Department of Veterans Affairs
Veterans' Family, Caregiver, and Survivor Advisory Committee
March 25, 2020

Committee Members Present:
Senator Elizabeth Dole, Committee Chair
Sherman Gillums Jr., Vice Chair
Lourdes E. "Alfie" Alvarado-Ramos
Bonnie Carroll
Paula Cobb
Melissa Comeau
S. Joe Crittenden
Harriet Dominique
Jennifer Dorn
Mona Gunn
BG (Ret.) Everett "Denton" Knapp
Dr. Robert L. Koffman
Gabriella Kubinyi
LTG (Ret.) Michael S. Linnington
Hollyanne Milley
Dr. Rebecca Porter
Katherine Shattuck
Sarah Verardo
Lee Woodruff

Committee Members Absent:
None

Ex-officio Present:
Mary Lazare

Department of Veterans Affairs Staff Present:
Dr. Lucille Beck
Dr. Betty Moseley Brown, Designated Federal Officer
Dr. Lynda Davis
Dr. Elyse Kaplan
Dr. Maria Llorente
Christine Merna
Jeffrey Moragne
Toni Bush Neal, Alternate Designated Federal Officer
Lisa Pape
Jennifer Perez
Eugene W. Skinner Jr., VEO FAC Team
Chihung Szeto, VEO FAC Team

Public Present: (Note: the meeting was virtual and open to the public, but attendance could not be taken or confirmed.)

Brittany McMaster (ERPi)
Nick Padua
Molly Ramsey
Colleen Schillmaier (ERPi)
Jonathan Selter
Steve Schwab
Christa Zimmerman (ERPi)

Day 1 - March 25, 2020

Call to Order, **Dr. Betty Moseley Brown, DFO**	**Dr. Betty Moseley Brown, DFO** • Dr. Betty Moseley Brown introduced herself as the VA's Designated Federal Officer (DFO); Toni Bush Neal served as the alternate DFO. Dr. Moseley Brown called the meeting to order at **9:00 a.m. EST**. Due to the meeting being virtual, she shared contact information for technical logistics: Participants were to email veofaca@va.gov for any logistical or technical issues, to request copies of the slides and submit any additional public comments with their name and contact information by 4:30 p.m. EST. • Dr. Moseley Brown thanked the committee members for taking the mandatory ethics training prior to the meeting. She also noted that usually the meeting minutes from the September 2019 meeting would be accepted in person, however due to the virtual format this would be done via email. Dr. Moseley Brown then turned the call over to the Chair, Senator Dole.
Welcome, Opening Remarks, Senator Elizabeth Dole, Committee Chair	**Sen. Elizabeth Dole, Committee Chair** • Senator Elizabeth Dole welcomed everyone and offered thoughts and prayers for those affected by COVID-19. She acknowledged the hard work being done across the government, at the Department of Veterans Affairs specifically, and in states and local communities to combat COVID-19. She called on the Committee to do everything possible to ensure that military families, caregivers, and survivors are supported at this critical time. • Sen. Dole stated that it was a privilege to welcome new members to the Committee. She shared that she is deeply honored to work with a Committee composed of such highly respected experts and leaders as it undertakes its critically important mission. She thanked members of the public for their interest and support of the Committee's work and for joining the call. • Sen. Dole then shared a message she had conveyed at the Committee's first meeting two years earlier: "Millions of people – military families, caregivers and survivors are counting on us to do great work. They're counting on us to be their voice. But to serve them effectively, we need to keep some principles in mind: First, we are not serving on this Committee as advocates for our respective organizations. We are here to represent the network of loved ones supporting America's veterans. Each of us will contribute the wisdom of

our experience, but we will leave our individual organizations' priorities at the door. Second, we will rely on evidence-based data to guide our priorities. Third, we will strive toward what I like to call the Noah Principle, which does not award prizes for predicting rain, only for building arks. We want to be solutions focused as we examine the problems before us to discover which ones are urgent, what is solvable, and which initiatives will make the greatest impact. Finally, we will not hesitate to raise difficult issues and problems. And we will not back down in searching for the answers. We will have some disagreements, but we've all been around long enough that we certainly know how to build consensus.

Over the last two years, the Committee has heard from research experts, clinical providers, VA leaders, and most importantly, directly from families, caregivers, survivors, and veterans. I'm deeply grateful to everyone who contributed to our efforts and supported the formulation of the twelve recommendations we released. Over the past year, a number of people at VA, but especially Dr. Lynda Davis, Chief Veterans Experience Officer, worked hard to ensure implementation of our recommendations as they were reviewed throughout that vast VA organization. Lynda was pushing hard at every turn.

