DEPARTMENT OF DEFENSE APPROPRIATIONS FOR FISCAL YEAR 2017

U.S. SENATE,
SUBCOMMITTEE OF THE COMMITTEE ON APPROPRIATIONS,
Washington, DC.

NONDEPARTMENTAL WITNESSES

[CLERK'S NOTE.—The subcommittee was unable to hold hearings on nondepartmental witnesses. The statements and letters of those submitting written testimony are as follows:]

PREPARED STATEMENT OF CROHN'S AND COLITIS FOUNDATION OF AMERICA

Chairman Thad Cochran, Ranking Member Durbin, and distinguished members of the Subcommittee, as you begin to craft the fiscal year 2017 Defense appropriations bill, the Crohn's and Colitis Foundation is pleased to submit this statement for the record asking you to provide $250 billion for the Department of Defense (DOD) Peer Reviewed Medical Research Program in addition to listing inflammatory bowel diseases (IBD) as a condition for study within the program as it has historically been included since 2008. These actions will ensure further advancements in understanding the linkage between active service and IBD and how to prevent or effectively treat these debilitating diseases.

CROHN'S AND COLITIS FOUNDATION OF AMERICA

The Crohn's & Colitis Foundation is the only national nonprofit, voluntary health organization dedicated to the fight against IBD. Its mission is to cure and prevent Crohn's disease and ulcerative colitis, and to improve the quality of life of children and adults affected by these diseases.

The Foundation's Research Program has four major goals:

1) Identity and fund the best peer-reviewed, investigator-initiated research in IBD;
2) Provide money that allows investigators to generate enough preliminary data to compete for funding from the National Institutes of Health (NIH);
3) Encourage outstanding investigators to choose a career in IBD research; and
4) Discover and support emerging areas of research that enhance our understanding of the causes and disease course of IBD.

Each year, the Foundation's National Scientific Advisory Committee (NSAC) which is comprised of thought leaders in IBD, conducts a peer review—modeled after that of the NIH—of more than 250 grant applications annually from all over the world. Grants are awarded strictly on the basis of scientific merit and relevance to Crohn's disease and ulcerative colitis. Through this process, the Crohn's & Colitis Foundation is able to fund only the very best IBD research in the world. The Foundation has played a role in many breakthroughs that have improved the lives of IBD patients. Of particular mention is the initial research study that led to the discovery of Remicade®, the only biologic drug available for both Crohn's disease and ulcerative colitis. The Foundation was also integral in funding work that led to identifying the first gene linked to Crohn's Disease, NOD/CARD15.

DEPARTMENT OF DEFENSE RESEARCH ACTIVITIES

CCFA requests that IBD be listed as a condition eligible for study in the Peer-Reviewed Medical Research Program in the fiscal year 2017 DOD Appropriations Bill.

The Peer Reviewed Medical Research Program (PRMRP), established in fiscal year 1999, has supported research across the full range of science and medicine, with an underlying goal of enhancing the health and well-being of military Service members, Veterans, retirees, and their family members. Program oversight is provided by a program review panel with joint military service and interagency representation. IBD has been listed consistently as a condition in the program since 2008.

Throughout history, military medical personnel have pioneered breakthroughs in response to war time needs, benefitting service members and civilians alike. The PRMRP is committed to funding research with the potential to profoundly impact the development and implementation of medical devices, drugs, and clinical practice guidelines that will enhance the precision and efficacy of diagnosis and treatment across the spectrum of healthcare settings.

IBD PREVALENCE INCREASES IN VA, UC MORE COMMON

The prevalence of Crohn's Disease and Ulcerative Colitis (collectively known as IBD) increased by two to threefold among veterans from 1998 to 2009. Researchers found nearly 17,000 unique incident cases of Crohn's Disease and over 26,000 cases of Ulcerative Colitis within the military population during this time. Due to the population studied, 94 percent of the cases were in men.[1] In 2009, the age and gender standardized prevalence rate of Crohn's Disease was 287 per 100,000 VA users and the prevalence rate for Ulcerative Colitis was 413 per 100,000 VA users.[1] Despite having a large population study, much is yet to be known about etiology or cause of these diseases, therefore continued research in this area is necessary to advance knowledge about IBD.

It is important to recognize that by increasing the Federal commitment to IBD research, we can improve the health of those brave Americans who serve in uniform and are suffering from inflammatory and gastrointestinal disorders. Gulf War illness and IBD have a disproportionate impact on active-duty U.S. Armed Forces and among Veterans. Certain environmental stressors are found to trigger an episode.

In order to identify the etiology of these disease, robust funding is needed at a level of $250 million in fiscal year 2017 so that advancements in this area can continue to be made. Thank you for the opportunity to submit the views of the Crohn's and Colitis community. Please do not hesitate to contact us should you have any questions or require additional information.

PREPARED STATEMENT OF DYSTONIA ADVOCACY NETWORK

Chairman Cochran and distinguished members of the Subcommittee, thank you for the opportunity to submit testimony on dystonia. On behalf of the community of individuals affected by dystonia and the Dystonia Advocacy Network, we request that "dystonia" continue to be included as a condition eligible for study in the Department of Defense (DOD) Peer-Reviewed Medical Research Program (PRMRP) in fiscal year 2017.

ABOUT DYSTONIA

Dystonia is characterized by persistent or intermittent muscle contractions causing abnormal, often repetitive, movements, postures, or both. The movements are usually patterned and twisting, and may resemble a tremor. Dystonia is often initiated or worsened by voluntary movements, and symptoms may "overflow" into adjacent muscles. Dystonia is classified by: 1. clinical characteristics (including age of onset, body distribution, nature of the symptoms, and associated features such as additional movement disorders or neurological symptoms) and 2. Cause (which includes changes or damage to the nervous system and inheritance). Doctors use these classifications to guide diagnosis and treatment.

ABOUT THE FOUNDATION

The mission of the DMRF is to advance research for more treatments and ultimately a cure, to promote awareness and education, and to support the needs and well-being of affected individuals and families. The membership of the DMRF is comprised of individuals living with all forms dystonia, their friends and families,

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[1] Hou JK, Kramer JR, Richardson P, Mei M, El-Serag HB. The Incidence and Prevalence of Inflammatory Bowel Disease Among U.S. Veterans: A National Cohort Study. Inflamm Bowel Dis. 2013 Feb 27. [Epub ahead of print] PubMed PMID: 23448789.

donors, healthcare professionals, and researchers, uniting people of all backgrounds and abilities to better serve those living with dystonia.

The Patient Perspective

"In 1975 I was in the Tennessee National Guard. I was riding in a personnel carrier, which is like a small tank. The driver was not watching where he was going and drove into a 14-foot ditch, straight down. I had a helmet on which probably saved my life. I got slammed into the wall, and it knocked the helmet off. My shoulder took most of the impact but it definitely hurt my neck quite a bit. I didn't have any use in my right arm for some time. Later on, I noticed my head was turning to the left. I went to the doctor and of course they didn't know what it was. Time progressed and it started to get worse. My head was pulling to the left, which made it very difficult to drive a car. Sometimes I sat sideways in the seat to do so. I finally went to some neurologists locally and they diagnosed it as torticollis [cervical dystonia]. At that time there wasn't a lot of botulinum toxin going around, so to speak, so they sent me to a center in Nashville. I tried botulinum toxin injections two or three times and then had a bit of a reaction and it didn't seem to help a whole lot."

Johnny McCoy is a U.S. Army Veteran who acquired cervical dystonia after a service-related injury.

CONCLUSION

Medical literature associates the onset of dystonia with traumatic injury, particularly traumatic head/brain injuries. Our men and women in uniform face a disproportionate risk of developing dystonia as a result of an injury sustained during their military service. Over recent years, the PRMRP has funded many dystonia research projects that have been crucial to increasing our scientific understanding of this condition. In the interest of further improving care for our dystonia-affected veterans, please once again support the inclusion of dystonia as a condition eligible for study through the PRMRP during the fiscal year 2017 appropriations process.

PRMRP Grants for Dystonia

Proposal Title	Principal Investigator	Institution	Program	Mechanism	Research Topic	Fiscal Year	Award Amount
Creation of a Mouse with Stress-Induced Dystonia: Control of an ATPase Chaperone	SWEADNER, KATHLEEN J	**Institution:** MASSACHUSETTS GENERAL HOSPITAL	PRMRP	Concept Award	**Primary:** Animal Models	2010	$118,843.00
Gene Expression-Based High-Throughput Screening (GE-HTS) to Identify Novel Therapeutics for Dystonia	BRAGG, D. CRISTOPHER	**Institution:** MASSACHUSETTS GENERAL HOSPITAL	PRMRP	Concept Award	**Primary:** Drug Development **Secondary:** Functional Study of Biological	2010	$131,126.38
Dopamine Dysfunction in DYT1 Dystonia	SHARMA, NUTAN	**Institution:** MASSACHUSETTS GENERAL HOSPITAL	PRMRP	Discovery Award	**Primary:** Neural Plasticity / **Secondary:** Cellular	2012	$176,800.00
Developing Gene Silencing for the Study and Treatment of Dystonia	GONZALEZ-ALEGRE, PEDRO	**Institution:** CHILDREN'S HOSPITAL, PHILADELPHIA	PRMRP	Investigator-Initiated Research Award	**Primary:** Gene Therapy (Includes Vector **Secondary:** Familial and Hereditary Disorders	2013	$1,132,500.00
Identifying Molecular Regulators of Neuronal Functions Affected in the Movement Disorder Dystonia	HARATA, NOBUTOSHI C	**Institution:** IOWA, UNIVERSITY OF	PRMRP	Investigator-Initiated Research Award	**Primary:** Neural Circuits **Secondary:**	2013	$1,132,500.00
Pathomechanisms of Dopamine Dysregulation in DYT1 Dystonia: Targets for Therapeutics	HESS, ELLEN J	**Institution:** EMORY UNIVERSITY	PRMRP	Investigator-Initiated Research Award	**Primary:** Neural Circuits **Secondary:** Pharmacology	2014	$1,852,239.00
A Novel Animal Model for Investigating the Neural Basis of Focal Dystonia	EVINGER, LESLIE C	**Institution:** NEW YORK, STATE UNIVERSITY OF, STONY BROOK	PRMRP	Investigator-Initiated Research Award	**Primary:** Neural Circuits **Secondary:** Animal Models	2014	$1,186,300.00

We appreciate that the Defense Appropriations Subcommittee and the Senate play important roles in crafting the annual eligible conditions list. The dystonia community urges you to continue inclusion of "dystonia" as a condition eligible for study through the PRMRP within the Committee Report accompanying the fiscal year 2017 Defense Appropriations Bill.

