



# Virtual RLS Advocacy Day – April 24, 2020

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HOW TO BEST PREPARE

# What is Virtual RLS Advocacy Day?

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On Friday, April 24<sup>th</sup>

Legislators from all over the country will receive phone calls and emails from the RLS community raising awareness and concern about issues that affect our everyday lives

The Foundation will be posting on social media all day long with information, encouragement and resources



# Thank you for your participation!

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Sharing your personal story is very impactful

You are helping our legislators better understand restless legs syndrome

You are giving voice for the restless legs syndrome community



# Our Agenda Today

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How Congress works

How can you contact your legislators

Legislative issue review

Questions



# Quick Overview

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## **3 Branches of Government**

Executive Branch (the Administration)-enforces laws

Judicial Branch (the Courts)-interprets laws

Legislative Branch (Congress)-creates and enacts laws



# Congressional Authority

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The power of the purse

Creating policy

Oversight of federal agencies



# The Senate

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Elected to 6 year terms

2 Senators from every state

100 Senators Total



# The House of Representatives

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Elected to 2 year terms

1 Representative from each district

435 Representatives Total





# Key Senate Committees

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Appropriations

Health, Education, Labor, and Pensions

Finance



# Key House Committees

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Appropriations

Energy & Commerce

Ways & Means



# Key Federal Healthcare Agencies

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National Institutes of Health (NIH)

Food and Drug Administration (FDA)

Centers for Medicare and Medicaid Services (CMS)

Centers for Disease Control and Prevention (CDC)

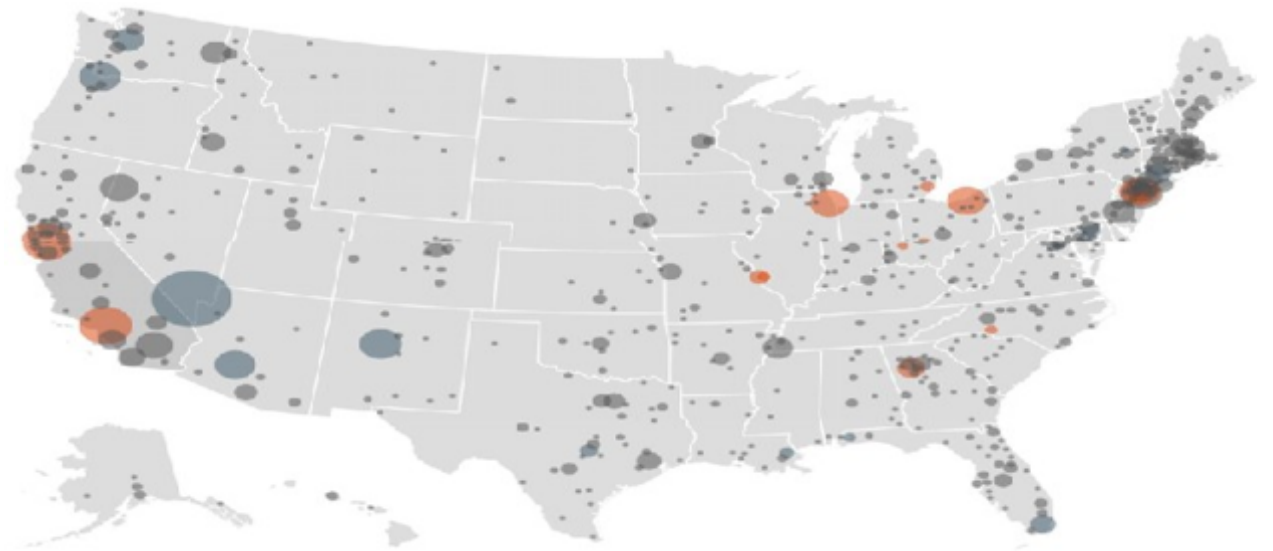


# A “Critical Mass” of Support

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A coordinated nationwide effort by grassroots advocates can help advance research, increase research funding, and improve overall health and healthcare.

Individual advocates work together with one voice to influence enough legislators to create meaningful change.



# Make Your Story Personal

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Keep it simple and concise

Share your experience

What has your journey been?

What challenges have you faced?



# Contacting Congress

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To contact your Senators and Representative:

1. Prepare for the discussion with materials and fact sheets provided.
2. Call your representative's district office.
3. Ask to speak with a staffer who handles health policy as well as the email address of the DC based health staffer. (see partial list in prep pack)
4. Follow-up with the staffer you spoke with via email, and continue to stay in touch with them throughout the year by sending them updates on RLS.



# Finding Your Senators

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To find and contact your U.S. Senator:

1. Visit the Senate website ([www.senate.gov](http://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 Senators' website, contact information, and links to an online contact form (forms vary by Senator).

# Finding Your Representatives

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To find and contact your U.S. Representative:

1. Visit the House of Representatives website ([www.house.gov](http://www.house.gov)).
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.





# How do I prepare?

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- Read the prep packet – download it at <https://www.rls.org/file/advocacy/April-24.2020-Virtual-RLS-Advocacy-Day-Prep-Packet-FINAL.pdf>
- Make a note any questions you have
- Prepare your RLS story – how has RLS changed your life?
- Write down your story. Keep it to 3-4 minutes
- Practice – saying it aloud many times will help you manage nerves & time pressures
- Follow the call and email script that was provided in your prep packet.



# Email and Phone Script

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The scripts can be found on page 2 of the prep pack available on the Advocacy page at [www.rls.org](http://www.rls.org). Please cc: [amber@rls.org](mailto:amber@rls.org) on all emails.

<https://www.rls.org/file/advocacy/April-24.2020-Virtual-RLS-Advocacy-Day-Prep-Packet-FINAL.pdf>

Please familiarize yourself with the scripts and the issue briefs included in your prep pack.



# Send us Your Results

Send us feedback at

<https://www.surveymonkey.com/r/VirtualAdvocate>

Who did you email?

Did you receive a reply?

Who did you speak with?

How did the conversation go?

Let us know of any questions asked by the staff.

Do we need to follow-up?

I participated! Here's what I did to raise RLS awareness with my legislators:

\* Did you call, email or both?

☐ Sent an Email

☐ Made a Phone Call

☐ Both

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If you sent multiple emails, how many did you send?

☐

Who did you email?

Did you receive a reply?

☐ Yes

☐ No

Please provide contact information for those that require follow-up. Include specific questions that need to be addressed.

Thank you for participating in our first Virtual RLS Advocacy Day! Every voice counts as we keep our legislators aware of the needs of the RLS Community.

# Phone Call Follow-up Email

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See prep pack for "Thank you" email template to send after phone calls.

# Washington Update

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2nd Session of the 116th Congress

Annual Budget and Appropriations Activity

Continued congressional focus on healthcare policy, including medical research and patient access



# Legislative Issue Review

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1. Medical Research
2. Appropriate Patient Access
3. Education and Awareness

# Medical Research

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- **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.



# Appropriate Patient Access

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- **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

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- **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.



# Questions?

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