When this Committee last met in September 2019, there was unanimous agreement that new, independent survey data from caregivers, military families, and survivors would be invaluable for the next phase of our work. I volunteered that my Foundation would lead an effort to undertake a national survey. Thanks to the outstanding efforts of my CEO, Steve Schwab and my COO, Jonathan Selter, McKinsey and Company responded in a major way, offering to formulate, deploy, and analyze a nationally representative survey of our 3 populations PRO BONO! My team worked very closely with McKinsey to build the survey quickly, effectively, and in time for today's meeting. Very special thanks to Mike Linnington and Wounded Warrior Project. Mike stepped forward to split the costs with my Foundation for survey recruitment resources. Heartfelt thanks to Bonnie Carroll and her team at TAPS for working hand-in-hand with us to formulate our survivor strategy and questions. And finally, thanks once again to Lynda Davis and her team at VA, who provided essential feedback on the architecture of the survey.

I am pleased to report that thousands of caregivers, survivors, and family members have been surveyed nationwide. And survey results will be presented later today. You will also receive updates on the VA Caregiver Support Program and implementation of the VA MISSION Act of 2018".

- Sen. Dole then introduced each Committee Member for a few comments.

Introductions of Committee Members	The following Committee Members introduced themselves: • **Bonnie Carroll, *Tragedy Assistance Program for Survivors (TAPS)*** - Ms. Carroll is a 2015 recipient of the Presidential Medal of Freedom. She is a military Veteran, the surviving spouse of Brigadier General Tom Carroll, and President and Founder of the Tragedy Assistance Program for Survivors (TAPS). • **Paula Cobb, *Philips***- Ms. Cobb is a proven executive with over 25 years of strategic development and marketing of technology solutions for large global enterprise companies and healthcare systems. • **Melissa Comeau, *American Red Cross***- Caregiver for her Marine husband, Ms. Comeau is an author and currently serves as the Director of Military and Veterans Caregiver Network of the American Red Cross. Ms. Comeau is a former Elizabeth Dole Fellow and her work is supported by a Master's of Science in Management in IT and Project Management. • **S. Joe Crittenden, *Secretary of Veterans Affairs for the Cherokee Nation***- In 2019, Mr. Crittenden was named as the Secretary of Veteran Affairs for the Cherokee Nation by Principal Chief Hoskin. He is the first citizen appointed to the newly created executive cabinet position. Before serving as Secretary of Veteran Affairs, he was elected to two terms as Cherokee Nation's Deputy Principal Chief in 2011 and again in 2015. He is a sixth-generation resident of the Cherokee Nation whose family has been here since the Trail of Tears. Secretary Crittenden served in the U.S. Navy from April 1964 until August 1967 during the Vietnam War. • **Harriet Dominique, *United Services Automobile Association (USAA)***- Ms. Dominique is Senior Vice President for Corporate Responsibility and Community Affairs at USAA. She is also President of USAA Foundation, Inc. and President of the USAA Education Foundation. She leads a team focused on improving military family resiliency. • **Jennifer "Jenna" Dorn, *Former CEO, American Academy of Physician Assistants***- Ms. Dorn has held several other federal leadership positions including Assistant Secretary for Policy at the Department of Labor and Associate Deputy Secretary at the Department of Transportation. • **Sherman Gillums, Jr., Committee Vice-Chair, *American Veterans (AMVETS)***- Mr. Gillums is the Chief Advocacy Officer of AMVETS and a disabled post-9/11 Marine Corps veteran. He is a widely respected commentator on veterans' issues and a published author on the topic. He's a graduate of University of San Diego School of Business Administration, and he completed his executive education at Harvard Business School. Mr. Gillum's wife, Tammie is an Army veteran of Operation Enduring Freedom and former Elizabeth Dole Fellow. • **Mona Gunn, *President of American Gold Star Mothers***- As a Gold Star Mother, Ms. Gunn continues the service of her son by assisting other Gold Star moms, serving veterans, active duty military and supporting patriotic events. In 2013, she was elected to the National Executive Board where she has served as National Flag Guard, National Banner Guard, National Service Officer and Legislative Chairman.