Thank you again for your time and your consideration of the dystonia community's requests.

PREPARED STATEMENT OF GBS|CIDP Foundation International

Chairman Cochran and distinguished members of the Subcommittee, thank you for the opportunity to submit testimony on GBS. On behalf of the community of individuals affected by Guillain-Barré Syndrome (GBS) and the GBS|CIDP Foundation

International, we request that 'Guillain-Barré Syndrome (GBS)' be included as a condition eligible for study in the Department of Defense (DOD) Peer-Reviewed Medical Research Program (PRMRP) in fiscal year 2017.

ABOUT GUILLAIN-BARRÉ SYNDROME

GBS is an inflammatory disorder of the peripheral nerves outside the brain and spinal cord. It is characterized by the rapid onset of numbness, weakness, and often paralysis of the legs, arms, breathing muscles, and face. Paralysis is ascending, meaning that it travels up the limbs from fingers and toes towards the torso. GBS can occur as an inappropriate immune system response to something as familiar as stomach flu where the body's immune system ends up attacking the nervous system. GBS can be life-threatening and hospitalization followed by prolonged and difficult recovery is often required.

ABOUT THE FOUNDATION

The GBS|CIDP Foundation International is the preeminent global non-profit organization supporting individuals and their families affected by Guillain-Barré syndrome (GBS), chronic inflammatory demyelinating polyneuropathy (CIDP), and related syndromes such as multifocal motor neuropathy (MMN) through a commitment to support, education, research, and advocacy.

THE PATIENT PERSPECTIVE

"My name is Michelle Mahurin and I am a GBS survivor.

I was an active duty member of the United States Air Force for 20 years when I contracted GBS in June of 2013. On June 13th, 2013, I became violently ill from a bad case of food poisoning. On June 21st, I began experiencing my first symptoms of GBS. On 24 June, I was finally admitted to the hospital. By 28 June, I was completely paralyzed and had gone into respiratory failure. I spent the next 10 days in the ICU before I was able to breathe on my own and was transferred to the inpatient rehabilitation wing in the hospital. It was there that I began to receive intense therapy, (5–6 hours a day, 6 days a week), that consisted of speech therapy (ST), occupational therapy (OT), and physical therapy (PT). On August 12th, I was finally discharged from the hospital and have since continued in various therapy programs for PT, OT and ST—to include Voice Therapy that I am currently receiving.

During the course of my recovery, I literally had to re-learn how to take care of myself. From the basics of being able to sit up on the side of the bed, to feeding and dressing myself, to being able to walk again and eventually being able to drive again. While I was recovering, I relied on my family to assist me with day-to-day tasks and to drive me to my various appointments.

On December 29, 2014 I was medically retired from the Air Force due to my GBS. Since being retired, I have been fortunate to be able to return back to working full time. However, it has not been an easy task for me. Even though I am considered recovered, I am not at the same level that I was prior to contracting GBS. I still battle through various residuals: neuropathy pain, fatigue/muscle weakness, occasional loss of balance, facial palsy, and weakened vocal cords. At one point, my fatigue was a constant battle; I didn't have any Quality of Life, (QoL), and honestly had considered quitting work. I expressed my concerns with my neurologist, who in turn, prescribed me Methylphenidate to help me with my fatigue. This medication does not eliminate my fatigue, but does increase my QoL by allowing me to be able to function in day-to-day activities and enjoy my family.

As you craft the fiscal year 2017 Department of Defense Appropriations Bill, I ask that you work with your colleagues to include "Guillain-Barré Syndrome (GBS)" as a condition eligible for study through the PRMRP. On behalf of all Guillain-Barré Syndrome-affected constituents, thank you for your consideration of my request."

—Excerpt from "My GBS Story", Michelle L. Mahurin, GS–09, DAF, Budget Analyst, 57th Maintenance Group, Nellis Air Force Base, NV.

"In 2012, I contracted Guillain-Barré Syndrome (GBS), a rare disease in which the immune system attacks the nerves. Most Doctors still have no experience with GBS, and in my case in a regional coastal hospital, they spent valuable days believing it to be end stage cancer. After finding no cancer, a neurologist was brought in, who diagnosed GBS, which led to my being flown to a major University Hospital. At the time, I was paralyzed from the neck down, on a ventilator and feeding tube, in a coma, and predicted to die.

UNC Hospitals, using IVIg, doubled, brought me out of acute danger, and I have spent the time since then recovering. While I am 71, and was perhaps impacted

more than a 21 year old, I believe it mistaken for major medical institutions to state that most make a full recovery. It would appear the definition of 'full recovery' might mean simply being able to function, at a survival level. I spent 3 years performing Physical Therapy two to three times per week, and can now walk, if somewhat awkwardly. Upon finally walking without a cane, I made plans to enter Nursing School. From January, 2015, until May, 2015, when I entered Nursing School, my PT and I worked directly on being able to have the type of physical skills demanded by Nursing. In December, 2015, I am proud to say that I earned a Certificate, and North Carolina License, as a CNA, the lowest level of Licensed Nursing! I remain in Nursing, headed to a RN, I hope, but it is very difficult. I love working with patients, as I am able!

I am now a Veteran's Administration patient, for which I'm happy. The VA may have the greatest expertise in nerve injuries, and it is my understanding that the VA was one of the original American institutions to recognize GBS, decades ago. Little is known about GBS, and the family of damaged nerve diseases. My own case fits neither the Acute GBS model, nor the Chronic GBS model, with my having multiple GBS attacks, while gradually recovering overall. The VA is working with my unique situation to find the best treatment regimen for me. Any Research could go a long way in helping Veterans and non-Veterans alike."

—Excerpt from "My GBS Story", Tim (Thomas E.) Hubbard, BSE, JD, CNA USMC 1963–68.

CONCLUSION

Medical literature has found that GBS occurs at a higher rate in U.S. military personnel than the general population. Military personnel, particularly deployed personnel, face an elevated risk of infections, viruses, and other potential triggers for GBS. The PRMRP has been incredibly successful in supporting meaningful research projects for other conditions that disproportionately impact military personnel and occur as a result of military service.

We appreciate that the Defense Appropriations Subcommittee and the Senate play important roles in crafting the annual eligible conditions list. The GBS community urges you to include "Guillain-Barré Syndrome (GBS)" as a condition eligible for study through the PRMRP within the Committee Report accompanying the fiscal year 2017 Defense Appropriations Bill.

Thank you again for your time and your consideration of the GBS community's requests.

PREPARED STATEMENT OF HUMAN FACTORS AND ERGONOMICS SOCIETY

On behalf of the Human Factors and Ergonomics Society (HFES), we are pleased to provide this written testimony to the Senate Appropriations Subcommittee on Defense and Related Agencies for the official record. HFES urges the Subcommittee to provide robust funding levels for Research, Development, Test, and Evaluation (RDT&E) at the Department of Defense (DOD) in the fiscal year 2017 appropriations process.

HFES and its members recognize and appreciate the challenging fiscal environment in which we as a nation currently find ourselves; however, we believe strongly that investment in scientific research serves as an important driver for innovation and the economy and for maintaining American global competitiveness. We thank the Subcommittee for its longtime recognition of the value of scientific and engineering research and its contribution to innovation in the U.S.

THE VALUE OF HUMAN FACTORS AND ERGONOMICS SCIENCE

HFES is a multidisciplinary professional association with over 4,500 individual members worldwide, including psychologists and other scientists, engineers, and designers, all with a common interest in designing safe and effective systems and equipment that maximize and adapt to human capabilities.

For over 50 years, the U.S. Federal Government has funded scientists and engineers to explore and better understand the relationship between humans, technology, and the environment. Originally stemming from urgent needs to improve the performance of humans using complex systems such as aircraft during World War II, the field of human factors and ergonomics (HF/E) works to develop safe, effective, and practical human use of technology. HF/E does this by developing scientific approaches for understanding this complex interface, also known as "human-systems integration." Today, HF/E is applied to fields as diverse as transportation, architecture, environmental design, consumer products, electronics and computers, energy

systems, medical devices, manufacturing, office automation, organizational design and management, aging, farming, health, sports and recreation, oil field operations, mining, forensics, and education.

With increasing reliance by Federal agencies and the private sector on technology-aided decisionmaking, HF/E is vital to effectively achieving our national objectives. While a large proportion of HF/E research exists at the intersection of science and practice—that is, HF/E is often viewed more at the "applied" end of the science continuum—the field also contributes to advancing "fundamental" scientific understanding of the interface between human decisionmaking, engineering, design, technology, and the world around us. The reach of HF/E is profound, touching nearly all aspects of human life from the healthcare sector, to the ways we travel, to the hand-held devices we use every day.

