TBI. But the persistence of
3 symptoms weighs very, very heavy in those
4 individuals who may have a validated history of
5 mild traumatic brain injury or concussion. But
6 there's a lot of data out there that suggests that
7 the persistence of symptoms over time is related
8 to post-traumatic stress. I don't think that
9 these things are really two different issues that
10 need to be stovepiped because the one common
11 denominator is the human brain. And it's all
12 synthesized up there and, you know, molecules and
13 chemicals and what have you. And whether it's a
14 concussive injury or whether or not it's the
15 chronic stress that's associated with it, both
16 issues have neurobiological changes. And
17 interestingly enough, many of those changes occur
18 in the same areas of the brain.

19 So, I think it's extremely important
20 that that be emphasized. Otherwise, we cut out a
21 tremendous number of the populations that we're
22 addressing and trying to serve. And, you know,

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105

1 again, one of the points I think that we need to
2 get across is there's no shame in having
3 post-traumatic stress. I mean, this is -- I often
4 wonder, those folks that come back and claim not
5 to have any post-traumatic stress at all who have
6 been in combat situations, I worry more about
7 those folks than I do the folks that have had some
8 harrowing experiences.

9 MS. CAMPBELL-KOTLER: Dr. Flynn, when
10 does post- traumatic stress become post-traumatic
11 stress disorder?

12 DR. FLYNN: well, I think when some of
13 the features of -- first of all, chronic stress
14 can be manifested in a number of general ways:
15 Through somatic complaints, through
16 neuropsychiatric problems, irritability,
17 agitation, what have you. But in using the strict
18 DSM criteria, when you get into the persistence of
19 things like nightmares, increased autonomic or
20 startle response, avoidance of stimuli that may
21 produce stressful reactions, re-experiencing
22 phenomena, this sort of thing, then you get into

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1 the criteria of the disorder itself. And I think
2 there's no need, you know, to alter, at this point
3 in time, the definition of post-traumatic stress
4 disorder because it's documented in the DSM-IV.
5 But there's a whole spectrum of things before you
6 get the full-blown disorder that can be related to
7 chronic persistent stress.

8 LTC. MAUFFRAY: So basically saying
9 there's not a separate diagnosis simply of
10 post-traumatic stress. Post- traumatic stress
11 disorder is the diagnosis?

12 DR. FLYNN: Well, post-traumatic -- you
13 know, again, one of the areas that I see that's
14 going on here, the conflict is, on the one hand,
15 the scientific neurobiological aspects of it, and,
16 on the other hand, the political correctness of
17 it. And you know, soldiers -- there's no
18 question. I've spoken with many, many soldiers
19 and, you know, it's fine to talk to them about
20 chronic stress and, again, if the history suggests
21 it, to validate the fact that it certainly sounds
22 like they had a traumatic brain injury, even

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1 though it's "classified" as mild. And we always
2 emphasize that "mild" is based upon an accepted
3 scientific definition. It is not a pejorative
4 judgment on what they are experiencing
5 subjectively.

6 But that having been said, they're much
7 more willing to accept the fact that they are
8 under a lot of stress and that stress has
9 exacerbated many of their symptoms. But when you
10 say disorder with that, that means that there is
11 something inherently impaired in that individual.
12 And granted, there are some folks, that with the
13 persistence of symptoms, they meet all the
14 criteria for PTSD, but it also interferes with
15 their ability to function in a normal manner on a
16 day-to-day basis and their lives become totally
17 disrupted by it.

18 well, you know, I don't think from the
19 psychiatric standpoint that they should shy away
20 from the fact that that may constitute a
21 full-blown disorder. But just to use the blanket
22 statement for any soldier returning who has a lot

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1 of stress associated with their experience in
2 theater, boy, they become very, very sensitive to
3 classifying them as a disorder.

4 MS. BENEDICT: And technically,
5 according to the DSM, prior to 30 days it's
6 considered acute stress disorder.

7 LTC. MAUFFRAY: Again, with the
8 disorder, though.

9 MS. BENEDICT: Again, with the disorder,
10 right. And so after 30 days, if they meet the
11 criteria according to the DSM, then they could be
12 given a diagnosis of PTSD. According to DSM.

13 I never, in the time that I worked with
14 anybody on the floor, gave anyone a diagnosis of
15 PTSD if they were just coming out of a combat
16 situation because I think even that 30 days, in
17 these types of situations, it was not unusual for
18 them to be still struggling 90 days post being out
19 of the combat situation. And in some ways we were
20 very sensitive to that disorder and putting that
21 in their records. So, it is a lot of gray area
22 where the combat --

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109

1 LTC. MAUFFRAY: So is there any
2 consensus -- I mean, that's one of the challenges
3 we often face. There's gray area and then it's in
4 print or it's on the web and it's not very gray
5 anymore. So --

6 MS. COHOON: That's why I brought it up.

7 You're talking about the (inaudible), so, you
8 know, here's an incident right now. So how do you
9 deal with that?

10 DR. FLYNN: And again, I think PTSD is
11 well defined and it is in print and you can find
12 it just about anyplace. But the real question is,
13 you know, do 90 percent of the soldiers that have
14 persistent symptoms, do they all have the
15 full-blown disorder? I think the notion there is
16 to classify them as having, you know, chronic
17 stress associated with this. It gets real gray
18 when you look at the fact that the very presence
19 of traumatic brain injury, you know, lends itself
20 to a higher susceptibility of developing post-
21 traumatic stress. And the degree of the acute
22 stress reaction itself at the time of the trauma

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110

1 also predisposes to, you know, the higher the
2 degree of acute stress, the more likely it is down
3 the line that they're going to develop chronic
4 post-traumatic stress.

5 But then we get into the neurobiology of
6 it and the same areas of the brain that are
7 commonly affected -- that can affect attention,
8 concentration, memory, and behavior -- are common
9 areas that are affected by both chronic stress and

10 also TBI. I mean, before we ever called this
11 PTSD, there were, you know, real prominent
12 neuroscientists in the field, like Robert
13 Sapolsky, et al., out of Stanford, who have made
14 their life surrounding the study of chronic stress
15 symptoms. And they have defined in a number of
16 papers all the changes that occur in the body,
17 from excessive secretion of glucocorticoids to
18 changes in synaptic arborization, to glutamate
19 neurotoxicity. Lots of scientific stuff that's
20 there that suggests that post-traumatic stress or
21 chronic stress, if you will, is a neurobiological
22 impairment, whether you want to call it a disorder

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111

1 or what. But there are changes in the brain that
2 are occurring for the worse. The positive thing
3 is that it's reversible with treatment.

