

# MILITARY CAREGIVERS: FAMILIES SERVING FOR THE LONG RUN

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## HEARING BEFORE THE SPECIAL COMMITTEE ON AGING UNITED STATES SENATE ONE HUNDRED FIFTEENTH CONGRESS

FIRST SESSION

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WASHINGTON, DC

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## **MILITARY CAREGIVERS: FAMILIES SERVING FOR THE LONG RUN**

**WEDNESDAY, JUNE 14, 2017**

U.S. SENATE,  
SPECIAL COMMITTEE ON AGING,  
*Washington, DC.*

The Committee met, pursuant to notice, at 2:34 p.m., in Room SD-106, Dirksen Senate Office Building, Hon. Susan Collins (Chairman of the Committee) presiding.

Present: Senators Collins, Tillis, Burr, Fischer, Casey, Blumenthal, Donnelly, Warren, and Cortez Masto.

### **OPENING STATEMENT OF SENATOR SUSAN M. COLLINS, CHAIRMAN**

The CHAIRMAN. This hearing will come to order.

Good afternoon. I welcome all of you—veterans, caregivers, and advocates, especially my former colleague Senator Elizabeth Dole, who is an extraordinary advocate for our military caregivers.

Our military families, heroes in plain clothing, are serving in America's cities and communities every single day.

The effects of military service often do not end with a tour of duty. For many veterans and their families, the journey sometimes extends for a lifetime. For some with both visible and invisible scars, the transition home is not easy. Recovery, too, can take decades. Along the way, mothers, fathers, wives, husbands, and other family members and friends step in to serve.

Today we will focus on those who care for America's veterans. In the United States, there are 5.5 million military caregivers. These family members and loved ones provide care on a constant and routine basis to our veterans. They are often vital in assisting veterans to make the transition all the way home. Military caregivers improve recovery, rehabilitation, and reintegration of wounded, injured, and disabled veterans.

The number of military caregivers has been on the rise as veterans from Iraq and Afghanistan return home. Approximately 20 percent of military caregivers today are caring for a post-9/11 veteran. The needs and experiences of post-9/11 veterans differ from those of pre-9/11 veterans. While veterans from past conflicts and wars are aging and facing age-related conditions including Alzheimer's and cardiovascular diseases, post-9/11 veterans tend to be younger and face higher rates of PTSD, depression, substance abuse, and traumatic brain injury. Today we will learn more about the unique needs of military caregivers and what we can do to better support them.

We will also unveil a RAND report, commissioned by the Elizabeth Dole Foundation, called "Improving Support for America's Hidden Heroes." This report is a research blueprint for the future that offers a vision to advance our understanding of caregiver needs.

Our military caregivers, like all caregivers, make many personal and financial sacrifices to ensure that their loved ones have the care they need. They may have to miss work, turn down promotions, or even leave the workforce altogether, creating what is at times an enormous financial strain for families. This toll affects the national economy as a whole. The loss in productivity just among post-9/11 caregivers costs our Nation approximately \$6 billion per year.

I have introduced bipartisan legislation that would better serve caregivers, including our military families. The RAISE Family Caregivers Act would require the Department of Health and Human Services to develop a national strategy to recognize and support our more than 40 million family caregivers. This bill, which I introduced with Senator Tammy Baldwin, has passed the HELP Committee, and I look forward to seeing it signed into law one day as a result of the advocacy of many who are here.

In addition, the bipartisan Military and Veteran Caregiver Services Improvement Act would expand eligibility for the VA's caregiver program to veterans of all generations, not just the post-9/11 generation. This is a program that helps veterans who are wounded, ill, or injured, by supporting and providing resources to those who have taken on the caregiver role for them.

And the Lifespan Respite Care Reauthorization Act would authorize \$15 million per year over the next 5 years to allow full-time caregivers to take a temporary break from their responsibilities. This respite care is crucial. It protects the health of caregivers, decreases the need for professional long-term care, and allow individuals who need care to remain in the comfort of their own homes.

Despite their enormous sacrifice, military caregivers typically do not receive awards and admiration that America's veterans deservedly do. We must never forget our military caregivers, who are also true heroes. America's military caregivers enable veterans living with visible and invisible injuries to recover, remain involved with their communities, and enjoy fuller lives. We should do all that we can to support them.

I am now pleased to turn to our Ranking Member, Senator Casey, for his opening remarks.

**OPENING STATEMENT OF SENATOR ROBERT P. CASEY, JR.,  
RANKING MEMBER**

Senator CASEY. Thank you, Chairman Collins. I appreciate you calling this hearing, and I want to thank you and so many others today.

I want to thank as well our former colleague Senator Dole for your tireless work on behalf of military caregivers.

Many of the brave men and women who have served our country in the armed forces return home bearing the marks of that service. Joining us today are some of those who served bravely so that America can remain the land of the free.

To paraphrase what my father once said, “We pray for military families and their loved ones serving around the globe; but we also pray for ourselves that we may be worthy of their valor.”

So thank you for your service to our country.

In order to better serve you, we are holding this hearing today to recognize not only our veterans, but the hidden heroes of the military, the estimated 5.5 million military caregivers across the country.

Military caregivers come in many different forms— spouses, family, friends, neighbors, and, of course, fellow veterans among them. The majority—roughly 60 percent—of those caregivers are women.

We will also hear from our witnesses caring for a loved one and understanding that caring for a loved one can be stressful. It can be stressful physically, emotionally, and financially.

We have made progress in helping our caregivers, but as our witnesses will tell us, we have to do more. We must strengthen the supports that are currently available and help more caregivers who need access to these supports.

Whether a soldier served in Vietnam or Afghanistan, their caregivers should receive the same benefits and support from the VA. That is why I am a cosponsor of bipartisan legislation to expand the supports and services available to caregivers.

Ensuring veterans and their families receive the care they need is also why I will continue to fight against efforts to decimate Medicaid.

A report released by the Congressional Research Service explains that not all veterans are eligible for medical care from the VA. And many veterans cannot access VA services, for example, because they do not have a VA facility nearby. Sometimes family members do not qualify for VA services. That is when other coverage options become important.

Medicaid provides health care to over 900,000 working-age veterans—340,000 of whom gained coverage following recent action by some states to expand Medicaid—and 660,000 veterans’ spouses covered as well.

For these families who served our country—and for millions more children, individuals with disabilities, and seniors—Medicaid must be protected.

Since it covers those 900,000 veterans and over 660,000 spouses, proposals to cut Medicaid and substantially change health care should be the subject of hearings.

So I look forward to hearing today from our witnesses about additional steps Congress can take to better support our Nation’s military caregivers and their families.

Thank you.

The CHAIRMAN. Thank you, Senator Casey.

This appears to be North Carolina day, but for the Aging Committee, it is always Maine and Pennsylvania’s day. But we are very fortunate that both Senators from North Carolina serve on the Committee, and one of our chief witnesses plus some of our veterans and caregivers are from North Carolina. So I would like to give Senator Burr and Senator Tillis the opportunity to welcome those who are here from your home states.

#### STATEMENT OF SENATOR RICHARD BURR

Senator BURR. Well, thank you, Chairman Collins and Ranking Member Casey, for holding this important hearing on military caregivers. I particularly want to thank you for allowing Senator Tillis and myself the opportunity to share the pleasure of introducing the fine North Carolina witnesses we have here to testify and represent here today.

Military caregivers is an extremely important issue nationally and certainly in North Carolina, where veterans make up 10 percent of our adult population. We have two power couples fighting for veterans represented here today, and for my half of the introductions, I want to welcome my former colleague in the United States Senate and good friend, Elizabeth Dole, back to the Senate. Senator Dole has a long and distinguished record of public service in and out of Government that many here know well. From leading the Department of Transportation to serving as Secretary of Labor to serving as president of the American Red Cross, Senator Dole has been there when her Nation called. And she has been there with grace and diligence.

What I want to salute her for today is but just the latest chapter in her story of public service, and that is her veterans advocacy. Not only has she stood by the side of a certain Army Captain, who also knows his way around these Senate halls, but she has also been a relentless advocate through the Elizabeth Dole Foundation of all of our Nation's veterans. Bob and Elizabeth Dole, whether they are in the halls of the United States Senate or the halls of Walter Reed, continue to serve our Nation and to speak up on behalf of the needs of veterans and their caregivers. I am glad that our Committee will be hearing from them today and learning important lessons about what is working and where we still need to improve.

I thank you, Senator Dole, for the grace and the steadfast attention you bring to any issue you tackle, and I know that your Senate family as well as our military caregiving community will be well served by hearing your voice today.

I now turn to my friend and colleague Senator Tillis, who will make additional introductions.

#### STATEMENT OF SENATOR THOM TILLIS

Senator TILLIS. Thank you, Senator Burr. Senator Dole, it is great to see you here. I appreciate you and this advocacy for hidden heroes. You and I have had many discussions about it. I enjoyed the kickoff, and I look forward to continuing to provide support.

Chairman Collins, I have the distinct privilege to introduce two other constituents, Mary and Tom Ward. I have met Mary and Tom Ward on a few different occasions now, and from time to time I even get to pet the dog. But they would not let me do it today.

But they have traveled here, and I have to say it is a real testament to their commitment to the issue of caregiving, not only for themselves but for everybody else. And I appreciate your leadership and advocacy, and we love it every time you come up here and visit.

Tom's service as a Marine dates back from 1972 to 1975, and in 1993, I think you were about 13 years into your marriage when



Tom contracted encephalitis, and after lengthy treatment, signs of cognitive difficulty surfaced.

In 2010, Tom was diagnosed with ALS. ALS is a progressive disease that veterans develop at rates higher than the general population. Mary will share her story as a caregiver for her husband, including the challenges serving as a caregiver and still continuing to remain employed, and actually advocate on behalf of all caregivers.

Madam Chair, I am pleased to have the Wards here today, and I appreciate their leadership. I look forward to their testimony.

I will also tell you, Tom and Mary, I am on the Veterans' Affairs Committee, which is meeting at the same time right now, and I am going to step out of this Committee and try to get back, because you all know the work that we do there is also directly related to this issue.

Also, you have my commitment as the Chair of the Personnel Subcommittee of Senate Armed Services that we are trying to get this right from the time somebody is in active service until the time they move their way through veteran status. Thank you for being here today.

Thank you, Madam Chair.

The CHAIRMAN. Thank you very much.

Although Senator Dole has already been introduced, I do want to add just a few comments about the work that she has done as the founder of the Elizabeth Dole Foundation and a champion for military caregivers.

Through the foundation, Senator Dole has shed light on the immense challenges facing our Nation's 5.5 million military caregivers, and she has really worked across the aisle. She actually brought Nancy Pelosi and me together to write an op-ed in support of a bill—not that that is that shocking, but around here these days that kind of bipartisan collaboration can be rare indeed—and that shows to me the work that Senator Dole has done to create a community of military caregivers through which they can connect, share advice, stories, and advocate for more support. And I want to point out that Senator Dole does this just as a volunteer, and I think her leadership has been extraordinary. I am familiar with the Dole Caregiver Fellowship Program and have had an individual from the State of Maine participate in that, and I just want to thank you for your service, and I look forward to hearing your testimony.

On the same panel we will hear from someone who my staff was all excited about meeting, and that is Ryan Phillippe. As many of you know, Ryan is an actor, director, and writer, and more important from today's perspective, he is also an ambassador of the Elizabeth Dole Foundation's Hidden Heroes Campaign, which helps connect military caregivers to critical resources and connect them with other caregivers. So, Ryan, thank you for supporting our hidden heroes who care for our veteran heroes each and every day.

Senator Dole, please proceed.

**STATEMENT OF SENATOR ELIZABETH DOLE, FOUNDER,  
ELIZABETH DOLE FOUNDATION**

Senator DOLE. Thank you so much. Thank you, Chairman Collins, Ranking Member Casey, and members of the Committee for calling today's hearing. By doing so, the Committee demonstrates its dedication to recognizing our Nation's military and veteran caregivers.

And, Chairman Collins, I owe you special thanks for your strong support of key legislation and the Hidden Heroes Caucus, which you are co-chairing. You are sending a very powerful signal that our Nation's leaders must stand with America's military caregivers. Thank you so very much.

This is not my first time testifying before the Senate Special Committee on Aging. Recently, I came across testimony I gave on June 29, 1978—39 years ago—when I was a member of the Federal Trade Commission. And like each of you, I once sat up there on the dais as a member of this Committee.

To be honest, with the many issues before the Senate, I did not know at that time the enormous benefit military and veteran caregivers are making to our Nation and the huge personal toll it is taking.

That all changed for me in 2011 when my husband, Bob, was hospitalized at Walter Reed. I became friends with young spouses, mothers, dads, sitting bedside, selflessly looking after their wounded, ill, or injured veteran. Their strength was incredible. Yet I could see they were carrying an emotional weight almost too heavy to bear. As they reeled over their loved one's injuries, they were being asked to make extremely difficult decisions without any preparation. And they were quietly wrestling with the fact that they might be serving in this new role for the rest of their lives.

Just as heartbreaking are the stories of pre-9/11 caregivers who have been supporting their loved ones for years, without any acknowledgment, struggling to care for the latent effects of undiagnosed post traumatic stress, Agent Orange, exposure to burn pits, or decades-old traumatic brain injuries that are now causing early-onset dementia. These caregivers are just as terrified, just as isolated, just as important to their veterans. But when they apply for the VA caregiver stipend, they are told that the timing of their veteran's service does not qualify them for support.

An incredible 5.5 million Americans act as military and veteran caregivers. They are serving in each of your states right now, dressing, bathing, and feeding our veterans, performing at-home injections, managing medications, staying on constant guard for emotional triggers. For many, it is a 24-hour job.

I established the Elizabeth Dole Foundation in 2012 to raise awareness and support for these hidden heroes. We began by commissioning the RAND Corporation to undertake the first comprehensive, nationwide, evidence-based research on military caregivers. RAND's experts concluded that the most important factor to a wounded warrior's recovery or improvement was a well-supported caregiver. This statement could have been the headline of the report, but it was overshadowed by more alarming findings.

The research uncovered high instances of isolation, physical ailments, depression, unemployment, debt, legal challenges, and

much, much more. They are doing a tremendous job, but they are clearly, clearly suffering under the circumstances.

There is also an economic argument for supporting military caregivers. They provide nearly \$14 billion dollars a year as an unpaid, voluntary workforce.

Last September, the Elizabeth Dole Foundation launched Hidden Heroes, a multifaceted campaign featuring a first-of-its-kind Web site full of carefully vetted resources and a safe, secure place for caregivers to connect with one another. We announced Hidden Heroes Cities, the galvanizing of communities to identify caregivers in their midst and the local resources to support them. I am proud to say we have recruited 100 cities to date, from Augusta to Pittsburgh, Charlotte to Las Vegas.

Our campaign is chaired by actor Tom Hanks, and the good-looking guy sitting next to me, Ryan Phillippe, is a Hidden Heroes Ambassador. Ryan is an award-winning actor and star of USA Network's "Shooter," where he plays the role of military veteran Bob Lee Swagger. More significantly, Ryan has close family ties to the military community, and he has become a passionate advocate for our caregivers. My heartfelt thanks to you, Ryan.

You know, they stopped production. He flew in, got here this morning on a red eye, and tonight he will head back to California on another red eye. God bless you, Ryan.

As you listen to Ryan and our other panelists, I urge you to consider taking two actions after today's hearing:

First, please make the bipartisan Military and Veteran Caregiver Services Improvement Act the law of the land. This bill will expand essential services for caregivers of all eras. It will also provide direct assistance with some of the top challenges that military caregivers face every day, including respite, child care, financial advice, legal counseling, and education. I have with me a letter signed by 43 Hidden Heroes partner organizations. In fact, they are all right here behind me, and they urgently hope that this particular life-changing legislation is going to pass.

Our second ask for today is that Congress invest in the critical research necessary to sustain positive outcomes for our caregivers in the coming years.

In the next panel, you will hear from Terri Tanielian, of RAND, who will unveil a blueprint focused on identifying urgent research priorities. We urge you to listen carefully and champion this research, which is critical to our ability to support military caregivers 5, 10, 20 years down the road.

And I have to tell you, based on what we already know, we expect more alarming issues to be uncovered. Anecdotally, we are hearing more about caregiver substance abuse and caregiver suicide. Marriages between veterans and caregivers are more vulnerable than ever. The strain of the urgent challenges now and the long road ahead is becoming too much for too many.

Our Nation has long admired and respected our military men and women who have served our country so valiantly. And we have always reserved a special honor for those who returned from service with physical and emotional scars.

Our goal now is an America where their caregivers are empowered, appreciated, and recognized for their service, an America

where military caregivers are woven into the very fabric of the Nation's appreciation of our military.

Thank you so very much.

The CHAIRMAN. Thank you so much, Senator Dole, for your very eloquent and persuasive testimony.

Mr. Phillippe.

**STATEMENT OF RYAN PHILLIPPE, ACTOR, DIRECTOR  
AND WRITER**

Mr. PHILLIPPE. Thank you, Senator Dole, for the kind words.

Before I get started, I want to take a moment in light of this morning's tragic events and thank the Capitol police, the Alexandria police, and other first responders who were able to assist our Members of Congress and their staff. I know I speak for all of us when I say that our thoughts and prayers are with them.

I also know I speak for everyone here when I say to Senator Dole that we are truly inspired by your leadership, vision, and tireless work on behalf of military caregivers. You are a shining light on our country's hidden heroes so that we can all honor their service.

And I want to thank each of you for the opportunity to be here today. It is truly an honor.