HUMAN FACTORS AND ERGONOMICS AT THE DEPARTMENT OF DEFENSE

HFES and its members believe strongly that Federal investment in DOD will have a direct and positive impact on the U.S. economy, national security, and the safety and well-being of Americans. It is for these reasons that HFES supports robust funding for DOD, especially for the Army Human Factors Engineering Technology applied research program and the Navy Personnel, Training, Simulation, and Human Factors program within Engineering and Manufacturing Development to encourage further advancements in the fields of technology, safety, and human factors, among others.

DOD has openly acknowledged the significance of human factors research and the potential for interagency collaboration through the creation of the Department of Defense Human Factors Engineering Technical Group (DOD HFE TAG). Composed of representatives from DOD, National Aeronautical and Space Association (NASA), Federal Aviation Administration (FAA), and the Department of Homeland Security (DHS), the scope of this working group is broad and its benefits are diverse.

In particular, the goals of DOD HFE TAG are to:

—Provide a mechanism for the timely exchange of technical information in the development and application of human factors engineering.

—Enhance coordination among government agencies involved in HF/E technology research, development, and application.

—Assist in the preparation and coordination of tri-service documents, and sponsor in-depth interaction, which aids in identifying HF/E technical issues and technology gaps.

This research undoubtedly affects the safety and well-being of American citizens and it is for this reason that we request robust funding levels for human factors research in DOD in fiscal year 2017.

CONCLUSION

Given DOD's critical role in supporting fundamental research and development across defense and engineering disciplines, HFES supports robust funding levels for DOD RDT&E programs, especially those that specifically fund human factors, in fiscal year 2017. These investments fund important research studies, enabling an evidence base, methodology, and measurements for improving organizational function, performance, and design across sectors and disciplines.

On behalf of HFES, we would like to thank you for the opportunity to provide this testimony. Please do not hesitate to contact us should you have any questions about HFES or HF/E research. HFES truly appreciates the Subcommittee's long history of support for scientific research and innovation.

[This statement was submitted by William S. Marras, Ph.D., CPE, President and Lynn Strother, Executive Director, Human Factors and Ergonomics Society.]

PREPARED STATEMENT OF INTERSTITIAL CYSTITIS ASSOCIATION

Chairman Cochran and distinguished members of the Subcommittee, thank you for the opportunity to submit testimony on interstitial cystitis. On behalf of the community of individuals affected by interstitial cystitis (IC) and the Interstitial Cystitis Association, we request that "interstitial cystitis (IC)" continue to be included as a condition eligible for study in the Department of Defense (DOD) Peer-Reviewed Medical Research Program (PRMRP) in fiscal year 2017.

ABOUT INTERSTITIAL CYSTITIS

Interstitial Cystitis (IC) is a chronic bladder condition affecting 4 to 12 million people in the U.S. We often say that interstitial cystitis is as hard to say as it is

to live with. It is also called IC, painful bladder syndrome (PBS), bladder pain syndrome (BPS), and chronic pelvic pain (CPP).

ABOUT THE FOUNDATION

The Interstitial Cystitis Association (ICA) advocates for research dedicated to discovery of a cure and better treatments, raises awareness, and serves as a central hub for the healthcare providers, researchers and millions of patients who suffer with constant urinary urgency and frequency and extreme bladder pain called IC, or interstitial cystitis.

THE PATIENT PERSPECTIVE

"I am writing to advocate for the inclusion of Interstitial Cystitis as a condition eligible for research funding through the Department of Defense's Peer Reviewed Medical Research Program.

I know I can't speak for all IC patients, but from what I have read, I believe it to be indicative of what almost all IC patients go through. I was diagnosed with IC in my early 20's (although the onset of symptoms can start at any age) and since then my life has been almost exclusively ruled by this condition. When I was in high school I dreamed of a career in the military, but by the time I graduated from the ROTC program, my dreams were over. After going to the ER too many times to count complaining of abdominal pain and frequent urination (every hour, 24 or more times a day), I was sent to doctor after doctor until I was finally diagnosed with IC. This process took almost 2 years because there is NO definitive test for IC. So they had to rule out EVERYTHING else, before they could tell me what I had.

Life did not improve after diagnosis because IC has NO CURE! Instead IC patients like myself have to change their entire WAY of life in order to achieve any QUALITY of life. The first thing I would like to address is the unremitting pain that I experience every day. This is every conscious moment of every single day. This is accompanied by urgency, frequency of urination, and sometimes incontinence, which makes traveling even short distances difficult. There are several things that you take for granted that I can no longer do. Because this condition affects my bladder lining, I have a very restrictive diet so I have to be very careful of what restaurants I go to. Going to the movies is almost impossible because I have to get up at least 3–4 times during the film. Walking any long distances is jarring for my bladder and increases pain, so even casual exercise or outdoor excursions are difficult for me. Even something as simple as visiting my family can be almost impossible, so they have to come to me. I have a very understanding husband, but intimacy is painful and I worry about the long term impact IC will have on my marriage, much less the ability to start a family. I am lucky because I do not have to work, but if I had to, I am not sure it would even be possible.

I know you are probably wondering why I am so miserable all the time? You probably are saying, why doesn't she get treatment for this condition. The truth is I do, but there really isn't much out there that helps. Diet, over-the-counter medications, and stress reduction are first line treatments according to the American Urological Association, but they barely help. Elmiron © is the only FDA approved medication for IC, but because of recent changes to prescription coverage brought on by Obamacare, a 1 month supply now costs $600 and is unaffordable. This medication can take up to 6 months to work, has a huge side effect profile, and only works for about half the patients who take it. I am currently under the care of a pain management doctor for pain, a psychiatrist for depression, and an urologist who does installations (putting medication directly into my bladder by cauterization). All this is done just so I have the motivation to wake up in the morning.

IC does not discriminate on sex, race, or age. It can strike anyone at any time, including those who have or are currently serving in the military. If we are to defend this country with as many people as possible, we need to put this chronic disease behind us. My life, and those of all IC patients is not one that we chose. However, it is up to YOU to make the choice to help us find an easier way for doctors to make a diagnosis, better treatment options so we can be productive citizens, and if luck is on our side, ultimately find a cure by allotting funding for IC in the next fiscal year."

—*A Hopeful IC Warrior*

CONCLUSION

IC is becoming increasingly prevalent among active personnel and veterans and is associated with post-traumatic stress disorder. DOD supports important research on medical conditions that impact military personnel, their families and veterans through the Peer-Reviewed Medical Research Program. Congress has historically in-

cluded IC in the list of eligible conditions for research under this program and IC researchers compete successfully each year.

We appreciate that the Defense Appropriations Subcommittee and the Senate play important roles in crafting the annual eligible conditions list. The IC community urges you to continue inclusion of "interstitial cystitis (IC)" as a condition eligible for study through the PRMRP within the Committee Report accompanying the fiscal year 2017 Defense Appropriations Bill.

Thank you again for your time and your consideration of the IC community's requests.

PREPARED STATEMENT OF NEPHCURE KIDNEY INTERNATIONAL

Chairman Cochran and distinguished members of the Subcommittee, thank you for the opportunity to submit testimony on FSGS. On behalf of the community of individuals affected by focal segmental glomerulosclerosis (FSGS) and NephCure Kidney International, we request that "focal segmental glomerulosclerosis (FSGS)" continue to be included as a condition eligible for study in the Department of Defense (DOD) Peer-Reviewed Medical Research Program (PRMRP) in fiscal year 2017.

ABOUT FOCAL SEGMENTAL GLOMERULOSCLEROSIS

Focal Segmental Glomerulosclerosis (FSGS) is a disease that attacks the kidney's filtering system (glomeruli) causing serious scarring. FSGS is one of the many causes of Nephrotic Syndrome, which occurs when valuable protein in the blood leaks into the urine (proteinuria). FSGS can cause end-stage renal disease (ESRD), at which point patients require dialysis or a kidney transplant. There is no cure and few treatments for FSGS, and it returns in approximately 30–40 percent of patients who receive kidney transplants.

ABOUT THE FOUNDATION

NephCure Kidney International is the only organization committed exclusively to support research seeking the cause of the potentially debilitating kidney disease Focal Segmental Glomerulosclerosis (FSGS) and the diseases that cause Nephrotic Syndrome, improve treatment, and find a cure.

THE PATIENT PERSPECTIVE

"I was diagnosed with Focal Segmental Glomerulosclerosis (FSGS) in July 2007 while serving in the U.S. Air Force Reserves. Previously, from January 2001—2007 (deployed for Operation Enduring Freedom in 2005), I had served on Active Duty with the U.S. Air Force. In 2007, while a patient at the VA Medical Center Dallas, my GFR was 31, and they decided to do a biopsy, which led to the diagnoses of FSGS.

Due to the decline of kidney function, I was placed on TDRL in October 2008 and was medically retired (PDRL) with 100 percent in May 2012 as an Air Force Staff Sergeant (E–5). My plans were to remain in the Air Force until retirement, however due to FSGS, this was not possible. It was a change for me to have to put the uniform in the closet and know that it was going to remain there.

In May 2009 my kidney function had deteriorated to a GFR of 15, and at that time I began hemodialysis treatments (in-center) on Mondays, Wednesdays, & Fridays for 4 hours per session. Due to sepsis, pericarditis, and other issues from dialysis, I was a frequent patient at the hospital; one visit lasted 1.5 months, most of which was in the Intensive Care Unit (ICU).