4 MAJ. VOGT: So one possibility is, you
5 know, to just have in there that post-traumatic
6 stress is very common and that we expect, you
7 know, given the environment stuff. But the other
8 suggestion would be, you know, at DCoE we do have
9 the Psychological Health Clinical Standards of
10 Care Directorate, and to have them -- again, we
11 want the messaging to be the same across DOD -- so
12 to have them sort of go through this portion and

13 sort of read it and make sure it is consistent
14 with the messaging that they are also pushing
15 forth.

16 LTC. MAUFFRAY: Yeah. If we are making
17 any changes, now is the time to make them, not
18 afterwards.

19 MAJ. VOGT: Right. So, you know, we can
20 definitely do that, and I'll ask them.

21 MS. COHOON: And my question was not
22 necessarily out of the current (inaudible).

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112

1 LTC. MAUFFRAY: Oh, I know. I know.
2 It's just if this is an issue, then we want to
3 resolve it while it's in a development phase and
4 not afterwards because that never works well.

5 MS. KILADA: This is Sandy. On a more
6 sort of hands-on level, the same discussion, but
7 we've made a lot of edits and a lot of changes
8 since I sent the PDFs to the contractor. And I'm
9 just wondering how we can best coordinate so that
10 those edits are reflected, you know, in the
11 electronic version.

12 LTC. MAUFFRAY: Were they done with any
13 kind of edit tracking on? Anything like that? Is
14 there anything indicating what the edits were?

15 MS. LLOYD-KOLKIN: I don't think so.

16 DHB-101509 (2)
LTC. MAUFFRAY: No?
17 MS. LLOYD-KOLKIN: Not that we know.
18 MS. KILADA: No. And I actually sent a
19 newer -- an updated version of the PDFs not long
20 before this meeting.
21 But since then, there have been even
22 more edits.

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113

1 LTC. MAUFFRAY: And when -- because
2 we're actually under a very, very, very, very
3 tight timeline on this and so when will the final,
4 final, final, final, final edits --
5 MS. KILADA: Today or tomorrow.
6 LTC. MAUFFRAY: So as soon as we can get
7 those, the better.
8 MS. KILADA: Okay. So just send a new
9 set of PDFs?
10 LTC. MAUFFRAY: Right. And just -- with
11 the indication that this is the -- it reminds me
12 of some of the files I've seen that some of the
13 developers where it's final, final, final, final,
14 final. The final final version.
15 MS. KILADA: well, that's exactly what
16 this is. Okay, thank you.
17 MAJ. VOGT: So what's the turnaround
18 that you need from the PTSD standpoint and the

19 PHS?

20 LTC. MAUFFRAY: The script is currently
21 being written. This particular portion, though,
22 doesn't play prominently in the Module 3 and so

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114

1 it's a little less time critical. I mean, we
2 could have a few weeks for this.

3 MAJ. VOGT: Okay.

4 LTC. MAUFFRAY: What we really want to
5 have here is we make this -- because at the end
6 we'll go through and we'll make a final scrub of
7 everything. We'll revoice over anything that
8 needs a new voice on it. And so we'd want all
9 this included in that rework.

10 MAJ. VOGT: Okay.

11 LTC. MAUFFRAY: Because if you pull it
12 out as a separate thing, then it's an additional
13 cost and just wasted effort.

14 MAJ. VOGT: So should they just go to
15 the website and review it or do you have a script
16 ready that I should send to them directly?

17 LTC. MAUFFRAY: From this particular
18 portion it's what's on the website.

19 MAJ. VOGT: Okay.

20 LTC. MAUFFRAY: So if they need to make
21 changes, you can actually just copy that, paste it

1 MS. CAMPBELL-KOTLER: So I don't think
2 you have a lot of new content changes.
3 LTC. MAUFFRAY: Okay.
4 MS. CAMPBELL-KOTLER: You know, I think
5 the PTS/PTSD issue is probably the biggest one.
6 LTC. MAUFFRAY: Right. Okay.
7 MS. CAMPBELL-KOTLER: So I don't think
8 you need to worry too much. But we will get you,
9 of course, the final.
10 LTC. MAUFFRAY: And one of the things
11 that as we were looking at it, there's obviously
12 -- a particular section is much more robust than
13 another and so from a development standpoint we
14 need things to be more symmetric across here. We
15 didn't want one massive section that somebody
16 would have to sit an hour through and then a
17 little five-minute piece or a little two-minute
18 piece, and so there are six sessions. I think you
19 guys, though, have 12 or 13 pieces in Module 3.
20 So, obviously, some of those, the content will
21 cross over what's being delivered in these
22 discussions and as it would be in a real-life

1 discussion. Somebody's not going to sit down
2 really in some kind of group session, some kind of
3 support group, and limit their discussion to one
4 particular thing. So there will be in these
5 sessions more than one topic potentially covered
6 in a particular session. I think some of them
7 were only 2 or 3 pages and one was 22 pages long.
8 So it would make it very unbalanced.

9 MS. CAMPBELL-KOTLER: But the content
10 will be there.

11 LTC. MAUFFRAY: The content will be
12 there. Right?

13 MS. CAMPBELL-KOTLER: The PDFs.

14 LTC. MAUFFRAY: Oh, yeah. The PDFs will
15 be there. And, in fact, like I said, as soon as
16 you're ready for the PDFs, we can upload those
17 whenever you like. Yes, sir?

18 DR. FLYNN: Just for what it's worth,
19 the irony is that the modules that we've prepared
20 are for moderate to severe traumatic brain injury
21 as of this point. And the irony is that the more
22 severe the traumatic brain injury, the less likely

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1 it is that there will be co-morbid PTSD associated
2 with it. So the co-morbidity of post-traumatic
Page 106

3 stress and PTSD is much more prominently tied to
4 mild traumatic brain injury or concussive injury.

5 Just one other question for my own
6 clarification. We're talking about the end of the
7 end of the end of our product, but correct me if
8 I'm wrong, before anything goes up on the web, all
9 this has to go through the DHB, the Congressional
10 process and all, before the okay is given, right?

