



LEGISLATIVE AGENDA **116th Congress, 1st Session**

About the Sleep Research Society

The 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 1,300 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. SRS promotes 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.

About Project Sleep

Project Sleep is a 501(c)(3) non-profit organization raising awareness about sleep health and sleep disorders by working with affected individuals and families across the country. Believing in the value of sleep, Project Sleep aims to improve public health by educating individuals and policymakers about the importance of sleep health and sleep disorders. Project Sleep will educate and empower individuals using events, campaigns and programs to bring people together and talk about sleep as a pillar of health.

Funding Recommendations

- **Please provide the Centers for Disease Control and Prevention (CDC) with a meaningful funding increase for FY 2020 and provided dedicated funding of at least \$250,000 for public health activities focused on “sleep and sleep disorders”.** CDC had been supporting the National Health Sleep Awareness Project (NHSAP) for many years, which is viewed by stakeholders as highly successful in advancing surveillance, public health, and awareness activities related to healthy sleep and various forgotten sleep disorders. Due to a stated lack of resources, CDC ended NHSAP in 2018 and currently lacks comprehensive public health activities in sleep and sleep disorders.
- Please provide the National Institutes of Health (NIH) with at least \$41.6 billion for FY 2020, a \$2.5 billion funding increase over FY 2019. The recent investment in NIH research has led to tremendous progress in the field of sleep and circadian. Additional investment is needed though to expand the research portfolios in forgotten sleep disorders and ensure the scientific breakthroughs are translated into improvements in therapies and care that benefit patients.
- Please continue to include “sleep disorders” on the list of conditions deemed eligible for study through the Department of Defense Peer-Reviewed Medical Research Program (PRMRP) for FY 2020. Annual participation in the PRMRP has led to notable advancements, particularly in the areas of fatigue, combat readiness, and stress, and this important work must continue moving forward.
- Please provide the VA Medical and Prosthetic Research Program with \$840 million for FY 2020, an increase of \$61 million over FY 2019. The VA has been a leader on sleep research, including in important areas such as the intersection of sleep and mental health. Additional resources will ensure these important emerging activities continue to move forward.
- Please reauthorize the Patient-Centered Outcomes Research Institute (PCORI) so that timely and valuable research focused on improving patient care can continue past FY 2019.

**Centers for Disease Control and Prevention
Sleep and Sleep Disorders Funding Request
FY 2020 Funding Request**

Background

Sleep is a significant public health issue. Healthy sleep impacts nearly every system of the body and the progression of many conditions. Moreover, sleep disorders are responsible for a litany of health and safety issues, and some of these conditions are easily identified and managed with proper awareness and education. While the Centers for Disease Control and Prevention (CDC) is tasked with addressing major public health threats and taking on activities that improve health and lower healthcare costs, CDC currently does not have a comprehensive sleep initiative.

Until the end of 2018, CDC had been supporting the National Healthy Sleep Awareness Project (NHSAP). This effort was valuable from a public health standpoint and highly-regarded by the sleep community. In fact, the modest annual federal investment drew great interest and participation from the Sleep Research Society, the American Academy of Sleep Medicine, and other patient and professional entities. Ultimately, NHSAP facilitated a number of successful awareness campaigns, surveillance activities, and professional publications.

CDC had supported NHSAP with discretionary resources for over five years and ended the project for FY 2019 citing a lack of dedicated funding. Sleep health aligns well with CDC's mission and public health efforts for sleep are as timely and relevant as similar efforts on obesity and smoking cessation. A sleep program at CDC will save and improve lives while lowering healthcare expenses.

Request

Please provide CDC's National Center for Chronic Disease Prevention and Health Promotion with a specific funding level of \$250,000 for public health activities focused on sleep and sleep disorders.

Justification

- When NHSAP was operating, it generated a notable return on investment and facilitated meaningful progress in a number of areas. Reinvigorating CDC sleep activities at this time will ensure that the public health advancements made under NHSAP are not lost and that emerging opportunities can be capitalized on.
- Due to the ongoing investment in sleep and forgotten sleep disorder research at NIH, DOD, and VA, there have been a number of recent breakthroughs in sleep research. An active sleep program at CDC will ensure scientific advancements are disseminated through professional education and public awareness to improve health outcomes.
- The connections between disordered sleep and health issues, such as obesity, as well as public health challenges, such as drowsy driving are well-established. A robust CDC program with active community engagement will improve sleep health and address related healthcare issues.