Luckily, on January 1, 2013, I received a kidney transplant and have been doing pretty well since. However with FSGS the threat remains that it could affect my transplanted kidney, thus returning me to dialysis treatments until I could receive another kidney transplant. I urge your committee to fund research for FSGS so that other service members and civilians do not have to go through the illnesses and pains of being on dialysis and the worries of the families they have caring for them."

—Anthony C. Whalen, SSgt, USAF (Ret)

"I volunteered for the draft in 1970 and entered the army on June 22, 1970. At that time I had protein in my urine but did not know what that meant. After discharge in 1972 my blood pressure was elevated and I still had protein in my urine. By 1981 my pressures remained high and I was referred to a nephrologist who did a biopsy confirming a diagnosis of Focal Glomerulosclerosis which they now call FSGS.

I received a kidney from my brother on April 30, 1987, that puts me out soon to be 29 years. I returned to work as a VA nurse 3 months after transplant and continue to work today at Peterson Regional Medical Center in Kerrville, Texas. I am proud to have served in the army and thank God for my brother and the opportunity to be transplanted. Help us fight FSGS—it is an insidious, life taking illness. A cure can be found. Funding research will help keep people working, paying taxes and keep them off dialysis."

—*Kent Bressler*

CONCLUSION

FSGS is a rare and devastating kidney disease that is a leading cause of end-stage renal disease (ESRD). Nearly 30,000 veterans suffer from ESRD and an additional 3,000 veterans are expected to reach ESRD each year with significant health disparities among African American due to variants of the APOL1 gene. In addition, researchers suggest there are new opportunities for investigating FSGS in the military population with respect to environmental exposures. More needs to be done to improve our understanding of the impact of FSGS among our military personnel and veterans.

We appreciate that the Defense Appropriations Subcommittee and the Senate play important roles in crafting the annual eligible conditions list. The FSGS community urges you to continued inclusion of "focal segmental glomerulosclerosis (FSGS)" as a condition eligible for study through the PRMRP within the Committee Report accompanying the fiscal year 2017 Defense Appropriations Bill.

Thank you again for your time and your consideration of the FSGS community's requests.

PREPARED STATEMENT OF KATHLEEN PROUT, MILITARY SURVIVING SPOUSE ADVOCATE

This testimony is prepared for the Senate Appropriations Committee, Subcommittee on Defense, regarding Appropriations for NDAA17, Outside Public Witness, March 18, 2016.

My name is Kathleen Prout of Coronado, CA. I am an active duty Navy surviving spouse in receipt of partial payment of SBP due to the DIC offset and DIC. I also am a volunteer survivor advocate and have been working on the elimination of the SBP–DIC Offset for 10 years. While my statement is personal, it is representative of all 63,000 SBP–DIC Offset surviving spouses. My purpose is to seek successful passage of S 979, a bill sponsored by Senator Bill Nelson, FL and Senator Susan Collins, ME.

My late husband, Rear Admiral James G. Prout III, USN, was serving in his 30th year in the Navy as the Battle Group Commander of Cruiser-Destroyer Group 3 with the USS *Carl Vinson*, CVN 70 as his flag ship, when the F–18 in which he was a passenger crashed while on official business. He was killed, and in a moment, my family's life changed forever. While family and friends were supportive, my children and I were left to go through the painful lifelong grief process. I was saddened and shocked to discover that the Navy, the military and the Department of Defense were far less supportive.

The Survivor Benefit Plan (SBP), a benefit my late husband earned, was not paid to me in full. When he died, I was told I would only be getting a fraction of the benefit he earned by serving his country for 30 years. The Casualty Assistance Officer explained that the Department of Defense's SBP is offset dollar for dollar by the amount of Dependency and Indemnity Compensation (DIC) paid by the Veterans Administration. DIC is paid to surviving spouses of service members who die on active duty or as a result of a service caused injury or condition. SBP and DIC, created by Congress are two separate programs paid for two separate purposes. One is an employer based benefit and the other is an indemnity compensation due to service to our Nation causing a premature death. Even stranger, the surviving spouse is the only beneficiary penalized. Any other insured interest in receipt of SBP is paid in full. Even in the case of a divorce, where SBP is considered "property", SBP may be paid in full to the former spouse and DIC paid to the current spouse. Full SBP is unfairly denied only to the un-remarried surviving spouse under age 57 of he/she who died on active duty or of causes related to military service after retirement. This is known as the SBP–DIC offset, and we must fight to end it.

My husband and I served as a team. I was responsible for not only our own family but the families of all those who served under him in his command. He worked 14–16 hour days consistently during his career and spent half of our marriage deployed. He was a hero, shot during a mission in Vietnam while working with SEAL TEAM

Boat Support Unit One, earning the Purple Heart and Bronze Star with V for valor. During our long marriage, he missed the birth of one of his children, and made the birth of our first by only a few hours, having been away on Navy business, countless birthdays, anniversaries, holidays and summers while I managed the children, our household, the automobiles, the moves, (It seems that the unwritten rule is for the service member to be away during the moving process, returning after the house is unpacked), the official entertaining at our own personal expense, being responsible for the well being of the spouses and children in the command and enabled him to do his job so well. We both served although I was unofficial and not compensated for my countless hours of volunteer work.

When I lost my husband, I lost 75 percent of our household income due to the SBP–DIC Offset and due to DIC being so low. My husband was retirement eligible and therefore I was eligible for SBP and flat rate DIC from the VA. DIC was implemented to make things right and to provide income to those surviving spouses and children of those whose demise was caused by service to our country. DIC was less than one eighth of his active duty compensation. I lost 75 percent of the income he earned. I was appalled to find that the government values the life and sacrifice of those who gave all at only $1254.19 cents a month. The value is close to the national poverty level versus what he was paid on active duty. As a Navy spouse, I was there for countless others who served our Nation as well as those who experienced loss. I moved 26 times to follow my husband's career at the sacrifice of my own career as an educator. I was appalled at how indifferent the Military bureaucracy treats the families who have paid the ultimate price.

These surviving spouses deserve better from their country.

To add insult to injury, as a result of the Sharp Case, *SHARP* vs. *United States*, remarried surviving spouses who are eligible for SBP and DIC who remarry after age 57, receive concurrent receipt of SBP and DIC. Un-remarried surviving spouses over age 57 remain offset.

RETENTION OF DIC WITH REMARRIAGE AT AGE 57 *SHARP, ET AL,* VS. *UNITED STATES*

The Veterans Benefits Act of 2003 (H.R. 2297, Section 101) provided for DIC with remarriage after age 57. The Department of Defense failed to implement this provision informally citing that a retiree is not a "veteran." Rep. Henry E. Brown, Jr, SC, Chr., Subcommittee on Benefits, House Committee on Veterans Affairs expressed in a letter dated April 13, 2004, that the intent of Congress was to retain DIC with Remarriage at age 57 without a "reduction in other Federal benefits" such as SBP. DOD's refusal to implement the fiscal year 2004 law eventually forced the widows to sue in "*SHARP* vs. *United States*." The intent of "The Veterans Benefits Act of 2003" was affirmed by Chief Judge Haldane Robert Mayer, Federal Court of Appeals, on August 26, 2009.

"As recognized by the trial court, there are many plausible explanations for Congress' decision to repeal the DIC–SBP offset only for surviving spouses who receive DIC by reason of their having remarried after age 57. Perhaps Congress intended to encourage marriage for older surviving spouses. Perhaps section 1311(e) simply represents a first step in an effort to eventually enact full repeal. After all, the service member paid for both benefits: SBP with premiums; DIC with his life. Perhaps it was recognition that the political process is the art of the possible, and that prudence counseled against making the perfect the enemy of the good. Whatever the reason, the government has failed to make the "extraordinary showing of [Congress'] contrary intentions" that would permit this court to construe section 1311(e) in a way that eviscerates its plain language."

CONCLUSION

"Accordingly, the judgment of the United States Court of Federal Claims is affirmed."

Affirmed: 2008–5105 10

1,102 remarried spouses over age 57 (fiscal year 2014) have applied for and received concurrent receipt of SBP and DIC.

Post 9/11 military surviving spouses are eligible to receive SBP as of a law change shortly after Sept 11, 2001. However, it is a hollow benefit as the majority of these surviving spouses' SBP is less than DIC, resulting in a total offset. The Department of Defense is saving an average of $1254.19 a month on each death by not having to pay all of the SBP earned and purchased by the service members who gave all. DOD is making a windfall profit off these deaths by not paying all of the purchased and earned SBP, by not refunding all the premiums paid by the service member with interest, and by charging interest on the taxable premium refunded to those

surviving spouses who do remarry after age 57. Those surviving spouses who marry again and have their offset eliminated are asked to refund the premiums back to DOD within three weeks or they are put on a payment plan with interest. No interest was refunded at the time of the death and this refund is tax deductible. This is over kill to say the least and unjust. SBP is taxable income. The premium refund was paid with pretax dollars so the refund should be in the same category, not taxable, particularly when it is not refunded in full.

SPECIAL SURVIVOR INDEMNITY ALLOWANCE

Congress established SSIA (Special Survivor Indemnity Allowance) in 2008 as an incremental funding towards eliminating the SBP–DIC Offset. It was a 10 year plan starting at $50 a month, increasing by $10 a month a year until it reached $90. It then increased to $150, $200, $275 in 2016 and sunsets at $310 a month in 2017. It is imperative for SSIA to be extended in the event that the offset is not eliminated or the impact will result in 63,000 surviving spouses receiving a $3700 a year reduction in survivor benefits starting Nov 1, 2017. The language to extend SSIA must be included in the base text of the NDAA17. Congressman Grayson, FL, has introduced HR 4519, to include in the base text NDAA17. H.R. 4519 would increase SSIA over 5 years: $400 in 2018; $475 in 2019; $600 in 2020; $700 in 2021 and $800 in 2022.

