

2020 Restless Legs Syndrome Foundation Virtual RLS Advocacy Day

The RLS Foundation "Hill Day" planned for April 24 in Washington, DC, has been moved online because of the current COVID-19 "Stay at Home" order and is now a virtual event.

The RLS community will not let the Coronavirus threat keep us down! Thank you for your participation in the first **Virtual RLS Advocacy Day** on Friday, April 24, 2020. Help us get the word out to members of Congress – increase their awareness of restless legs syndrome, educate them about RLS and enlist their help for our community. Congressional offices have been monitoring daily developments of the virus and have adapted new policies on contact based on new CDC guidelines. We are encouraging our community to email and/or call your representatives to discuss the policy priorities of the RLS community. Our plan is to shower legislators on April 24 with emails and calls about RLS! Read our blog for more details: https://rlsfoundation.blogspot.com/2020/04/4ls-advocacy-from-wherever-you-are.html

Take action

- Email your two Senators and your Member of the House of Representatives to share your experience with RLS and to ask them to help us (specific asks included in email templates below) Emails will be sent through contact form on your Representative's website.
- Call the offices of your two Senators and your Member of the House of Representatives
 to share your experience with RLS and ask them to help us (specific asks included in call
 scripts below) See attached partial Health Legislative Assistant (HLA) list for names,
 emails and phone numbers.

Making Contact

To find and contact your U.S. Senate Representative:

- 1. Visit the Senate website www.senate.gov
- 2. Conduct a search using the **Find Your Senators** pull-down menu in the upper right corner (select your state and click Go).
- 3. On the results page is a link to the Senator's website, contact information, and links to an online contact form (forms vary by Senator).
- 4. To email: copy and paste your email script into the contact form found on their website, make edits and submit.

To call: choose an office location and follow the call script on page 2.

To find and contact your U.S. House Representative:

1. Visit the House of Representatives website <u>www.house.gov</u>

- 2. Conduct a search using the **Find Your Representative** zip code search box in the upper right corner (enter your zip code and click Go).
- 3. On the results page is a photo of your Representative(s), links to the Representative's personal website and online contact form, and a local map.
- 4. In the event your zip code overlaps with multiple congressional districts, the results page will include boxes for you to enter your zip code+4 or mailing address to find the correct Representative. If you need help finding your +4 zip code use the USPS Zip Code Lookup.
- 5. To email: copy and paste your email script into the contact form found on their website, make edits and submit.

To call: Look up Health Legislative Assistant (HLA) on partial list attached and follow the call script on page 2. If your HLA is not listed, call the office and ask to speak to the Health LA.

Follow Up

The RLS Foundation would like to hear from you after your email or call to your representatives to receive valuable feedback information. Please complete this short survey to let us know what you did to advocate for RLS. If there is any follow-up that you would like us to do, please provide us with their contact information and any questions that you would like answered.

Complete the survey here: www.surveymonkey.com/r/VirtualAdvocate

SAMPLE EMAIL COPY

My name is and I live in I am an advocate with the Restless Legs Syndrome Foundation (RLS Foundation). Currently, is the United States nearly 12 million men, women and children suffer from RLS—it is a neurological sensory-motor circadian disorder that causes a distressing urge to move the legs and, in some cases, other parts of the body such as the arms. RLS may have profound disruptive effects on sleep quality, quantity and overall quality of life. There is no known cure for RLS.
{Share your RLS experience. Be concise and let them know how RLS has affected your life. Some contact forms have character limits – recommend no more than approximately 8 sentence for your story.}
I am writing today to ask for (Name of Senator or Representative)'s help and supposin these important areas: • Increase funding at the National Institutes of Health—\$44.7 billion in the FY 2021 Labor-HHS-Education Appropriations bill to fund critical research to find treatments at a cure for RLS.
• Continue to include "sleep disorders" as a condition eligible for study through the

• Protect the needs of RLS patients who depend on appropriate access to low-total daily dose opioid therapy to manage the most severe forms of the disease. Ensure that RLS

2021 Defense Appropriations Bill.

Department of Defense Peer-Reviewed Medical Research Program (PRMRP) in the FY

- patients retain access to physician-directed care and treatment using opioids when crafting legislation, policy, and regulations aimed at drug abuse and addiction.
- Support provider education to minimize misdiagnosis and incorrect treatment of this misunderstood disease. The CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) supports several programs that work to increase public awareness and improve professional education. Please provide \$5 million for the National Neurological Conditions Surveillance System (NNCSS) and \$5 million for a Chronic Diseases Education and Awareness Program.