National Health Sleep Awareness Project at CDC Historical Overview & Successes Summary

Public Health Messages:



Provider Education:

HEALTHY SLEEP

Pediatric Populations at High Risk for Sleep Apnea
Daniel Combs, MD and Srisram Parthasarathy, MD

The prevalence of sleep apnea in children is estimated to be 1.2% to 5.9% but in certain groups, it may be as high as 10%.

Obstructive Sleep Apnea in Commercial Drivers
Eric O'Shea, DO and Anthony Teas, MD

The estimated prevalence of OSA in the US general population is 4%. Risk factors include obesity, male sex, increasing age, increased neck circumference, and a family history of OSA.

HEALTHY SLEEP

Teenagers: Sleep Patterns and School Performance
Matthew T. Jordan, MD and Daniel G. Glass, MD, FAASM

As a result of teenagers being chronically sleep-deprived, there is a negative impact on their academic performance.

Stroke and Obstructive Sleep Apnea
Cathy Goldstein, MD, PhD

A 22-year-old male with a past medical history of hypertension and obesity presented to the hospital with acute onset of right-sided facial droop and difficulty speaking.

Scientific Publications:

Development of the National Healthy Sleep Awareness Project Sleep Health Surveillance Questionnaire

Christy L. Magerl, MD, MPH, James R. Calk, PhD, Linda C. Day, PhD, DDC, et al.

High School Start Times and the Impact on High School Students: What We Know, and What We Hope to Learn

Christy L. Magerl, MD, MPH, James R. Calk, PhD, Linda C. Day, PhD, DDC, et al.

Quality Measure for Screening for Adult Obstructive Sleep Apnea by Primary Care Physicians

Christy L. Magerl, MD, MPH, James R. Calk, PhD, Linda C. Day, PhD, DDC, et al.

Development of the Measure

Congress of the United States
Washington, DC 20515

March 28, 2019

The Honorable Rosa DeLauro
Chairwoman
House Appropriations Subcommittee on Labor,
Health-Human Services, Education, and Related
Agencies

The Honorable Tom Cole
Ranking Member
House Appropriations Subcommittee on Labor,
Health-Human Services, Education, and Related
Agencies

The Honorable Pete Visclosky
Chairman
House Appropriations Subcommittee on Defense

The Honorable Ken Calvert
Ranking Member
House Appropriations Subcommittee on Defense

Dear Chairwoman DeLauro and Chairman Visclosky, and Ranking Members Cole and Calvert:

As you consider appropriations for Fiscal Year (FY) 2020, we write to request the inclusion of timely committee recommendations on sleep and sleep disorders within the Committee Report accompanying the House FY 2020 Labor, Health and Human Services, Education, and Related Agencies (LHHS) Appropriations Bill. We would also like to request the continued inclusion of "sleep disorders" as a condition eligible for study through the Department of Defense (DoD) Peer-Reviewed Medical Research Program (PRMRP) within the Committee Report accompanying the FY 2020 DoD Appropriations Bill.

With the recent investments in the National Institutes of Health (NIH), the sleep and circadian research portfolio has grown and facilitated meaningful scientific progress, which includes the 2017 Nobel Prize in Physiology or Medicine. While this progress is certainly encouraging, more work is needed to deliver breakthroughs for patients impacted by debilitating sleep disorders. The National Center on Sleep Disorders Research at NIH is reinvigorating coordinated research activities in this area and their emerging efforts should be encouraged. Therefore, we respectfully recommend the Committee include the following report language in the accompanying report of its FY 2020 LHHS bill:

*"Sleep Disorders.—*The committee commends the recent expansion and advancement of the sleep and circadian research portfolio under the coordination of the National Center on Sleep Disorders Research. The committee encourages dedicated research activities on specific sleep disorders, such as narcolepsy and restless legs syndrome, to ensure scientific progress benefits patients impacted by debilitating conditions disordering their sleep and biological rhythms."

Sleep impacts nearly every system of the body and affects the progression of many medical conditions. Millions of Americans are impacted by sleep disorders and, in general, healthy sleep is a major public health and safety issue. However, the Centers for Disease Control and Prevention (CDC) recently sunset the only public health effort focused on sleep, the National Healthy Sleep Awareness Project (NHSAP), citing a lack of dedicated resources. Public health activities focused on sleep and sleep disorders at CDC need to be reinvigorated as soon as possible. To that end, we also ask the Committee to provide \$250,000 to the CDC's National Center for Chronic Disease Prevention and Health Promotion to support

surveillance, public awareness, professional education, and stakeholder collaboration to advance public health activities focused on "sleep and sleep disorders".