- **BG Everett "Denton" Knapp, *(USA Retired), Tierney Center for Veterans Services, Goodwill Orange County, CA***- Mr. Knapp is also Chairman of the Orange County Veterans and Military Families Collaborative. He retired from the Army as a Colonel after 30 years of active federal service and continues to serve as a Brigadier General in the California State Guard.
- **Robert L. Koffman, M.O., *Retired Medical Navy Officer-*** Dr. Koffman is a retired 30-year Naval Medical Officer. Dr. Koffman is a disabled Veteran and Behavioral Health practitioner who continues to provide care for Veterans as a Red Cross volunteer.
- **Gabriella Kubinyi, *Veterans of Foreign Wars (VFW) and Gold Star Wife***- As a military surviving spouse, Ms. Kubinyi understands what survivors face when they lose a loved one. She also has experience communicating with caregivers and survivors about federal and state benefits.
- **LTG Michael S. Linnington, *(USA Retired), Wounded Warrior Project***- Lieutenant General Linnington has 35 years of military and leadership experience. He is the Chief Executive Officer of Wounded Warrior Project and oversees a wide range of programs that impact Veterans, families, and caregivers.
- **Rebecca Porter, PhD, *President and CEO Military Child Education Coalition***- A proven leader with more than three decades of military service and numerous accomplishments, Dr. Porter has held prominent leadership positions as the Director of the Center for Personal Development at the United States Military Academy at West Point, New York (2005-2007); Chief of Psychology at Walter Reed Army Medical Center in Washington, DC (2009-2010); and Director of the DiLorenzo TRICARE Health Clinic of the Pentagon (2015-2016). Dr. Porter is a Distinguished Military Graduate (1983) from the University of Washington.
- **Lee Woodruff, *Bob Woodruff Foundation***- Ms. Woodruff is co-founder of the Bob Woodruff Foundation that helps Servicemembers and families heal from wounds of war and supports families, caregivers, and survivors.
- **Sara Verardo, *CEO, The Independence Fund***- Ms. Verardo briefs Senior White House, Military, and Congressional officials on client needs and manages a national Veteran organization that to date has distributed more than sixty-five million dollars.
- **Katherine "Kate" Shattuck, *Senior Client Partner of Global Financial Markets, Korn Ferry-*** Ms. Shattuck is an Army Veteran, Veteran caregiver and a former member of the Board of Student Veterans of America. She received the Richard Ferry Transforming Lives Award for participating in the firm's military recruiting effort.
- **Lourdes E. "Alfie" Alvarado-Ramos, *Director of the Washington State Department of VA-*** Director Alvarado-Ramos has an extensive medical leadership background both in the U.S. Army and in State government. She culminated her 22-year active duty career as the Command Sergeant Major of Madigan Army Medical Center and Troop Command.
- **Hollyanne Milley, *Military Spouse***- Ms. Milley has served as a Senior Advisor for many organizations, including the Red Cross, United Service

	Organizations (USO), Parent/School Liaison, Tragedy Assistance Program for Survivors, Easter Seals, and Army Emergency Relief, to name a few. While her husband was deployed, she was also a liaison at Walter Reed, greeting all wounded 101st soldiers on arrival.
Veterans Experience Office Update, Dr. Lynda Davis, Chief Veterans Experience Officer	Dr. Lynda Davis, Chief Veterans Experience Officer • Dr. Lynda Davis thanked the Committee members for accepting the Secretary's invitation to serve. She noted that it is a distinguished Federal Advisory Committee because of the members, Chair and Vice Chair, but also because it is the first of its kind and is historic. The Committee represents the shared commitment everyone has with the federal government, and especially with the VA, to support those who care for our heroes - Veterans, families, caregivers, and survivors, who are often hidden heroes. • Dr. Davis expressed her appreciation for the resources and services she receives as a caregiver for three people, with the challenge of two being quarantined currently. She noted that it is a challenging time and that the Committee should focus on the positive difference they have made and will continue to make. • She then led the group through reviewing the status of the recommendations the Committee made in the last session and highlighted a few things the Veterans Experience Office (VEO) is doing to provide exceptional customer service to Veterans, families, caregivers, and survivors to have the best access and experience in receiving their benefits. She also indicated that handouts would be distributed which summarize the recommendations as well as one-pagers with resources.
Committee Work to Date, Dr. Lynda Davis, Chief Veterans Experience Officer	Dr. Lynda Davis, Chief Veterans Experience Officer • The Committee was established in 2017 and its first report came out in October of 2018 with 12 recommendations, including an identification of all federal programs that serve Veterans, families, caregivers, and survivors. This is underway now in collaboration with colleagues at Health and Human Services (HHS) Administration on Community Living (ACL). Mary Lazare, ex-officio from the ACL was on the call. The Congressionally mandated Recognize, Assist, Include, Support and Engage (RAISE) Task Force will summarize the federal programs as well as others. • The Committee recommended the centralization of policy and programs that support the demographic served. Everything the VA does is governed by the Code of Federal Regulations which the VA amended in May 2019 because of the actions of this Committee to include the recognition of the status of Veterans families, caregivers, and survivors. Not all programs are open to these groups but every policy and regulation from the VA is governed by the Code will now consider these groups. • A recommendation was made to collaborate with non-profit organizations more effectively and fund some of their innovations. VEO has created Memoranda of Agreement with many organizations to ensure utilization of

resources and outreach with these organizations. A regular meeting is held with these groups where best practices are shared and any organization interested in attending can inquire with Dr. Davis for additional information.

