



## **2019 RLS Advocacy Day on the Hill**

### **Advocacy Update and Legislative Issue Review**

**Presented By:**  
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# Webinar Overview

- Washington Update
- The Importance of Advocacy
- Legislative Issue Review
- Itinerary and Logistics of the Day
- Questions

# Washington Update

- Despite the circus, it's business as usual...
- Budget & Appropriations
- Health Care Reform
- Federal Opioid Coverage and Access Policy

# Why Advocacy?

## US CONGRESS

**Make Laws/Policy**

**Oversight of Agencies**

**Power of the Purse**

**Legislators Work for You**

**Member-Driven Process**

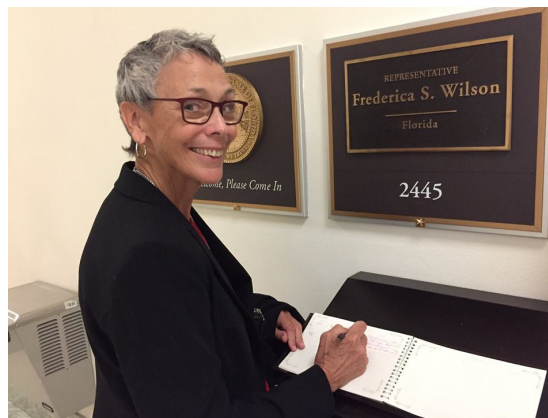
**At the Table or on the Menu**

## FEDERAL AGENCIES



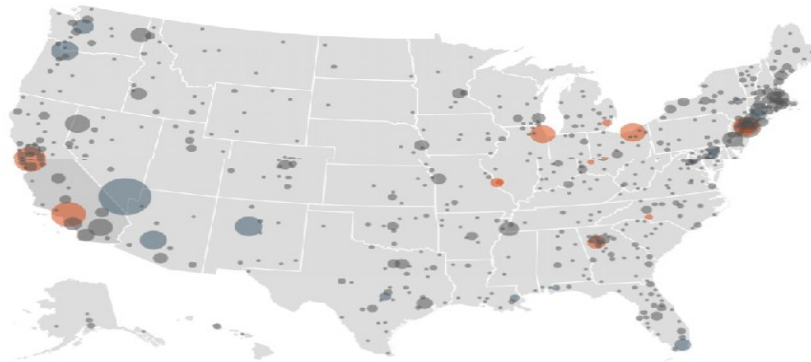
## What Advocates Do

- ☐ Educate
- ☐ Use their story to raise awareness
- ☐ Make local connections
- ☐ Ask for specific actions
- ☐ Work together



# A “Critical Mass” of Support

- ❑ A coordinated nationwide effort by grassroots advocates can help increase research funding and improve overall patient outcomes.
- ❑ Individual advocates work together with one voice to influence enough legislators to create meaningful change.



## **Making an Effective Visit**

- ☐ Before Your Meetings**
- ☐ During Your Meetings**
- ☐ After Your Meetings**



# Before Your Meetings

## Review

- ☐ Learn about the issues
- ☐ Prepare your story
- ☐ Meet your teammates
- ☐ Make a plan for discussing the issues with congressional offices

## & Prepare

- ☐ Attend the webinar and prep session (and ask questions)
- ☐ Travel with your team to the House visits and then the Senate visits
- ☐ Prepare to pass through airport style security at congressional buildings



# During Your Meetings

## ON Capitol Hill

- ☐ Introduce the group
- ☐ Talk about RLS
- ☐ Tell your personal stories
- ☐ Introduce the issues
- ☐ Give them the leave behind folder
- ☐ Use questions as a chance to follow up
- ☐ Get the staffers business card

## Just Remember

- ☐ The constituent(s) should lead the meeting
- ☐ Everyone should contribute
- ☐ Thank the staff repeatedly
- ☐ Remain mindful of the time and think on your feet

**Most Importantly**

**BE PREPARED  
TO TELL YOUR  
STORY!**



# After Your Meetings

## The End of The Day

- ☐ Attend the debriefing session
- ☐ Complete the feedback form
- ☐ Bring up any questions asked by staff

## Later ON

- ☐ Keep the staff business cards
- ☐ Send the staff the follow up thank you e-mail (provided next week)

# Legislative Issue Review

## Three Key Areas

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

## **Increase Medical Research**

☐ **National Institutes of Health**

☐ **Department of Defense**

## **NIH Funding**

### **Background**

- ☐ NIH is currently funded at \$39 billion
- ☐ NIH coordinates RLS research through NINDS, NHLBI, NIDA, NIMH, etc.