The DoD is a leader on sleep research with critical projects on combat readiness, fatigue, and the relationship between sleep and mental health challenges. These projects are often coordinated with NIH and the Veterans Administration, but they are made possible through the PRMRP. To that end, we request the continued inclusion of "sleep disorders" on the PRMRP's annual eligible conditions through the Committee Report accompanying the FY 2020 DoD Appropriations Bill. Maintaining "sleep disorders" in the PRMRP will ensure these important research projects can continue to move forward.

On behalf of the sleep disorders community, we appreciate your consideration of our request and your willingness to engage on these critical issues.

Sincerely,



ADAM B. SCHIFF
Member of Congress



JAN SCHAKOWSKY
Member of Congress



JACKIE SPEIER
Member of Congress



BILL FOSTER
Member of Congress



ALCEE L. HASTINGS
Member of Congress



ALBIO SIRES
Member of Congress



TERRI A. SEWELL
Member of Congress



DAVID B. MCKINLEY, P.E.
Member of Congress



SUZANNE BONAMICI
Member of Congress



MIKE D. ROGERS
Member of Congress



PETER A. DeFAZIO
Member of Congress



DIANA DeGETTE
Member of Congress



STEPHEN F. LYNCH
Member of Congress



BRIAN FITZPATRICK
Member of Congress



MIKE LEVIN
Member of Congress



ELISSA SLOTKIN
Member of Congress



LISA BLUNT ROCHESTER
Member of Congress



LUCY McBATH M.C.
Member of Congress




PRAMILA JAYAPAL
Member of Congress



SUSAN A. DAVIS
Member of Congress



MIKIE SHERRILL
Member of Congress



AYANNA PRESSLEY
Member of Congress



SEAN CASTEN
Member of Congress



JAMES P. McGOVERN
Member of Congress



TED W. LIEU
Member of Congress



JEFFERSON VAN DREW
Member of Congress



A. DONALD McEACHIN
Member of Congress



CHRIS PAPPAS
Member of Congress



DEBBIE MUCARSEL-POWELL
Member of Congress



RAJA KRISHNAMOORTHY
Member of Congress



BRIAN MAST
Member of Congress



February 22, 2019

The Honorable Richard Shelby
Chairman
Committee on Appropriations
Subcommittee on Defense
U.S. Senate
Washington, D.C. 20510

The Honorable Richard Durbin
Ranking Member
Committee on Appropriations
Subcommittee on Defense
U.S. Senate
Washington, D.C. 20510

The Honorable Pete Visclosky
Chairman
Committee on Appropriations
Subcommittee on Defense
U.S. House of Representatives
Washington, D.C. 20515

The Honorable Ken Calvert
Ranking Member
Committee on Appropriations
Subcommittee on Defense
U.S. House of Representatives
Washington, D.C. 20515

Dear Chairmen Shelby and Visclosky, and Ranking Members Durbin and Calvert:

Thank you for your leadership on medical research and patient care issues. I write you today on behalf of the Sleep Research Society (SRS) to ask that you ensure “sleep disorders” are once again included on the eligible conditions list within the Committee Report accompanying the Senate’s FY 2020 Defense Appropriations Bill to facilitate further study through the Department of Defense Peer-Reviewed Medical Research Program (PRMRP).

The 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 1,300 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. SRS promotes 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.

For many years, Congress has listed “sleep disorders” as a condition eligible for study through the PRMRP. This opportunity has been tremendously important and significantly advanced our scientific understanding of key issues. Sleep disorders research has relevance to nearly every body system and many medical conditions, not to mention applications for combat readiness and preparedness as well as implications for PTSD, stress, and related disorders. Through the PRMRP, the military has become a leading facilitator and coordinator of sleep disorders research, which has led to notable progress and meaningful partnerships with the stakeholder community.

On behalf of the SRS and the broader sleep disorders community, thank you for your time and your consideration of this request.

Sincerely,

A handwritten signature in blue ink, appearing to read 'Andrew Krystal'.

Andrew Krystal, MD, MS
President