- There were two recommendations around the effort to collect and analyze data on delivery of services which are underway. One recommendation was to collect data on children as caregivers which the Center of Excellence for Veteran and Caregiver Research headed by Dr. Luci Leykum, is pursuing. Four pilot programs are underway at the Center: 1) a Caregiver Training Project (a collaboration with the Caregiver Initiative and Elizabeth Dole Foundation) is assessing unmet needs and barriers experienced by caregivers trying to access resources; 2) a survey of high-need, high-risk Veterans and their caregivers to assess intensive primary care models incorporating functional data points; 3) an analysis of the challenges that children have, which look specifically at youth in a caregiving household first; and 4) the first group of Center Fellows has been identified.
- Regarding changes and innovations at the Veterans Health Administration (VHA), there are new centers of innovation. At VHA, the Innovation Ecosystem Office in the Policy Office and the Office of Enterprise Integration both look at ways to work closely with partner organizations in communities. They identify how to create cost-savings, increase timeliness and high-quality access, and provide more evidence-based and supportive services for Veterans and their families.
- Regarding the recommendation to effectively raise awareness of the caregiving role in the community, the VA Office of Public Affairs and VEO's Communications Office have considered many ways to support our Veterans, families, caregivers and survivors.
    - In addition to press releases there is a newsletter that reaches more than 10 million Veterans and their families each week. It includes information on VA services, and organizations that work with our Veterans, families, caregivers, and survivors.
    - Community groups are also reached through Community Veterans Engagement Boards (CVEBs). There is a Lunch-and-Learn series, which includes 160 CVEBs that has been launched.
    - For the first time, texts are being sent out to Veterans. The week prior to this Committee meeting, 8.8 million texts went out to Veterans with a direct link to access services and information related to COVID-19.
    - Communications are being expanded to reach all Veterans, not just those enrolled. Information in these communications includes how to access telehealth services, where mobile Vet centers are in your community, and how to access to urgent care.
    - The White House Hotline is also a helpful resource. My VA 311 is largely dedicated to taking all calls regarding the MISSION Act,

benefits, and COVID-19. Both lines are staffed by Veterans, Veteran family members, or caregivers.

  - Veterans Signals (VSignals) is being used as a survey instrument. All Veterans who go to a VA Medical Facility for outpatient services are surveyed. There has been a 20% response rate, with responses being both qualitative and quantitative. The qualitative response provides the real experiences of our care facilities told by Veterans, caregivers, families. Quantitative responses provide opportunity to analyze the data based on age, gender, and geographic location. This data allows VEO to provide immediate service recovery, address the need of the Veterans and to improve the program if challenges exist. This information is shared with the Directors at the specific facilities and they can take action. VEO also has a Service Recovery Department to insure we are doing the best job in responding.

- The Choose Home Initiative was also highlighted. There are 9.4 million Veterans ages 65 or over. Half of these Veterans receive VA healthcare. Choose Home uses a predictive analytic tool that identifies those at highest risk for nursing home placement. There are about 22,000 Veterans at risk for institutionalization when home-based care is the best for the Veteran and family. Many have gone to polytrauma rehab centers or suffer from traumatic brain injuries (TBI). Twenty-one pilot sites implemented Choose Home, where the nursing and social work VA teams worked with their community partners to determine how to best serve families, caregivers and Veterans at home. They developed recommendations to streamline referrals, coordinate assessments, create a uniform approach for scale and scope of services, coordinate programs both within a facility, and in the community- including Community Veterans Engagement Boards (CVEB) and caregiver-friendly cities working very closely with HHS and the Administration on Community Living (ACL) on collaborating home-based care, and with the Corporation for National Community Service who has authority to provide 250 volunteers for in-home care and Caregiver support to 400 Veterans in five pilot sites: San Antonio, Pittsburgh, Las Vegas, Missoula and Colorado Springs.
- VSignals is also getting feedback on COVID-19. There was an increase of 2,000 comments in the last month on the experience of Veterans in the facilities. There are helpful resources including a website and the White House Hotline is always available for any concern. The number is: 855-948-2311.

Sen. Dole, Committee Chair

- This Committee has championed initiatives to ensure that caregivers are not dropped from the Program of Comprehensive Assistance for Family Caregivers precipitously, without advanced notice. The MISSION Act regulations under review provide a 60-day transition period.