Thank you for any help you can provide; please consider me a resource for you and your office about any RLS-related issues or questions.

Sincerely,

[Name] [Address] [City,State], [Zip]

SAMPLE CALL SCRIPT

Good Morning/Afternoon,

I am an advocate with the Restless Legs Syndrome Foundation (RLS Foundation). Currently, in the United States nearly 12 million men, women and children suffer from RLS—it is a neurological sensory-motor circadian disorder that causes a distressing urge to move the legs and, in some cases, other parts of the body such as the arms. RLS may have profound disruptive effects on sleep quality, quantity and overall quality of life. There is no known cure for RLS.

{Share your RLS experience. Be concise and let them know how RLS has affected your life.}

I am writing today to ask for _____ (Name of Senator or Representative)'s help and support in these important areas:

- Increase funding at the National Institutes of Health—\$44.7 billion in the FY 2021 Labor-HHS-Education Appropriations bill to fund critical research to find treatments and a cure for RLS.
- Continue to include "sleep disorders" as a condition eligible for study through the Department of Defense Peer-Reviewed Medical Research Program (PRMRP) in the FY 2021 Defense Appropriations Bill.
- Protect the needs of RLS patients who depend on appropriate access to low-total daily
 dose opioid therapy to manage the most severe forms of the disease. Ensure that RLS
 patients retain access to physician-directed care and treatment using opioids when
 crafting legislation, policy, and regulations aimed at drug abuse and addiction.
- Support provider education to minimize misdiagnosis and incorrect treatment of this
 misunderstood disease. The CDC's National Center for Chronic Disease Prevention and
 Health Promotion (NCCDPHP) supports several programs that work to increase public
 awareness and improve professional education. Please provide \$5 million for the National
 Neurological Conditions Surveillance System (NNCSS) and \$5 million for a Chronic
 Diseases Education and Awareness Program.

Thank you for any help you can provide; please consider me a resource for you and your office about any RLS-related issues or questions.

SAMPLE THANK YOU EMAIL (sent after a phone call)

Dear,(name of Staffer you spoke too)
Thank you for taking my phone call and for allowing me to and share my experience with restless legs syndrome. I am asking(insert name of Senator or Representative) for support in these areas:
 Increased funding at the National Institutes of Health Continue to include sleep disorders as a condition eligible for study Protect the needs of patient communities who depend on appropriate access to opioids used in low- total daily doses to manage severe forms of the disease Support for key programs at the CDC including the creation of a Chronic Disease Education and Awareness Program.
I hope you will advance the outlined legislative and appropriations items that will help to improve health outcome for RLS patients by bolstering medical research, improving access to treatment, and increasing education and awareness.
Help us to improve the lives of RLS patients. This severely misunderstood and underdiagnosed neurological disorder has no cure and is in desperate need of's (insert name of Senator of Representative) support.
Thank you again for your time and consideration of these requests.
Sincerely,
[Name] [Address] [City,State], [Zip]



Restless Legs Syndrome Foundation Legislative Agenda 116th Congress, 2nd Session

About The Foundation

The Restless Legs Syndrome (RLS) Foundation is a 501(c)(3) nonprofit organization dedicated to improving the lives of men, women and children who live with restless legs syndrome (RLS), an often-devastating disease. Founded in 1989, the Foundation's goals are to increase awareness, improve treatments and, through research, find a cure for RLS. The Foundation serves healthcare providers, researchers, 5,500 members, and millions of people in the U.S. and around the world who have RLS. The RLS Foundation has members in every state, local support groups, and a

research grant program that has awarded over \$1.8 million to fund medical research on RLS causes and treatments.