PETITION

I started a petition on www.change.org to bring attention to this issue. Hopefully, if I can gather enough support, the government will not ignore us any longer. I have 76,438 signatures as of today and growing. The American public is in favor of eliminating this unjust offset. Here is the link to my petition: https://www.change.org/p/stop-denying-earned-survivor-benefits-to-military-surviving-spouses?recruiter=242689561&utm__source=share__petition&utm__medium=copylink.

SURVIVOR BENEFIT ELIGIBILITY

The President and the Congress of the United States, a Government "of the people, by the people, and for the people," have previously determined eligibility of surviving spouses for the Department of Defense's (DOD) Survivor Benefit Plan (SBP). When SBP was created in 1972 as a premium-based survivor benefit of military retirement, those who died on active duty with 20 or more years of military service were equally recognized as "retirement eligible," and their surviving spouses were also eligible for SBP.

In 2001,within days of the 9/11 tragedy, Congress swiftly enacted legislation to expand eligibility for SBP to all surviving spouses of active duty deaths. Senator Kay Bailey Hutchison, TX, spoke the words quoted below on September 20, 2001, on the floor of the Senate to introduce her amendment to the Senate NDAA02.

"On September 11, we were reminded of how real that sacrifice is, and how critical those contributions are... This is why I introduced legislation in June [S. 1037] to ensure that all military personnel who die in the line of duly, like those who died serving their country at the Pentagon, are able to receive retirement benefits they have earned. In the military, personnel are not vested in retirement benefits unless they have served 20 years or more, or unless the services medically retire them before death. Clearly, someone who dies in the line of duty cannot fulfill either of these requirements, meaning their families do not receive their pro rata share of retirement pensions. It is horrible enough for a family to lose a loved one-it is an even greater hardship for them to not receive these earned benefits..."

—Senator Hutchison, TX

The Congress realized the injustice of failing to provide the SBP to all surviving spouses of active duty deaths, and also recognized that those active duty service members who died the youngest paid the "highest price" and made the "greatest sacrifice." These surviving spouses soon realized that this expanded SBP eligibility was a hollow benefit to the younger widows because the DIC offset to SBP eliminated all or most of any benefit they should have received. There are 62,094 surviving spouses (fiscal year 2014) eligible for both SBP and DIC. About 4,580 surviving spouses are a result of active duty deaths. Surviving spouses receive an average SBP of $1,099 mo. The flat rate DIC paid in fiscal year 2015 is $l,254.19 per month. 37,685 of these 62,094 surviving spouses receive an SBP benefit less than DIC, which appears to profit DOD.The SBP annuity for retirees is a premium based, voluntary election benefit with the retiree paying 64 percent of the premium; the government's contribution is 36 percent (fiscal year 2014). In designing the original SBP benefit, Congress concluded "military surviving spouses should receive the

same considerations as civil service surviving spouses." [House Report 99–718, p. 211, accompanying H. R. 4428, 99th Congress, 2nd Session (1986)] The Survivor Benefit, created the Federal Civil Service Annuity, was the first military benefit sold to retirees and provided to "retirement eligible" Active Duty deaths without premiums in order to assure their surviving spouse a continued portion of retired pay. SBP eligible children and parents, and insured interest annuitants have no offset with DIC. The Federal Civil Service annuity has no offset with DIC.

Senator Bill Nelson—SASC Testimony April 13, 2011:

"...So, Mr. Chairman, I had a little bit of experience in insurance, before I came to the Senate, as the elected insurance commissioner of Florida. And this offset is troubling when somebody buys an insurance policy and there's another government program over here, called Dependency Indemnity. And I know of no purchased annuity that would deny payment based on the receipt of a different payment".

THE MILITARY RETIREMENT TRUST FUND

The Military Retirement Trust Fund (MRF) holds and disburses the Survivor Benefit annuity of $3.78 Billion annually to 274,259 surviving spouses (fiscal year 2014) included in the total outlay of $56,620 Billion annually from the Trust Fund. The Congressional Budget Office estimates a cost of $500 Million a year to restore SBP to eligible DIC surviving spouses which is less than 1 percent of the total outlay of the MRF. The Trust Fund has absorbed the cost of the elimination of the SBP/DIC offset for remarried widows over age 57 and other new categories of active duty SBP eligibility since 9/11/01.

The GAO report [GA0–06–837–R], "Actuarial Soundness of the DOD Survivor Benefit Plan," dated July 26, 2006, found that the Military Retirement Trust Fund will maintain actuarial soundness with the provision of SBP without offset by DIC to all military SBP eligible widows."

There has been a great reluctance on the part of Congress and the Administration to find the funding or to ask the taxpayer to make a small sacrifice in recognition of the greater sacrifice made by service members who have died in service to their country. The taxpayer should bear all funding of a "Cost of War" to include equal payment of DOD's Survivor Benefit Annuity to all military widow(er)s without penalty of a military service related death.

DOD's Compensation Officials brief the annual public meeting for the Board of Actuaries (Military Retirement Trust Fund) each year,

—Board of Actuaries meeting, July 22, 2005: the Assistant Director of Compensation explained a "Philosophy Shift" in Congress in that DOD, VA, and Social Security Systems are becoming "additive" [to retired pay replacing the tradition "double dipping" rules.] He further stated that current duplication does not have a well defined basis and may have inconsistencies and inequities that need to be addressed.

—Board of Actuaries meeting, August 28, 2009. Assistant Director of Compensation briefs on NDAAIO, S. 1390, Section 652, Repeal of requirement of reduction of SBP survivor annuities by DIC Dependency and Indemnity Compensation. He explains that the repeal of SBP/DIC is opposed by OSD. The repeal would leave 540 thousand "second class" survivors who are not eligible for both SBP and DIC. How could a survivor feel "second class" if the service member did not die of a military related cause?

"The Eleventh Quadrennial Review of Military Compensation" (p. 17) defines benefits of military retirement as deferred compensation earned while on active status. The deferred compensation is officially estimated at 28 percent of Regular Military Compensation by the Government Accountability Office (GAO).The Social Security/SBP Offset at age 62 was repealed in 2004. The cost for the repeal of the SS/SBP age 62 was a provision included in P. L. 108–375 and cost $14 Billion over 10 years. Why was the social security offset to SBP eligible surviving spouses of non-service connected deaths coordinated and passed with the provision of concurrent receipt for disabled retirees only instead of also adding surviving spouses of disabled retirees? SBP/DIC surviving spouses are at least equally deserving of their Survivor Benefit Annuity. The majority of the DIC eligible surviving spouses don't even receive the SBP annuity to benefit from the repealed offset by Social Security.

LEGISLATIVE HISTORY—HOUSE AND SENATE

Since 1999, Congress has passed about a dozen pieces of legislation that incrementally restored military retired pay and SBP to those who were affected by dual compensation laws. In the House of Representatives, since the 107th Session of Congress, there have been 10 bills, 2 discharge petitions, and one motion to recommit

the NDAA07 regarding the elimination of the SBP/DIC offset. The co-sponsors of these bills have numbered from 44 to 352 in different sessions of Congress. It is mind boggling to see the inconsistency with which elected officials support these bills by putting their name on the bill...so fearful of accusations of spending too much money rather than making laws based on traditional public policy. Loyal sponsors of the legislation have been Rep. Henry Brown, SC, Rep. Solomon Ortiz, TX, Rep. Chet Edwards, TX, Rep. Walter B. Jones, NC; and Rep. Joe Wilson, SC.

The NDAA08 included a provision to establish a Special Survivor Indemnity Allowance (SSIA) with an initial payment of $50/month the first year increasing $10 a month until the payment reaches $310/month in 2017. HASC Chairman Ike Skelton, MO, personally negotiated funds to increase the SSIA to $310/month and extend the time it sunsets to October, 2017.

In the Senate, Senator Bill Nelson, Fl. has remained a loyal champion since 2001 and the 107th Congress. He has introduced 8 bills and several Senate Amendments to the NDAA. It is disappointing to watch the contradictions with the support of various Senators and Congressmen. Newly elected Senator Barack Obama, IL, attended the Feb. 3, 2005 hearing before the Senate Veteran Affairs Committee as a Member of the Committee. Senator Obama attended a Gold Star Wives Memorial Day reception in 2007 and his remarks recognized the significant sacrifices surviving families had made. It is so difficult to understand that President Obama has not adhered to his own beliefs stated at the Senate Hearing of being inspired to follow through by his sense of our significant sacrifices. He cosponsored S. 935 (05–24–07) and SA 4979 (06–24–08), bills to eliminate the SBP/DIC offset. He voted for the Senate Amendment to the NDAA09 even though it wasn't funded. The elimination of the SBP/DIC offset has never been included in the President Obama's budget even though the White House staff has convened meetings on the topic.

CONCLUSION

DEAD and DISABLED service members are a consequence of war. The surviving families of American Heroes are the long term cost of war. The payment of SBP assures all surviving military spouses their pro rata share of earned retired pay (and clearly, someone who dies on active duty does not have the opportunity to pay SBP premiums).