Welcome: Advisory Committee Management Office (ACMO) and Overview of Federal Advisory Committee (FAC), Jeffery Moragne, Director VA ACMO	Jeffery Moragne, Director VA ACMO • Mr. Moragne informed the Committee of the left and right boundaries of the Federal Advisory Committee Act- the legal authority for Committee Members and shared best practices and tools for efficiency in execution of duties. • A slide deck was presented and a Committee Charter and VA Committee Members Handbook were provided. • The Federal Advisory Committee Act (FACA) was created in 1972. It reduced the number from 8,000 Federal Advisory Committees to 1,000 by eliminating duplicity and overlapping missions. Today there are approximately 1,025 Federal Advisory Committees. • FACA gives legal authority to establish or terminate a committee and key tenets are transparency and accountability. It applies any time a committee meets and they must have signed Charter. • The DFO must be present during any committee or subcommittee meetings. The public is invited to attend per the Sunshine Act. Notice of a meeting must be published in Federal Register 15 days prior to the meeting. The agenda must be coordinated with program offices and DFO. The DFO must maintain records and minutes must be signed by the Chair within 90 days after meeting is held. • Membership must be balanced and reflect the constituency of those served including skillset, experience and demographics. • A quorum must be present for legal meeting (50% of membership plus one). If you fall below quorum the meeting becomes an Ad Hoc Subcommittee and must brief the parent committee when quorum is present. • Members giving feedback to legislative and governing bodies is permitted only as a private citizen. Members cannot present as an authority representing the committee. The DFO will provide guidance if you are asked to speak to a group. • Private meetings are permitted for preparatory work as a committee, delegating assignments or research, or for doing administrative work. • Best practices include: o Master your calendar and plan for 18 months- determine subcommittee and parent committee meetings against public, professional and personal commitments. o Know your role- read the Charter and the VA Committee Members Handbook which contain information on ethics requirements, conflicts of interest and a portfolio of committees for collaboration and guidelines. o Subcommittees- The Charter allows you to have subcommittees, but the Secretary must be informed via a letter. Subcommittees

	are permitted to meet privately as their product must be presented to the parent committee and the public. o At the end of each meeting each member will have an opportunity to weigh-in and comment on the content of the meeting. o Regarding cross committee collaboration, there are 25 committees in the VA's portfolio, you can form subcommittees and work groups with them and garner their research so as not to duplicate efforts. o Vet your recommendations and use a SMART template as a guide to building recommendations: Specific, Measurable, Actionable, Realistic and Time-based (SMART). Once a report is submitted to DFO, the Secretary will have it within 10 days without comments or concurrence. In 120 days, the Secretary will have the vetted report with comments and concurrence for review. o Annual Field visits can be done as a committee or subcommittee. They are beneficial to the stakeholders to demonstrate that a committee is working on the things they have been charged with. **Dr. Betty Moseley Brown, Designated Federal Officer (DFO)** • Dr. Moseley Brown introduced herself as the DFO and identified Toni Bush Neal as the alternate.
Jonathan Selter, COO, Elizabeth Dole Foundation Impact Survey	**Jonathan Selter, COO, Elizabeth Dole Foundation** • Mr. Selter thanked the Wounded Warrior Project for helping the Dole Foundation with costs, participant recruitment, and input on survey design. He also thanked Tragedy Assistance Program for Survivors (TAPS) and the Center of Excellence for Veteran and Caregiver Research for involvement in the survey design. Mr. Selter then presented slides detailing the Impact Survey. • Background information: o The goal of survey was to provide actionable data and insight to support and inform the Committee's work and recommendations in this next two-year term. Objectives were to obtain solid demographic information on families, caregivers and survivors, obtain actionable data on their needs, gaps in our existing support network and thoughts on possible interventions. o The definition of the three populations- Families, Caregivers, and Survivors followed the FAC Charter. Collected demographic data allows us to filter the populations as needed. o The goal of the survey design was that sample responses must reflect the underlying population that the Committee serves and there should be statistical significance overall but also specific to the three groups. There was a high degree of rigor to trust the results, the confidence interval was 95% and margin of error was three percent.

- Question structure followed the industry best practice overseen by the Council of American Survey Research Organizations (CASRO) which provides ethics and best practice for market research. Goal of the questions was to identify what needs are out there and which organizations can take action for which needs not to presuppose that any organization is responsible for the identified need.

- Overview of Survey Results:
  - Satisfaction level: There is room for improvement overall. This is not the fault of VA or any particular organization, but results from this and other surveys indicate that the broader ecosystem of support networks has potential for growth and improvement
  - Information resources: Results indicate VA is an important source of information, but half of the respondents viewed four or more organizations as very important resources of information.
  - Common needs across the three groups: 1) Coordination of care; 2) awareness of benefits; 3) access to healthcare; and 4) coordination of care between the Department of Defense (DoD) and VA or between VA and private sector providers.
  - Highest satisfaction needs: The top of the list of high satisfaction needs are Survivors being able to connect with other survivors (TAPS).
  - Lowest satisfaction needs: Commonly include awareness of community benefits and mental health resources. Mental health needs for families included managing effects of parental mental health on a child's wellbeing. Caregiver needs included their own mental health and survivors indicated a need for assistance accessing resources for family members.
- Deep dives into data were performed regarding the three separate groups (Families, Caregivers, Survivors) and included trends by demographics to examine barriers and needs.
  - Families deep dive: Fifty two percent of family respondents are current caregivers. Sixty percent work full-time and 3.8% are unemployed. Employment issues came up frequently in responses. Barriers included healthcare related needs, connection to military infrastructure, transition from military to Veteran process, education on private healthcare, and creating communities of Veterans.
  - Caregivers deep dive: Thirty hours/week was the average number of hours caregiving by Veteran caregivers.57% provide over 40 hours/week with no other support. Thirty five percent do not live with their care recipient, the majority are parents caring for a wounded or disabled Veteran child. Barriers to intervention included managing personal daily tasks, resource awareness challenges, stigma in asking for help with and/or taking time for