My experience growing up in a military family helped prepare me for this role, for this moment. Both my grandfathers fought in World War II—one in the Pacific theater, the other was a Bronze Star winner for fighting on the ground in Berlin. My dad was in the Navy during Vietnam. My uncles were both Seabees and infantrymen during that same period of time. All the members of my family who served thankfully returned, but each and every one were affected in one way or another.

I have had the opportunity as well to work with countless veterans and those currently enlisted on various film and television projects, and all of this adds to my deep respect for our vets and the understanding that they are our Nation's true heroes.

These days, I have been recently working with the Elizabeth Dole Foundation, and that is how I learned about a different kind of hero: our military caregivers. They are hidden heroes, family members or friends caring for warriors who return home from service with physical and emotional scars. And today we are here to ask for your help and urge you to take action.

And if you know anything about Senator Dole, which you must, she does not take no for an answer.

[Laughter.]

Mr. PHILLIPPE. She will hold you accountable, she will hold all of us accountable, because our Nation's military and veteran caregivers deserve it.

Over a lifetime of care, military caregivers face tremendous challenges, and right now they have very few resources to help them. It is on all of us to fix that.

Right now, military caregivers are shouldering this responsibility of care alone. They do not expect or ask for help, but the work they do merits more than just a display of gratitude. We owe our military and veteran caregivers purposeful action and lifelong support.

Something struck me in Senator Dole's remarks I want to emphasize. The foundation's research found that military caregivers

play an essential role in the recovery process of our veterans and in improving their quality of life.

And I quote, "The best chance for a wounded warrior to recover and thrive is having a strong, well-supported caregiver."

Yet this role imposes a substantial physical, emotional, and financial toll on the caregivers and their families. We can do better.

And that is why we are here. We need to sign into law some very important legislation.

For starters, I am speaking specifically about the recently re-introduced Military and Veteran Caregiver Services Improvement Act—bipartisan legislation, introduced in both the House and Senate, to make expanded resources available to military and veteran caregivers of all eras.

This bill strengthens and expands vital programs that support caregivers nationwide and ensures that caregivers are recognized for their service in tangible ways.

For example, if passed, pre-9/11 military caregivers would have the same support we give to our post-9/11 caregivers. I mean, Bob Dole served before 9/11. We are talking about caregivers for the heroes who served with him and the generations that followed. Their caregivers not only need but deserve our assistance.

The VA's Caregiver Program should be available to all caregivers caring for all veterans, regardless of when they served.

The bill also supports caregivers for veterans with service-related invisible injuries, like TBI and PTS, in the same way we help caregivers with veterans who have visible wounds. It should not matter whether we see the scar or not to give our veterans and the caregivers the resources they need.

It also provides assistance with child care, financial advice, legal counseling, and education, which are all top, and currently unmet, needs. Ultimately, by signing onto this bill, you will have a positive impact on the health and well-being of our Nation's veterans and military families for a long time to come.

As a Hidden Heroes Ambassador, I have had the privilege to meet with military caregivers across the country. And as I speak before you now, I cannot help but think about Megan and her husband, Matt, a Marine Corps veteran who honorably served two tours in Iraq. Megan and Matt are high school sweethearts, and when you meet them, you know it. They live in Connecticut now. They are a young couple. They are in love. Yet they have a long road ahead of them.

As a result of injuries received during his combat service, Matt now suffers from a traumatic brain injury and PTS. Megan, his wife and primary caregiver, is by his side every day, helping him as he struggles with wounds that we cannot see, invisible wounds that most of us in this room cannot imagine.

Megan explained to me that she never pictured herself as a caregiver for her husband, especially so soon into her marriage, but Matt needs her. It is a day-in, day-out, 24/7 responsibility, managing doctor appointments, juggling medications, always on high alert looking out for things that might trigger Matt's PTS, and all, I might add, while raising three young boys.

Megan is making the most of things, but she needs our help. In fact, there are 5.5 million military caregivers like Megan, quietly

serving in communities across America. And they can no longer go it alone. They need us, and they need you.

I ask you again, members of the Committee, and all of you here today to give your full support to the military caregivers serving our Nation. Senators, please sign onto the Military Caregiver Services Improvement Act and each of the pieces of legislation outlined.

To everyone here today and watching across the country, please seek out military caregivers in your cities and towns, direct them to support and resources at HiddenHeroes.org, and ask how you can help.

Thank you.

The CHAIRMAN. Thank you very much for your testimony, and thank you also for your thoughtful acknowledgment of the bravery and extraordinary courage of the two Capitol Hill police officers this morning during the attack that stunned and has saddened all of us. Without their bravery, the injuries would have been far, far worse. We heard at our Republican lunch today a firsthand account from one of the Senators who was present, and it is very clear that without the two police officers putting their own lives in harm's way—and, indeed, both of them were wounded—there would have been deaths as well as injuries resulting from this attack. So thank you very much for acknowledging our law enforcement and first responders.

Senator Dole, you mentioned two very important priorities. One is removing the disparity in the essential services that are provided so that it does not matter when you served your country. And second was the need to continue with critical research. Could you elaborate on the second area of the critical research? We are finding out that there are more connections between certain diseases and military service, such as ALS, than we ever realized. And if you could discuss that priority a little more, that would be helpful.

Senator DOLE. Right. And I am so pleased that Terri Tanielian of the RAND Corporation, who is one of the researchers in the 2014 RAND report from which so much else has flowed, is going to be here to testify in a little while.

Let me just start with that 2014 report because this was the first national, comprehensive, evidence-based research that has ever been done on this population, military and veteran caregivers. And the RAND report illustrated a number of areas where there were gaps in services. And the legislation that we are focused on today, the Military and Veteran Caregiver Services Improvement Act, picks up on those gaps, and that is why we are so anxious to see that pass, because RAND has pointed out through their important research exactly what is needed. Now there is legislation to provide what is needed. So we need to pass that legislation.

Now let us look down the road. So many of our caregivers are very young. They are in their 20s and their 30s, the post-9/11 caregivers. You think about that, they literally may be caregivers for a long period of time. In fact, I was making a speech recently. One of my caregiver fellows was with me, and she made comments. And when she finished her remarks, she said, "I am 30 years old, and I will be a caregiver for the next 50 years."

Now, do we know now how to prepare to support these caregivers 5 years down the road, 10 years, 20 years down the road? No, we

do not. That is why this research that Terri will describe is so important. We need to understand. For example, how will the needs of a care recipient change over time? How does the caregiving responsibility impact the outcome on the caregiver? And, also, we need longitudinal research. But it is very important—I cannot stress enough how much we need your help to make sure that this research is undertaken right away, because once we get the results of the research that will be proposed today, we can then spread that to all of our partners. We have a national coalition of about 300 organizations, and there are many who will want to try to utilize that research along with us to try to come up with the right services to help these caregivers down the road.

Right now, it is really alarming—alarming—how little we know about how to care for them down the road, and many of them will be undertaking these caregiving services for decades.

The CHAIRMAN. Thank you.

Mr. Phillippe, could you tell us what you have learned in your meetings with military caregivers? Are there certain lessons that you have learned or that you think we should know?

Mr. PHILLIPPE. I think something that really stands out to me in the conversation I have had is the strain on the family unit itself, the fact that a lot of caregivers have to put their lives on hold, their potential dreams, occupations they might have wanted to pursue, to take care of their veteran. I think that some of the stresses related to that full-time job and what it takes away from, even parenting or those sorts of things, that is why I think the respite aspect to this act is very important, giving some relief and some time off, some time to be your own person, and then return to your job as a caretaker with the required energy.

That was something—you know, keeping families together I think is a big part of this act in my mind. As a father, that is something that is important to me. I think that there is a lot of stress and strains that come with dealing with these injuries and being a military and veteran caregiver that can be really disruptive potentially to a relationship, to the family unit. So that is something that I have heard from quite a few people I have sat with.

The CHAIRMAN. Thank you.

Senator Casey?

Senator CASEY. Thank you, Madam Chair.

I will start with Senator Dole. Senator Dole, during your testimony you mentioned that caregivers to veterans from every era should be treated equally when it comes to the eligibility for VA programs like the Comprehensive Assistance for Family Caregivers Program. I agree with you, and I think people in both parties do. But it is the state of the law now that only caregivers from veterans who served after 9/11 are eligible for the Comprehensive Assistance for Family Caregivers Program.

Since you and your organization work with caregivers for veterans of all eras, all conflicts, can you just describe to us in more detail how expanding the program would benefit those caregivers from pre-9/11?

Senator DOLE. Yes. The caregivers from pre-9/11 have been providing services for years, and they have had no acknowledgment.

They are not acknowledged for what they are doing, and they are receiving very, very little in the way of services.

The illnesses and the wounds and injuries of these veterans from earlier eras are compounded as they age by the aging process. So you have not only the war-related wounds, illnesses, and injuries, but you have the compounding of those, for example, the advent of ALS or Parkinson's disease, and certainly mobility difficulties and chronic pain, some forms of cancer.

So here are these pre-9/11 caregivers dealing with all of this, totally unacknowledged, with very little support. And I think it is clear that they need to have the same kind of opportunities. When they have the most severe injuries that they are dealing with, they need to be a part of the Comprehensive Caregiver Program. And this would mean then that they have respite care. Respite is so important, because, you know, when you are almost burned out, how can you provide the best quality care for our veterans? And we are talking about those who have borne the battle.

Now, our country made a sacred vow to serve those who have borne the battle. That is who we are talking about, the caregivers of these individuals, and they deserve to have the best possible care so that they are not depressed and facing immune system problems and heart problems. But that is what is happening now, a great deal of stress and anxiety and depression.

And so it very important that we provide respite care and that we ensure that these caregivers are able to have, for example, some mental health counseling. If they are in the Comprehensive Program, they are going to have a stipend. They are also going to have health insurance if they do not have health insurance. It would be provided, the CHAMPVA health insurance. So they deserve this, and it is really unfair that they do not have it now. I think there is every reason to move quickly. And the sooner that we can get the legislation passed, we can begin, our community, to develop the services to meet these needs that are unique on the part of pre-9/11 veterans and their caregivers. They are unique needs, and we need to move quickly to tailor our programs to service those needs.

Senator CASEY. Well, I think your testimony today will help us move that legislation. That, I think, goes without saying, and we are grateful you are here.

Senator DOLE. Well, you know, may I add that we have been really proposing this legislation for several years. It would be so nice to see it passed before the end of the year, please.

Senator CASEY. Well, that is a good goal for the end of the year.

Senator DOLE. Okay.

Senator CASEY. Probably on most days you will be more persuasive than I will be, so we will need you to come back.

In the same vein about providing the best possible care and coverage, I mentioned earlier about Medicaid that some veterans, some 900,000, because of their own circumstances, are covered by Medicaid. That is the coverage that they have. And I also mentioned there are 660,000 spouses who receive that benefit as well.

Do you think that Medicaid can play a critical role in providing health care to veterans, their caregivers, and families? What is your sense of that? And I am assuming you run into people that have that kind of coverage.



Senator DOLE. Right. Well, we know from our caregivers who are enrolled in Medicaid that the program provides valuable—it is an extra coverage or valuable supplement for some of the expenses that the VA program does not cover. And then for those who are not on their veteran's health care plan, they would be under the same system as civilians. And I think the RAND report indicated 20 percent of military caregivers fall under the federal poverty line, and those particular individuals would find that Medicaid certainly would be one of the best options for their health insurance.

Senator CASEY. Thank you, Madam Chair.

The CHAIRMAN. I am now delighted to call upon one of the Committee's most active members, Senator Cortez Masto.

Senator CORTEZ MASTO. Thank you. Thank you, Madam Chair. And welcome. Thank you both for being here.

Senator Dole, thank you for everything you are doing in this space, and particularly addressing this important issue for our military caregivers. You talked about respite care, which is absolutely agree—

Senator DOLE. Yes.

Senator CORTEZ MASTO. [continuing]. It is key to really bringing some relief and additional services. But if you do not mind, talk a little bit about the isolation piece as well that occurs and why respite care will bring some relief.

But there are other things that we should be doing to address isolation that I have seen with respect to caregivers, military caregivers as well.

Senator DOLE. Right. You know, it is amazing. As we have met with many caregivers, they really do not understand that they are a caregiver. And I think our earlier RAND research also pointed this out, that many of them do not see themselves as a caregiver. In other words, "Well, I am just his mother. Of course, I am going to take care of him." "I am the spouse. I am looking after my husband," or "my wife." And so they do not understand that they are caregivers, and if they would just raise their hand, there are some resources available to them.

And so we are trying to urge these caregivers to come out of the shadows and to go to—we have a state-of-the-art Web site. It is one of its kind that is specifically designed for military and veteran caregivers. They go to that Web site, HiddenHeroes.org. They will find a whole community of caregivers that they can talk to, they can compare notes, they can learn from one another, and there are several hundred carefully, carefully vetted resources on that Web site, and we will continue to grow those resources.

But it is vitally important. We find that when a caregiver is so isolated, so alone, they do not know there are others out there. And they are just trying to—they are struggling trying to deal with everything all by themselves. And you can imagine, you know, think about this in a family where let us say there is a difficulty. It may be post traumatic stress or traumatic brain injury. The children in the family are having to be very careful as they move around; the spouse is trying to prevent triggers that could set off an emotional response. The kids cannot have children over for a sleepover. You know, it is a delicate situation. And they are dealing with all of

this, and yet in most cases, they do not even realize that there are others they might connect with.

And once they connect, even with just one other person, one other caregiver, it is like magic. It is like a life-changing experience. And as we bring them together in larger numbers, I think they are able to support and help one another, and that has been one of the joys. I feel like our caregiver fellows—and we have them from all 50 states. They are like extended family of mine. I consider them part of my family, you know. But that isolation, you are absolutely right, is such a big issue, and we need to bring them out of the shadows and connect them with others.

And respite, you know, how can they provide the kind of quality care that these heroes of ours who have borne the battle deserve? How they can provide it if they are exhausted? You know, the respite is so important, and the Lifespan Respite Care Act is just vitally important. And we need to get that passed immediately so that the states can begin to tailor services to the caregivers.

Senator CORTEZ MASTO. Thank you, and so let me follow up on that because I absolutely agree, but here is the biggest challenge I also see, and let me open this up to Mr. Phillippe as well. How do you make them aware of the services that are available to them? This is the biggest challenge, the education, the awareness piece, how you bring that back into the communities.

Senator DOLE. Right.

Senator CORTEZ MASTO. And make sure they know that there are resources, number one, which is the most important, and then where to go to find out about it.

Senator DOLE. Yes. Let me mention Hidden Heroes Cities. This is something that we initiated last September, and I promise I will not talk too long because this is really your question, I think. But Hidden Heroes Cities, the idea is we now have 100 cities, and we continue to grow these. But we are reaching out to mayors and to other local leaders across the country, and the idea is that they will form a committee, we will help them to understand how to inspire caregivers in that local community to come forward, to identify the caregivers in that community. And then they will determine what resources do we have at the local level that can be extended to these caregivers and, where there are gaps in services, how can we fill those gaps? What is our strategy going to be? And we find that this is working very well as a way of reaching out to the caregivers.

Also, in our national coalition, we have so many wonderful organizations that have chapters all across America. And, again, we need to reach out to them where they are, and that is at the local level. So we have to drive down to the local level what is happening.

But I think clearly it is a matter of doing this in a number of different ways, also the kind of awareness campaign that we are involved in right now with Ryan Phillippe. He is doing public service announcements for us. He is going to events and speaking. Our caregiver fellows are speaking at Rotary Clubs and other local organizations, and the word is getting out more and more. We are trying to raise awareness in many different ways on many different levels.

Senator CORTEZ MASTO. Okay. Mr. Phillippe?

Mr. PHILLIPPE. One of the things that came up time and again talking with families was that there has been a frustration that the veterans' programs and support groups vary so much from state to state, even from city to county certain times. There were families that I talked to who would move to an area where they knew there were better facilities, better programs. And I think part of what Hidden Heroes would like to eventually implement is some sort of a national VA standard for how we treat our military caregivers and, therefore, our veterans.

I think that as complex as that may seem, I think there is a way to do it. I think it just takes the right kind of people behind it.

Senator CORTEZ MASTO. I think we have got the right people behind it to give us that initial catalyst and push.

Senator DOLE. We need you.

Senator CORTEZ MASTO. Thank you. Thank you very much.

Senator DOLE. Thank you.

The CHAIRMAN. Thank you, Senator.

I was going to move to the next panel, but it is my understanding that Senator Warren is on her way, and since we know how to filibuster, we will—

[Laughter.]

The CHAIRMAN. We will go on a little more until she arrives. And there was actually a question that I wanted to ask you, Senator Dole, and that is, have you found that there is a difference in the needs of military caregivers versus civilian caregivers? I do not know whether that is something that you have looked into, but I was curious, if you have, whether you found a difference.

Senator DOLE. Well, the RAND report has told us that the military and veteran caregivers are experiencing a much higher rate of negative health consequences as a result of their caregiving services. They are experiencing these incredible difficulties in terms of anxiety and depression and immune system problems. And, you know, I think that is something where we come back to the respite. It is so very important to give them a chance to just break away a little bit and to be able to recharge their batteries.

But I think that the RAISE Family Caregiver Act is also very important, and I know that you are sponsoring that, and it is important because it will provide for coordinating services across the Government in a way that makes them more efficient, the caregiving services. And we believe strongly in the need to coordinate between the VA, the DOD, the Department of Labor, HHS, and others that are involved in any way in caregiving. And it also will provide best practices and lessons learned that can be utilized by the military and veteran community, caregiver community. And anytime that you can spotlight what is going on, the labor of love that is taking place in these homes, anytime we can spotlight that it is a wonderful thing to do.

So I hope that that piece of legislation is going to pass because if we want to foster a Nation that supports hidden heroes, all hidden heroes, these wonderful caregivers, then it is important to pass both pieces of legislation.