About Restless Legs Syndrome

RLS is a serious neurological disease that devastates the lives of millions of Americans. An estimated 12 million men, women and children in the U.S. have RLS. One in 33 adults (3%) needs daily clinical treatment. Treatment is life-long, and there is no cure. People with RLS experience an overwhelming, agitating and uncontrollable urge to move their legs, which is only relieved by moving or walking. RLS is at its strongest in the evening and at night, severely disrupting sleep. It is 3 to 4 times more common in women than men, and twice as common in older Americans.

The sleep loss caused by RLS robs people of the ability to work and live normally, and may lead to depression, anxiety and suicidal thoughts. The RLS Foundation loses members every year to suicide because their symptoms become unbearable. Profound sleep loss puts people with RLS at risk for hypertension, diabetes, heart attack, stroke and Alzheimer's disease.

RLS treatment options are limited; FDA-approved RLS treatments do not provide life-long coverage. First-line medications don't work for some patients, and over time actually make the disease worse for many others due to a serious side effect known as augmentation.

For the millions of people who have chronic, unrelenting, nightly RLS symptoms, opioids are an established, highly effective treatment option when first-line therapies have failed. Opioids, taken in low total daily doses, bring dramatic relief to an estimated 90% to 95% of RLS patients.

It's important to note that RLS is not chronic pain; it has a distinctly different underlying neuropathology. RLS is a neurological disease impacting sleep and is best managed by neurologists and sleep specialists. Clinical experience among experts who treat severe RLS with opioids has not shown the degree of drug misuse, dependency or addiction that is commonly associated with opioid treatment for chronic pain. RLS expert experience also indicates that the dose of opioids used to manage RLS is significantly lower than that used to treat chronic pain effectively. Evidence-based clinical guidelines published in Mayo Clinic Proceedings are available for clinicians to appropriately prescribe opioids for RLS.

From the Patient's Perspective Kathryn Camp, M.S. December 13, 2019



In 2007, I was diagnosed with RLS following years of fitful sleep that left me exhausted and sleepy during the day. Pramipexole (Mirapex), a dopamine agonist that is also used to treat Parkinson's disease, was immediately prescribed.

Mirapex was a lifesaver! I was finally getting uninterrupted sleep and could function during the day. However, gradually over the next couple of years, the dose had to be increased to maintain effectiveness, until I was being

advised by my primary care doctor to take very high doses to control worsening symptoms. These symptoms were now occurring during the day as well as at night. This paradoxical situation – where the very medicine supposed to help my symptoms actually made them worse – is known as augmentation. Yet my life revolved around taking this drug. Not having access to this medication would leave me writhing on the floor with symptoms that are difficult to describe, but which terrified me should I run out or not have enough if delayed returning home from travel.

I was very fortunate to find a certified RLS provider at an RLS Foundation Quality Care Center to help me to discontinue the medication. He warned me that it would be a rough course; and indeed, it was. It took almost 3 weeks to transition off Mirapex. By working closely with my doctor, I began a regimen of a very low total daily dose of opioids (hydrocodone) taken before bed. This has controlled the worst of my symptoms without the horrible side effects of a dopamine agonist.

However, taking opioids on a daily basis has one very serious issue: Thus far, my insurance company covers this drug, and my pharmacy is willing to fill the prescription – but given the current climate of the "opioid crisis," I am fearful that I might lose access to this therapy.

RLS is a chronic neurological sleep disorder that controls my life and the lives of countless others. Safe and effective medications – and someday, even a cure – will require an investment in research and clinical trials. I know how lucky I am to have good health insurance and a dedicated physician who specializes in RLS to guide me through the complexities of RLS care.

I'm educated, have worked in healthcare for decades, and live in an area rich with resources, yet I struggle daily with RLS. How do you think it's going for those without my advantages?