11 MS. CAMPBELL-KOTLER: I think the DHB
12 and then Ms. Embrey's office, and then I think
13 after that we could put it on the web if there is
14 no problem. So it doesn't have to wait for
15 Congress or anything.

16 CDR. FEEKS: This is Ed Feeks. You are
17 correct. It's presented as a recommendation from
18 the Defense Health Board to the secretary of
19 Defense through the assistant secretary of Defense
20 for Health Affairs and the undersecretary of
21 Defense for Personnel and Readiness. Once that
22 recommendation is accepted, then it constitutes

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119

1 the final product.

2 LTC. MAUFFRAY: And let me ask a
3 question maybe I don't want to know the answer to.
4 What is the likelihood following that presentation
5 on November 12th that there would be further

6 changes requested? Because we have a deadlines
7 that's not very far beyond that.

8 CDR. FEEKS: Yeah. This is Commander
9 Feeks again. I think judging from the reception
10 that it got at the last meeting, and the kinds of
11 changes that we're talking about here being, as
12 Meg said, not substantive, but, you know, minor
13 details, we might see some of that. But I'd be
14 surprised if we saw any sort of substantive or a
15 recommendation for a substantive change.

16 LTC. MAUFFRAY: Okay.

17 MS. MOESSNER: Each individual member
18 from the DHB is being mailed a copy. You know,
19 that's why the rush to print this week or early
20 next week, so that they can have a copy in their
21 hands a couple of weeks before we present.

22 CDR. FEEKS: Yeah. And just as a

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120

1 clarification, this is to the 20-odd members of
2 the core board, not the 150- odd members of the
3 whole board itself?

4 MS. MOESSNER: Right. Right. Okay,
5 excellent. Really, thank you. I agree. This is
6 just an amazing resource. I'm so glad that we
7 joined forces back when, and that as a Panel
8 everybody agreed that this was a wonderful place

9 to house the multimedia aspect of the curriculum.
10 So, fabulous.

11 It is a little after noon. Why don't we
12 break until 1:00? Again, those of us who were
13 going to meet to talk about marketing, maybe we'll
14 load up on that corner and we'll talk a little
15 bit. And then we'll just have a couple of items
16 after lunch. And again, I certainly hope to get
17 us out of here on time, if not a little bit
18 earlier. So we'll still aim for that.

19 So, lunch break.

20 (Whereupon, at 12:00 p.m., a
21 luncheon recess was taken.)

22

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121

1 A F T E R N O O N S E S S I O N

2 (1:29 p.m.)

3 MS. MOESSNER: Okay, everybody. I think
4 we'll do the last blast here and get everybody out
5 of here on time.

6 It is 1:30, and I just have a couple of
7 things. I think the main topic right now was to
8 update the Panel on where we are with the mild TBI
9 content, the so-called Module 5. And so I think
10 my memory will be correct here, but it was Pam,
11 Megumi, Fred, and myself who offered to take the

12 content and to continue to work on it after the
13 last meeting.

14 So, we did that. And the latest version
15 -- at least the one I have -- is down to about 28
16 pages. We stalled out a little bit this summer
17 because of our schedules. We, frankly, just
18 completely ran out of time to do much else with
19 it. And so we are -- I think I've talked to
20 everybody, but I think we're willing to continue
21 to see this project through to whatever it might
22 turn out to be. But just wanted to let you know

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122

1 that, again, the work continues on this. And I
2 think as at least sort of content expert people,
3 we're happy to continue to work on it.

4 I have, for about the last year,
5 wherever I traveled, been asking people within VA
6 and DOD, well, what -- to make sure we're not
7 duplicating efforts, you know, what exists? What
8 do you -- when you meet with a family and a
9 soldier with suspected or confirmed mild TBI, what
10 do you say to them? What do you give them? Where
11 do you direct them?

12 And it seems that there still is a need
13 for a print product or something that, again, will
14 be posted online for people to download. Because

15 I, again, this is a very informal, casual survey
16 of a handful of places and people, but it doesn't
17 seem to be anything consistent is being used at
18 this point in time. And I don't know, I mean, I
19 would open that up for discussion, if you've heard
20 of new efforts in this area. What I don't want to
21 do is spend a lot more time on this and then we
22 realize somebody else is working on something in a

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123

1 parallel manner. But I haven't heard of anything.
2 And anybody who works in DOD or VA
3 programs or services, is there anything? I know
4 there's a one-page fax sheet that sounds like
5 people often download. It looks like the audience
6 for a couple of the things that are being given
7 out around the country are for the patient kind of
8 in that acute stage of recovery from mild TBI. It
9 doesn't look like there's ever been anything
10 focused on the family, you know, educating them
11 about the complexities of this injury or diagnosis
12 and the PTS or PTSD overlay and all of that. I'm
13 not finding anything. So that does seem to be a
14 gap.

15 I know there's been -- as we've had
16 discussions about this in the past, there's been
17 widespread support because of the sheer numbers of

18 people coming back with this particular kind of
19 injury. The DHB is certainly interested as we've
20 spoken to them over the last year and a half of
21 meetings. They always ask, you know, yes, where
22 is that project? Yes, we would support that work.

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124

1 continue. So I'll just open it up for
2 any kind of discussion. I will mention, actually,
3 quickly, two other things. Kelly is actually, you
4 know, obviously for the CDC, there's a piece that
5 the CDC has put out for -- oh, this has been
6 available for years, hasn't it? I know we print
7 it at Mayo.

8 MS. SARMIENTO: Yeah, (inaudible).

9 MS. MOESSNER: About year 2000. Okay.
10 About year 2000, the CDC worked with several
11 organizations to put together facts about
12 concussion and injury, where to get help. Most of
13 us who work in the civilian world actually
14 reproduce this at our own centers, so this is a
15 widely used piece on brain injury; you know, more
16 typical concussion. Now and again there are other
17 issues for this particular population, but at
18 least this has been updated. So we'll make sure
19 that our work or what we are trying to pull
20 together, you know, matches up against this since

21 this is also being updated at this point in time.
22 I think there's actually a little information on

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125

1 mild TBI on your website. You know, we need to do
2 some comparison.