The CHAIRMAN. Thank you.

Senator Warren?

Senator WARREN. Thank you, Madam Chair, and thank you all for being here with us today, and especially thank you to the caregivers and their veteran spouses who are able to join us today.

You know, Senator Dole, I want to say thank you for coming to see me earlier this year in order to tell me about the support that caregivers provide every day to wounded or ill veterans and servicemembers. Your foundation conducts a fellows program in which caregivers are selected to advocate for caregivers and ensure that they have the resources that they need. And one of those caregivers, Emery Popoloski, is sitting right here in the front row. She is a former fellow and is from Massachusetts. And not only does she care for her husband, Charlie, who served in the Army, she actually helps manage the caregiver fellows program, and she is here today, and I just want to say a very public thank you to Emery. Thank you for being here, Emery.

You know, I am reminded, though, by Emery's being here that caregivers often need additional support for traveling to various appointments, child care services, mental health counseling, and other resources. And current law authorizes the VA to directly provide a stipend and other support services to caregivers of injured veterans from the wars of Iraq and Afghanistan, but does not authorize the agency to provide this direct additional support to caregivers of veterans from pre-9/11 wars. This seems wrong, particularly because elderly veterans are a potentially vulnerable group.

Now, Senator Dole, I know that you addressed this in your testimony, but this is really important, so I want to come back and underline here. When it comes to providing additional support services directly to caregivers, what are the consequences of classifying caregivers of veterans from post-9/11 wars separately from caregivers of veterans of earlier wars?

Senator DOLE. It is a very unfair situation. We need the legislation we are focused on today so that as soon as possible we can begin to meet the very unique needs of the pre-9/11 servicemembers and their caregivers. And it is so frustrating to me because these caregivers pre-9/11 have been providing services for years with no acknowledgment, without anyone really acknowledging the great work and services that they are providing and without the resources to be able to provide some respite care for them, an opportunity to have a stipend, which can be very helpful to them. They deserve to have the same benefits that post-9/11 veterans do when they are dealing with the most serious injuries, illnesses, and wounds, not only those war-related wounds but how they have been compounded by the aging process, which means that now you have the advent of things like Parkinson's and ALS and some cancers, plus just all the things that happen as you get older. You are less mobile, and you have more pain, and they are dealing with all of this without the support that they absolutely deserve.

So I am hoping that this legislation really could be passed quickly before the end of the year so that we can begin to really focus on the kinds of services that they need. The faster it is passed, the quicker all this community can begin to provide services addressed to those particular individuals.

Senator WARREN. Well, I know that Chairwoman Collins and Senator Murray have introduced a bill on this, and I just want to say I am with you. I really hope this goes forward, and goes forward as soon as possible.

I also want to ask another question. I know that some caregivers of elderly veterans requiring long-term, in-home, personal care can qualify for VA's aid and attendance benefit. But I also know that some scam artists have targeted veterans by charging them fees for obtaining this benefit even though the application is free.

Senator Rubio and I also have a bill that would direct the VA to work with other federal agencies to crack down on these scams because I think it is just really important here.

If I can, I want to hit one more point, and then if the Chair will indulge me for just a minute here. I come from a military family. All three of my brothers served. But that is not as common as it used to be. America has the world's best fighting force, but many people in our country no longer have a personal connection to our military. And as a result, they often do not know about the sacrifices of either the servicemember or the sacrifices of their caregivers.

Senator Dole, do you think that the sense of isolation felt by some military and veteran caregivers is a reflection of a broader divide between ordinary citizens and our military? And do you just have a few thoughts you might give us—I am really out of time here, but a few thoughts you might give us about how we help heal that divide?

Senator DOLE. Yes. I think that the isolation does—you are right on point on this, no question about it. You know, when you realize that less than 1 percent are serving today defending our freedom and our security, most Americans have no idea what is going on in military homes today. And it is amazing. We have done an outreach to a number of organizations as we put together our national coalition. And whether we are talking with people in government or nonprofit organizations or we are talking with business leaders, maybe it is the faith community, often I hear, "I had no idea. What can we do to help?"

And there has been such an outpouring from this whole group that we have got this wonderful coalition, but there is no question that people just do not—you know, they do not know what is happening in the homes, so how are we going to address that?

Well, one of the major goals of my foundation is raising awareness, and thanks to Ryan, he is helping us to raise awareness with the public service announcements, with the events that he attends, and working with our caregiver fellows and caregivers across America, meeting with them. And certainly the Hidden Heroes Campaign, the Hidden Heroes Cities, all of that is designed to raise awareness, to be able to help people to understand we need their support across the country.

Hidden Heroes Cities is an example of driving down to the local level the concern for finding and identifying caregivers, and we have a lot of mayors and their teams working across America to raise awareness, to find the caregivers and lead them to the kind of support that we can give them.

Senator WARREN. Well, thank you again. Thank you for all you are both doing. We appreciate it.

Senator DOLE. Thank you.

Senator WARREN. Thank you, Madam Chair.

The CHAIRMAN. Thank you.

Senator Casey?

Senator CASEY. Yes, I know we have to wrap up soon, but, Mr. Phillippe, I wanted to ask you a question about your own interaction with veterans and their families. You mentioned in your testimony your own family background and also the time you have spent with people like Megan and Matt, living in Connecticut. What can you tell us about any kind of common themes that you hear or things that we should be aware of that veterans and their caregivers raise? Anything you can share with us about concerns they have or maybe some issues that we did not cover today?

Mr. PHILLIPPE. Yeah, I mean, what comes to mind immediately when you ask that is the idea of how unprepared some of our caregivers are for the role that they are immediately inserted into, the lack of education and training that goes along with having someone be prepared to take care of a disabled vet. I feel like that is something that can also be addressed. There is a bit of that in the bill about even helping with financial aid, having these families that now have extra costs because only one can work, or maybe not at all if they have a 24/7 job taking care of their vet. And so figuring out how to readjust their finances and to also allow for support for the children even and understanding, okay, you know, mom or dad is having this issue and we have to be gentle for this reason. It is not always the easiest thing to convey to someone who is young. A lot of these caregiver men and women are young and have not had the life experience or the actual physical training experience that a lot of nurses have in other capacities. So I think that is a big part of it.

And what I always come back to is if we do not help our caregivers, what happens to our veterans? And when something happens to our veterans, that shame is something that we all share. And you see the rates of self-harm, the rates of drug and alcohol abuse go up when a veteran is left alone, when the marriage does not work, when their caregiver cannot handle it anymore. And I think it is up to us to offset those stresses and to try to keep those families together and to keep our vets healthy.

Senator CASEY. Thank you very much.

The CHAIRMAN. Senator Cortez Masto? I just wanted to give you a chance. Thank you.

I want to thank this panel for your truly compelling testimony. When Senator Dole first came to see me, it was after Senator Bob Dole had had a very rough year and had been in Walter Reed virtually the entire year. And I remember how impressed I was that rather than focusing just on her own situation, she told me of the stories of the veterans and their family members whom she had met at Walter Reed. And I know that is what inspired you to get involved in this. And it is so typical of the selfless service that you have given to your Nation your whole life, and I am very grateful for your raising public awareness of something that we truly need to act on.

Senator DOLE. Thank you.

The CHAIRMAN. And, Mr. Phillippe, thank you for making such an effort, especially when I learned that you took the red eye here and the red eye back.

Mr. PHILLIPPE. It is worth it.

The CHAIRMAN. I know how brutal that is. But I was not surprised when you said that you could not say no to Elizabeth Dole because all of us have found that to be the case, which is why I am co-chair of the Hidden Heroes Caucus today.

[Laughter.]

The CHAIRMAN. But it is indeed a worthy cause, and we do need to eliminate this disparity. I see in my own family where my mother for the last 8 years—my mother is 90 years old—has taken care of my now 91-year-old father, who is a World War II veteran who was wounded twice in the Battle of the Bulge, earned two Purple Hearts and a Bronze Star. And trying to get respite care is just so difficult.

And I think that is the number one challenge. I really do.

My mother has been extraordinary in doing that for 8 years, but as you both have pointed out, we now have Iraq and Afghanistan veterans whose loved ones may be in the caregiver role for 50 years, and we need to do a far better job of giving them the support that those who have borne the battle have earned.

So thank you very much for being here today and for sharing your advice and guidance with us. Thank you.

Senator DOLE. Thank you so much.

The CHAIRMAN. I now want to call up our second panel of witnesses.

[Pause.]

The CHAIRMAN. And while you are getting settled, I will note that we have two service dogs with us today who I know are very important to the veterans and their families who are here. I would invite them to testify as well if I could figure out how. I know how smart they are, that is for sure. Thank you.

First on this panel, I would like to introduce Ms. Terri Tanielian. Ms. Tanielian is the senior behavioral scientist for the RAND Corporation and former director of the RAND Center for Military Health Policy Research. She has led numerous studies examining the needs of veterans and their families and co-directed the RAND Corporation's 2014 study, "Hidden Heroes: America's Military Caregivers." Ms. Tanielian—I hope I am saying that right—co-directed RAND's newest study on military caregivers called "Improving Support for America's Hidden Heroes: A Research Blueprint," which is being released today.

Senator Tillis mentioned our distinguished witnesses from North Carolina, but let me give a little reminder. We are going to be hearing from Mary and Thomas Ward, both of whom will testify today. Mrs. Ward is a 2016 Elizabeth Dole Fellow and a caregiver to her husband, a pre-9/11 Marine Corps veteran who lives with service-connected ALS. I thank you both for your service, and I look forward to your testimony today. And thank you for being here.

We will next hear from two individuals from the great State of Maine—from Levant, Maine, to be specific—Melanie and Sergeant

First Class Joe—everybody has a hard name today—Swoboda. Got it right. Mrs. Swoboda is a 2016 Elizabeth Dole Fellow and a caregiver to her husband, a post-9/11 veteran who served in the Army for 18 years, including three tours in Iraq. Mrs. Swoboda has been her husband's caretaker for more than 10 years and helps him with his physical injuries and post traumatic stress syndrome. In addition, Mrs. Swoboda has a degree in education and has taught in the military community for more than 15 years, so I thank you both for your service and look forward to hearing your testimony.

And I would now like to ask our Ranking Member to introduce his witnesses.

Senator CASEY. Thank you, Chairman Collins. It is my pleasure to introduce our witnesses from Alum Bank, Pennsylvania, Sergeant Samuel Ickes and Wanda. Sergeant, we are grateful to you for your many years of service to our country in the Army in Panama, Iraq, and Afghanistan. I am also pleased to welcome your wife, Wanda, to the hearing today, and it was a pleasure to meet both of you today.

Wanda is a hero in her own right, a hidden hero, as Senator Dole would tell us. In addition to being a caregiver for her husband, Wanda is a full-time student at the University of Pittsburgh at Johnstown and a Dole Caregiver Fellow. Thank you for your family's service to our country, and thank you for being here with us today at the hearing.

The CHAIRMAN. And I add my thanks as well.

We will start with Ms. Tanielian.

**STATEMENT OF TERRI TANIELIAN, M.A., SENIOR BEHAVIORAL SCIENTIST, RAND CORPORATION**

Ms. TANIELIAN. Thank you, Chairman Collins, Ranking Member Casey, and distinguished Committee members. My name is Terri Tanielian, and I am a senior scientist at the RAND Corporation, where I study the health and well-being of servicemembers, veterans, their families, and their caregivers.

Many of our Nation's 20 million veterans have conditions or disabilities that require ongoing care. Supporting these veterans is a cadre of spouses, parents, and friends who provide unpaid, informal support with activities that enable them to live fuller lives.

With the support of the Elizabeth Dole Foundation, I have led three sequential studies focused on this important population. Our 2014 study, which you heard about today, "Hidden Heroes," provided the first in-depth picture of military and veteran caregivers. It estimated the value they contribute to our society and exposed the risks they face as a result of their roles. Four of the study's findings were of particular surprise.

First, of the 5.5 million military caregivers, 20 percent, or 1.1 million, were supporting an individual who served after September 11th.

Second, post-9/11 caregivers are different than pre-9/11 caregivers. They are younger, more likely to be spouses, and more likely to be in the labor force, which means they are working and providing care to a veteran.



Third, post-9/11 caregivers were ineligible for many support programs because of their age, relationship to, or the condition of their care recipient.

Fourth, we found significant threats to the future of military caregiving, especially as parents who are serving as caregivers are aging themselves and may soon be unable to fill those caregiving duties.

Our newest report is a research blueprint designed to ensure better support for military and veteran caregivers. This blueprint was informed by input from more than 175 stakeholders, including policy and program officials, researchers, clinicians, philanthropists, advocates, care recipients, and caregivers themselves. We generated consensus around ten high-priority research objectives, all of which are outlined in my written testimony. Today, however, I will focus on four that underscore the need for longitudinal research that will track these issues over time.

One priority that we identified is to study how caregiving affects caregivers. Such research could help inform programs and policies designed to mitigate any adverse effects of caregiving, particularly with regard to mental health, employment, and family well-being.

A second priority is to examine how caregiving affects the children of caregivers. No research has yet documented the effect of caregiving on children, though most stakeholders consider this to be a vital topic. Such studies should focus on the impact that caregiving has on parenting as well as the short- and long-term effects on children who serve as caregivers themselves.

A third priority is to examine how care recipients needs change over time. As individuals age or recover from their injuries, their needs and demands for caregiving will change, and this may affect the duties and strain on the caregiver.

The fourth priority for research is to assess how programs and policies impact caregiver well-being. We know very little about the impact of current programs on military caregiver outcomes, yet knowing what works and for whom is an important consideration for developing sound policies and funding worthy efforts.

To conduct studies designed to fulfill the blueprint we released today, a number of conditions must be met. Members of the Senate can take critical steps to facilitate an environment conducive to research on military caregivers. This means providing adequate and sustained funding as well as requiring research for decision making when making decisions about the future of caregiver support programs.

Our report also outlines several potential strategies for using this blueprint, including creating a research center of excellence specifically focused on military and veteran caregivers. It will be important for such a center to have multidisciplinary expertise as well as a broad focus to ensure that all of the outlined research objectives and special populations that are of importance to the veteran caregiving community are included in its mission.

I will conclude by reiterating that the role of our blueprint is to convey a vision for future investments in research that will lead to improved support for military and veteran caregivers. Thank you for the opportunity to share this testimony with the Committee, and I look forward to your questions.

The CHAIRMAN. Thank you very much.

I would now like to call upon the Wards to testify. Thank you.  
Mrs. Ward.

**STATEMENT OF MARY WARD AND THOMAS WARD, VETERAN  
CAREGIVER AND VETERAN**

Ms. WARD. Good afternoon, and thank you, Chairman Collins and Ranking Member Casey, for inviting me and my husband, Tom, to this hearing on military and veteran caregivers. I am humbled to be here alongside a force of nature like Senator Dole, an advocate like Ryan Phillippe, an expert like Terri Tanielian, and my peers.

I became a Dole Caregiver Fellow in 2016, but my journey as a caregiver started long before then. On June 21, 2010, Tom was diagnosed with ALS. Prior to that, in 1993, Tom had been disabled from encephalitis. He has required care from me since then, but the all-encompassing care of ALS is intense.

I had his care figured out and organized until ALS came along. It is a devastating diagnosis—excuse me—but for me it was like getting sucker punched. Tom and I are that couple that fell in love almost instantly in 1979, and my grief has known no bounds. I know how this disease works. It will steal his life, and if I am not careful it will take mine as well. The work ahead as his caregiver is daunting at best. I am certain that I am not up to the task alone, yet for the most part I know I will have to be.

In 2008, ALS was made a presumptive illness for veterans. Veterans are twice as likely to get ALS as non-veterans, and more than 4,500 veterans at a given time have ALS. Tom served in the U.S. Marine Corps from 1972 to 1975 so he qualified for benefits, and enter the VA into our lives.

I had not considered myself Tom's caregiver until later in my life. I was committed to our vows and love for each other. A caregiver to me meant someone who was paid to come in and provide services. In 2013, I saw an interview with Senator Elizabeth Dole about caregivers, and that was my epiphany that I was a caregiver.

ALS is a catastrophic disease, physically, emotionally, and financially. There is never a day that goes by that I am not grateful for all the VA does to support Tom as he battles ALS. The challenge lies in ensuring that he gets what he needs in a timely fashion: the correct breathing mask, medications, equipment, and so on. And while I work on managing resources available from the VA, at the same time I am taking care of Tom and teaching Advanced Placement U.S. Government and Politics online. Tom's need for assistance is non-stop. He is moving towards dependence rather than independence, and that is never going to change.

One huge worry I have is the financial aspect of my future. I teach high school online so I can care for Tom but have done so at a significant salary reduction which has impacted my future retirement funds. I save diligently, but I am deeply concerned that as his dependence grows I will need to pay for assistance out of pocket as the VA will only provide 28 hours of care a week, and that will never be enough if Tom lives to full paralysis.

We have two adult children who cannot assist in their dad's care. Our daughter is a second grade teacher in Charlotte. Our son is a

sergeant first class with 14 years in the Army and currently a drill sergeant. Their dad is their hero and would help in a heartbeat if it was possible. The best thing they can do is to continue to grow their careers; that is the kind of help we want from them.

Being a foundation fellow has been life changing for me. I have developed lifelong friendships with other fellows. Senator Elizabeth Dole has encouraged us to be "solutionists," and so we are, with each other and with other caregivers.

As a pre-9/11 caregiver, the VA offers me almost nothing. I receive no caregiver training from the VA, no stipend, no support other than a monthly national call with focused topics, and a few months ago was denied respite hours.