To sum up, I believe that full SBP should be paid to all recipients without DIC offset I urge the Members of Congress to be mindful of their obligation to protect these surviving spouses just as their deceased service members have protected our Nation. Military Widows are reluctant to participate in the process of legislative change. Their lives have been about caring for others. They have made such great sacrifices all their lives in the tradition of military families. There is also an expectation that legislative officials will do their job. Correcting this offset of the DOD's Survivor Benefit is a moral obligation, which now stands before Congress and the President.

I'm calling on Congress to provide surviving spouses with 100 percent of the Survivor Benefit Plan promised. Our government is reneging on a voluntarily purchased insurance annuity to assure the surviving spouse receives a portion of the retired pay the service member earned. When a service member makes the ultimate sacrifice, their family shouldn't have to worry about how they will survive.

Please end the SBP–DIC offset for military surviving spouses and pass HR 1594, (Rep. Joe Wilson, SC) and S 979, (Senators Nelson, FL and Collins, ME), the bills to change the law and end this unjust offset and Congressman Grayson, FL, Bill HR 4519 to extend and increase SSIA.

PREPARED STATEMENT OF PULMONARY HYPERTENSION ASSOCIATION

Chairman Cochran and distinguished members of the Subcommittee, thank you for the opportunity to submit testimony on pulmonary hypertension. On behalf of the community of individuals affected by pulmonary hypertension and the Pulmonary Hypertension Association (PHA), we request that "respiratory health" be once again included as a condition eligible for study in the Department of Defense (DOD) Peer-Reviewed Medical Research Program (PRMRP) in fiscal year 2017.

ABOUT PULMONARY HYPERTENSION

Pulmonary hypertension (PH) is a disabling and often fatal condition simply described as high blood pressure in the lungs. It affects people of all ages, races and ethnic backgrounds. Although anyone can get PH, there are risk factors that make some people more susceptible.

Treatment and prognosis vary depending on the type of PH. In one type, pulmonary arterial hypertension (PAH), the arteries in the lungs become too narrow to handle the amount of blood that must be pumped through the lungs. This causes several things to happen: a backup of blood in the veins returning blood to the heart; an increase in the pressure that the right side of the heart has to pump against to push blood through the lungs; and a strain on the right side of the heart due to the increased work that it has to do. If this increased pressure is not treated, the right side of the heart can become overworked, become very weak and may possibly fail. Because blood has difficulty getting through the lungs to pick up oxygen, blood oxygen level may be lower than normal. This can put a strain not only on the heart, but also decrease the amount of oxygen getting to the brain.

There is currently no cure for PAH. Twelve treatment options are available to help patients manage their disease and feel better day to day but even with treatment, life expectancy with PAH is limited.

ABOUT THE ASSOCIATION

From simple beginnings—four women who met around a kitchen table in Florida in 1991—the Pulmonary Hypertension Association has evolved into an international community of over 16,000 pulmonary hypertension patients, caregivers, family members and healthcare professionals.

We are now the largest and oldest PH association in the world, and we are changing the history of an illness. In the 25 years since that first meeting, the number of FDA-approved PH treatments has grown from 0 to 14, PHA research programs have been supported by commitments of more than $17 million, and more than two dozen Pulmonary Hypertension Care Centers have completed PHA's accreditation process.

PHA is a 501(c)(3) nonprofit organization that relies on donations to fund its many programs, including the nation's largest PH patient and caregiver support group network, lifesaving early diagnosis awareness and education programs, specialty care resources, and research to find ways to prevent and cure PH. For 12 consecutive years, PHA has received the highest rating—four stars—for fiscal accountability and transparency from Charity Navigator, placing it in the top half of 1 percent of all rated charities.

We continue to work every day to end isolation, provide education, involve our constituents in everything we do, and find a cure for pulmonary hypertension.

THE PATIENT PERSPECTIVE

The Hicks Family

Carl Hicks is a former Army Ranger and a retired Colonel who led the first battalion into Iraq during the first Iraq war. Every member of his family was touched by pulmonary hypertension after the diagnosis of his daughter Meghan in 1994. We share their story here, in Carl's own words:

We're sorry Colonel Hicks, your daughter Meaghan has contracted primary pulmonary hypertension. She likely has less than a year to live and there is nothing we can do for her.

"Those words were spoken in the spring of 1994 at Walter Reed Army Medical Center. They marked the start down the trail of tears for a young military family that, only hours before, had been in Germany. My family's journey down this trail hasn't ended yet, even though Meaghan's fight came to an end with her death on January 30, 2009. She was 27.

Pulmonary hypertension (PH) struck our family, as it so often does, without warning. One day, we had a beautiful, healthy, energetic 12-year old gymnast, the next, a child with a death sentence being robbed of every breath by this heinous disease. The toll of this fight was far-reaching. Over the years, every decision of any consequence in the family was considered first with regards to its impact on Meaghan and her struggle for breath.

The investment made by our country in my career was lost, as I left the service to stay nearer my family. The costs for Meaghan's medical care, spread over the nearly 14 years of our fight, ran well into the seven figures. Meghan even underwent a heart and dual-lung transplant. These challenges, though, were nothing compared to the psychological toll of losing Meaghan who had fought so hard for something we all take for granted, a breath of air."

Jessica Armstrong

In 2011, at the age of 29, GS12 Human Terrain Analyst Jessica (Puglisi) Armstrong who was serving in Afghanistan as Department of the Army Civilian began experiencing progressive shortness of breath dizziness, and exercise intolerance. Jes-

sica reported her symptoms multiple times. The first time she was told that she needed to eat more, then she was diagnosed with dehydration. As her symptoms continued to progress, as is the case with many PH patients, she was told she had asthma and given a series of inhalers. Two months later, she fainted for no apparent reason. A CT scan revealed blood clots in her lungs and Jessica was medically evacuated to Germany and then to the U.S. Six months after her fist symptoms, she was given a clean bill of health and orders to return to Afghanistan. Not feeling better she sought a second opinion at a civilian hospital where she was finally given a complete work up and diagnosed with chronic thromboembolic pulmonary hypertension.

Jessica had a unique form of PH due to blood clots that can be mitigated with a pulmonary thromboendarterectomy (PTE)—a complex surgery that involves opening the chest cavity and stopping circulation for up to twenty minutes. She describes the surgery, which she underwent at the University of California San Diego, as "more painful than I could ever imagine." She notes that UCSD's PTE program did not begin until 1990 and even now, despite being recognized as the global leaders on this procedure, UCSD has only completed about 3,000 surgeries. The procedure that saved Jessica's life was developed in her lifetime.

Jessica was terminated from Army employment and spent more than $60,000 out of pocket on medical expenses which she has not been able to recoup. She was forced to begin a civilian job just two weeks after her PTE in order to obtain health insurance. Despite this, Jessica is, in many ways, one of the lucky ones. I am glad to report that she is now doing well and serving an integral role at PHA as the Senior Manager of our Early Diagnosis Campaign.

CONCLUSION

For many years "pulmonary hypertension" was recognized as a condition eligible for study and more recently the category "respiratory health" has allowed PH researchers to continue to compete for research funding through the PRMRP. Absent PH's inclusion in the PRMRP, please once again recognize "respiratory health" as a category of study in fiscal year 2017 so critical research can continue to move forward (see below).

We appreciate that the Defense Appropriations Subcommittee and the Senate play important roles in crafting the annual eligible conditions list. For many years "pulmonary hypertension" was recognized as a condition eligible for study and more recently the category "respiratory health" has allowed PH researchers to continue to compete for research funding through the PRMRP. Absent PH's inclusion in the PRMRP, please once again recognize "respiratory health" as a category of study in fiscal year 2017 so critical research can continue to move forward (see below).

Pulmonary Hypertension Grants Funded Through the PRMRP

Proposal Title	Principal Investigator	Institution	Program	Mechanism	Research Topic	Fiscal Year	Award Amount
S-nitrosylation and the Development of Pulmonary Hypertension	PALMER, LISA A	**Institution:** VIRGINIA, UNIVERSITY OF, SCHOOL OF MEDICINE	PRMRP	Investigator-Initiated	**Primary:** Functional Study of Biological Molecules **Secondary:** Animal Models	2006	$946,875.00
Development of Novel Rho Kinase Inhibitors for Treatment of Pulmonary Hypertension	JARNAGIN, KURT	**Institution:** ANACOR PHARMACEUTICALS	PRMRP	Investigator-Initiated Research Award -	**Primary:** Drug Development	2013	$519,575.00
Development of Novel Rho Kinase Inhibitors for Treatment of Pulmonary Hypertension	HART, MIKE	**Performing Institution:** VA MEDICAL CENTER, ATLANTA, GA **Contracting Institution:** ATLANTA RESEARCH AND EDUCATION FOUNDATION, INC.	PRMRP	Investigator-Initiated Research Award - Partnering PI Option	**Primary:** Drug Development	2013	$344,701.00
Inflammatory Role of Macrophage Xanthine Oxidoreductase in Pulmonary Hypertension: Implications for Novel Therapeutic Approaches	FINI, MEHDI	**Institution:** COLORADO, UNIVERSITY OF, AT DENVER	PRMRP	Discovery Award	**Primary:** Inflammation **Secondary:** Biomarkers	2013	$193,948.00
Metabolic and Epigenetic Interactions Regulate Vascular Phenotypic Change and Maintenance in Pulmonary Hypertension	STENMARK, KURT	**Institution:** COLORADO, UNIVERSITY OF, AT DENVER	PRMRP	Investigator-Initiated Research Award	**Primary:** Metabolism **Secondary:** Inflammation	2014	$1,866,000.00

Thank you again for your time and your consideration of the PH community's requests.