3 And again, as has been pointed out
4 earlier, to keep the messages consistent. It is
5 challenging. Fred and I were just talking. I bet
6 it's going -- this will be much, much shorter than
7 our lengthy curriculum, but it's much more
8 challenging to write because it's just -- again,
9 it is a controversial issue and it will be in
10 writing. So it's made it a little harder to pull
11 together and to figure out what to do with it.

12 So, comments? Questions? Any concerns?
13 Please.

14 LCDR. HERBIG: This is Herbig. Just one
15 question. Where are we with the mild traumatic
16 brain injury versus post-concussive syndrome
17 debate? Anywhere? Bueller?

18 MS. MOESSNER: That's right.

19 DR. FLYNN: You know, again, there are
20 certain definitions to this. And post-concussive
21 syndrome is usually associated with the somatic,
22 cognitive, and neuropsychiatric symptoms that

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1 occur within the first three months following a
2 mild traumatic brain injury. Thereafter, up to or
3 over a year if there's a persistence of symptoms,
4 it's oftentimes referred to as the persistent
5 post-concussive state. It's a little bit of a
6 misnomer because most of the literature that's out
7 on persistent post-concussive state concludes that
8 most of those persistent symptoms are oftentimes
9 due to neuropsychiatric co-morbidities, a
10 post-traumatic stress, and that sort of thing, and
11 not necessarily the direct sequella of the
12 traumatic brain injury itself.

13 I think why this becomes such a moving
14 target is because there is so much new information
15 coming out on mild TBI. And of course, the
16 emphasis in the literature is that usually you see
17 normal scans if you do a CT or a MRI or what have
18 you, that these objective tests are really mostly
19 within normal limits. There are no real set
20 neurological markers for the condition. And yet,
21 some of the studies that are being done with
22 diffusion tensor imaging and also functional MRI

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1 are, in fact, showing up some deficits. And
2 specifically, it's not just throwing somebody in a
3 scanner and doing it, but it's testing cognitive
4 function at the time, like working memory, for
5 example, where you may pick up, you know, deficits
6 in executive function in somebody who has had a
7 TBI versus a "normal control."

8 So, I have the feeling that the
9 literature on this is changing so rapidly and we
10 used to think that all mild TBIs due to the
11 typical example of an acceleration- deceleration
12 injury, 85 percent of those would improve within a
13 manner of weeks to a couple of months. Then you
14 would have the 15 percent that would have these
15 persistent symptoms, oftentimes interrelated with
16 psychological problems. But now there's the big
17 question of is blast, as in etiology, completely
18 different from acceleration-deceleration? And if
19 so, you know, are the aftereffects of this more
20 persistent? Do they last longer?

21 Then there's, again, the gray zone of
22 the acute trauma that caused the concussion to

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1 happen. If there are observations of really
2 strong psychological conditions, like watching a
3 buddy blown to bits, then this factors in, too.
4 And there's indications that that acute stressor,
5 and just having the TBI itself, will lend itself
6 to being more susceptible to developing
7 longstanding post-traumatic stress.

8 So, there's lots of things. And it was
9 suggested -- I think, Meg, when she talked to me
10 about this -- it's because of the rapid changing
11 pace of the information coming out on mild
12 traumatic brain injury that maybe this is more
13 geared to an exclusive web-based material rather
14 than to put it in print to only have it be
15 outdated as soon as it's ready for publication.

16 Megumi, do you want to add to that?

17 MAJ. VOGT: No. I think the only other
18 thing that makes MTBI sort of its own separate
19 entity in terms of how we have to deal with it in
20 the military is the cumulative concussion piece.
21 I mean, that is huge and it's getting lots and
22 lots and lots of attention, so. And just the

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129

1 increasing amounts of research in literature to
2 show its effects, so.

3 MS. MOESSNER: Thank you. Mike?

4 MR. WELSH: I had a question, Dr. Flynn.
5 In some of that new research that's come to light
6 in some of these studies, one thing that I always
7 think is different with these traumatic brain
8 injuries from a motor vehicle accident or sports
9 injury is the over-pressurization that the
10 military personnel are exposed to in the vehicles.
11 Is that being looked at as well, the effects of
12 the over-pressurization?

13 DR. FLYNN: The answer to that, Mike, is
14 yes. And usually when we talk about the etiology
15 of a blast, the major emphasis is on the primary
16 effects of the blast, which is the overpressure
17 wave. One of the things that's interesting about
18 that is some of the research that's coming out in
19 Jeff Ling's lab and all is demonstrating that
20 there really isn't a whole lot of movement in an
21 acceleration-deceleration manner to the head and
22 neck area at the time of the over pressurization.

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130

1 So, therefore, whether or not this has to do with
2 direct penetration of the blast wave through the
3 skull -- or there's a lot of evidence to suggest
4 also from previous animal studies that just the
5 overpressure wave being, you know, directed at
6 other body parts, like visceral organs, lungs,

7 gut, what have you -- that there's a transmission
8 effect secondarily that can cause brain injury and
9 brain damage. And some of the theories there that
10 Chernak from Hopkins proposes is that this may be
11 a transmissible wave via things like blood vessels
12 and all that have an open lumen. So, yeah, the
13 answer to your question is there's a lot of things
14 that are going on in this regard.

15 The one thing I think when blast is
16 discussed that we often forget is that there are
17 secondary, tertiary, and cortinary effects of
18 this. And the secondary and tertiary effects have
19 to do with the individual being thrown against
20 something or having their head strike something.
21 And again, so that brings in both the
22 acceleration-deceleration and direct impact. And

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131

1 also having their body lifted up, thrown through
2 the air, and their head landing on an object, a
3 hard object. And remember, after the blast comes
4 all the other debris, the rocks and all the crap
5 that the enemy has put in one of these IEDs that
6 may also have a direct impact on the skull.

7 So, it's not a -- when we say a "blast,"
8 by no means is it a pure entity that involves just
9 one etiology or one mechanism. But it certainly

10 seems like with most of the people doing research
11 in this area, that it is somewhat of a different
12 animal due to the overpressure effect.

13 MR. WELSH: The pressure is going to get
14 worse. The pressure you could expect to get even
15 more severe because of the new vehicles that are
16 being filled at the MRAP. They're a larger,
17 heavier vehicle that offers more protection for
18 the occupants. But the enemy is very adaptive.
19 So as we build a stronger, bigger, more capable
20 vehicle, they build a more powerful, stronger
21 explosive. And that's -- it's not the destruction
22 of the vehicle that's killing the marines and

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132

1 soldiers in Afghanistan; it's that 30-ton vehicle
2 being thrown through the air.