I am one voice among many who need consistent and compassionate help as we carry this heavy responsibility caring for our veteran. And there is still so much that we do not know. We need to cultivate a better understanding of the needs of caregivers through research like the kind you heard about from Terri. And we need action. I hope you will consider passing the Military and Veteran Caregiver Services Improvement Act to help caregivers like me.

Thank you for your time and consideration today. I welcome your questions for myself and my husband, Tom.

The CHAIRMAN. Thank you so much, Mrs. Ward, for your very moving testimony. I cannot imagine anyone having listened to what you just said voting against our bill. So I hope that we can spread your testimony widely, and I really thank you for being here today.

Mrs. Swoboda.

**STATEMENT OF MELANIE SWOBODA AND JOE SWOBODA,  
VETERAN CAREGIVER AND VETERAN**

Ms. SWOBODA. Good afternoon, Senators, and thank you, Chairman Collins and Ranking Member Casey, for having Joe and I at this hearing on military and veteran caregivers.

My husband, retired Sergeant First Class Joseph Swoboda, is a three-time combat veteran of Operation Iraqi Freedom. He was deployed during the initial invasion in 2003, again in 2005, and again in 2007. Each time, the deployments were longer and longer. In 2003, he left for 8 months, in 2005 for 12 months, and in 2007, Joe was overseas for approximately 15 months.

During the initial invasion and again in 2005, Joe sustained injuries in two explosions, in one of which he lost consciousness. However, because of the intensity of the fighting, there was no time for him to be checked by medics, so he shook it off and remained in the battle. Years later, the injuries he sustained would become impossible to ignore.

This several-year period of rapid deployments was a whirlwind. Even when Joe was home, he was not home. When he was not at war, he was training for war in field exercises, so there was no time to recognize he was having any mental health or neurological issues. He had to push through it, as did I.

After the third deployment, Joe asked to be given an assignment where he could train without being deployed. However, when he stopped going to combat, that was when the problems really start-

ed, when we finally had the opportunity to slow down, and these difficulties he was having started coming to light.

I knew he was struggling. He was home, but he had never really come back from Iraq. A fellow soldier, who was also a trusted friend, saw his struggle, too, and thankfully insisted that Joe seek help for the overwhelming symptoms he was experiencing as a result of his traumatic brain injuries and post traumatic stress. The invisibility of his wounds meant most in the Army had never recognized Joe as being injured.

Once these symptoms began to affect his work, Joe was medically retired from the Army, and during his out-processing, a staff member at Fort Benning handed me an application for the VA Caregiver Program. I filled out the paperwork, but I was not really sure what I was applying for. Of course, even when Joe had still been active duty, I was his caregiver, but I had never recognized it. All of the tasks I was doing were the ones you will hear any caregiver talk about: I was managing his medications, I was raising the kids alone, I was managing finances, and I was helping him remember things that he could no longer remember.

I love my husband, and I would absolutely care for him regardless, but having caregiver support programs in place is so important to me because for the first time in 20 years, I can breathe. I cannot imagine how much harder this would be without those programs, but I know millions of caregivers manage every single day.

It is still stressful, there is still a lot I have to do, but having the financial support of receiving a stipend and the opportunity for respite care has been crucial for my family.

There are days when I think I cannot go on like this, I cannot have this much stress and pressure on me. And it is not just the stress on me. I also see how the stress of caregiving affects our children, too. Respite services, though, give us all an opportunity to recharge.

Support systems like the Dole Caregiver Fellowship, with the network of knowledgeable caregivers who can help answer so many questions and programs offered by the VA such as the Caregiver Support Program make this sustainable for me and for so many other caregivers.

This kind of support should be available to all military and veteran caregivers, whatever era their veteran served. It is really helping people. It is really making a difference. I hope that you will consider supporting and passing the Military and Veteran Caregiver Services Improvement Act to do just that.

Thank you so much for your time this afternoon. I look forward to answering any questions you may have.

The CHAIRMAN. Thank you so much, Mrs. Swoboda, for sharing your story with our Committee.

Mrs. Ickes.

#### **STATEMENT OF WANDA ICKES AND SAMUEL ICKES, VETERAN CAREGIVER AND VETERAN**

Ms. ICKES. Thank you, Chairman Collins and Ranking Member Casey, for inviting my husband and I here today to testify. I would also like to thank the Elizabeth Dole Foundation and Senator Dole, Ryan Phillippe, and Terri Tanielian for taking the time to be here

today. It is humbling to have voices like theirs speak on behalf of caregivers like myself.

It is my hope that by sharing a small part of my journey as a caregiver with this Committee that you can ensure future caregivers do not face the same hurdles that my husband and I—and other caregivers—have had to overcome.

My husband, Sam, had been married to the Army long before he married me. In the 1980s, he was an Army Ranger in Panama in Operation Just Cause, though he still saw action with the 3rd Ranger Battalion. That is when he suffered his first TBI. Later, he was in a bad accident that got a lot of metal put in his body, so much that the Army said he could not perform his duties anymore and released him.

After 9/11, he couldn't not do the job the Army trained him to do. He went and got every waiver he needed so he could go back into the Reserves as an MP, a military police officer. He signed up for every single deployment. He was deployed more than he was not. Over the course of those deployments, Sam earned three Purple Hearts. He did his job. He brought every single person back alive. He went above and beyond his duty.

Sam came back from his deployments looking like the same person, but he did not come back acting like the same person. When you meet him, when you speak to him for a few minutes, he looks like everybody else. Talk to him a little bit longer, and you can see his issues in his eyes, in the way he talks. Sam undeniably still lives with the effects of the war.

One day, when Sam was home on leave from his deployment, he had gone into the backyard to grill dinner. After he was gone for a while, longer than dinner should have taken, I glanced out the window and saw flames lapping at the side of the house. I did not hear Sam doing anything about it. I ran outside and saw that he was just standing there, wide-eyed, staring at the fire eating away at our house. I pushed him away and closed the grill to put out the fire, and that is when I realized he had some serious issues. That is when I realized that he would need more help, a little extra help. But the Army did not see it that way.

When he came back from his last deployment, where he suffered his last major TBI, the Army released him and said he was healthy enough to go back to civilian life. In the 60 days of leave that he had earned between leaving the military and going back to his old job, I began noticing more of the little things that were different about him. He was stuttering, he could not process things, his memory was terrible. He was very distant.

I took him to the VA, and I pushed the issue. Sam was not the same person. The more I talked about the issues he was having, the more the doctors realized I was right. But I had to write to the Senator to get the Army doctors to reevaluate him so he could be given the right benefits from the military, the ones that he had earned.

It should not have been that difficult. The Army should have sent him back to civilian life—I am sorry. The Army was going to send him back to civilian life and he could not hold a job. He could have ended up homeless, or worse. I could not and would not let that happen. I had to figure out everything out on my own. I had

to make it right for him and for us. When he came back with his issues, I stepped up because he could not. I took control because he could not. And I became his caregiver.

When we had access to the VA Caregiver Program, it was very good to us. It allowed me to have respite time as a caregiver, to have the down time and respite time that I could focus on me. And that stipend, you cannot put a dollar sign on it.

As you consider how to improve the lives of caregivers, know that the Military and Veteran Caregiver Services Improvement Act makes important strides in improving coordination between the Department of Defense and the VA when servicemembers are transitioning into civilian life and in extending a priceless stipend to so many caregivers and veterans in need. Those are certainly policies that would have helped Sam and I as we figured out our new life. I hope you will support this legislation and help ensure it to be signed into law.

Thank you for allowing me this opportunity to share, and I look forward to your questions.

The CHAIRMAN. Thank you so much for your testimony, and I want to thank all of you for being here today and sharing your personal stories with us. It really makes a difference.

You know, a lot of times we talk about numbers here in the Senate, and we talk about, for example, that there are 5.5 million military caregivers. But when you put a human face on it and you hear the individual stories, it makes such a difference. It makes it so real.

Let me go across, starting with the Wards and then the Swobodas and then the Ickeses, and ask a question of all of you. I often hear that caregivers are very reluctant to ask for help or support, and, Mary and Melanie, it sounds like in your case you did not think of yourselves as caregivers initially, as being that role. Others may be just hesitant to ask for help, and many simply are unaware of what help there is out there, although I think we would all agree it is not adequate and it is not fair that there is this disparity.

But I would ask, starting with you, Mrs. Ward, how can we better help military caregivers overcome the barriers of their own willingness to accept help?

Ms. WARD. So, well, for me personally, I think I would have needed somebody to ask me to have some help, which is probably true of many other caregivers. I think I am just one of many when it comes to that.

I think for us, getting a diagnosis of ALS meant an enormous amount of stress and work in the future, work for me, and I probably would have really benefitted by having somebody reach out to me, maybe even separate from Tom. I think it is very difficult to be the care recipient and hear the kind of stress it will be for their caregiver, because they are not a burden but it could feel like a burden. And I think it would really be okay if we had somebody take us aside and speak with us and be available for us for questions and to kind of help us brush ourselves off and get moving in the direction that we need to, to still try to have the best life that we can.

The CHAIRMAN. Thank you.

Melanie?

Ms. SWOBODA. I think it would have been helpful to me to have had more education about caregiving during my husband's Med Board process. During this process there are many briefings that are held to help the soldier transition out of the military. So I think that having—and it could be very simple as training someone who is already giving briefings about other aspects of out-processing, to present information to potential caregivers.

Much of the information I have learned along the way came from social media outlets, and organizations like the Elizabeth Dole Foundation are definitely leading the way in disseminating information and, more importantly, helping caregivers to self-identify.

But I agree with you, Senator, that it is difficult for us who love our spouses so much to identify as caregiving because we do it because in sickness and in health, and we take that literally. So thank you.

The CHAIRMAN. Thank you.

Wanda?

Ms. ICKES. Well, I agree with Melanie, the fact that the veterans have their out-processing, and they are told what happens next. We are not, you know, especially if there is any insight as to the issues that the veterans are having, that they might need caregiving, they might not, you know, be the same as when they left. It would be great if we were given the same out-processing briefing that they are.

But in our case, he was a reservist, and there is no local FRG or anything to kind of steer me. I was on my own. I had to figure it out as I went. We both did. He has had the advantage that he had the military behind him telling him where to turn, you know, and what to do, and I did not have that.

The CHAIRMAN. Thank you.

Ms. Tanielian, I am astounded to learn from your testimony that there has not been a single study performed on the impact of caregiving on children, and Mrs. Swoboda talked about the impact for her in trying to balance raising children at the same time. Why has there been so little research done on the whole area of military and veteran caregivers? Thank goodness for the Elizabeth Dole Foundation, but, in general, when you look at the literature, it is astounding how little research has been done.

Ms. Tanielian. Well, you are right. When you look at the literature, what you do find is that most of what we have learned about caregiving is from research that has looked at caregiving to the elderly or caregiving to individuals who suffer from age-related conditions and chronic conditions—dementia, cancer, and the like.

I should note that those studies and those findings are relevant for military and veteran caregivers, particularly as we know that 80 percent of our military and veteran caregivers are of the pre-9/11 era and are tending to issues that are also associated with age, although our veterans are at higher risk for some of those conditions.

The VA has been a leader in doing research on veteran caregivers, particularly around some of those age-related conditions—dementia, for example. But often the challenge in getting research conducted or programs initiated is having awareness that there are

issues that may need to be studied. So I would say awareness is a challenge, but also funding, making sure that there is funding available for researchers to be able to implement studies on a specific population or in a specific disease or clinical condition area that also includes caregiving.

As we look towards better solutions to improve the care that we can provide for specific populations, just as we have seen with support programs, caregivers become kind of like that offshoot or that incidental population that is served. And so we are hopeful by bringing attention and crafting this blueprint that will give some facilitation to the research that needs to be conducted to answer so many of those knowledge gaps, including about children.

The CHAIRMAN. Thank you.

Senator Casey?

Senator CASEY. Thanks very much, I wanted to reiterate the thanks that Chairman Collins expressed to each of you for your testimony. This cannot be easy, and I know that this is not the way you spend most of your days providing testimony in a Senate hearing.

I was struck by the personal reflections that each of you had about the challenge of caregiving in your own experience. Mary, when you said early in your testimony about getting the diagnosis, you said it was like getting sucker punched and what that was like for you and like it would be for anyone.

Melanie, when you said having caregiver support programs “for the first time in 20 years, I can breathe,” I think that gives us a sense of how difficult this is.

And, Wanda, you said, “I stepped up because he could not,” which is, I think, something that each of you could say about your caregiving.

Sometimes we have hearings in Congress, and we are not sure about the impact around the country. But anyone who is watching this or will watch it later or hear about it or read about it I think would be inspired by your testimony. So I hope you understand that you are helping others in the manner that you testified.

I guess in so many ways you may think that this kind of service you are rendering is simply a natural act, right? It is an act of love for someone that you have spent most of your life with. But in another sense, when we consider what you have had to be dealing with all these years, it is an indication that you in your own way have been triumphant over something very difficult. And we are grateful to have the chance to hear it up close in your testimony.

Wanda, I will start my question with you. I know that in your case you were once part of the VA Comprehensive Caregiver Program, but recently the Department informed you that you would no longer be eligible for the program. How has that decision changed your ability to care for your husband and also yourself?

Ms. ICKES. We were recently told that we graduated. I guess that is supposed to be a good thing. For us it is not. The stipend that I received, that we received, we used that for my respite. Sam belongs to a hunting camp, and he goes there a lot for his respite care. With TBI and PTSD, he needs to, you know—he needs the solitude and things, and that is where he would go. But he cannot go by himself. Most of his care is safety issues for him, and I can-



not just let—it is several states away. I cannot allow him to go there himself. The money that we received, the stipend we received was used for both of our respite. He would go away; he would have someone accompany him. I was able to pay them travel and pay them for meals and to be away. And that was his respite care and mine because I knew he was being taken care of. He was being cared for. So I had my down time also. Now we do not have that.

The stipend also allowed me to go back to school to get my degree because he is 100 percent disabled. He is not permitted to work. So whatever we want in our house, in our life, for the rest of our lives, is going to have to come from me. The stipend was enormous for us. It was not a lot dollar-wise, but we depended on it to be there just for the little bit of time to get me through school so I could, you know, get a career going and make the money that we are losing from him.

Do you want to add anything?

Mr. ICKES. I just did not understand when they told me I graduated from a program that—today is the best I am going to be. Tomorrow, I slip each—it might just be a little bit, but every day you slip a little more with TBI or PTSD. Yeah, you will find a common ground, but you are still going to lose that short-term memory. The issues are still going to be there. Every day just gets a little tougher. I mean, you kind of adjust your life to it, but I do not understand how they can tell you that you graduated from a program when it feels like you just stepped into the program.

Senator CASEY. Well, I appreciate that, and I know you both understand others have had the same experience. I know that the VA has initiated an internal review of these eligibility decisions and placed a moratorium on any further benefit revocations. So while we are happy about that, that no one is being discharged from the program in that fashion, it is very little solace to you and to others at this time that lost those benefits.

We have a letter to the VA indicating that and also urging them to re-enroll those who were discharged with insufficient explanation until the review is completed and the procedures can be improved. So we are going to continue to work on this.

Thank you.

The CHAIRMAN. Thank you.

Senator Tillis?

Senator TILLIS. Thank you, Madam Chair. Since I have been gone, I went over to the Veterans' Affairs Committee, and I told them I was at this Committee and how we need to make it a priority to look at actually addressing some of the things that the Ranking Member, Senator Casey, mentioned, some of the revocations and disruption of service.

Here is one thing that I ask. I never miss an opportunity in this venue. We have got a lot of red tape to cut through in the VA and the DOD. Between now and the time we get through it, let your Senate offices and your home states be the scissors. Every single one of us, we have opened—I have been here for 2½ years. That is how long I have been in the Senate. We have opened up our 10,000th case in those 2½ years helping people, 6,000 of which are veterans-related. The next time that you deal with the VA on benefits that you are entitled to and you are not getting the right an-

swer, let your next phone call be to the Senator of your choice in your state. Make it our job because we owe it to you.

First and foremost, I want to thank all of you for your service, both the spouses and the men here who served.

Ms. Tanielian, I want to—I know, by the way, I have just got to go back and brag again on Tom and Mary. They come up here for a number of things. They were at Senator Dole's kickoff for Hidden Heroes. They have come up and advocated for ALS research. You are continuing to serve. Not only are you serving your household, Ms. Ward, but you are out here doing a great service for everybody else who needs your voice.

But, Ms. Tanielian, I want to talk more—and you are talking to somebody who is just in the unique position of being on this Committee, the Veterans' Affairs Committee, and the Chair of the Personnel Subcommittee. Wanda talked about transition. You know, we have talked about the need to do a better job of identifying potential—either caregivers right at transition or at some point in the life cycle of the veteran. I know that you have suggested in the blueprint additional research. Can you give me an idea of—there are a couple of things. One, how do we glue together that entire chain? How do we identify servicemembers that may not even know that they may need care so that we are better alerted and better prepared at the time that they do? And, also, what sorts of—I really think that we have to touch on the economic case for doing this. If the burden continues to increase on caregivers, then we will have fewer caregivers. And we will end up having to pay a price for less care and less valuable care to the veteran.

So to what extent does your research or do you think research should be focused on, one, gluing this VA, DOD, the veterans service organizations, the network that comes together in addition to the family caregiver, research on that, and then research on the business case so that we can go and talk about why funding—this is a dollar well spent. For one thing, it is a debt that we owe every single one of you. For another thing, I think it makes fiscal sense at some level.