PREPARED STATEMENT OF SCLERODERMA FOUNDATION

Chairman Cochran and distinguished members of the Subcommittee, thank you for the opportunity to submit testimony on scleroderma. On behalf of the community of individuals affected by scleroderma and the Scleroderma Foundation, we request that 'scleroderma' be once again included as a condition eligible for study in the Department of Defense (DOD) Peer-Reviewed Medical Research Program (PRMRP) in fiscal year 2017.

ABOUT SCLERODERMA

Scleroderma, or systemic sclerosis, is a chronic connective tissue disease generally classified as one of the autoimmune rheumatic diseases. The word "scleroderma" comes from two Greek words: "sclero" meaning hard, and "derma" meaning skin. Hardening of the skin is one of the most visible manifestations of the disease. The disease has been called "progressive systemic sclerosis," but the use of that term has been discouraged since it has been found that scleroderma is not necessarily progressive. The disease varies from patient-to-patient. It is estimated that about 300,000 Americans have scleroderma. About one third of those people have the systemic form of scleroderma. Since scleroderma presents with symptoms similar to other autoimmune diseases, diagnosis is difficult. There may be many misdiagnosed or undiagnosed cases. Currently, there is no cure for scleroderma.

ABOUT THE FOUNDATION

The Scleroderma Foundation is dedicated to the concerns of people whose lives have been impacted by the autoimmune disease scleroderma, also known as systemic sclerosis, and related conditions. Its threefold mission of support, education, and research guides the Foundation's work in providing education programs for patients and their families, peer-to-peer support through its nationwide network of chapters and support groups, advocacy efforts to increase awareness of the disease among the general public and the medical community. The Foundation also has a research program that funds clinical research to find the cause and cure for scleroderma and related conditions.

THE PATIENT PERSPECTIVE

"My constantly aching hands begged for mercy of just one day without pain. My joints started to feel like they were being torn away from my body. Anytime I touched something cold, my hands would tingle and burn. Painful sores started appearing on my knuckles. You stole my skin color and with that went my confidence. It was like I was turning into a mummy as my skin tightened with collagen, day by day. I was beginning to need help performing small tasks. Opening a water bottle or turning a key in the door started to become difficult. Standing for long periods of time made my hips radiate with pain. In 2012 I had to stop working, at 24 years old. The definition of normal as I knew it was being torn down and built into something completely new. And so was my soul.

I now need help with everything! Getting dressed, washing my hair, cleaning, doing laundry; pretty much anything I have to use my hands for. You stole my independence. I had to learn to swallow my pride and ask for help. It's a tough thing to do, especially when you're at an age that's supposed to be your prime. Friends and family around me have blossomed into caregivers and helping me has become second nature to them. It's a beautiful thing when those surrounding you automatically adapt to your disability. Support is the lifeboat that keeps me afloat."

—Excerpt from "My Letter to Scleroderma", Jessica Messingale, Coconut Creek, Florida

CONCLUSION

For over 10 years, scleroderma has been listed as a condition eligible for study through the DOD PRMRP. Since fiscal year 2005, the opportunity for scleroderma researchers to compete for funding through this mechanism led to over $10 million in scleroderma research funding (see below) as well as the initiation of meaningful research projects. Research on the underlying mechanisms of scleroderma is showing relevance to all fibrosis, which occurs at higher rates among individuals who served in the military and our veterans. Further, military service-associated environmental triggers, particularly silica, solvent, and radiation exposure, are believed to be potential triggers for scleroderma in individuals that are genetically predisposed to it.

Scleroderma Grants Funded Through the PRMRP

Proposal Title	Principal Investigator	Institution	Program	Mechanism	Research Topic	Fiscal Year	Award Amount
Biomarkers for Amyotrophic Lateral Sclerosis in Active Duty Military - BALSAM	MILLHORN, DAVID E	**Institution:** CINCINNATI, UNIVERSITY OF	PRMRP	Investigator-Initiated	**Primary:** Clinical **Secondary:** Proteomics	2005	$673,024.21
Do Tau Mutations Increase Susceptibility to Amyotrophic Lateral Sclerosis?	DAWSON, HANA N	**Performing Institution:** DUKE UNIVERSITY MEDICAL CENTER **Contracting Institution:** DUKE UNIVERSITY	PRMRP	Investigator-Initiated	**Primary:** Functional Study of Biological Molecules **Secondary:** Not Otherwise Specified	2005	$977,803.10
The Integrative Studies of Genetic and Environmental Factors in Systemic Sclerosis	ZHOU, XIAODONG	**Institution:** TEXAS, UNIVERSITY OF, HEALTH SCIENCE CENTER AT HOUSTON	PRMRP	Investigator-Initiated	**Primary:** Chemical/Physical **Secondary:** Proteomics	2006	$928,125.00
Imaging Effects of Neurotrophic Factor Genes on Brain Plasticity and Repair in Multiple Sclerosis	WISHART, HEATHER A	**Institution:** DARTMOUTH COLLEGE	PRMRP	Investigator-Initiated Research Award	**Primary:** Clinical **Secondary:** Magnetic Resonance Imaging	2008	$1,422,000.00
Mobilization of Neural Precursors in the Circulating Blood of Patients with Multiple Sclerosis	BONGARZONE, ERNESTO	**Institution:** ILLINOIS, UNIVERSITY OF, CHICAGO	PRMRP	Investigator-Initiated Research	**Primary:** Neural **Secondary:** Cellular	2008	$933,381.00
Therapeutic Remyelination Strategies in a Novel Model of Multiple Sclerosis: Japanese Macaque Encephalomyelitis	SHERMAN, LARRY S	**Institution:** OREGON HEALTH & SCIENCE UNIVERSITY	PRMRP	Investigator-Initiated Research	**Primary:** Animal Models	2008	$1,472,732.51
A Phase I Assessment of Mesenchymal Stem Cells for the Treatment of Multiple Sclerosis	COHEN, JEFFREY A	**Institution:** CLEVELAND CLINIC FOUNDATION	PRMRP	Clinical Trial Award	**Primary:** Pharmacology **Secondary:** Neural	2009	$2,418,169.00
Environmental Mycobiome Modifiers of Inflammation and Fibrosis in Systemic Sclerosis	WHITFIELD, MICHAEL	**Institution:** DARTMOUTH COLLEGE	PRMRP	Investigator-Initiated Research Award -	**Primary:** Biomarkers **Secondary:** Autoimmunity and Autoimmune Disease	2013	$737,300.00
Environmental Mycobiome Modifiers of Inflammation and Fibrosis in Systemic Sclerosis	ARRON, SARAH	**Institution:** CALIFORNIA, UNIVERSITY OF, SAN FRANCISCO	PRMRP	Investigator-Initiated Research Award -	**Primary:** Biomarkers **Secondary:** Autoimmunity and Autoimmune Disease	2013	$427,500.00

We appreciate that the Defense Appropriations Subcommittee and the Senate play important roles in crafting the annual eligible conditions list. The scleroderma community urges you to include "scleroderma" as a condition eligible for study through the PRMRP within the Committee Report accompanying the fiscal year 2017 Defense Appropriations Bill.

Thank you again for your time and your consideration of the scleroderma community's requests.

PREPARED STATEMENT OF SLEEP RESEARCH SOCIETY

Chairman Thad Cochran, Ranking Member Durbin, and distinguished members of the Subcommittee, as you begin to craft the fiscal year 2017 Defense appropriations bill, the Sleep Research Society is pleased to submit this statement for the record asking you to provide $250 billion for the Department of Defense (DOD) Peer Reviewed Medical Research Program in addition to listing sleep disorders as a condition for study within the program as it has historically been included since 2013. These actions will ensure further advancements in understanding the linkage between active service and sleep disorders such as sleep apnea, insomnia, and PTSD, and how to prevent or effectively treat them.

SLEEP RESEARCH SOCIETY

SRS was established in 1961 by a group of scientists who shared a common goal to foster scientific investigations on all aspects of sleep and sleep disorders. Since that time, SRS has grown into a professional society comprising over 1,100 researchers nationwide. From promising trainees to accomplished senior level investigators, sleep research has expanded into areas such as psychology, neuroanatomy, pharmacology, cardiology, immunology, metabolism, genomics, and healthy living. SRS recognizes the importance of educating the public about the connection between sleep and health outcomes. We promote training and education in sleep research, public awareness, and evidence-based policy, in addition to hosting forums for the exchange of scientific knowledge pertaining to sleep and circadian rhythms.

According to an Institute of Medicine's report entitled, "Sleep Disorder and Sleep Deprivation: An Unmet Public Health Problem" (2006), chronic sleep and circadian disturbances and disorders are a very real and relevant issue in today's society as they affect 50–70 million Americans across all demographic groups. Sleep deprivation is a major safety issue, particular in reference to drowsy driving, where it is a factor in 20 percent of motor vehicle injuries. The widespread effect of sleep disorders on every age group poses a public health risk, extending from the ability to learn to maintain a healthy lifestyle. Furthermore, it is important to recognize that sleep disorders and circadian disturbances are often an indicator of, or a precursor to other major diseases and disorders including; obesity, diabetes, hypertension, car-

diovascular disease, stroke, depression, bipolar disorder, and substance abuse. Another increasingly detrimental condition affecting 15 percent of the population is sleep-disordered breathing, including obstructive sleep apnea. Sleep apnea results in excessive daytime somnolence, poor performance, increased frequency of road traffic accidents, and arterial hypertension. Studies show that 85 percent of 725 troops returning home from Afghanistan and Iraq had a sleep disorder and the most common was obstructive sleep apnea (51 percent). If left untreated, obstructive sleep apnea has significant negative impacts on health, including early mortality.