3 CDR. MILLER: Commander Miller. The
4 Gray Team had gone in already once last year. The
5 Gray Team was once again -- right now, as you
6 know, Colonel Jaffee is there now and I'm taking
7 Dr. Kelly in in November, so, there's going to be
8 -- within two or three months we have been ordered
9 by the assistant commandant of the Marine Corps to
10 meet with Colonel Jaffee's team and put together a
11 way ahead for the diagnosis and treatment of mild
12 TBI on the battlefield.

DHB-101509 (2)

13 You know, the Marine Corps general
14 that's in charge of the Marines that are in
15 Helmand Province right now put out a directive
16 that said three strikes and you're out. That is
17 not what anybody wants right now. They're also --
18 we've been directed by the assistant commandant of
19 the Marine Corps to try to find a location in
20 Afghanistan to put a diagnostic and treatment
21 center in Afghanistan someplace. So, I know the
22 first Gray Team is looking at that. We're going

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133

1 to look at it from a different perspective and
2 then we're going to meet sometime and try to put
3 the way ahead. So there will be lots of changes
4 in the next six months, I think, coming down on
5 mild TBI.

6 MS. MOESSNER: Yeah. And I'm glad you
7 brought that up because Larry and I talked
8 yesterday, too, about, you know, Jim Kelly has
9 done work in mild traumatic brain injury, more
10 related to sports concussion, for decades and is
11 now, as you know, the new director of MICOE. And
12 so it might behoove us to connect with he and his
13 team as this seems like something that they would
14 obviously -- could use in their new center, you
15 know, that's opening up in 2010. So we thought he

16 seems like a natural resource to work with right
17 away as well. So we'll plan on doing that.

18 MS. COHOON: Kathy had mentioned
19 yesterday the results coming back from the sensors
20 they put in the helmets.

21 And I think that will be a big plus.
22 And I know the first round of sensors they put out

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134

1 are pretty -- how do you say -- archaic. But at
2 least they are some sort of measurement. But
3 there are newer devices that actually can measure
4 much more in-depth. And when you were talking
5 about mild TBI, most of the service members that
6 are dealing with the type that Fred just talked
7 about aren't your mild. It's the ones that were
8 in several vehicles back or maybe they were on the
9 side of the road, and those are the ones that
10 still are getting the wave blasts. But we're not
11 exactly sure as far as what is transpiring.

12 when you're putting the curriculum
13 together, again, it's for the caregiver.

14 MS. MOESSNER: Right.

15 MS. COHOON: So the thought process has
16 to be what they're going to be expecting once the
17 individual comes home.

18 And so I think Shannon touched a little

19 bit on that yesterday, that if they're going to
20 keep them in theater, we need to be educating
21 those that are back here when they get their
22 pre-deployment briefs and during-deployment briefs

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135

1 as far as what the updated information is. But
2 making sure that when you're putting the
3 curriculum together that you're focusing on the
4 caregiver, as in the spouse or mom or dad, not the
5 caregiver of the provider putting your piece
6 together.

7 MS. MOESSNER: Thank you.

8 MAJ. VOGT: As we put this together, you
9 know, I know we've talked about it before, but it
10 is definitely geared toward those with the
11 persistent symptoms. Like, the last thing we want
12 to do is have this -- I know we're talking about a
13 web-based product that anybody can download and
14 look at, but as we write it, we need to make sure
15 that this is for those with persistent symptoms,
16 not everybody with concussion. Because that will
17 definitely send the wrong message.

18 MS. MOESSNER: Right. Right. Kelly?

19 MS. SARMIENTO: Yeah. On that point, we
20 -- in talking with a lot of TBI survivors and
21 others, you know, working on education stuff, with

22 DHB-101509 (2)
the audience, in terms of recovery, when you're --

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136

1 I think it's important to show that most people
2 with mild TBI are going to recover. And so I
3 think having that positive tone is important. But
4 also, to put that, you know, even though a doctor
5 may call it a mild TBI, that doesn't mean their
6 symptoms are mild. And I think there's a little
7 bit of -- at least the feedback we get, and we try
8 to be very careful about that, is when someone
9 says, oh, I have a mild concussion or mild TBI,
10 they think it's just something to -- it doesn't
11 have that serious note on it.

12 And I know that's just how it's
13 classified as TBI. So, in our educational
14 materials we try to put in the new purple book,
15 that, you know, mild TBI, your physician or doctor
16 or health care provider may call it that, but that
17 doesn't mean your symptoms are mild or you may not
18 be experiencing that.

19 And the other thing I wanted to ask is,
20 it seems like MTBI and concussion are used
21 interchangeably. In our materials we don't do
22 that because there's a lot of debate about that.

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Page 123

1 We just say MTBI, concussion is a form or a type
2 of mild TBI. So I don't know if there's a
3 consensus here how people feel, but I know in our
4 stuff we don't make them interchangeable.
5 Concussion, obviously, is much more widely known
6 in the wording. And you see in the media -- I
7 think it's confused a lot, especially in sports,
8 like mild concussion, or you hear that sort of
9 thing, so people combine the names. If there's
10 consensus and that's how you want it -- but I just
11 wanted to point that out, that in our materials we
12 do not -- we don't do that.

13 MAJ. VOGT: What I would say is that,
14 you know, at least at DCoE, what we try to do is
15 use more the concussion just from a STRATCOM
16 perspective, say -- because people think, oh, TBI,
17 it just portrays this like much more severe, you
18 know, that injury is always going to be there type
19 though. That being said, it was very interesting
20 because in our recent operationalizing, you know,
21 as we tried to operationalize the MTBI-deployed
22 protocols, there was a very strong component of

1 the conference attendees that were pushing to use
2 "MTBI" exclusively and take away "concussion"
3 because they thought it minimized it. So, you
4 know, even though that is the approach that we are
5 taking now, it is not a -- that is an ongoing
6 debate.

7 MS. SARMIENTO: Yeah. It's a really
8 hard thing. I think for our youth, our sports, we
9 use a lot "concussion" because sports and all, and
10 kids, that's usually more of a common term that
11 we've tested. And we asked our target audiences
12 about that. But for our physician materials, our
13 technical, our research materials, we use MTBI.
14 But we do tend to use -- you can see right in the
15 intro of that book, you know, that it's a type of.
16 And so it's -- it is a tough thing.