MS. Tanielian. So thank you. Those are great questions, and I am going to start with your second question first and then turn to the other one around transition. And you are absolutely right. Making the business case is often what motivates individuals to pay attention to something, and so quantifying the societal cost savings of caregiving, in fact, was one of our research priorities in the blueprint. And while stakeholders felt this was highly important and very critical, they also wanted it to include research that would document the costs that they experienced, not just the savings that they contribute but the costs that they accrue as well, in financial and economic terms. That can be costs, you know, associated with lost productivity, costs associated with, you know, support programs or health care utilization as well. So really a need to do research that looks at the cost as well as the cost-effectiveness of different programs that we can put in place. And so we need much more research in those areas.

On the transition piece and what can we do to better identify caregivers, in our 2014 study we made a series of recommendations, and they were in four categories, and the first really was

around empowering caregivers through a number of different strategies to help themselves identify but also help systems identify them.

There have been a number of new programs that have been implemented, including in the Department of Defense, to try to identify individuals who are serving as caregivers and provide them with education, training, and peer support.

We called attention to the need to look at eligibility criteria for different programs across different federal agencies to ensure that those eligibility criteria were defined in ways that were, in fact, intended to target the population who is providing care and service to our military servicemembers and veterans.

But we also talked about the need to put in place appropriate education and training so that individuals who may not understand that their caregivers become aware of what it will entail.

We also talked about the need to create environments that are more sensitive to caregivers. Health care providers. Health care providers should be conducting caregiving needs assessments when they are interacting with their patients. And if someone indicates that they have caregiving needs, then the health care provider should be asking to speak with their caregiver and learning more about that caregiver and doing their own needs assessment to understand what it is that the caregiver needs to have their health issues addressed as well.

Senator TILLIS. Thank you. Madam Chair, if I may just for a second, the VA the week before last announced that they are implementing an electronic medical record system that has the same platform that the DOD has. Now we have an opportunity to really talk about a better integration using the data in the electronic health record from the DOD and using the right kind of analytics to even better increase our understanding on the people who need the help the most.

The last thing I will leave you with is there is a whole group of people out there. At some level, each and every one of you have benefitted from some VA benefits, either now or in the past. But we also have pre-9/11 veterans, particularly dating back to the Vietnam War, a whole class of veterans that may have gotten an other than honorable discharge, and those circumstances of that discharge may have very much had something to do with traumatic brain injury or PTS, and we simply did not know how to categorize it. So what we also have to do is look back and see that group of people that not only the caregivers are struggling, but they never even had a single bit of the safety net of VA benefits coming out with an honorable discharge, and that is something else we need to look at going forward.

Thank you, Madam Chair.

The CHAIRMAN. Thank you very much, Senator.

Senator Cortez Masto?

Senator CORTEZ MASTO. Thank you. Thank you, Madam Chair. And thank you to all of you.

Let me follow up really quickly with Ms. Tanielian on the discussion you were just having. First of all, thank you for this blueprint. I think it is fantastic, and I hope there are many folks, including many here in Congress, who pick this up and have wonderful ideas

on how we can address some of the issues we are talking about today.

But one of the things that you brought up which I am a big fan of is creating a research center of excellence. Can you talk a little bit more about that and what you envision that would look like?

Ms. TANELIAN. Sure. We identified the need for—or we suggested a potential strategy around creating a research center of excellence because it would provide the opportunity to give strategic pursuit to the research objectives that we identified by providing kind of a nest egg of funding and leadership, to bring together the field and the community to really jump-start some of the needed research. So there are multiple ways and multiple examples of other research centers of excellence, but we suggested it because we thought a center of excellence specifically focused on military and veteran caregiving research would go a long way to make sure that we can get started on filling the knowledge gaps that we identified and pursuing the research objectives that the stakeholder community agreed are of high importance right away.

Senator CORTEZ MASTO. Are there already models out there that can be replicated or emulated, or however, that we could look to or best practices that could help jump-start that?

Ms. TANELIAN. There are many examples that already exist. Given the topic—and there are certainly a number of different ways to go about establishing something in the federal agencies or in the federal sector or putting something into the private sector. And there are advantages and disadvantages with all of those different approaches.

Ultimately, I think given the topic and military and veteran caregiving, there are certainly examples of where the VA has established other centers of excellence where they conduct research in partnership with outside organizations to really ensure the leadership and funding and momentum to pull together the research community in a multidisciplinary way to pursue strategically and intentionally the research objectives that we identified.

Senator CORTEZ MASTO. Thank you. And then let me just say to the Wards, Swobodas, and the Ickeses, thank you so much for being here. First of all, let me mirror what my colleagues have said. Thank you for your service, not only your active service in our military and protecting our country, but your continued service, sacrifices made both by, gentlemen, you as well as your family members. So thank you.

And, honestly, you know, part of me is sitting here thinking this is unconscionable that we even have to have this discussion, that we are not doing everything we can to take care of you and your families when you have put your lives on the line to protect our freedoms and our democracy. It is just ridiculous to me.

So I want you to know, at least from all our perspectives—I am speaking for my colleagues, but I know they believe this—that your words are not ringing hollow.

We have got to do something. And the last thing we want to do is have something like this just sit on a shelf somewhere and have your words go nowhere. So you are hearing that commitment. Already we have put some action items in place, as you have heard.

Let me ask you this, and I think, Mrs. Ward, you talked about this. Mary, you highlighted in your comments that you were denied respite care by the VA a couple of months ago. Is that correct? And can you talk a little bit about that and give me a little background on why that occurred?

Ms. WARD. Yes, I was denied respite care in the fall, and actually it was to come here in Washington, D.C., as a fellow for the summit in September. And I put in for respite care so there would be somebody a few hours a day to help Tom. He needs help cooking, getting dressed. It is not like an amputation, so it is not like, oh, he absolutely cannot do a thing. He can feed himself, but he cannot cook for himself. And the person from the VA who did the intake with me, I mean, I will just be honest. Here are her words: "We do not provide people to come and cook and clean." And I said, "Okay." I mean, I told her the truth. That is what I needed. I suppose I could have said other things, but I just told her the truth. So I dealt with it on a personal level. I handled it. Tom ate meatloaf every night for a few nights while I was gone, and I had some people check in with him, and we handled it. But it will never happen again. I will never go away again without having somebody there to care for him or he will have to come with me. That is just the way it has to be. The potential for a fall—he still can ambulate some around the home—is too great.

Senator CORTEZ MASTO. Thank you all for telling your stories today and having your voices heard. Really, our goal is to make sure you make a difference in others' lives as well, so thank you.

The CHAIRMAN. Senator Blumenthal.

Senator BLUMENTHAL. Thank you very much, Madam Chairwoman, and thank you so much for having this hearing. And I want to thank all of you for being here today. There are few topics of greater importance to any of us who serve here, and particularly because I serve on the Armed Services Committee and on the Veterans' Affairs Committee. As a matter of fact, I apologize for being late because I just left a hearing at the Veterans' Affairs Committee.

I would like to ask members of the panel, since we are scrutinizing the budget there, whether you think that the VA's budget is sufficient to help with caregivers—and we are trying to expand this effort; as you know, Senator Murray and the Veterans' Affairs Committee has led this effort long before I was there, but I am an enthusiastic co-supporter—whether the resources are sufficient and whether they are focused in the right areas.

Mr. SWOBODA. I would like to say, sir, that it makes sense to me that if more caregivers were out there for our veterans—and, first, let me say this, what it is like to be a combat veteran away from combat. I just met a World War II veteran a few weeks ago. He was at a place back home in Maine called the Cole Museum, and they take time to spend time with veterans and sort of ground them and give them a reason to be alive. You know, combat veterans, when we are overseas, we are so used to being so on edge, things going on around us all the time. You are going 1,000 miles an hour. Then when you come home to the "Land of McDonald's," what I call it, nothing is happening. You know, you are still going 1,000 miles an hour, but there is nothing going on.

So a combat veteran will either—without support like my wife, you know, being my caregiver, she grounds me. If a veteran is grounded and given a purpose to continue on, they do not fall into suicide; they do not fall into alcohol. This particular World War II veteran had just come out of his house 5 years ago. He did not want anything to do with anybody since World War II. How many years has that been? The guy has missed his whole life, until somebody finally got to him, and not necessarily his caregiver, but somebody grounded him. And that is why caregivers are so important to combat veterans. We have to be grounded. We know that there are no IEDs on I-95. But we know in our brains that we have to look. You cannot stop that. So we need somebody there to ground us, and that is what caregivers do.

Senator BLUMENTHAL. And two of our four children have served, both deployed, one in the Marine Corps, the other in the Navy. So I know what you mean. They are probably in less need of grounding than I am a lot of the time.

Mr. SWOBODA. Yeah.

Senator BLUMENTHAL. Not that anything that we do here is in any way similar in any way to combat. But I have seen this countless times in Connecticut, and that is why I have tried to work through the VA, and that is why I am asking the question about support from the Veterans Administration.

Mr. SWOBODA. May I add, sir?

Senator BLUMENTHAL. Sure.

Mr. SWOBODA. It makes sense to me that if there were more caregivers, the VA would have to spend less money on mental health. You know, they would have to spend less money on mileage to go to a doctor, because that caregiver is there, that caregiver is being paid to be there for them. My wife has a master's degree. She is a school teacher. She has had to step way down just to be there for me. And she is happy to do that, and I would much rather have her than anybody else. But there is a sacrifice there.

Senator BLUMENTHAL. Well, I want to thank you both for your service, and I mean both of you. And I thank the countless other caregivers for their service. This point is one that I make. We tend to thank the veteran for her or his service, and the caregivers are equally deserving of thanks. So I appreciate your being here and giving a face and a voice to that very important point. Thank you.

Thank you, Madam Chair.

The CHAIRMAN. Thank you, Senator.

Today we have had an extraordinary hearing, hearing from the caregivers, seeing our veterans who have served our country so well. Listening to such terrific advocates as Senator Elizabeth Dole and Ryan Phillippe has truly been a moving experience. And I do believe that the testimony that you have given us, supported by the work the RAND Corporation has done, will help us advance the three bills that we have talked about today.

This Committee does not have legislative jurisdiction, but what we do have is the ability to shine a spotlight on an issue that has not received the attention that it deserves. And with your help, that is exactly what we have done today.

I could not help but think as I listened to the testimony today that there is a reason that we use the words "military family," be-

cause as we have seen from the testimony of Mary, of Melanie, of Wanda, when a person joins the military, the whole family serves. And that service can last a lifetime.

It is very clear to me that our Nation's 5.5 million military caregivers who face such substantial emotional and financial issues each and every day need far more support than we have been giving. And I am just so grateful that you are willing to come and share your personal stories with us, because that, along with the RAND Corporation study and the determined advocacy of the woman who will not take no for an answer, Senator Elizabeth Dole, and the ambassador of her group, Ryan Phillippe, will allow us to get something done. And I just want to assure you of my personal commitment in that regard.

Senator Casey, do you have any final comments that you want to make?

Senator CASEY. Yes, briefly. Thank you, Madam Chair, and I want to thank our witnesses. Maybe Wanda said it best. Wanda, you said in your testimony about Sam, you said, "He did his job. He went above and beyond his duty." I think that could be said not only of Sam but of you and of Melanie and Joe and Mary and Tom. We are grateful that you have been willing to do that in your lives, but also grateful that you are willing to share it and give us both inspiration and information about why we need to pass these legislative items as well as to do other advocacy on your behalf and on behalf of those that we represent.

So thanks for being here and thanks for serving your country in more ways than one.

The CHAIRMAN. Committee members will have until Friday, June 23rd, to submit any additional questions for the record which we may be getting to you. But, again, my profound thanks to all of our witnesses today, to my Ranking Member, and to all the Committee members who participated in today's hearing. And thank you also to our dedicated staff. We could not do it without them as well.

Thank you for being here, and this concludes our hearing.

[Whereupon, at 4:38 p.m., the Committee was adjourned.]





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## **APPENDIX**

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## **Prepared Witness Statements**

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**Prepared Statement of Senator Elizabeth Dole, Founder,  
Elizabeth Dole Foundation**

Thank you Chairman Collins, Ranking Member Casey, and members of the committee for calling today's hearing.

By doing so, the committee demonstrates its dedication to recognizing our nation's hidden heroes—their honorable service, their enormous sacrifice, and their selfless daily, and often lifelong, journey of care.

Chairman Collins, I owe you special thanks for your support of key legislation and the Hidden Heroes Caucus, sending a strong signal that our nation's leaders must stand with America's military caregivers. Thank you so very much.

This is not my first time testifying before the Senate Special Committee on Aging. Recently, I came across testimony I gave on June 29, 1978—39 years ago, as a member of the Federal Trade Commission. And, like each of you, I once sat up there on the dais as a member of this committee.

To be honest, with the many issues before the Senate, I didn't know at the time the true benefit military and veteran caregivers are making to our Nation. And the huge personal toll it is taking.

That all changed for me in 2011 when my husband Bob was hospitalized at Walter Reed. I became friends with young spouses, mothers, dads ... sitting bedside, selflessly looking after their wounded, ill or injured veteran. Their strength was incredible. Yet, I could see they were carrying an emotional weight almost too heavy to bear. As they reeled over their loved one's injuries, they were being asked to make extremely difficult decisions without any preparation. And they were quietly wrestling with the fact that they might be serving in this new role for the rest of their lives.

As I visited with them day in and day out, my eyes were opened to the critical role these caregivers play in helping our wounded warriors recover and thrive. And sadly, how much stress is placed on them by the tremendous responsibilities they take on, without any real preparation, often in isolation, and with very little support.

Just as heartbreaking are the stories of pre-9/11 caregivers who have been supporting their loved ones for years, struggling to care for the latent effects of undiagnosed post-traumatic stress, Agent Orange, exposure to burn pits, or decades-old traumatic brain injuries that are now causing early on-set dementia. These caregivers are just as terrified. Just as isolated. Just as important to their veterans. But when they apply for the VA Caregiver stipend, they are told that the timing of their veteran's service does not qualify them for support.

I established the Elizabeth Dole Foundation in 2012 to raise awareness and support, empower military caregivers and recognize their service to our Nation. We began by commissioning the RAND Corporation to develop the first comprehensive, nationwide, evidence-based research on military caregivers.

At the time, we knew so little, but realized we needed to uncover exactly ... Who are military caregivers? How many are there in America? What roles do they play? What are their needs? How old are they? What kind of support do they provide? And for what type of injuries?

There are 5.5 million Hidden Heroes in our Nation. Each provides daily support and care around various functions of day-to-day life. These women and men manage medications, schedule and coordinate appointments, provide emotional and physical support, arrange for rehabilitation, handle legal and financial challenges, and more.

Caregivers support every generation, from World War II veterans, like my husband Bob, to injured service members of our current operations. In fact, there are 1.1 million military caregivers, most under the age of 30 with children in the home, who care for post-9/11 era veterans and service members.

Though caregivers may not always be easy to recognize, they are all around us.

Our research also helped clearly define the broad societal benefits of caregiving. RAND's experts concluded that the most important factor to a wounded warrior's recovery or improvement was a well-supported caregiver. This Statement could have been the headline of the report, but it was overshadowed by more alarming findings.

We discovered that by nearly every measure, military and veteran caregivers were suffering under the weight of their responsibilities. The study found high instances of isolation, physical ailments, depression, unemployment, debt, and much, much more.

Yes, caregivers are vital to those who were injured while protecting our freedom and our security. But if we do not come to the aid of these hidden heroes, a crucial, irreplaceable support system for disabled service members and veterans will be imperiled.

There is also an economic argument for supporting military caregivers. They provide nearly \$14 billion dollars a year as an unpaid, voluntary workforce—enormous costs that would otherwise be borne by our society.

These women and men do not necessarily think of themselves as caregivers—for example, “I’m just the spouse taking care of my husband, the mother caring for my son”—and they feel uncomfortable asking for help. This makes it difficult to identify them, and in turn, difficult to connect them to the support they might need.

And, very few services and helpful resources are designed specifically for military caregivers. We want to solve these problems by providing a continuum of care across a lifetime.

That’s why, in addition to continuing our research partnership with RAND, the Elizabeth Dole Foundation is actively working with leaders in government as well as the private sector, nonprofits, and the faith-based community.

Last September, we launched Hidden Heroes, a multifaceted campaign to expose the tremendous challenges and long-term needs faced by our nation’s military caregivers and to inspire fellow Americans to seek solutions. We also introduced HiddenHeroes.org, a first of its kind Web site full of carefully *vetted resources* and a safe, secure place for caregivers to connect with one another. In less than a year, more than 60,000 caregivers and concerned citizens have come to the site to search for information and to take action to help.

Our campaign is chaired by actor Tom Hanks, and we have enlisted the help of several other high-profile individuals as Hidden Heroes Ambassadors, like Ryan Phillippe. Ryan is a multi-award winning actor and star of NBCUniversal/USA Network’s conspiracy thriller, *Shooter*. He plays the role of military veteran, Bob Lee Swagger. More significantly, Ryan has close family ties to the military community.

In real life, Ryan is using his own “swagger” to privately meet with military caregivers across the country to help amplify their voices. Our Hidden Heroes Campaign features Ryan in a national public service announcement that has been seen across the country in newspapers, magazines, on TV and digitally.

Ryan, your work with us is extraordinary. My heartfelt thanks to you!

We also announced Hidden Heroes Cities, the galvanizing of communities to identify caregivers in their midst and the local resources to support them. I am proud to say we have recruited 100 cities to date, from Augusta to Phoenix, from Pittsburgh to Nashville.

This is where the real action is happening. We need to wrap our arms around these caregivers where they live and inspire them to raise their hands so that our communities can deliver the support they deserve. We are asking you to encourage cities in your States to become Hidden Heroes Cities.

Most importantly, we are not doing this alone. In the Foundation’s National Coalition, there are more than 300 partners. The VA, local, state, and federal leaders, faith-based organizations, VSOs and MSOs, philanthropists, corporations, even the media, are helping to power the Hidden Heroes movement.