	self-care, community connection and isolation, and online forums can help with isolation and support in managing caregiver tasks and personal needs. There is a significant jump in needs between caregiving for eight hours or less per week versus over nine hours. ○ Survivors deep dive: Forty eight percent of survivors used to be caregivers. Top needs include awareness of benefits from VA and community organizations and access to health insurance for family members and resources on communications to appropriately communicate death or other changes in the family to children. • Findings within each Cohort groups ○ Families: health care, employment and childcare, transition from active duty to Veteran, lack of connection to military infrastructure is a key barrier across a variety of needs, intervention needed in education on the private healthcare market. ○ Caregivers: awareness of benefits, care management and coordination, daily tasks, needs are acute for over nine hours per week of caregiving, barriers around stigma and anxiety to getting help, guilt and anxiety in leaving recipient with another caregiver, isolation, household management, sharing of information, intervention needed in exploring support networks. ○ Survivors: awareness of benefits and healthcare, communicate changes in family, 18 to 34 years old- financial planning and selfcare, resources and education on finances. • Four committee members shared their support of the study content.
Updates on: MISSION Act: Care in the Community Including Program of Comprehensive Assistance for Family Caregivers, Lisa Pape, Deputy Chief Patient Care Services Officer for Care Management and Social Work and, Dr. Elyse Kaplan, Deputy Director, Caregiver Support Program	**Lisa Pape, Deputy Chief Patient Care Services Officer for Care Management and Social Work** • Ms. Pape acknowledged Dr. Lucille Beck, Deputy Undersecretary for Health Patient Care Services, Dr. Maria Llorente, Assistant Deputy Undersecretary for Health Patient Care Services, Jennifer Perez, Acting Director, Caregiver Support Program, and Dr. Elyse Kaplan, Deputy Director, Caregiver Support Program. • She then presented a slide deck on some of the things her office has been working on to ensure that the VA is taking care of caregivers and the Veterans they are caring for. • Ms. Pape described the umbrella of the Caregiver Support Program: ○ The Program of General Caregiver Support Services is open to all Veterans and caregivers who are needing support from VA Medical Centers (VAMC). ○ Ms. Pape identified: general caregiver population-training and education, caregiver support phone lines, Resources for Enhancing All Caregivers Health VA (REACH VA), self-care courses, and other additional courses. Anyone in a caregiving role for a Veteran is eligible for these services. This program does not get a lot of publicity, but it is available.

- The Program of Comprehensive Assistance for Family Caregivers (PCAFC) provides a monthly stipend, enhanced mental health care, and travel benefits.
- 19,436 caregivers are in the Program of Comprehensive Assistance (PCAFC).
- Other VHA services available for eligible Veterans include: Adult day care services, respite care, home telehealth, and more.
- Major program priorities from the previous FAC meeting included standardization of the PCAFC, increasing staffing, engaging discussions on eligibility, transitioning stipend methodologies, tier structure, daily meetings with IT program offices to continue building platforms, and expanding the PCAFC under the MISSION Act.

Dr. Elyse Kaplan, Deputy Director, Caregiver Support Program

- Dr. Kaplan covered growth and enhancements to the Caregiver Support Program (CSP) over the past year.
  - Currently, 19,436 Veterans and caregivers are served and this number is expected to quadruple with MISSION Act expansion. The Program must adapt services and strategies to support the changing Veteran and caregiver in larger numbers and the aging population within this group. The PCAFC will shift focus to moderate and high need personal care services.
  - IT development has more than three phases of MISSION Act expansion:
    - One: In December of 2019, replaced the Caregiver Application Tracker with Caregiver Record Management Application (CARMA);
    - Two: In January of 2020, integrated automated stipend payments, including dramatic expansion over several months;
    - Three: Automation of forms interfacing with legacy systems and the ability to apply to the program in online application.
  - VHA stood up an outreach and communications platform. It includes a robust and multi-faceted campaign to reach and engage Veterans and caregivers in this expanded population. Currently they are working toward field readiness, to ensure they are prepared and engaged in training and developing staff nationwide.
  - There will be an interprofessional centralized appeals and eligibility team at every Veteran Integrated Service Network (VISN) to ensure consistency across eligibility requirements. Veterans, caregivers and advocates have shared that eligibility

requirements were not consistent from one VA Medical Center to the next. Currently 145 Medical Centers make individual and independent decisions. Moving forward, there will be 18 regional teams trained by VA Central Office (VACO) to make and implement these standards. Full-time VISN regional leads were hired around the country and there will be one FTE dedicated entirely to caregiver support.