17 And then you guys -- I know I mentioned
18 to you earlier, but you're welcome to also use --
19 or, you know, take a look at our MTBI toolkit for
20 physicians. That was updated, I think, last year.
21 We have a little bit of language on military, but
22 very small because it's for the private practice

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1 physicians. And we have the new MTBI guidelines
2 that are coming out. So those are obviously

3 resources you can use.

4 LTC. MAUFFRAY: That discussion over
5 MTBI and concussion was a lengthy one as we were
6 going through this development process. And the
7 best consensus we could get at the time was
8 advocating using them synonymously and almost
9 making them interchangeable terms. And so clearly
10 it's an unresolved topic.

11 DR. FLYNN: I think one of the big
12 driving issues for that is -- first of all, I
13 agree with Kelly. If you look at the literature,
14 the grading of mild TBI from 1 to 3, concussion
15 encompasses only an overlap between two of those
16 grades. But now we're using it synonymously with
17 mild TBI. And part of the driving force behind
18 that, I have to say, was initially when DOD would
19 -- I know the Department of the Army, when they
20 would send out their request for recording how
21 many people had a mild TBI, they didn't use it in
22 the past tense; they used it in the present tense.

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140

1 How many of your soldiers have mild TBI? Implying
2 that they're walking around with active brain
3 damage. And we made a big deal about saying it
4 should be referred to in the past tense because
5 the overwhelming majority of them after, you know,
Page 126

6 a mild TBI-concussive injury, returned to a normal
7 baseline. So that when we see them, we validate
8 the history of a mild TBI having occurred, but
9 that doesn't mean that they're walking around with
10 one right now.

11 So, now the term went to "concussion,"
12 and how it's "had" a concussion, you know, rather
13 than "have" a concussion. So a lot of this is
14 really semantics and kind of mollifying the impact
15 of what one word is compared to another. So it's
16 more kind of dancing around the issue, to be
17 honest with you.

18 LTC. MAUFFRAY: Unfortunately, in this
19 kind of realm, the semantics have costs.

20 DR. FLYNN: Yeah, absolutely.

21 LTC. MAUFFRAY: And they're constantly
22 being battered back and forth.

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141

1 DR. FLYNN: Well, I think one of the big
2 issues now, as Megumi was just mentioning, is the
3 idea of many of these recurrent deployments and
4 recurrent concussions. And now with a lot of the
5 information that's coming out from
6 neuropathological studies with NFL players, that
7 chronic cumulative concussions can lead to, you
8 know, a chronic, traumatic encephalopathy picture

9 which results in dementia. So the big question
10 remains with recurrent deployments and all when we
11 have soldiers with so many concussions, how many
12 does it take to really be concerned about who is
13 going to develop a dementia 20, 30 years down the
14 pike?

15 And also, one of the issues that is real
16 touchy, but I think needs to be taken into
17 consideration, is just like other forms of
18 dementia, we know that there is a higher instilled
19 risk based upon genetic makeup and certain genetic
20 markers. And I think they're starting to look at
21 a lot of these NFL players that develop this
22 chronic static encephalopathy, you know, many of

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142

1 them were ApoE4-positive. And of course, that's a
2 high-risk factor for Alzheimer's disease, as well.
3 So that's something else I think that probably
4 somebody is going to be looking at when soldiers
5 come onboard.

6 MS. MOESSNER: You know, as I page
7 through the draft, the latest draft we've been
8 working on, we are making an attempt to focus this
9 on the family as an audience in that we did do
10 some cutting and pasting of, you know, what are
11 the effects that you might see in your loved one?

12 How might you help support them at home or at work
13 or in, you know, various venues of life? So it is
14 -- you know, there are some introductory remarks
15 about some of the controversial and some of the
16 overlay issues, but that it really continues to be
17 a guide to try to help the families support their
18 soldier or veteran.

19 So does that sound like still the
20 direction that makes some sense here? Again, if
21 they are experiencing some of these, you know,
22 fairly common sequella -- and again, these are for

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143

1 people who have persistent symptoms of headache
2 and fatigue and irritability and cognitive
3 inefficiencies and so forth. How can you help
4 support them?

5 MS. COHOON: Again, what about as far as
6 what if I'm a parent and it's my child who has
7 mild TBI? Have you thought about you guys
8 expanding it so at least there's a piece in there
9 of that? I mean, all of us who have kids, I mean,
10 you know, they run around the swimming pool and
11 you're like, ah, you know. And I know several
12 friends that have been in the ER and their child
13 now has a concussion, that if you're going to
14 build this --

15 MS. MOESSNER: Maybe we should include
16 --

17 MS. COHOON: -- for that population?
18 Just a thought.

19 MS. MOESSNER: Sure. Absolutely.

20 MS. CAMPBELL-KOTLER: This is Meg. We
21 had a large discussion about this mild TBI issue,
22 I guess. It was at the January meeting. And I

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144

1 thought that the agreement was that this was going
2 to be more of a patient education tool because we
3 did not want to imply that if you had a mild TBI
4 you would need a family caregiver. So that's one
5 thing I'm a little concerned about as I hear the
6 discussion.

7 But I could see where you would want
8 someone who has persistent post-concussive
9 syndrome -- where the family would want to have
10 guidance on many of the things that are already in
11 this manual. And would someone at that point be
12 appropriate to receive the manual? Or should we
13 guide this document more toward family education
14 when there is persistent post-concussive syndrome,
15 rather than call it mild TBI?

16 DR. FLYNN: I can tell you out of just
17 our experience alone, when we talk to spouses,

18 they don't come in and complain about how their,
19 you know, husband's headache affects them or
20 whatever. They come in and they complain about
21 how he is irritable, edgy, impulsive, yells at the
22 kids, quick to jump at things, and so on and so

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145

1 forth. So, clearly the behavioral features, I
2 think, rank number one with the concerns of -- I
3 call them partners, rather than caregivers. And
4 that's the key thing. I mean, they want their
5 partnership with their spouse back. And they feel
6 like they've assumed more of a parental role
7 rather than as a partnership role. But I think
8 that ranks ahead of some of the cognitive
9 features. They will say that, well, he's
10 forgetful and he has trouble with that, but
11 without question, the thing that concerns family
12 members the most are the tendency to be irritable,
13 agitated, anxious, jumpy.