The VA Caregiver Program is one great example of what happens when coalitions come together to work with Congress to address gaps in services. And we continue to press for needed reforms and to collaborate with the VA to make this program much more efficient and more accessible to a broader range of military caregivers.

As you listen to Ryan and our other panelists, I urge you to consider taking two actions after today’s hearing:

First, make the bipartisan Military and Veteran Caregiver Services Improvement Act the law of the land.

This bill will expand essential services for caregivers of all eras. It will also provide direct assistance with some of the top challenges military caregivers face every day including respite, childcare, financial advice, legal counseling, and education.

I have with me a letter signed by 30 Hidden Heroes partner organizations. It calls on Congress to urgently pass this piece of life-changing legislation. This is the third year in a row we have asked for passage of this critical legislation—let’s make it the law of the land this year.

Our second ask is that Congress invest in the critical research necessary to *sustain* positive outcomes for our caregivers in the coming years.

In the next panel, you’ll hear from Terri Tanielian, Senior Behavioral Scientist at the RAND Corporation.

As a follow up to our 2014 study, the Elizabeth Dole Foundation commissioned RAND last year to develop a blueprint to forecast the most important areas where additional research is required in order to effectively support military caregivers’ long term needs.

Terri will share key findings of the research blueprint today, which was released just this morning. These findings can inform us all—public, private, nonprofit, and local communities—on the most urgent areas where we need additional research.

We urge congressional leaders to champion this research critical to our support of military caregivers five, ten, 20 years out ... to work with us to provide funding to address these urgent research gaps.

And I have to tell you ... Based on what we already know, we expect more alarming issues to be uncovered. Anecdotally, we are hearing more about caregiver substance abuse and caregiver suicide. Marriages between veterans and caregivers are more vulnerable than ever—the strain of the urgent challenges now and the long road ahead is becoming too much for too many.

Additionally, I want you to hear from some of our Hidden Heroes. There is truly no better way to appreciate their service and sacrifice than hearing directly from them.

We hope their testimony inspires each of you to join the bipartisan Hidden Heroes Caucus. I hope you'll be an advocate with your colleagues in the Senate and in the House. Show Americans that we can come together around the most important issues of our day.

There is much work yet to be done to ensure our hidden heroes are empowered with the same support and love they give so selflessly every day. And, as I said, we cannot do it alone. We need your help.

Our nation has long admired and respected our military men and women who have served our country so valiantly. And we have always reserved a special honor for those who returned from service with physical and emotional scars.

Our goal now is an America where caregivers are empowered, appreciated and recognized for their service, an America where military caregivers are woven into the very fabric of the nation's appreciation of our military.

Thank you so very much.

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#### **Prepared Statement of Ryan Phillippe, Actor, Director, and Writer**

Thank you, Senator Dole, for your kind words.

I know I speak for everyone here, when I say that we are truly inspired by your leadership, vision and tireless work on behalf of military caregivers. You are bringing our country's Hidden Heroes out of the shadows to honor their service. And I want to thank each of you for this opportunity today.

My experience growing up in a military family helped me prepare for this role. You see, my father and both of my grandfathers served in the military. I grew up with a deep respect for our veterans and an understanding that they are our nation's real heroes.

These days, it is a privilege and a great honor to play a veteran in my latest role, as Bob Lee Swagger on USA Network's Shooter.

Now, thanks to the Elizabeth Dole Foundation, I've learned about a different kind of hero—our military caregivers. They are Hidden Heroes, family members or friends caring for warriors who return home from service with physical and emotional scars.

And today, we are here to ask for your help and urge you to take action.

And, if you know anything about Senator Dole, she doesn't take no for an answer! She will hold you—all of us—accountable. Because our nation's military and veteran caregivers deserve it.

Over a lifetime of care, military caregivers face tremendous challenges and, right now, they have very few resources to help them.

It's on all of us to fix that.

Right now, military caregivers are shouldering this responsibility of care alone. They don't expect or ask for help, but the work they do merits more than just a display of gratitude. We owe our military and veteran caregivers purposeful action and life-long support.

Something struck me in Senator Dole's remarks I want to emphasize.

The Foundation's research found that military caregivers play an essential role in the recovery process of our veterans, and in improving their quality of life.

And I quote, "The best chance for a wounded warrior to recover and thrive is having a strong, well-supported caregiver."

Yet, this role imposes a substantial physical, emotional, and financial toll on the caregivers and their families. We can do better.

This is why we're here. We need to sign into law some very important legislation.

For starters, I'm speaking specifically about the recently reintroduced Military and Veteran Caregiver Services Improvement Act—bipartisan legislation, introduced in both the House and Senate, to make expanded resources available to military and veteran caregivers of all eras.

By signing onto this bill—you will strengthen and expand vital programs that support caregivers nationwide, and ensure that caregivers are recognized for their service in tangible ways.

And, ultimately, we will have a positive impact on the health and well-being of our nation's veterans and military families for a long time to come.

Here's a snapshot of what the Act will do:

- The VA's caregiver program should be available to all caregivers caring for all veterans regardless of when they served. If passed, pre-9/11 military caregivers would have the same support we give to our post-9/11 caregivers. Look, Bob Dole served before 9/11. We are talking about caregivers for the heroes who served with him and the generations that followed. Their caregivers not only need but deserve our assistance.
- The Act would expand essential respite services for military caregivers. They should receive some relief from their duties. Some time off from their 24-hour a day, 7 days a week responsibility to run errands, pick up their kids from school, or relax. They need it. Let's give it to them.
- It would better coordinate and align caregiver services across the VA system, government agencies and private services, so no matter where you live in our country, as a military caregiver, you have access to support.
- The bill would support caregivers for veterans with service-related invisible injuries, like TBI, in the same way we help caregivers with veterans who have visible wounds. It shouldn't matter whether we see the scar or not to give our veterans and caregivers the resources they need.

And finally, it provides assistance with childcare, financial advice, legal counseling, and education, which are all top, and currently unmet, needs.

As a Hidden Heroes Ambassador, I've had the privilege to meet with military caregivers across the country. As I speak before you now, I can't help but think about Megan and her husband Matt, a Marine Corps veteran who honorably served two tours in Iraq. Megan and Matt are high school sweethearts and man, when you meet them, you know it. They now live in Connecticut.

They are a young couple. They are in love. And yet, they have a long road ahead. As a result of injuries received during his combat service, Matt now suffers from a traumatic brain injury and PTSD. Megan, his wife and primary caregiver, is by his side every day, helping him as he struggles with wounds we can't see, invisible wounds that most of us in this room could never imagine.

Megan explained to me that she never pictured herself as a caregiver for her husband, especially so soon in her marriage, but Matt needs her. It is a day in and day out, 24-7 responsibility, managing doctors appointments, juggling medications, always on high alert looking out for "things" that might trigger Matt's PTSD and, all, I might add, while raising three young boys.

Megan is making the most of things, but she needs our help. In fact, there are 5.5 million military caregivers like Megan, quietly serving in communities across America. They can no longer go it alone. They need us. They need you.

I ask you again, members of the Committee, and all of you here today, to give your full support to the military caregivers serving our Nation. Senators, please sign onto the Military Caregiver Services Improvement Act and each of the pieces of legislation outlined.

To everyone here today and watching across the country, please seek out the military caregivers in your cities and towns, direct them to support and resources at *HiddenHeroes.org* and ask how you can help.

Thank you.

## Creating Better Support for our Nation's Hidden Heroes

### A Research Blueprint for Military and Veteran Caregivers

Terri Tanielian  
Senior Behavioral Scientist

CT-478  
Testimony presented before the Senate Special Committee on Aging on June 14, 2017.





For more information on this publication, visit [www.rand.org/pubs/testimonies/CT478.html](http://www.rand.org/pubs/testimonies/CT478.html)

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*Creating Better Support for Our Nation's Hidden Heroes: A Research Blueprint Military and Veteran Caregivers*

Testimony of Terri Tanielian<sup>1</sup>  
The RAND Corporation<sup>2</sup>

Before the Special Committee on Aging  
United States Senate

June 14, 2017

**T**hank you, Chairman Collins, Ranking Member Casey, and distinguished committee members for inviting me to testify today. My name is Terri Tanielian and I am a senior behavioral scientist at the RAND Corporation, where I have studied issues that impact military servicemembers, veterans, their families, and their caregivers for the past 17 years. During this time, and with funding support from the Elizabeth Dole Foundation, I have led three sequential studies focused on the individuals who provide care and assistance to our nation's wounded, ill, and injured veterans.

The three studies conducted at RAND have been critical in shining a light on the number and characteristics of military and veteran caregivers, as well as the burdens they face.<sup>3</sup> Before I outline the recommendations from our newest report designed to inform future research on military and veteran caregivers, I would like to provide a bit of context about why focusing on this population is so important.

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<sup>1</sup> The opinions and conclusions expressed in this testimony are the author's alone and should not be interpreted as representing those of the RAND Corporation or any of the sponsors of its research.

<sup>2</sup> The RAND Corporation is a research organization that develops solutions to public policy challenges to help make communities throughout the world safer and more secure, healthier and more prosperous. RAND is nonprofit, nonpartisan, and committed to the public interest.

<sup>3</sup> Rajeev Ramchand, Terri Tanielian, Michael P. Fisher, Christine Anne Vaughan, Thomas E. Trail, Caroline Batka, Phoenix Voorhies, Michael Robbins, Eric Robinson, and Bonnie Ghosh-Dastidar, *Hidden Heroes: America's Military Caregivers*, Santa Monica, Calif.: RAND Corporation, RR-499-TEDE, 2014. We use the term military and veteran caregiver to include both those caring for a current member of the military (including active-duty, reserve, and National Guard members) and those caring for a former member of the military (commonly referred to as a veteran).

## The Caregiving Context

There are more than 20 million veterans living in the United States today, many of whom have service-connected conditions or disabilities that require ongoing support and care. Supporting these wounded, ill, and injured warriors are the nation's "hidden heroes"—caregivers who provide unpaid, informal support with activities that enable current and former U.S. servicemembers to live fuller lives. They are an essential component of the nation's care for returning warriors. Recently, these caregivers have been the subject of much national attention. Starting in 2010, new federal programs were created to ensure improved support for caregivers; however, at the time, little was known about the characteristics and needs of this population.

In 2014, the RAND Corporation published work supported by the Elizabeth Dole Foundation titled *Hidden Heroes: America's Military Caregivers*.<sup>4</sup> This study was the first to rigorously assess how many caregivers were aiding current and former servicemembers, their characteristics, the value they contribute to society, and the risks they face as a result of their caregiving roles. The RAND study also examined the existing programs and policies that support military and veteran caregivers and highlighted gaps in that support landscape.

Four of the study findings were of particular importance and serve as context for our newest report. First, of the 5.5 million individuals who were providing care and assistance to a current or former member of the U.S. armed forces, 20 percent (1.1 million) were supporting an individual who served after the terrorist attacks of September 11, 2001 (9/11). Second, the study found that post-9/11 caregivers were different from caregivers for persons who served before 9/11. Most significantly, they were younger, more were spouses, and more were in the labor force themselves. Third, while there were many programs designed to support caregivers, post-9/11 caregivers were ineligible for many of them because the person they were caring for was too young; they were not related to the servicemember; or they were caring for a person with a condition such as posttraumatic stress disorder or traumatic brain injury, and existing programs were for caregivers of persons with cancer or Alzheimer's. Fourth, the study identified significant threats to the future of military caregiving—based, most notably, on aging parents serving as caregivers who may need caregivers themselves, as well as the increasing stress faced by young spouses.

Based on these and other findings, the 2014 RAND report outlined recommendations for ensuring better support for military and veteran caregivers in the future. Among these recommendations was a call for increased investment in research on the population. Specifically, the recommendation was to:

- Ensure continued research into the evolving need for caregiving assistance among U.S. servicemembers and veterans, particularly for post-9/11 servicemembers as they age, and the resulting evolving demands on their caregivers.
- Conduct additional and continued research to document the needs of and outcomes for caregivers so that interventions can be better tailored or targeted to reduce or mitigate the negative consequences associated with caregiving.

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<sup>4</sup> Ramchand et al., 2014.

- Increase the amount of research that identifies the efficacy (i.e., whether an intervention has the intended effect under ideal circumstances) and effectiveness (i.e., whether an intervention has the intended effect in usual, real-world conditions) of caregiver support programs and policies to ensure that resources are being used efficiently and that evidence-based programs and policies are promulgated. Where programs and policies have not been rigorously assessed, they should nevertheless be rooted in relevant outcome data and the best available research findings.

Since the release of the 2014 study, there has been action on many of the recommendations, including additional research funded to evaluate military and veteran caregiver support programs. For example, the Department of Veterans Affairs (VA) launched an evaluation of its Comprehensive Caregiver Support Program, and the Bristol Myers Squibb Foundation funded an evaluation of the Military Veteran Caregiver Network. While these studies will yield valuable insights on whether specific programs have been effective, longitudinal research is still needed to inform our understanding of how caregiver needs evolve over time as caregivers age and their care recipients' needs change, how specific programs are working, and how caregiving affects specific subgroups of caregivers.

### The Need for a Research Blueprint

Recognizing the need for future research on caregiving, the Elizabeth Dole Foundation requested that RAND develop a research blueprint to guide future national investments in this area. To craft this research blueprint, we reviewed the literature, conducted a survey, and solicited information in a structured, web-based exercise from several groups of stakeholders: policy and program officials, government officials, researchers, clinicians, funders, advocates, care recipients, and caregivers. Through these processes, more than 175 individual stakeholders provided input to guide the development of the blueprint and generate consensus around the research priorities. The blueprint is intended to convey a vision for future research that will build more effective support for military and veteran caregivers. There are many potential ways this blueprint can be used by different stakeholder groups, but by sharing it with you, we hope it will serve as a guide for understanding existing gaps in the knowledge base about military and veteran caregivers and inform your thoughts about opportunities for how to invest in new research initiatives that affect our nation's veterans and their caregivers.

### The Blueprint: Ten High Priority Research Objectives

We identified ten high-priority research objectives to further the field of research into military and veteran caregiving. These are:

1. **Who are the nation's military and veteran caregivers?** There are gaps in the existing knowledge about certain groups of military and veteran caregivers, as well as caregivers more broadly—for example, children serving as caregivers, caregivers for whom English is not a first language, male caregivers, caregivers with preexisting or chronic medical conditions, college-aged caregivers, caregivers with disabled children, and caregivers for those who served in the military before 9/11. As the needs of care recipients change,

demographic trends shift, and the landscape of care for families continues to transform, describing caregivers will become increasingly important.

2. **What societal cost savings can be attributed to caregivers?** Caregivers play a critical role in supporting the needs of their care recipients, often enabling them to live in noninstitutionalized settings. The reliance on informal caregivers often defrays costs associated with formal caregiving. Smaller families, an increasingly aging population, and women's growing participation in the workforce are among the trends that will change not only who assumes the role of a caregiver but also the cost savings attributed to caregiving. Understanding who military and veteran caregivers are and the benefits they convey to society can help guide programs and policies for caregivers that would lead to a more direct effect.
3. **How does caregiving affect caregivers?** Little is known about the longer-term impact of caregiving on military and veteran caregivers. Understanding how caregiving affects caregivers could help inform programs and policies designed to mitigate any adverse effects. In particular, it is important to focus on health (particularly mental health), employment (and associated loss of income or loss of job opportunities), and family well-being (including family strain, divorce, and abuse). However, there are also positive consequences of caregiving, and studies should seek to identify these effects as well.
4. **How does caregiving affect the children of caregivers?** Most stakeholders who participated in our data collection identified the effects of caregiving on children as a vital topic, but we identified no study documenting this effect. The following aspects merit attention: children directly serving as caregivers, the impact of being a child in a home with someone (usually a parent) caring for an individual with a mental health issue, the impact of caregiving on parenting and the associated effect on children, and both short-term (e.g., school performance, attachment issues, socialization, adverse behavior, and mental health) and long-term effects of caregiving on children.
5. **How does caregiving affect care recipients?** Caregivers play an essential role in supporting the recovery and reintegration of our wounded, ill, and injured veterans by helping coordinate medical care, administer medications, and provide supportive environments. More studies are needed to examine the impact of caregiving on care recipient outcomes, particularly long-term outcomes. Such research is critical for justifying continued support for programs and services for caregivers.
6. **How do care recipient needs change over time?** As individuals age or recover, their needs and demands for caregiving may change, and this may affect the duties and strain on the caregiver. However, only two studies published to date have examined how care recipients' needs change over time. Future research in this area could ensure that caregiver skills and knowledge keep pace with the changes in care recipient needs over time.
7. **What factors are associated with caregiver and care recipient harm (that is, any situation in which a care recipient is abusing the caregiver or vice versa)?** Fraud, harm, and abuse are often unpopular topics of discussion, but research with civilian populations indicates that this area deserves serious attention. The effort is complicated by the stigma associated with admitting that a caregiver or care recipient is abusive in some way, but understanding the extent to which these issues occur and why they occur is important for safeguarding caregivers and care recipients and minimizing adverse consequences.

8. **What strategies make effective programs more accessible to more caregivers?** Few studies have focused on the accessibility of caregiver programs, and no research has been conducted to understand the efficacy or effectiveness of workplace policies to support caregivers.
9. **How effective are programs and policies for ensuring caregiver well-being?** Knowing what works and for whom is an important consideration, not only for ensuring that caregivers' needs are being met but also for developing sound policies and funding worthy efforts. Many programs and policies have been promulgated in health care settings, in the workplace, and in the social support arena with the intent of improving caregiver well-being. The vast majority of research is on the effectiveness of programs enhancing caregivers' abilities to provide care, including informal and formal education and training, assessments of caregiver knowledge and information programs, and programs using new technologies (e.g., telehealth, smartphones) to help with caregiving tasks. More research is needed to focus on proving the effectiveness of specific caregiver interventions.
10. **How effective are programs and policies for supporting caregivers' ability to provide care?** Caregivers who contributed to our data collection felt that they did not have the information they needed to provide required care and were unaware of research on the effectiveness of key programs. They also criticized the ongoing, exhausting, and often disorganized bureaucratic aspects of programs and policies.