### **Congressional ASK**

- ☐ Please provide NIH with at least \$41.6 billion (a \$2.5 billion increase) in FY 2020
- ☐ Please work to expand and advance the RLS research portfolio

## **DOD Peer-Reviewed Medical Research Program (PRMRP)**

### **Background**

- ☐ Funding is up to \$350 million from \$20 million just a few years ago
- ☐ Only funds research into conditions that Congress deems “eligible for study”
- ☐ Being included one year is no guarantee of being included again the next cycle

### **Congressional ASK**

- ☐ Actively support “sleep disorders” in the PRMRP in FY 2020
- ☐ Maintain funding of at least \$350 million for PRMRP moving forward.

# Key Opioid Access Messages for Policymakers

## Appropriate Patient Access

**❑ Please maintain access to low total daily doses of opioids for RLS patients who use them appropriately to treat their condition.**

Many federal, state, and private health coverage policies affecting the practice of pain management require that patients:

- ❖ Are tried on other recognized chronic-pain management treatment before starting opioids.
- ❖ Secure an opioid prescription through certified pain management professionals.
- ❖ Have their medications reduced over time (or provided in minimal quantities).
- ❖ Generally, limit access to opioids.

While valid for chronic pain treatment, these policies are not appropriate for evaluating the use of opioids to treat RLS. RLS is not related to chronic pain. RLS is a neurological disease impacting sleep and should be managed by a neurologist or sleep disorders specialist. Moderate to severe RLS is almost always a life-long disease. When opioids are indicated to treat RLS, the condition specifically requires that opioid medications are not reduced over time. Please work with your colleagues in Congress to ensure that RLS patients retain access to physician-directed care and treatment.

## Education & Awareness

**□ Please support programs at the CDC to expand RLS surveillance, provider education, & public awareness**

### Background

Poor provider education on Restless Legs Syndrome routinely leads to misdiagnosis and under-treatment for patients. Improved provider education and public awareness can drastically bolster effective treatment outcomes for patients.

### Congressional Asks

#### **National Neurological Conditions Surveillance System (NNCSS)**

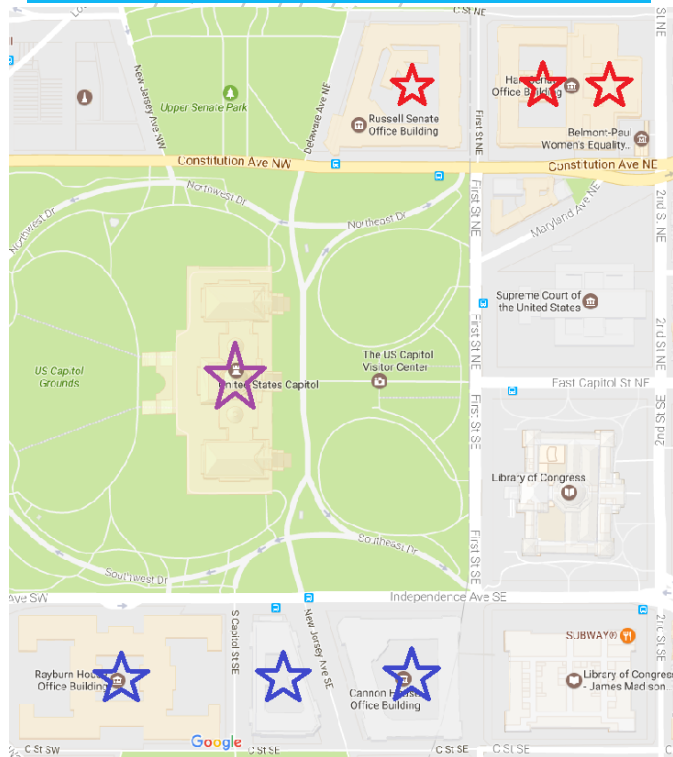
- Please provide \$5 million for the National Neurological Conditions Surveillance System (NNCSS) for FY 2020. The NNCSS at the Centers for Chronic Disease Control and Prevention (CDC) collects and synthesizes data to help increase our understanding of neurological disorders and to support further neurologic research.