14 So, and again, I think that's an
15 opportunity to emphasize the importance of kind of
16 a multidisciplinary approach, that while we may be
17 taking a look at neurological features and all,
18 it's extremely important, you know, to get help
19 for the behavioral features. And in some cases,
20 actually even for, you know, marital counseling

21 and all along the way.

22 MS. CAMPBELL-KOTLER: And this is in the

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146

1 first three months?

2 DR. FLYNN: Not only the first three
3 months, but even more persistent symptoms further
4 down the pike.

5 MS. CAMPBELL-KOTLER: Right.

6 DR. FLYNN: You know, it's the one thing
7 about mild TBI. Most of these guys when they
8 incur a mild TBI, they may be out of the action
9 for a short period of time, but most of them are
10 sent back to their units and will return with
11 their units. And when we see them stateside, many
12 of them are months out from the actual TBI itself.
13 And yet, a good percentage of them still have
14 symptoms.

15 MS. CAMPBELL-KOTLER: So maybe a family
16 guide to the management of -- family guide to --
17 what to expect when your loved one --

18 DR. FLYNN: Dealing and coping with.

19 MS. CAMPBELL-KOTLER: Right, right,
20 right.

21 MS. MOESSNER: Yeah. We hadn't actually
22 settled on a title because we were struggling with

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147

1 that very issue. who is your audience? I think
2 we kept returning to somehow educating and
3 informing and supporting the people around the
4 injured person, whatever you want to call them.
5 You're right. A lot of time they don't need 24/7
6 daily caregiving, but this certainly affects the
7 lives of their families.

8 Do you want to start with Carolyn?

9 Sure.

10 MS. ROCCHIO: Carolyn. I think the
11 greater need is -- because their appearance
12 doesn't usually change. The expectation is that
13 they're okay. And I think the families,
14 particularly, and the children, never understand
15 how daddy is changed. And I think that the
16 families need to know the kind of sequella that
17 follow this kind of injury so when it hits,
18 they're prepared for it and they're not wondering,
19 you know, what's happened to him? Daddy has
20 become so mean and I don't understand why. They
21 need to understand there is a why.

22 MS. MOESSNER: Good. Thank you. Yes,

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1 please.

2 COL. FORTUIN: The point on -- and this
3 is such a tricky area.

4 MS. MOESSNER: I know.

5 COL. FORTUIN: But you know, the
6 audiences here, from my perspective, too, are not
7 only the family members, but your larger family
8 within the military being your unit members, as
9 well, your first sergeant and so on. And for the
10 Reserve component, their employers. And Meg, you
11 worked on the webpage with the Department of
12 Labor, I think, and I think that this sort of
13 information is going to be key for those folks who
14 are back out in the community, as well as the
15 unit, the commanders, first sergeants, and so on.
16 So I think expanding the audience for this
17 particular one is going to be pretty important.

18 MS. SARMIENTO: If the focus is the
19 patient -- the overall patient audience and it's
20 expanding out a little bit, I think that purple
21 book that's been out for a while touches on a lot
22 of the topics that we've been discussing, an

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1 overview of the injury. It's about 10 pages; it's
2 small. We print it in the small version, but we
3 try to keep it short. So it's about like an
4 overview -- a quick overview, signs and symptoms.
5 And then there's danger signs. And then it talks
6 about kids and older adults. And so when to get
7 immediate help. So if there's all of a sudden --
8 that's a question we get all the time. When do I
9 go to the emergency department and when are they
10 just post-concussive symptoms where I can just see
11 my doctor the following day? So we include that
12 information.

13 We have Getting Better. And then we do
14 have information for caregivers. It's not
15 extensive. We try to keep it very short and
16 concise and at a reading level that's appropriate.
17 So, if that's something that you want to use and
18 adapt, you know, you're more than welcome if
19 that's helpful. And then we have some other
20 general factsheets in prevention that are written
21 for patients overall. So that's something that we
22 can definitely help out and support with because

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150

1 that's part of our mission at CDC, so.

2 MS. MOESSNER: wonderful.

3 MS. BENEDICT: I think where you're

4 going to need to be a bit -- and Kelly, do you use
5 the word "caregivers" when you're talking about
6 the mild TBI patient?

7 MS. MOESSNER: Like, right now that
8 section is entitled, "Help for Families and
9 Caregivers."

10 MS. BENEDICT: I think that might be the
11 one area you need to be careful about who you sort
12 of address this to because you're right, I think
13 there are a lot of folks out there, like Fred
14 said, family members who are coming in and talking
15 about the behavioral changes, but don't
16 necessarily think of themselves in that role at
17 all. I mean, they're just a stressed spouse and
18 they might feel a little bit more like a parent,
19 but I think it would be presumptuous of us to
20 label them caregivers and maybe not a good idea to
21 do so.

22 MS. SARMIENTO: Yeah.

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151

1 MS. MAXWELL: (inaudible) family
2 advocates?

3 MS. BENEDICT: Something. Yeah.

4 MS. SARMIENTO: Yeah. Because it also
5 includes kids in there, a lot -- we use "family"
6 and "caregiver" because there may be a parent or

7 there may be a caregiver of a child or an older
8 adult, and so that's why we use that general term.
9 I think in this group and this audience, I think
10 "caregiver" has a certain meaning. I think in the
11 general public it doesn't. I don't think the
12 general public has the same connotation. So we do
13 it to be encompassing, I think, of the parental
14 role because not everybody is going to be a
15 parent. And then the family, obviously, it's
16 more.

17 MS. PRIES: Maybe a possible title might
18 be "Understanding" --

19 Rose Mary. Maybe a possible title might
20 be either "Understanding Mild TBI" because that
21 could really be understanding for all parties
22 concerned, or "Coping" or "Living with Mild TBI"

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152

1 because that's what these people are really doing.
2 They're coping on a day-to-day basis, whether
3 you're the person with the injury or the, you
4 know, the family. Because I feel what we
5 frequently see is that people want coping skills.
6 They want to understand, number one. And they
7 want to have skills that will help them cope on a
8 day-to-day basis.