Legislative and Policy Priorities

Medical Research

- Please provide the National Institutes of Health (NIH) with at least \$44.7 billion in fiscal year (FY) 2021. Important research on RLS is funded across NIH Institutes and Centers, including the National Institute of Neurological Disorders and Stroke (NINDS), the National Heart, Lung, and Blood Institute (NHLBI), the National Institute on Drug Abuse (NIDA), and the National Institute of Mental Health (NIMH). Sustained funding commitments are needed to identify better treatments and a cure for this devastating disorder.
- Please continue to include "sleep disorders" in the Department of Defense Peer-Reviewed Medical Research Program (PRMRP) and the Combat Readiness Medical Research Program for FY 2021. RLS is a major sleep disorder that affects an estimated 40,000 active duty military personnel.

Patient Access to Appropriate Treatments

• Please accommodate the needs of patients who rely on the regular use of low-total daily doses of opioids to manage their RLS. As you consider new legislation and work with federal agencies to address the opioid epidemic, please support a diagnosis-appropriate *safe harbor* for RLS patients, so they do not face arbitrary barriers. RLS patients need for their physicians to be able to prescribe opioids appropriately and without undue restriction.

Education and Awareness

- Please provide \$5 million for the National Neurological Conditions Surveillance System (NNCSS) for FY 2021. The NNCSS at the Centers for Chronic Disease Control and Prevention (CDC) collects and synthesizes data to help increase our understanding of neurological disorders and to support further neurologic research. RLS remains a severely misunderstood and underdiagnosed neurological disorder, and increased surveillance is vital to improving patient outcomes.
- Please provide at least \$5,000,000 for the Chronic Diseases Education and Awareness Program at the Centers for Disease Control and Prevention (CDC). With the cessation of the National Healthy Sleep Awareness Project (NHSAP), CDC presently has no active public health activities dedicated to sleep or sleep disorders, despite the fact that sleep affects nearly every body system and many chronic diseases. Please allow the valuable scientific and public health efforts started during the NHSAP to continue.

ISSUE BRIEF

"Increase Funding for the National Institutes of Health"

(This will be of particular interest to members of the House and Senate Appropriations Committees)

Background

The National Institutes of Health (NIH) is the world's foremost biomedical research enterprise. Much of the research activities supported by NIH do not take place in Washington, DC, but at academic medical centers across the country. Medical researchers compete for funding for their projects by submitting grants and going through a peer-review process that ensures the highest-quality grants receive funding.

Presently, NIH supports important research on RLS across different Institutes and Centers, including the National Institute of Neurological Disorders and Stroke (NINDS), the National Heart, Lung, and Blood Institute (NHLBI), the National Institute on Drug Abuse (NIDA), and the National Institute of Mental Health (NIMH).

The Issue

Each year, Congress balances medical research against other federal priorities and decides how much funding will be provided to NIH through the appropriations process. Over the past few years, NIH has received meaningful funding increases, but for more research to be conducted on RLS, the overall budget of NIH needs sustained growth.

In FY 2020, Congress provided NIH with a meaningful funding increase of \$3 billion to bring the agency's funding to \$44.7 billion. This trend needs to continue to expand and advance research activities

ISSUE BRIEF

"Continue to include sleep disorders as a condition in the Peer-Reviewed medical Research Program"

(This will be of particular interest to members of the House and Senate Appropriations Committees)

Background

The Department of Defense (DOD) supports medical research into conditions that affect veterans and active duty military personnel through its Peer-Reviewed Medical Research Program (PRMRP). Unlike the National Institutes of Health, which fund any meritorious research proposal, the PRMRP only funds research into conditions that have been connected to military service. These are named on a list within the Committee Report accompanying the annual Defense appropriations bill. Appearing on the list deems the condition "eligible for study" for approximately one fiscal year.

"Sleep disorders" has been listed regularly as an eligible condition for almost a decade, and, as a result, important RLS research projects are eligible for funding by the PRMRP. For "sleep disorders" to continue to be listed as a condition eligible for study, it must be included in the FY

2021 Defense appropriations bill. For this to occur, there must be strong support for this action in both the House and Senate, particularly among key members of the House and Senate Defense Appropriations Subcommittees.

