

Letter: Support the National Center on Sleep Disorders Research and Request a Timely Update on the Narcolepsy Research Portfolio

February 16, 2018

Dear Colleague:

As you may know, the National Center on Sleep Disorders Research (NCSDR) coordinates research into sleep, circadian, and sleep disorders across the National Institutes of Health (NIH). Over recent years, NCSDR has helped facilitate significant scientific progress in the sleep research portfolio, most notably in 2017 when NIH-supported scientists won the Nobel Prize in Physiology and Medicine for work in this area on the body's biological clock. Please join me in recognizing NCSDR for its leadership in this area while also requesting meaningful feedback on the status of research in sleep disorders, particularly narcolepsy.

Narcolepsy is a chronic neurological disorder in which the brain loses the ability to maintain normal sleep and wake states. There is no cure and treatment options are limited. Narcolepsy can be disruptive and debilitating; with symptoms that include extreme sleepiness, sleep paralysis, cataplexy (a sudden inability to move), and hypnagogic hallucinations. It is estimated that narcolepsy affects roughly 200,000 Americans, including children.

Please join me in sending the following letter to NCSDR requesting a specific update on the size, scope, and direction of the narcolepsy portfolio. We hope to learn how the narcolepsy portfolio is progressing at NIH and how basic, translational, and clinical research opportunities are being leveraged to ensure that breakthroughs in basic science become therapies and tools that improve the lives of affected individuals. With this information we can better support the work of NCSDR and ensure that our affected constituents continue to see healthcare improvements.

To sign on to this letter, please contact Anthony Theissen in my office at Anthony.Theissen@mail.house.gov or 5-4176 by COB Friday, March 2nd. Thank you for your time and consideration of this request.

Sincerely,

Adam B. Schiff
Member of Congress

Dr. Michael Twery, PhD
Director
National Center on Sleep Disorders Research
National Institutes of Health
6701 Rockledge Drive, Room 10170
Bethesda, MD 20892

Dear Dr. Twery:

Thank you for your leadership as Director of the National Center on Sleep Disorders Research (NCSDR) and your efforts in advancing sleep and circadian research across the National Institutes of Health (NIH). We write today to request an update on the current size, scope, and direction of the narcolepsy research portfolio within NCSDR.

We applaud NIH's steadfast dedication to sleep and circadian research and recognize the recent scientific breakthroughs within the field— particularly the awarding of the 2017 Nobel Prize in Medicine to NIH grantees for their work in circadian rhythm research. Certainly, the recent annual investments in NIH are supporting innovative sleep and circadian research in a meaningful way.

We understand that sleep disorder and deficiency research is touched upon by a broad swath of medical disciplines, given the influence sleep has on nearly every aspect of human biology and related medical conditions. Yet we are concerned by the fact that sleep disorders, as a particular area of research, have historically been underfunded and that activities within this focus previously emphasized basic science in lieu of clinical and translational research activities.

Although NIH has seen a recent increase in investment in sleep research, it is unclear the amount of time and resources that have been specifically dedicated to sleep disorders, both common and rare, with particular attention to narcolepsy. As you know, narcolepsy is a sleep disorder involving irregular patterns in Rapid Eye Movement (REM) Sleep and significant disruptions of the normal sleep/wake cycle. Though we recognize the importance of the multidisciplinary approach to sleep research taken by NIH as a whole, we explicitly request insight into how current resources are impacting the scope of the narcolepsy portfolio within NCSDR.

Given NCSDR's role in coordinating sleep research across the various NIH Divisions and Centers, we request your feedback on the current state of the narcolepsy research portfolio. Moreover, please inform us of how the allocation of additional resources and the overall investment in sleep research are impacting the size and scope of narcolepsy-specific activities. Lastly, we would appreciate an update on the direction and strategic vision for the narcolepsy portfolio, addressing the full spectrum of medical research being undertaken.

We look forward to hearing from you soon regarding this important matter. Moving forward, we hope to further support NIH and NCSDR, including sleep, circadian, and narcolepsy research activities.

Sincerely,

Member of Congress

Member of Congress