### Setting the Conditions for Success

Just as in architecture, a research blueprint is only a vision or plan. Multiple conditions must be met to conduct studies designed to fulfill the research blueprint. Two of the more important conditions are ensuring consistency in terms and definitions and creating an environment conducive to research.

**Ensuring consistency in terms and definitions.** Variations in terms and definitions about who and what constitutes caregiving can lead to different inclusion and exclusion criteria for studies which can, in turn, lead to differences in estimates and conclusions about the needs of the population. For example, the definition we use does not necessitate that a military and veteran caregiver have a familial relationship with the care recipient or provide assistance for specific activities of daily living. We define military and veteran caregivers as:

*Anyone who provides unpaid care and assistance for, or manages the care of, a current or former member of the U.S. military, National Guard, or reserves who has an illness, injury, or condition for which they require outside support.*

It is also essential to have well-defined outcomes of interest and to use accepted, validated measures. Doing so will enable more-rigorous comparison of studies and evaluation of program outcomes.

**Creating an environment conducive to research.** For additional research on military and veteran caregivers to proceed, other enablers will be necessary. These include ensuring an environment that is conducive to facilitating, conducting, and using research. Enablers of such an environment include:

- *Funding.* Funding can come from many sources across the public and private sectors. Most of the research to date on military and veteran caregivers has been funded by either the federal government (e.g., the VA and Department of Defense) or the nonprofit, philanthropic sector. However, other funders may be interested in and amenable to supporting research on military and veteran caregivers. Such funding will be necessary to ensure that sufficient resources are available to support rigorous research on the population.
- *Research workforce.* Conducting research requires appropriately trained individuals to perform studies with rigor and to contribute their findings to the knowledge base. Many types of researchers from multiple disciplines will be needed to implement a research blueprint. Whether researchers are quantitatively or qualitatively focused, it is important that they use methods appropriate to the research objective and publish their findings so they are available to the research, advocacy, and decisionmaking communities. The process of technical peer review often helps to ensure the quality of the research and should be incorporated both at the time of funding or research implementation and at the publication or reporting phase. As more funding becomes available and research priorities are articulated, more researchers may be drawn to the field and help expand and strengthen the science.
- *Community participation.* Ultimately, successfully implementing studies of military and veteran caregivers will require participation from relevant parties, whether these are caregivers or the programs or settings designed to support caregivers. Ensuring that the perspectives of these constituencies are appropriately considered and addressed in the design and conduct of research can be instrumental in facilitating successful implementation. Thus, it is important to establish mechanisms to formally engage members of the military and veteran caregiver stakeholder community in identifying research questions, implementing studies, and using research findings. This could happen at the individual study level or, perhaps, at the portfolio-management level within a funding organization. An additional strategy would be to draw on Participatory Action Research, which is an established, mutually beneficial framework for systematically incorporating the views and needs of advocates and the communities of people they seek to help. Given the existing knowledge and zeal among Elizabeth Dole Foundation fellows, Participatory Action Research would be an effective means of leveraging advocates' strengths in future research efforts.
- *Vocal champions.* The imperative to increase the knowledge base and research funding to support such studies can be generated and influenced by the affected community. Those who advocate better support for military and veteran caregivers can be important vocal champions in encouraging policymakers across the government and nongovernment sectors to increase their support for and reliance on research. This can include increases in research budgets, as well as increased demand for policymakers and program officials to require rigorous evidence to inform decisionmaking. Thus, policymakers are also important champions and ambassadors for research. Making stakeholders and advocates an integral part of the research process increases the salience of the work and facilitates better dissemination and implementation of the findings.
- *Translating research into practice.* Generating new knowledge will be important, but enhancing support for military and veteran caregivers will require translating findings into practice. Without specific dissemination or facilitation efforts, it can often take more

than a decade for new findings to influence routine practice. It is possible to shorten this timeline, but it requires specific intention to do so. Past RAND research has identified ten strategies that often promote the translation of research into practice; those strategies include creating incentives for implementing new findings in practice and using evaluation findings in decisionmaking.<sup>5</sup> These tasks are typically outside the scope of individual researchers and may require stakeholder groups to take the lead in facilitating them.

### Using the Blueprint

Ideally, the research blueprint we have created will become a common reference point for the various stakeholder communities as they work toward a common goal of improving support for military and veteran caregivers. Two strategies for gaining support for, adopting, and implementing the blueprint are establishing partnerships and creating a caregiving research center of excellence.

**Establish partnerships.** The military and veteran caregiver stakeholder community should partner with some of the many organizations that are interested in research on various aspects of caregiving. For example, the National Academies of Science, Engineering, and Medicine's Committee on Family Caregiving for Older Adults released a report in September 2016 outlining recommendations aimed at addressing the health, economic, and social issues facing family caregivers of older Americans.<sup>6</sup> Among other recommendations, the committee suggested that the VA and the Department of Health and Human Services create a public-private, multistakeholder fund for research and innovation to accelerate the pace of change in addressing the needs of caregiving families. The research objectives that we evaluated and arrayed within this blueprint can all be nested within these larger objectives and used as a basis for informing how the VA and Department of Defense in particular can support and implement this recommendation.

Additional partnerships and consortia with other caregiver organizations could be established to call for increased research investment across the governmental and nongovernmental sector, encourage the research community to focus on caregiving, and demand more evidence-based decisionmaking for future caregiver support programs and policies.

**Create a research center of excellence.** A research center of excellence specifically focused on military and veteran caregiving could foster the strategic pursuit of the research blueprint and begin to address the knowledge gaps outlined in our report, thus promoting better support for military and veteran caregivers. Such a center of excellence could be implemented within a federal agency or be established in the private sector. Ultimately, it will be important for such a research center of excellence to have broad, multidisciplinary expertise as well as a broad focus to ensure that all of the research objectives and special populations of importance to the military and veteran caregiving community are included in its mission.

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<sup>5</sup> Ramchand et al., 2014.

<sup>6</sup> National Academies of Sciences, Engineering, and Medicine, *Families Caring for an Aging America*, Washington, D.C.: National Academies Press, 2016.



## Conclusion

As I noted in my introduction, the role of this blueprint is to convey a vision for future research that will build support for military and veteran caregivers. In essence, the blueprint becomes a guide for the community to use in prioritizing and facilitating future research. It is not a manual for how research should be pursued; stakeholders may use the blueprint differently as they craft their own specific activities. For example, caregivers and their advocates can use the blueprint as a reference point to encourage funding organizations to expand research opportunities in each of the areas outlined. The funding community can use the blueprint as a reference or guide to creating research priorities for allocating their research budgets. Policy makers can also use the blueprint as a guide for understanding existing gaps in the knowledge base and to inform investment for new research initiatives as they consider changes to existing programs and portfolios. As researchers design future studies, they can refer to the blueprint as a source of stakeholder-endorsed research objectives. In this manner, it is our intent that the blueprint becomes a mechanism and common reference point as we all work toward a common goal of improving support for military and veteran caregivers by conducting rigorous research.

Thank you for the opportunity to share this testimony with the committee.

**Prepared Statement of Mary Ward and Thomas Ward,  
Veteran Caregiver and Veteran**

Good afternoon and thank you Chairman Collins and Ranking Member Casey for inviting me and my husband, Tom, to this hearing on military and veteran caregivers. I am humbled to be here alongside a force of nature like Senator Dole, an advocate like Ryan Phillippe, an expert like Terri Tanielian, and my peers.

I became a Dole Caregiver Fellow in 2016, but my journey as a caregiver started long before then. In June 21, 2010, Tom was diagnosed with ALS. Prior to that, in 1993, Tom had been disabled from encephalitis. He has required care from me since then, but the all-encompassing care of ALS is intense.

I had his care figured out and organized until ALS came along. It's a devastating diagnosis. For me it was like getting sucker punched. Tom and I are that couple that fell in love almost instantly in 1979. My grief has known no bounds. I know how this disease works. It will steal his life, and if I am not careful it will take mine as well. The work ahead as his caregiver is daunting at best. I am certain that I am not up to the task, alone, yet for the most part I know I will have to be.

In 2008, ALS was made a presumptive illness for veterans. Veterans are twice as likely to get ALS as non-veterans and more than 4,500 veterans at a given time have ALS. Tom served in the US Marine Corps from 1972–1975 so he qualified for benefits. Enter the VA into our lives.

I had not considered myself Tom's caregiver until later in my life. I was committed to our vows and love for each other. A caregiver to me meant someone who was paid to come in and provide services. In 2013 I saw an interview with Senator Elizabeth Dole about caregivers; that was my epiphany, that I was a caregiver.

ALS is a catastrophic disease: physically, emotionally, and financially. There is never a day that goes by that I am not grateful for all the VA does to support Tom as he battles ALS. The challenge lies in ensuring that he gets what he needs in a timely fashion: the correct breathing mask, medications, equipment, and so on. While I work on managing resources available from the VA, at the same time I am taking care of Tom and teaching Advanced Placement U.S. Government and Politics online. Tom's need for assistance is non-stop. He is moving toward dependence rather than independence. That is never going to change.

One huge worry I have is the financial aspect of my future. I teach high school online so I can care for Tom but have done so at a significant salary reduction which has impacted my future retirement funds. I save diligently but I am deeply concerned that as his dependence grows I will need to pay for assistance out of pocket as the VA will only provide 28 hours of care a week, and that will never be enough if Tom lives to full paralysis.

We have two adult children who cannot assist in their dad's care. Our daughter is a 2nd grade teacher in Charlotte. Our son is a sergeant first class with 14 years in the Army and currently a drill sergeant. Their dad is their hero and would help in a heartbeat if it was possible. The best thing they can do is to continue to grow in their careers; that is the kind of help we want from them.

Being a Foundation Fellow has been life changing for me. I have developed life-long friendships with other fellows. Senator Elizabeth Dole has encouraged us to be "solutionists" and so we are, with each other, and with other caregivers.

As a pre-9/11 caregiver the VA offers me almost nothing. I receive no caregiver training from the VA, no stipend, no support other than a monthly national call with focused topics, and a few months ago was denied respite hours.

I am one voice, among many, who need consistent, and compassionate help as we carry this heavy responsibility caring for our veteran. And there is still so much that we don't know. We need to cultivate a better understanding of the needs of caregivers through research like the kind you heard about from Terri. And we need action. I hope you will consider passing the Military and Veteran Caregiver Services Improvement Act to help caregivers like me. Thank you for your time and consideration today. I welcome your questions for myself and my husband, Tom.

**Prepared Statement of Melanie Swoboda and Joe Swoboda,  
Veteran Caregiver and Veteran**

Good afternoon, senators, and thank you Chairman Collins and Ranking Member Casey for having Joe and I at this hearing on military and veteran caregivers.

My husband, retired Sergeant First Class Joseph Swoboda, is a three-time combat veteran of Operation Iraqi Freedom. He was deployed during the initial invasion in 2003, again in 2005, and again in 2007. Each time, the deployments were longer and longer. In 2003, he left for 8 months, in 2005 for 12 months and in 2007, Joe was overseas for 15 months.

During the initial invasion, and again in 2005, Joe sustained injuries in two explosions, in both of which he lost consciousness. However, because of the intensity of the fighting, there was no time for him to be checked by medics, so he shook it off and remained in the battle. Years later, the injuries he sustained would become impossible to ignore.

This several years period of rapid deployments was a whirlwind. Even when Joe was home, he was not home—when he was not at war, he was training for war, in field exercises, so there was no time to recognize he was having any mental health issues. He had to push through it, and so did I.

After the third deployment, Joe asked to be given an assignment where he could train without being deployed. However, when he stopped going to combat, that was when the problems really started, when we finally had the opportunity to slow down, and these difficulties he was having started coming to light.

I knew he was struggling—he was home, but he had never really come back from Iraq. A fellow soldier, who was also a trusted friend saw his struggle, too, and thankfully, insisted that Joe seek help for the overwhelming symptoms he was experiencing as a result of his Traumatic Brain Injuries and Post Traumatic Stress. The invisibility of his wounds meant most in the Army had never recognized Joe as being injured.

Once these symptoms began to affect his work, Joe was medically retired from the Army and during his out processing, a staff member at Ft. Benning handed me an application for the VA Caregiver Program. I filled out the paperwork, but I wasn't really sure what I was applying for. Of course, even when Joe had still been active duty, I was his caregiver, but I had never recognized it. All of the tasks I was doing were the ones you'll hear any caregiver talk about: I was managing his medications, I was raising the kids alone, I was managing finances, and I was helping him remember things that he could no longer remember.

I love my husband, and I would absolutely care for him regardless, but having caregiver support programs in place is so important to me because for the first time in 20 years, I can breathe. I can't imagine how much harder this would be without those programs—but I know millions of caregivers manage every single day.

It's still stressful, there's still a lot I have to do, but having the financial support of receiving a stipend and the opportunity for respite care has been crucial for my family.

There are days when I think I can't go on like this, I can't have this much stress and pressure on me. And it's not just the stress on me, I also see how the stress of caregiving affects our children, too. Respite services, though, give all of us an opportunity to recharge.

Support systems like the Dole Caregiver Fellowship, with the network of knowledgeable caregivers who can help answer so many questions, and programs offered by the VA such as the Caregiver Support Program make this sustainable for me and for so many other caregivers.

This kind of support should be available to all military and veteran caregivers, whatever era their veteran served. It's really helping people. It's really making a difference. I hope that you will consider supporting and passing the Military and Veteran Caregiver Services Improvement Act to do just that.

Thank you so much for your time this afternoon. I look forward to answering any questions you may have.

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**Prepared Statement of Wanda Ickes and Samuel Ickes,  
Veteran Caregiver and Veteran**

Thank you Chairman Collins and Ranking Member Casey for inviting me here today to testify. I would also like to thank the Elizabeth Dole Foundation and Senator Dole, Ryan Phillippe, and Terri Tanielian for taking the time to be here today. It is humbling to have voices like theirs speak on behalf of caregivers like myself.

It is my hope that by sharing a small part of my journey as a caregiver with this committee that you can ensure future caregivers do not face the same hurdles that my husband and I—and other caregivers—have had to overcome.

My husband Sam had been married to the Army long before he married me. In the 80's, he was an Army Ranger which meant despite it being so-called "peacetime", he still saw action. That's when he suffered his first TBI, in Panama. Later, he was in a bad accident that got a lot of metal put in his body, so much that the Army said he couldn't do his job anymore and released him.

After 9/11, he couldn't not do the job the Army trained him to do. He went and got every waiver he needed so he could go back in the Reserves as an MP, a military policeman. He signed up for every single deployment. He was deployed more than

he was not. Over the course of those deployments, Sam earned three Purple Hearts. He did his job. He brought every single person back alive. He went above and beyond his duty.

Sam came back from his deployments looking like the same person, but he didn't come back acting like the same person. When you meet him, when you speak to him for a couple minutes, he looks like anyone else. Talk to him a little bit longer, and you start to see his issues in his eyes, in the way he talks. Sam undeniably still lives with the effects of war.

One day, when Sam was home on leave from a deployment, he had gone into the backyard to grill dinner. After he had been gone a while, longer than dinner should have taken, I glanced out the window and saw flames lapping at the side of the house. But I didn't hear Sam doing anything about it. I ran outside and saw Sam was just standing there, wide-eyed, staring at the fire eating away at our house. I pushed him away, closed the grill, put the fire out, and that's when I realized he had some serious issues. That's when I realized he would need some extra help. The Army didn't see it that way.

When Sam came back from that last deployment, where he suffered his last major TBI, the Army released him and said he was healthy enough to go back to his civilian life. In the 60 days of leave he had between leaving the military and going back to his old job, I began noticing more of the little things that were different about him. He was stuttering, he couldn't process things, his memory was terrible. He was different, distant.

I took him to the VA, and I pushed the issue. Sam wasn't the same person. The more I talked about the issues he was having, the more the doctors realized I was right. But I had to write my Senator to get the Army doctors to reevaluate him so he would get the right benefits from the military.

It should not have been that hard. The Army was going to send him back to civilian life and he couldn't hold a job. He could have ended up homeless. Or worse. I couldn't and wouldn't let that happen. I had to figure out everything out on my own. I had to make it right for him, for us. When he came back with his issues, I stepped up because he couldn't. I took control because he couldn't. I became his caregiver.

When we had access to the VA Caregiver Program, it was very good to us. It allowed me to have respite time as a caregiver. To have the downtime, the respite time when I could focus on me, that stipend, you can't put dollar signs on it.

As you consider how to improve the lives of caregivers, know that the Military and Veteran Caregiver Services Improvement Act makes important strides in improving coordination between the Department of Defense and the VA when service members are transitioning into civilian life and in extending a priceless stipend to so many caregivers and veterans in need. Those are certainly policies that would have helped me and Sam as we figured out this new life. I hope you will support this legislation and help ensure it is signed into law.

Thank you for allowing me this opportunity to share and I look forward to your questions.