- Every caregiver that is part of PCAFC participates in mandated training for admission to the program. As the demographic of Veterans and caregivers is changing- aging, different phases of life with different physical capabilities- their medical and mental health issues become more complex. The core curriculum of training is expanded to address the needs of the changing caregiver population needs.
- In phase one, through MISSION Act, VHA has hired 685 staff nationwide over the past six months. This has enabled the current program to be staffed and enhanced and will expand the general Caregiver Support Program and services. Over 140 Medical Centers have hired a full-time provider to give general caregiver support service to any walk of life regardless of their eligibility for the PCAFC, Veterans that are caregivers and/or caregivers that have previously been in the PCAFC. The hope is for a wider reach to provide care and support for all caregivers in VA's system.
- The second phase of hiring will occur in Spring and includes meeting with VA leadership and Manpower to insure appropriate staffing models.
- VHA held one training for VISN regional leads, a discussion and idea exchange for staff to hear from the frontline who have been providing care for many years. There will be three upcoming trainings: one for centralized eligibility and two more for overall expansion in a train-the-trainer model. A Toolkit was also developed focusing on suicide prevention for the caregiver. The Campaign for Inclusive Care and the Academy was launched to train providers on how to integrate caregivers into their healthcare team.
- Many caregivers in the VA system could benefit from supportive services, training, outreach, peer support, mentoring. Isolation is a major problem for caregivers nationwide and engaging caregivers in our general support services. VHA has the resources and ability to do it but we need help to get the message out across the Enterprise.

- **Dr. Kaplan then discussed the Proposed Rule and Regulations issued March 5th:**
  - A comparison document was provided listing PCAFC current regulations versus the proposed rule. It was developed to drive

a conversation and empower conversations with caregivers and Veterans to explain the regulations. The Proposed Rule is a comprehensive, robust, and complicated document. It is 240 pages, with a lot of information to digest.

- Two frequently asked questions (FAQ) documents were created, one for overall participants of the program and one for legacy participants. The meeting attendees were encouraged to reply and submit public comments through the Federal Register.
- The proposed rule is now available for public comment for a 60-day period which ends on May 5th. All comments will be responded to and any changes or suggestions will be integrated into the final rule.
- There is a proposed change to the definition of "serious injury" because of the legal rationale and justification to consider a serious illness or disease equivalent to a serious injury. This will be beneficial to most Veterans and caregivers. Previously, if a Veteran had a diagnosis of Multiple Sclerosis (MS), Lou Gehrig's disease or dementia, they would not have qualified for this program. As people age, medical issues become intertwined and it is difficult to find the original diagnosis that brings about these services. The link between serious injury and the need for personal care services has been decoupled which enables more care to be provided for a wider range of caregivers and Veterans.
- It is also included that a serious injury would be defined as a service- connected disability at 70%. This number is grounded in VA history and other things VHA has done. Historically, 70% is the point where VA would provide long-term care services for a Veteran. In the current population of 19,800 Veterans and caregivers in this program, over 90% have a service-connected disability. This 70% would not significantly affect a Veteran's eligibility in qualifying for services.
- Personal care services are available for six continuous months based on: A. The inability to perform and ADL-requiring personal care services each time an ADL needs to be completed; B. The need for supervision, protection or instruction on a daily basis- having a functional impairment that directly impact the individual's ability to maintain his or her personal safety on a daily basis. In the past, program eligibility was based on a diagnosis or symptoms, shifting focus- it is no longer based on a single diagnosis or symptoms.
- Vice Chair Sherman Gillums Jr. asked:
  Has there been any thought given to a rating of Special Monthly Compensation (SMC) R1 or R2 for aide attendance?

Are those evaluations still happening if this was granted on a VA disability claim for a Veteran?
Dr. Kaplan replied:
We spoke with the Veterans Benefits Administration (VBA) when talking about percentage and a way to better define a serious injury. We found that if we move forward with providing this eligibility based on monthly compensation, a very low percentage of current participants would qualify. It would be a large exclusionary factor to this program and dramatically limit eligibility in the current and in future populations.
Mr. Gillums commented:
Not as exclusionary criteria, but if a Veteran has it (in those specific cases, excluding others that didn't have it) would the 70% line mark be enough to satisfy the need? Am I still eligible to go through the evaluation if I am 70% or if I am someone who is SMC R1 or R2? Is it going to be the same across the board no matter what your VA rating already can tell you?
To which Dr. Kaplan replied:
We are working with VBA now and it is much larger than the Caregiver Support Program and ensuring that VHA and many programs that VHA leadership and VBA are coordinating to best address the needs and limit the redundancy and duplicity that may cause additional burden.