Sleep and circadian rhythm scientists engage in sleep research and public health awareness activities through DOD. The language proposed above helps to foster the research advancements that the DOD has been making towards treatments and prevention measures for sleep disorders and improving sleep quality, as this is an area that disproportionately affects the health of armed military members in California and nationwide. Additional funding is needed in the overall Peer reviewed medical research program to ensure a robust competition for grant funding, given the prevalence of sleep disorders and poor sleep quality among armed servicemen.

A new study found a high prevalence of sleep disorders and a startlingly high rate of short sleep duration among active duty military personnel. The study suggests the need for a cultural change toward appropriate sleep practices throughout the military. Results show that the majority of participants (85.1 percent) had a clinically relevant sleep disorder. Obstructive sleep apnea (OSA) was the most frequent diagnosis (51.2 percent), followed by insomnia (24.7 percent). Participants' mean self-reported home sleep duration was only 5.74 hours per night, and 41.8 percent reported sleeping five hours or less per night

Sleep disorders are one of the most common symptoms of military personnel who return from deployment. Comorbid insomnia and OSA is a frequent diagnosis in military personnel referred for evaluation of sleep disturbances after deployment.

Sleep apnea is difficult to treat and may explain the refractory nature of many service-related diagnoses.[2]

Thank you for the opportunity to submit the views of the sleep research community. Please do not hesitate to contact us should you have any questions or require additional information.

PREPARED STATEMENT OF TUBERCULOSIS ROUNDTABLE

The TB Roundtable, a coalition of over 15 research, public health and health professional associations working to support global and domestic tuberculosis (TB) control and research, thanks Chairman Cochran and Ranking Member Durbin and fellow members of the committee for this opportunity to provide written testimony to discuss important health threats to our military, including TB. Our testimony will outline the importance of TB research and development dollars to our Nation's military. We are writing to request that you maintain TB, a deadly airborne infectious disease, in the Congressionally Directed Medical Research Program (CDMRP) Peer Reviewed Medical Research Program (PRMRP) disease list in fiscal year 2017 DOD appropriations legislation.

As you know, the men and women in our Armed Forces are responsible for protecting our Nation from threats domestically and abroad. A critical element of DOD's mission is supporting infectious disease research, which it conducts at various facilities such as the Walter Reed Army Institute of Research and the Naval Medical Research Center.

Since DOD cannot programmatically fund every disease that could cause harm to our Nation's military personnel, Congress fills this gap in research through the CDMRP, which presents a critical opportunity for Congress to directly influence research funding by providing a list of approved diseases eligible for competitive grant opportunities via the PRMRP. TB was placed on this list in fiscal year 2016 after a 4-year absence, and it is important to maintain its position on the list now that it is recognized by the World Health Organization (WHO) as causing more deaths than any other single infectious disease agent.[3]

TB killed approximately 1.5 million people in 2014. Additionally, 9.6 million people developed active TB in 2014, with an estimated 480,000 of those cases being multidrug-resistant (MDR) including 9.7 percent that were extensively drug-resist-

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[2] Mysliwiec, Vincent et al. "Sleep Disorders in U.S. Military Personnel: A High Rate of Comorbid Insomnia and Obstructive Sleep Apnea." Chest 144.2 (2013): 549—557. PMC. Web. 26 Feb. 2016.

[3] The World Health Organization, 2015 Global Tuberculosis Report, Executive Summary, Page 1.

ant (XDR), which is even more deadly and costly to treat.[4] While these statistics are alarming, more concerning is the lack of research funding going towards new tools and treatments for one of humanity's oldest diseases. The only available vaccine for TB, Bacille Calmette-Guérin (BCG), is only moderately effective in preventing TB in infants and young children—and it doesn't adequately protect teens and adults. Current treatment regimens are long, expensive, and difficult to implement in many parts of the world. Treatment side effects are painful and long-lasting, including permanent hearing loss. Accurately diagnosing TB, and in particular detecting drug resistance, is still lengthy, complex, and costly.

Our military's global footprint means that American military men and women are posted in countries or regions that experience high rates of TB infection. For instance, in Europe where 80,000 troops and dependents are stationed, there were 320,000 cases of TB and 72,000 cases of MDR–TB in 2014. In the Western Pacific region, 61,000 troops and dependents live amidst 1.4 million cases of TB and 71,000 cases of MDR–TB, according to the most recent WHO estimates.[5, 6]

Pacific Pathways, an Army short rotation program, puts American forces directly in countries with high TB burdens such as the Philippines, Indonesia, and Thailand, and cycles them back to American bases in the Pacific and the U.S.[7] This program could potentially create a migration pattern for TB from high-burden East Asia and Pacific countries directly back to the United States. Worse still, drug-resistant TB is contagious and poses a serious threat to public health in the U.S. if no new interventions are created, according to the U.S. Centers for Disease Control and Prevention.

In addition to threatening our military, TB poses tremendous difficulties for many of our allies abroad. Outbreaks of MDR–TB around the world could cause drug shortages, severe economic consequences and possibly extensive fatalities. Funding research and development now can make this scenario less likely in the future.

For these reasons, more research into TB and related vaccine technologies, treatments, and diagnostics is imperative if we want to avoid tragic scenarios of MDR- and XDR–TB outbreaks in the future. TB was included on the approved disease list in the fiscal year 2016 CDMRP PRMRP, and we must continue to recognize the threat TB poses to our military and the American public. We therefore strongly encourage you to include the disease again in the fiscal year 2017 CDMRP PRMRP.

PREPARED STATEMENT OF U.S. HEREDITARY ANGIOEDEMA ASSOCIATION

Chairman Cochran and distinguished members of the Subcommittee, thank you for the opportunity to submit testimony on Hereditary Angioedema (HAE). On behalf of the community of individuals affected by HAE and the U.S. Hereditary Angioedema Association (U.S. HAEA), we request that 'hereditary angioedema' be once again included as a condition eligible for study in the Department of Defense (DOD) Peer-Reviewed Medical Research Program (PRMRP) in fiscal year 2017.

ABOUT HAE

HAE is a rare and potentially life-threatening condition that occurs in about 1 in 10,000 to 1 in 50,000 people. HAE symptoms include episodes of edema (swelling) in various body parts including the hands, feet, face and airway. In addition, patients often have bouts of excruciating abdominal pain, nausea and vomiting that is caused by swelling in the intestinal wall. Airway swelling is particularly dangerous because it can lead to death by asphyxiation.

ABOUT U.S. HAEA

U.S. HAEA is a non-profit patient advocacy organization dedicated to serving the estimated 6,000 HAE sufferers in the U.S. We provide a support network and a wide range of personalized services for patients and their families. We are also committed to advancing clinical research designed to improve the lives of HAE patients and ultimately find a cure.

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[4] Ibid.

[5] Defense Manpower Center, Total Military Personnel and Dependent End Strength By Service, Regional Area, and Country, Sept. 30. 2015, https://www.dmdc.osd.mil/appj/dwp/rest/download?fileName=DRS__54601__309__Report__P1509.xlsx&groupName=milRegionCountry.

[6] The World Health Organization, 2015 Global Tuberculosis Report, Regional Profiles Annex, http://www.who.int/tb/publications/global__report/gtbr15__annex03.pdf?ua=1.

[7] U.S Army Pacific Readiness and the Strategic Balance https://www.usarpac.army.mil/pdfs/Pacific%20Pathways%2016%20Tri-fold.pdf.

PATIENT STORIES

"I was medically retired from the Air Force in 1981 with almost 10-years of service from Angioedema, as it was called back then and Delayed Pressure Urticaria, both, which are very painful and deliberating. It wasn't until 2007 that I became aware that there was a blood test to prove without a doubt that I suffered from Hereditary Angioedema where medicines were available to me through the efforts of the U.S. HAEA and their medical contributors/Doctors. To this day, the VA has done nothing to assist me with treatment or medications necessary to treat HAE. Please Senators, help change this."

—S/Sgt Mark Clark, Wood Village, Oregon

"I was first diagnosed with Hereditary Angioedema when serving our great country in the USAF in 1960 while on temporary duty at Walter Reed Hospital. However, there was no treatment at that time to help control the swelling and extreme vomiting during the episodes other than using epinephrine when the swelling was in my throat. Our daughter is also afflicted with this condition since birth and was intubated to save her life at the University Hospital (Minneapolis) a couple of years ago. Today there is some help, but more needs to be done."

—Don Anderson, East Bethel, Mississippi

"I have been suffering with this disease since birth. I have several episodes a year, but lately it has been very month. I suffer from chronic pain in my abdomen with the nausea and vomiting regularly and also swelling of my face, hands, and feet. I am an educator and work around children so therefore, if I have swelling I am unable to attend school. I sometimes end up going close to the end of the breakout. It would really be a blessing to find a cure for it or some type of treatment. There is none now."

—Sharron Crowner, Marion, South Carolina

CONCLUSION

On behalf of the community of individuals affected by HAE, especially those who serve or have served in the Armed Forces, we thank the Subcommittee for including HAE in the Peer-Reviewed Medical Research Program every year since fiscal year 2012. The HAE scientific community has shown great interest in the program and has competed successfully for over $1 million in research awards to help find innovative therapies and a cure. We urge the Subcommittee to continue to include 'hereditary angioedema' as an eligible condition for study in the DOD PRMRP in fiscal year 2017.

Thank you for the opportunity to submit the views of the HAE patient community.