#### **Sleep Disorders Education and Awareness**

- Please provide at least \$250,000 in line-item funding for sleep and sleep disorders public health activities at the CDC's Center for Chronic Disease Prevention and Health Promotion. 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.

# Restless Legs Syndrome Foundation Capitol Hill Advocacy Day Itinerary Friday, May 3<sup>rd</sup>, 2019

## Logistics of the Day



**8:30am - 9:45am**

**Welcome Session and Advocacy Training**

188 Russell Senate Office Building  
2 Constitution Avenue NE  
Washington, DC 20515

**10:00am - 12:00pm**

**Senate Legislative Visits**

**12:00pm**

**Lunch**

Dirksen Cafeteria (Basement Level)

**1:30pm**

**Group Photo | Walk across Capitol Hill**

Location: East Front of the Capitol Building

**2:00pm - 4:00pm**

**House Legislative Visits**

**4:00pm**

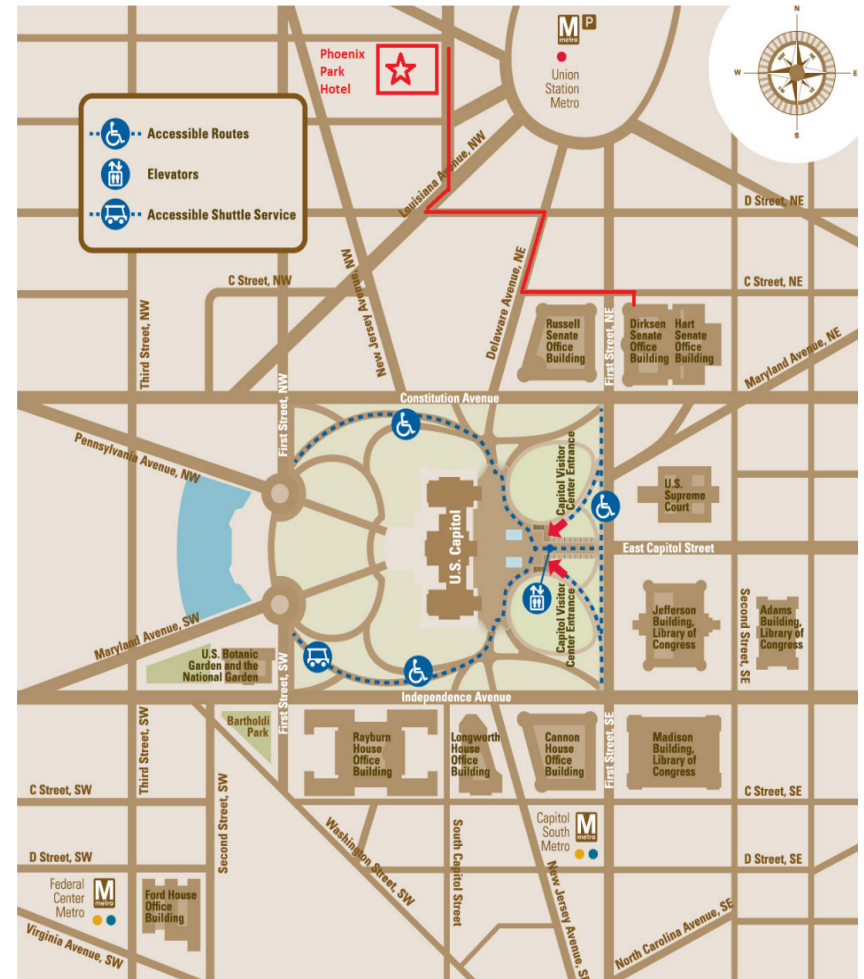
**Debrief (Optional)**

Location: Longworth Cafeteria (Basement Level)



# Tips for Navigating Capitol Hill

- Wear comfortable shoes!
- Business casual attire is considered appropriate.
- Bring a camera.
- Airport Style Security
- Crossing over from the Senate to the House
  - Taxi!
- Give us a call.



# Questions?

Thank you for your time!

Peter Herzog

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