- There are new benefits within the regulation to provide financial planning and legal services to assist primary family caregiver in managing personal finance of the caregiver and Veteran as applicable (includes household budget, debt management, retirement planning, and legal services such as power of attorney, advanced directive, or guardianship).
- There was also a shift in stipend payment methodology. The Bureau of Labor Statistics (BLS) combined rate is equivalent and consistent nationwide. VHA modified their ratio and continued to increase even if BLS went up but never decreased even if their rating declined. It was inequitable as some caregivers received consistently more and some received significantly less, in some cases 100% less, than the rest of the country.
- Committee Member Sarah Verardo asked:
  We have a concern in the proposal where it says the caregiver must provide care personally to the Veteran. I work outside the home and my husband needs 24-hour supervisory and nursing care. Are we understanding correctly that the caregiver is not eligible for the program?
  Dr. Kaplan replied:
  That is a complicated question that we are still working out the

details. Within VA some services are additive and some are exclusionary. If that impacts you directly, we encourage you to reach out and we can explain it in more depth.
Ms. Verardo replied:
We have heard from about maybe 100 caregivers who are in this situation. Many of whom are caring for catastrophically wounded Veterans and work and outsource some care that is not provided by VA. In my case, I do that with supervisory care. It's not really a personal thing I am trying to understand, others who would have that question, too.
Dr. Kaplan:
VHA provides a lot of additional and supplemental services- Veteran-Directed Care. Services are being given or a financial component is given to outsource care as needed.

- VHA has heard that quarterly monitoring visits are burdensome for caregivers and difficult for staff. Caregivers felt the visits were punitive. There has been a shift to a wellness visit conducted every 180 days and focused on the wellness and safety of the Veteran and caregiver. An annual home visit and annual reassessment will continue but can overlap with a home visit as one visit.
- How do we continue to care for current participants and expand strategic shift? When the proposed rule goes into effect all current participants in PCAFC will become legacy participants. Within 12 months they will have a reassessment. If they are still eligible, they are brought into the new program at Level one or Level two. If they are ineligible, they have 60-day advanced notice of discharge and 90 days of extended benefits. Veterans and caregivers are encouraged to get reassessed as early as possible. Services, benefits and stipend will not change during that time and they will have many months of receiving robust discharge services and planning for the future. If they wait until the end of that year they will not have as much time to utilize the transition services (17 months of services if they are assessed early versus approximately five months if they wait until the end of the year).
- Committee Member Lourdes E. "Alfie" Alvarado-Ramos asked:
Regarding the resources that have been deployed to every Medical Center to have a caregiver provider- Is this an expectation of the Medical Center? Sometimes a center will have a provider with this as an additional duty and it stretches the resources. Is it the expectation that the center has a provider who does the PCAFC?
Dr. Kaplan replied:
There is at least one Caregiver Support Coordinator at every Medical Center that is dedicated 100% to caregiver support.

VISN lead is now 100% dedicated to implementing caregiver support. Some Medical Centers might have seven staff. Every Medical Center was given the opportunity to expand their staff to what they think they needed with resources from the Caregiver Support Office and VHA. Nationwide, 680 full time for caregiver support staff were funded. Some Medical Centers only hired a few, based on what they felt they needed depending on their demographics. The administrative duties of this program are significant and we wanted to provide additional staff who would provide clinical care and support directly to caregivers.

- Committee Member Melissa Comeau asked:
  Has there been any discussion about extending the time for public comment on this Federal Register due to COVID-19?
  Dr. Kaplan answered:
  We are looking into this. COVID-19 is on all of our minds. Understandably, the country and VA is very focused on COVID-19. We are looking into it but I don't know right now.
  Ms. Comeau then asked:
  Regarding the program of General Caregiver Support, how does the caregiver know that they are in that program? Is there a distinction in the IT system? Is there regular outreach in letting them know they are a part of this program of General Caregiver Support?
  Dr. Kaplan replied:
  Caregiver Record Management Application (CARMA) is our advanced user-friendly system and it is able to distinguish between them. Because of CARMA and hiring staff nationwide, we have enhanced all of our programming nationally and have leadership buy-in and agreement at every Medical Center, and every region or VISN is involved in implementation of the General Caregiver Support Services Program. There are a lot of investments and people will find out if they are in it. They have to ask to be enrolled as a Veteran or caregiver and will not be enrolled without their knowledge. This is going to be an independent program and provide those wraparound services.
- Committee Chair Senator Elizabeth Dole commented and asked:
  The Foundation has prepared a summary memo on the regulation that we will distribute publicly after today's meeting. It will include feedback from our partner Military Service Organizations (MSOs) and Veteran Service Organizations (VSOs) with whom we had a call prior to these proceedings. What is the status of hiring a new Director of the Caregiver Support Program?
  Ms. Pape replied:

	It is a long and arduous process, we have delivered an offer to someone and we are awaiting word. The person does not live in-state so there are some challenges surrounding that as we get through this COVID-19 virus and limited travel. We should have a response in the next few days and will finalize and make an announcement.
Public Comment	• *[Public Comments Attached]*
Wrap up & Adjourn	• Senator Elizabeth Dole adjourned the meeting at **12:21 p.m. EST**

Approved
Dr. Betty Moseley Brown, DFO

Approved
Sen. Elizabeth Dole, Chair