Talking Points

- Over the past decade, "sleep disorders" has been listed as a condition eligible for study through the Department of Defense Peer-Reviewed Medical Research Program (PRMRP).
- Please work with your colleagues to ensure that "sleep disorders" is listed once again in the FY 2021 Defense Appropriations Bill.
- The RLS and sleep research community asks that your office contact your colleagues on the Defense Appropriations Subcommittee to communicate your support for this request.

ISSUE BRIEF

Maintain Appropriate Access to Low Total Daily Doses of Opioids for RLS Patients

Background

The opioid epidemic has ravaged communities across the country. While Congress debates solutions to this crisis, they must consider and protect the needs of patient communities who depend on appropriate access to low total daily doses of opioid therapies to manage debilitating conditions.

Current treatment recommendations for RLS include several medications that do not provide life-long relief. For many patients, after months or a few years of relief, some prescribed medications worsen the disease, as a result of a phenomenon called "augmentation." When this occurs, low-total daily doses of opioid medications are often the *only* effective treatment available. Clinical studies have shown that addiction and dependence are not common complications for affected individuals, since the total daily dose of opioids used to manage RLS is quite low.

Talking Points

- RLS is not a chronic pain condition; opioids are used to treat the underlying neuropathology issues associated with RLS, not a sensation of pain. If patients ever lose access to opioid therapies, they will lose the ability to manage their RLS, resulting in severe loss of sleep, continuous misery, and worse.
- Any emerging proposals or rules aimed at combating the opioid epidemic must provide *safe harbor* for the low-total daily dosage effective in treating RLS.
- As Congress considers proper definitions of expected norms for opioid prescribing, the RLS community implores legislators to consider the perspective of prescribers practicing

in specialty and subspecialty care that utilize opioid therapies in low-total daily doses, particularly for neurological conditions and movement disorders.

- When low-total daily doses of opioids are indicated to treat RLS, the condition specifically requires that opioid medications are not reduced over time. Research continues to show that addiction and dependence are not common complications for affected individuals, as the total daily dose of opioids used to manage RLS is quite low.
- The needs of RLS patients who depend on regular use of low-total daily doses of opioids to manage their disease must be considered in crafting legislation, policy, and regulations aimed at drug abuse and addiction. Please work with your colleagues in Congress to ensure that RLS patients retain access to physician-directed care and treatment.



Support Increased Prevention and Awareness

Background

RLS is a serious neurological disease that devastates the lives of millions of Americans. An estimated 12 million men, women and children in the US have RLS. One in 33 adults (3 percent) needs daily clinical treatment. Treatment is life-long, and there is no cure for RLS.

Poor professional and public awareness remain serious barriers to early and effective treatment. CDC leads public awareness campaigns on health issues, conducts surveillance and epidemiology studies, and tracks emerging and established public health threats.

Through its National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP), the CDC supports several programs that work to improve chronic disease education and awareness. These programs work to:

- Find out how these diseases affect populations in the United States
- Study interventions to find out what works best to prevent and control these diseases
- Share information to help Americans understand risk factors and how to reduce prevalence

Talking Points

- Poor provider education on Restless Legs Syndrome routinely leads to misdiagnosis and under-treatment for patients. Delay and misdirection of treatment often results in irreparable harm to patients. Improved provider education can drastically bolster effective treatment outcomes for patients. The CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) supports several programs that work to increase public awareness and improve professional education.
- Please work with your colleagues to provide the Centers for Disease Control and Prevention (CDC) with a funding level of at least \$8.3 billion for FY 2021 and encourage collaboration with stakeholders.

- Please provide \$5 million for the National Neurological Conditions Surveillance System (NNCSS) for FY 2021. The NNCSS at the Centers for Chronic Disease Control and Prevention (CDC) collects and synthesizes data to help increase our understanding of neurological disorders and to support further neurologic research.
- Please provide at least \$5,000,000 for the Chronic Diseases Education and Awareness Program at the Centers for Disease Control and Prevention (CDC). With the cessation of the National Healthy Sleep Awareness Project (NHSAP), CDC presently has no active public health activities dedicated to sleep or sleep disorders, despite the fact that sleep affects nearly every body system and many chronic diseases. Please allow the valuable scientific and public health efforts started during the NHSAP to continue.

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