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**Additional Statements for the Record**

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**WOUNDED WARRIOR PROJECT**

**STATEMENT FOR THE RECORD**

**SPECIAL COMMITTEE ON AGING  
 UNITED STATES SENATE**

**JUNE 19, 2017**

Chairman Collins, Ranking Member Casey, and Members of the Committee:

Thank you for convening the United States Senate Special Committee on Aging for the *Military Caregivers: Families Serving for the Long Run* hearing. We appreciate this forum to highlight the service and sacrifice of our country's 5.5 million military caregivers. Too often, these men and women serve in the shadows, rarely getting the same recognition as the injured veterans they care for. We are grateful for your focus on this deserving population. We also appreciate the opportunity to offer a statement for the record and wish to highlight two of the many ways in which Congress could help caregivers of the most seriously injured veterans.

First, Congress should work collaboratively with the Department of Veterans' Affairs ("VA") to improve options for veterans who are so seriously injured that they are at risk of ending up in a geriatric nursing home. At present, when a veteran's injury prevents him or her from living independently at home, an institution focused on an elderly patient population is often the only option. Although, for some veterans, this is the safest and best option, for others, it is an unacceptable result. Geriatric programming is particularly problematic for veterans of the post-9/11 conflicts who may be in their 20s or 30s, with long lives ahead of them. This state of affairs places a tremendous burden on caregivers to either keep veterans at home or risk losing them to an institution.

In response to this challenge, Wounded Warrior Project started a new program several years ago called the Independence Program, which supports veterans and service members living with moderate to severe traumatic brain injury. Through this program, we bring together veterans with their full support teams, including caregivers and medical staff, to create individualized plans to ensure as independent and community based a future as possible. In addition to clinical services, these plans incorporate the vital

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non-clinical community based services such as alternative therapies and life skills coaching. The program provides support to caregivers by taking some care responsibilities off of their plates and creating time for respite. Ideally, it prevents burnout and helps caregivers keep veterans in their homes.

Although we are seeing encouraging outcomes for the 612 families in the Independence Program, we will never be able to achieve the scalability of governmental care programs. That said, the Independence Program could be a model for VA and other governmental programs, multiplying its impact. We would appreciate the opportunity to talk further with both Congress and VA about this exciting possibility.

Second, Congress should work collaboratively with VA to improve the Family Caregiver Program, which provides important benefits, including monthly stipends, medical coverage, training, counseling, and respite care for caregivers of seriously injured veterans. Along with our fellow veterans' organizations, WWP led the charge for the creation of this program in 2010, and we are deeply invested in its success. We are troubled by reports that the program has been inconsistently administered, particularly with regard to decisions to reduce or eliminate benefits. We believe reform is needed and applaud Secretary Shulkin's recent decision to pause revocations while the agency performs a thorough review of the program. As VA pauses to review revocations, we offer the agency our full support. Along with our fellow veterans' organizations, we have made a number of suggestions for reform as outlined in the letters to Secretary Shulkin attached as [Exhibit A](#) and [Exhibit B](#). We were honored to collaborate with the Elizabeth Dole Foundation and others on these proposals.

Although we strongly believe the current Family Caregiver Program must be improved, we are hesitant – at this moment – to make the call that it should be expanded. We understand and appreciate the idea behind S. 591, the Military and Veteran Caregiver Services Improvement Act of 2017, which would expand the stipend benefits in the Family Caregiver Program to all generations. We fully support our brothers and sisters in arms and believe that caregivers of all generations are deserving of the same level of comprehensive assistance and support as the post-9/11 generation. We are concerned, however, that at a time when VA is struggling to implement the current program – and when anger and frustration regarding the program are pervasive among enrollees – expansion to prior generations would stretch current resources and processes too thin, jeopardizing the integrity of the program and the services that it provides. This concern is especially pressing given that VA has confirmed it, taking the position that they do not have the resources or capacity to handle an expanded program.

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While we believe in expansion, we suggest that it should be done once the current program has sufficient funding and implementation of eligibility, programming, and appeals is consistent across the board.

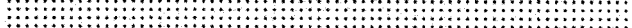
Thank you once again for the opportunity to offer our views.

Sincerely,

Lt. Gen. Michael S. Linnington (ret.)  
Chief Executive Officer  
Wounded Warrior Project

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## EXHIBIT A

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April 27, 2017

The Honorable David Shulkin  
 Secretary of Veterans Affairs  
 United States Department of Veterans Affairs  
 810 Vermont Avenue, N.W.  
 Washington, D.C. 20420

Re: Issues Affecting Caregivers of Seriously Injured Veterans

Dear Secretary Shulkin:

Thank you for the invitation to attend today's signing of the Executive Order on accountability in the VA. We appreciated your attendance at Soldier Ride DC at the White House earlier this month and we see all of these engagements as expressions of your commitment to our veterans and families, including those of the post 9/11 generation. I write today to discuss an issue of particular importance to that generation—the treatment of those who care for the most seriously wounded.

We support your recent decision to take immediate action halting revocations of Family Caregiver Program benefits while you conduct a review. I know my team has been in close communication with yours, passing along stories of caregivers who have encountered difficulties being dropped or reduced in tier-level support. We are grateful that you took the action you did in ordering an internal review, and we look forward to working with you and your team to make any necessary improvements needed as the review is completed.

One additional area I'd like to share with you (which I recently shared with SecDef Mattis) is information on Wounded Warrior Project's (WWP) reach, and our impact; so you know what resources you have at your disposal for coordination/collaboration on a wider scale. Over the last ten years, WWP has invested nearly a billion dollars in free programs and services to service members, veterans, and their families. Briefly, here are some additional metrics you will find of interest in terms of our investment and reach:

- \$152 M in physical health and wellness programs (86% of injured post-9/11 veterans are overweight or obese);
- \$181 M in counseling service members on VA benefits and providing career placement services; and
- \$327 M in mental health support programs, including for our Warrior Care Network, where we are partnered with Emory Healthcare, Massachusetts General Hospital, Rush University Medical Center, and UCLA Health to help these men and women become more resilient and healthy. We're only a year in, and we've already logged over 31,000 clinical hours.

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We have invested \$17 million in our partner organizations and we've committed to investing \$26 million over the next 5 years, and have plans to continue to invest in additional organizations beyond our current portfolio. Since inception, we've provided financial support to 98 organizations.

As we work together, it will be important that we know your legislative initiatives so we can work together with our partner VSOs to be advocates on the Hill for you and those you serve.

Not unlike Secretary Mattis, I know you share concerns regarding closing the civ/mil divide across the country. One way to do so is through organizations like ours, as our reach includes:

- o 6 million donors;
- o 3.5 million followers on our social media channels; and
- o 100,000 service members, veterans and family members who we communicate with on a weekly basis.

Over the years, WWP has had over one million post-9/11 veterans attend WWP-sponsored events, or take advantage of our life changing programs and services. Together, with our partners, we've been force multipliers that have reached 3.5 million service members, veterans, and families.

WWP is proud of our impact and reach but one of our key areas of focus is our Independence Program which serves more than 1,300 of the most seriously wounded and their caregivers. It provides intensive case management, life skills coaching, and other individualized services to enable veterans with moderate to severe traumatic brain injury to remain in their homes or in as independent an environment as possible. WWP works closely with a family caregiver to identify and fill needs, preventing institutionalization wherever possible.

It would be easy for us to convene a group of veterans and caregivers from across the country to sit down with you at a time and place of your choosing. These individuals can offer specific perspectives and insight on issues that relate to your top ten priorities – especially the caregiver stipend issue that is currently at the forefront of everyone's minds.

I look forward to continuing to work with you to honor those who care for the seriously injured. You have our commitment that we will do whatever we can to further the best interests of this population.

Sincerely,



Lt. Gen. Michael S. Linnington (Retired)

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May 9, 2017

The Honorable David Shulkin  
 Secretary of Veterans Affairs  
 United States Department of Veterans Affairs  
 810 Vermont Avenue, N.W.  
 Washington, D.C. 20420

Re: VA Review of the Family Caregiver Program

Dear Secretary Shulkin:

I want to thank you for the work you and your team have done over the last three weeks reviewing the Family Caregiver Program (the "Program"). As you know, Wounded Warrior Project ("WWP") led the charge for the creation of the Program in 2010 and has worked with VA and Congress to address challenges with implementation. We remain deeply committed to making the Program as effective as possible as we address the needs of those who care for the most seriously injured veterans of the post-9/11 generation.

As you continue to review the program, we ask you to take into account the following considerations. Please note that this is not an exhaustive list and that we will continue to work with you, your staff, and the greater community to identify challenges and create improvements.

1. **Consistency and Transparency in Eligibility Determinations.** We have seen significant variations from location to location in eligibility and tier level determinations and also in the type of notification provided to caregivers and veterans. We hope to work with VA to create mechanisms for consistency and transparency. At a minimum, veterans who are revoked or who have their tier level adjusted should receive a detailed explanation of rationale in the context of 38 C.F.R. § 71. Such explanation must be sufficiently detailed to allow the veteran to use it to challenge the determination.
2. **Enhance the Appeals Process.** One essential mechanism for consistency and fairness is a meaningful appeals process in which veterans can challenge erroneous eligibility and tier level determinations. Despite the widespread allegations of wrongful revocations that gave rise to this review, in our experience, successful appeals through the VHA system have been extremely rare. Given the nature of the Program, adjustments should be made to the clinical appeals process for review of eligibility and tier level determinations.

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These adjustments include: (1) providing the same due process and appellate rights that exist in the VBA context; (2) continuing benefits until appeals are resolved; (3) allowing the veteran to present private medical opinions; (4) allowing the veteran to appear for a personal hearing to bring forth additional evidence; and (5) allowing the veteran to provide sworn testimony under the guidance of an accredited representative.

3. **Ensure Meaningful Consultation with the Medical Care Team.** The law and regulations are clear that decisions about eligibility and tier level should be made by the veteran's medical care team. Nonetheless, caregivers and veterans have reported that caregiver support coordinators ("CSCs") wield strong influence over medical care teams, and that, in some cases, CSCs make decisions on their own. Safeguards must be established to ensure that the medical care team is more than a rubber stamp in the decision making process, and that medical care team involvement is transparent to the veteran and caregiver.
4. **Require Communication with Caregivers.** Caregivers must be present and involved in assessments that give rise to change in tier level or revocation. Especially where mental health challenges are involved, caregivers can provide the insight necessary to reach correct and comprehensive conclusions. Nonetheless, we have heard many accounts of caregivers who were not allowed to participate. One account from a survey WWP conducted in 2014 is below:

*My husband was interviewed by his VA physician, but I was not allowed to go in and assist him and help him remember things and help give an accurate picture of his functioning and health. His physician had only seen him a couple of times, we were told this was the reason he was going in for an interview/assessment. The assessment was supposed to provide the understanding of my warrior's needs. Since I was not there, and my warrior does not recall the entire interview, I do not know if the doctor really got a good understanding of the situation.*

Although this account is dated, we continue to hear similar stories of this nature, especially in certain localities.

5. **Review Revocations and Tier Reductions.** We know you are aware of the many veterans and caregivers who have reported erroneous determinations, and that is why you are conducting this review. Given these reports, in the interest of fairness, we ask for review of all revocations and tier reductions that have taken place since program inception. We understand that this would place a significant workload on program staff and therefore propose a triaged approach in which cases where tier 3 veterans were completely revoked

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are addressed first. An adjustment this dramatic should be extremely rare and suggests irregularities.

**6. Improve Transition Services.** As Program stipends were not intended to be a permanent benefit in all situations, there will certainly be cases where veterans are no longer eligible for the Program due to changed circumstances. Where this occurs, VA should provide transition services and education regarding health care options, employment possibilities, and vocational training. CSCs should be provided with a comprehensive list of transition services available in their community through VA, state veterans agencies, and the private and nonprofit sectors.

**7. Extend the Moratorium on Revocations until the Review is Complete.** We understand the moratorium expired yesterday but that your review will continue for several months. As problems with the program have already been acknowledged, we should not allow caregivers to be removed from the program until those problems are fixed.

Caregivers provide a vital service, often giving up careers and opportunities in order to care for our nation's heroes, and we owe it to them to provide the support they need. We look forward to continuing to work with you, your staff, and the greater community to address these issues and others that arise through the course of our conversations.

Sincerely,



Lt. Gen. Michael S. Linnington (ret.)  
Chief Executive Officer  
Wounded Warrior Project

DUTY ★ HONOR ★ COURAGE ★ COMMITMENT ★ INTEGRITY ★ COUNTRY ★ SERVICE

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EXHIBIT B

May 15, 2017

The Honorable David J. Shulkin  
U.S. Department of Veterans Affairs  
810 Vermont Ave. NW  
Washington, D.C. 20571

Dear Secretary Shulkin,

We applaud your recent decision to halt the revocation process and conduct an internal review of the Program of Comprehensive Assistance for Family Caregivers. Your decision is an acknowledgement that the VA cares about the success of this program and is committed to the difficult task of improvement. Now that you have the spotlight on this program, we urge you to capitalize on this momentum to implement changes that will improve its structure and support.

As you conduct the review, we, as organizations with a direct line to caregivers, would like to offer some perspective on the issues that have challenged this program since its inception. These thoughts are informed by the experiences and stories of caregivers themselves, and can be broken down into four main themes.

***Transparency***

Perhaps the greatest concern we hear is the lack of clarity and transparency in communicating aspects of the program to veterans, their caregivers, and outside partners. We encourage you to:

1. Mandate that upon revocation or tier lowering for failing to meet eligibility requirements, caregivers receive their veteran's eligibility assessment "scoresheet," within one week of the decision, so that they can prepare a proper appeal should they choose to do so.
2. Ensure that caregivers have a chance to provide feedback to medical care teams and Caregiver Support Coordinators (CSC) as they make eligibility and tier level determinations. Currently, many caregivers are not included in that process.
3. Establish an internal communications plan that originates in the VA Central Office and conveys clear and consistent policies across all Veteran Integrated Service Networks (VISNs).
4. Create a newsletter or listserv that disseminates up-to-date information about the program to military service organizations (MSOs), veteran service organizations (VSOs), and other not for profit organizations active in the caregiver space.

***Standardization***

Hand in hand with transparency comes standardization of Caregiver Program processes. Because each VA Medical Center operates as its own entity, the execution of the program can vary from VISN to VISN. While we respect each Center's ability to self-determine its own needs, when operational authority supersedes policy implementation, it creates an inconsistent, and at times unfair, program environment for caregivers. To remedy this, we recommend the following:

1. Grant the National Director (Meg Kabat) more operational authority to ensure that national policy is executed properly on a regional level. Limit the VISN's authority to change or adapt Caregiver Program policy in the course of their day-to-day operations.
2. Finalize and disseminate a policy directive that establishes a standard appeals process and clarifies eligibility requirements.

EXHIBIT B

3. Update and improve the notices that caregivers receive upon being removed or lowered a tier within the program. Ensure that caregivers who are not removed for cause continue to receive their stipend for 90 days after removal to allow for adjustment and minimize financial burden.
4. Create an organizational document or flow chart (similar to the Integrated Disability Evaluation System (IDES) timeline) detailing the structure of the VA Caregiver Program, the appeals process, and points where the veteran and caregiver must make decisions.
5. Update the VA Caregiver Program website regularly to reflect the most accurate information, including the final "Roles and Responsibilities" document.
6. Keep the moratorium on program removal in place until the identified issues have been addressed.

**Education**

Many of the obstacles to the success of the VA Caregiver Program can be overcome through education of caregivers, service providers, and the public. Right now, many caregivers do not understand the scope and nature of the program, and we, as organizations, do not always feel empowered to give them accurate information. There are several ways to address this:

1. Begin communicating with caregivers and veterans before they enter the VA system (i.e. through TAP, the IDES process, within Warrior Transition Units, etc.).
2. Create a guide for caregivers and family members that communicates all of their options for support within the VA system (not just the Caregiver Program).
3. Implement grand rounds training with key service providers and medical facility staff to educate them on the importance of the caregiver in the recovery of the veteran.
4. Communicate updates and changes within the Caregiver Program to caregivers, not for profit organizations, and other partners to ensure that we are communicating the most accurate information to our constituents.

**Validation**

Caregivers are invaluable in the recovery and support of our nation's veterans. And yet many times they are still not regarded as integral members of the veterans' care team. As part of its commitment to becoming the best customer service organization in government, the VA must fully embrace the caregiver and family members as partners in the path towards rehabilitation and recovery.

1. Currently, the revocation and tier lowering processes feel like a penalty for the caregiver, who may not be financially or emotionally prepared to leave the program. Upon improvement of the veteran, the VA should begin to regularly check in with the caregiver to prepare him or her for the possibility of revocation or tier lowering. Such an initiative could include referrals to employment programs, messages of encouragement, and information regarding other programs offered by the VA.
2. Caregivers largely neglect self-care in favor of their caregiving responsibilities. Instituting "wellness checks" for caregivers in tandem with their veteran's medical appointments would ensure that the caregiver is taking proper care of his/her mental and physical health, thus preventing caregiver burnout and illness.

We hope these recommendations will be useful to you as you conduct your review in the weeks and months ahead. Please call upon us to assist you as you undertake this tremendous task; the burden of ensuring support for these caregivers does not – and should not – fall to the VA alone. As military community organizations dedicated to championing caregivers, we are committed to working with you to support, educate, and inform caregivers nationwide.

EXHIBIT B

Sincerely,

The Elizabeth Dole Foundation

AARP

America's Warrior Partnership

American Legion

American Legion Auxiliary

ARCH National Respite Network and Resource Center

Blue Star Families

Caregiver Action Network

Code of Support Foundation

Dog Tag Inc.

Easterseals

Give an Hour

Hope For The Warriors

Iraq and Afghanistan Veterans of America (IAVA)

Military Child Education Coalition

Military Officers Association Of America (MOAA)

National Military Family Association

Paralyzed Veterans of America

PsychArmor Institute

Quality of Life Foundation

Rosalynn Carter Institute for Caregiving

Square Deal for Vets

Wounded Warrior Project

Yellow Ribbon Fund