9 MS. MOESSNER: Good, thank you.

10 Shannon?

11 MS. MAXWELL: Shannon. I was just going
12 to add that my husband, who still needs me around,
13 but hates the term "caregiver," he refuses to
14 allow me to use it in the house. It just rubs him
15 wrong. So I would imagine --

16 MS. MOESSNER: So be very cautious.

17 MS. MAXWELL: -- that people with mild
18 TBI, too, especially, would not take to that very
19 well.

20 MS. SARMIENTO: (inaudible) something
21 called "Understanding Traumatic Brain Injury."
22 There was a DVD and a factsheet that came out two

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153

1 years ago.

2 MS. CAMPBELL-KOTLER: Yeah. Colin
3 Powell introduces the DVD. But it tends to focus
4 more on moderate and severe than mild.

5 MS. SARMIENTO: Yeah. Well, I was just
6 thinking for the title. I don't know --

7 MS. CAMPBELL-KOTLER: Oh, I see.

8 MS. SARMIENTO: -- since you already
9 have a product like that. I don't know how much
10 it's disseminated.

11 MS. CAMPBELL-KOTLER: Yeah. It's widely
12 disseminated, but I think we could -- if you

13 called it "Understanding MTBI" it would be a
14 different product.

15 MS. SARMIENTO: Yeah. I think a lot of
16 brain injury associations also have lots of
17 content on this sort of thing. So I guess -- I'm
18 trying to, I guess, understand a little bit of the
19 -- I understand the importance of this section,
20 but maybe the purpose and overall the focus of it.
21 And it sounds like that's why you're asking for
22 input. But instead of repurposing stuff that

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1 already exists, whether it be just referring
2 people out or focusing it specifically -- really
3 targeting towards the caregiver. Because
4 expanding out to all patients, I think there's
5 lots of stuff on that already.

6 MS. MOESSNER: Yeah. There is actually
7 -- and we have talked about this, I think,
8 probably at every meeting to some degree -- about,
9 right, there is a lot that exists. Again, most of
10 us around the country use your piece. That's
11 actually what most of the model systems use, is
12 the piece that you actually put out, Kelly. But I
13 think it's some of the special issues of this
14 population that's different than what we've been
15 historically used to in the civilian world.

DHB-101509 (2)

16

MS. SARMIENTO: Sure.

17

MS. MOESSNER: There seems to be --

18

there's nothing that exists that helps explain

19

some of that and acknowledge the blast injury or

20

the repetitive nature of some of the -- you know,

21

we get people, obviously, in sports who have

22

multiple concussions. But in the general

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155

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population, not quite as common. People are

2

getting older and falling all the time, that sort

3

of thing. But there did seem to be widespread

4

support, like, this is different enough that maybe

5

we can't just ship people off to some of the

6

things that have existed, you know, in the past,

7

so.

8

COL. FORTUIN: And there are still

9

benefits and resources unique to this population,

10

as well.

11

MS. MOESSNER: Precisely. Precisely,

12

so. Well, good. Thank you very much. I think,

13

again, the group of us is willing to continue to

14

kind of trudge along. I did have a discussion

15

with Meg about does DVBC, you know, still have

16

some, you know, support and staff they can devote

17

to working with us that we would be willing to

18

continue to volunteer some time to move it

DHB-101509 (2)

19 forward? And I got a yes on that, so. Okay.

20 Sounds good. We'll keep you posted.

21 And I think two final comments. One is

22 I will -- the marketing group met in the corner

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156

1 over here and we're reworking that plan. And we
2 will summarize that for the DHB meeting and move
3 forward with that.

4 As far as the DHB meeting, again, any of
5 those of you who are local and want to attend,
6 that would be wonderful. We will somehow let you
7 know how that turned out.

8 So we'll make sure that we communicate
9 out to the entire Panel, you know, what was the
10 response, what were the recommendations that came
11 out of that final meeting, so that you have some
12 word about that. So we'll put something together
13 after that meeting.

14 And then finally, I need to mention that
15 Sandy, who has been, you know, wildly supportive
16 of our efforts, is leaving DVBIC and so she was
17 going to say a few words.

18 MS. KILADA: Thanks, Anne. I just
19 wanted to say that it's been a pleasure working
20 with everybody. There's not one time that I've
21 sent an e-mail or needed something when I didn't

22 DHB-101509 (2)
get just a slew of responses and willingness to

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157

1 help and great input. And so it's been really
2 neat working with this group. And I've learned so
3 much.

4 Now that it's getting closer and
5 becoming more real, it's a little bit sad. So
6 thank you all. But it's gratifying to see where
7 this is, you know, where this has come and leaving
8 it knowing the potential it has to help
9 caregivers. So, thank you.

10 MS. MOESSNER: Yes. Thank you for your
11 time. I think -- any other --

12 MS. CAMPBELL-KOTLER: I just would like
13 to say that it has certainly been my honor and
14 pleasure to work with each one of you, that I've
15 learned a great deal from each one of you. And
16 again, everything that you've brought to the table
17 and your willingness to work so hard on this
18 project has been so gratifying. And I'm just
19 thrilled that we can all feel so proud of what
20 we've done together. And I hope that I'll be able
21 to call on each of you to help out as need arises
22 from your various levels of expertise because I

1 know that you're committed to this product and
2 want to see it disseminated and used effectively.
3 I'll be letting you know how things are going.
4 MS. MOESSNER: Other comments?
5 Otherwise, I would ask Commander Feeks to
6 officially close today's meeting.
7 Anything else?
8 SPEAKER: (inaudible)
9 MS. MOESSNER: That's right. Absent his
10 gavel.
11 CDR. FEEKS: That's right. Okay.
12 Before I close the meeting I want to join my voice
13 to those of the others in expressing my extreme
14 gratitude. First, support staff, Meg and Kenesha,
15 Dytrea; and the departing Sandy -- I'm sorry
16 you're going. It's been great working with you.
17 And the writers, Donna and Gloria, wonderful job.
18 And especially I want to thank you all, the
19 members of the Panel, for doing such a fabulous
20 job. Thank you for serving. It's been great
21 interacting with you. I'm sorry to see it come to
22 a close, but it means that you've accomplished the

1 task that Congress and the secretary asked you to
2 do, and I appreciate that.

3 All right then, this meeting of the
4 Traumatic Brain Injury.

5 MS. MOESSNER: Thank you.

6 (Applause)

7 (whereupon, at 2:10 p.m., the
8 PROCEEDINGS were adjourned.)

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