

# NIGHTWALKERS

*In search of a good night's sleep*

Winter 2020

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#### Warning and Disclaimer

Persons suspecting that they may have RLS should consult a qualified healthcare provider. Literature that is distributed by the Restless Legs Syndrome Foundation, including this magazine, is offered for information purposes only and should not be considered a substitute for the advice of a healthcare provider.

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## From the Director

# Let's Make This a Decade of Progress

As we begin a new decade, we have much to celebrate. Over the past 10 years, we have accomplished a great deal to raise awareness and educate about RLS, to seek better treatment options, and to fund research that leads us closer to identifying the causes and a cure for RLS – a disease that affects over 12 million men, women and children in the US.

Our work in these areas continues. This takes commitment from our organization and from you, our members. You are our barometer, providing us with readings on our challenges, our successes and how we can best serve you. Our RLS Foundation leadership and staff are your champions. Here's a preview of what we have in store for 2020:

- Our Board of Directors has kicked off a strategic planning effort to ensure we continue meeting the needs of RLS patients and their families.
- Our Scientific and Medical Advisory Board is revamping the RLS Foundation Research Grant Program to accelerate our quest to identify better treatments and a cure.
- The advisory board also is revising the RLS treatment algorithm to provide up-to-date clinical guidelines on the diagnosis, treatment and management of RLS worldwide.
- The RLS Foundation will hold a second national RLS patient symposium. See the back cover for details.
- Advocating to legislators and policy makers will be at the forefront. We are committed to serving as your voice on Capitol Hill, and will continue to make known the needs for increased medical research funding, for RLS education, and for a safe harbor in legislation and policies to protect appropriate access to opioid therapy for RLS patients.

We won't settle for good; we seek to be great. These bold initiatives are made possible by a "special sauce" – the support of members like you who give above and beyond membership dues to help advance our mission.

Our destiny is in our hands; let's commit to making this a decade of progress!

We do this together, as always.

Karla M. Dzienkowski, RN, BSN  
Executive Director  
Restless Legs Syndrome Foundation



Karla M. Dzienkowski, RN, BSN  
Executive Director

## Do Your Part: Support RLS Advocacy!

The RLS Foundation's advocacy initiative is funded solely by gifts from generous individuals in the RLS community. Please consider supporting this work in 2020 by making a donation to the RLS Advocacy Initiative. Visit [www.rls.org](http://www.rls.org) or call 512-366-9109. Thank you for your support!



# 2020 Federal Spending Package Supports RLS Research

The RLS Foundation continues to advocate for the RLS community on Capitol Hill and across federal agencies. 2019 was an active year, and the Foundation was successful in helping to secure recommendations from Congress through the appropriations process.

Notably, the federal funding bill encourages sleep disorders research at the National Institutes of Health (NIH) – and for the first time, specifically lists “restless legs syndrome.” In late December, Congress passed its final bills, and the president signed both to fund the government in fiscal year 2020.

Following are some of the key recommendations and funding that were included in this important legislation.

## Medical Research

National Institutes of Health (NIH):

- Congress appropriated \$41.7 billion for the NIH – an increase of \$2.6 billion over the 2019 fiscal year. The RLS Foundation worked alongside the broader patient community to ensure that the NIH received a substantial increase in funding to continue vital research that will benefit patients.
- Congress included the following recommendations:
  - *Sleep and Circadian-Dependent Mechanisms Contributing to Opiate Use Disorder*. The funding bill specifically recognizes work by the National Institute on Drug Abuse (NIDA) and the National Institute of Neurological Disorders and Stroke (NINDS) to address the opioid crisis through innovative research directions. The bill notes “the promise that research on sleep and circadian mechanisms can play in the prevention and treatment of opiate use disorder” and encourages relevant NIH institutes and centers to work collaboratively to “continue the exploration of innovative research pathways.”
  - *Sleep Disorders*. The bill commends “the recent expansion and advancement of the sleep and circadian research portfolio under the coordination of the National Center on Sleep Disorders Research (NCSDR),” and “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.”
- The fiscal year (FY) 2020 NIH Congressional Justification (a document with detailed estimates and justifications for research activities) also emphasizes that restless legs syndrome research continues to be a promising direction for the NCSDR.

Department of Defense:

- The Peer-Reviewed Medical Research Program has been funded at \$360 million for FY2020, and *sleep disorders* has been included again as a category eligible for funding.

## Professional Education

Centers for Disease Control and Prevention (CDC):

- Congress budgeted \$5 million for the National Neurological Conditions Surveillance System. This initiative aims to expand surveillance of neurological conditions, providing data to increase the understanding of these disorders and to further support neurological research. The system will initially focus on multiple sclerosis and Parkinson’s disease, with the goal to eventually expand surveillance of many neurological conditions.

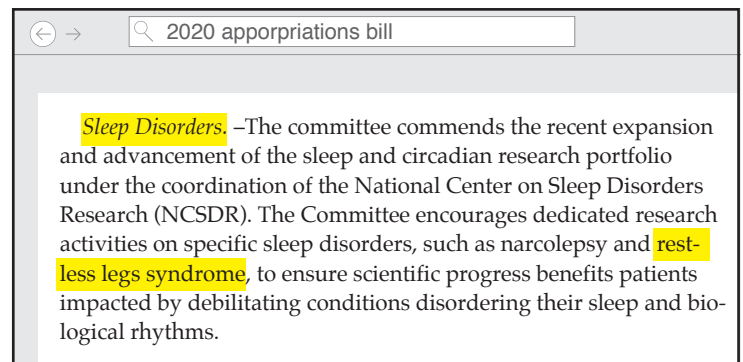
Department of Veteran’s Affairs:

- *Sleep Disorders*. The Department of Veteran’s Affairs was previously directed by Congress to assign a program manager for sleep disorders. The new funding bill requires that the Department provide an update to Congress by June 30, 2020. This is an important first step in improving coordination of sleep disorders research across federal agencies and in broader activities.

None of this progress would be possible without the many RLS patients and others across the country who have connected with their legislators locally and in Washington to share their personal stories.

While the RLS community has accomplished much, more needs to be done. In 2020, Congress will continue to take legislative action on funding the government, advancing critical research, and addressing the opioid crisis. The RLS Foundation will continue to advocate for appropriate access to opioid therapy at low total daily doses for RLS patients through targeted outreach to federal agencies and key congressional committees.

The RLS Foundation is looking for individuals to get involved in legislative activities and share their experiences with leaders in Washington. Are you ready to step up? To learn more about RLS advocacy and to view free educational webinars, visit the “Get Involved” section of [www.rls.org](http://www.rls.org) or contact the Foundation at [info@rls.org](mailto:info@rls.org).



## FDA Warns of Breathing Issues with Gabapentin, Pregabalin

The US Food and Drug Administration (FDA) has issued a warning that serious breathing difficulties may occur in people who have respiratory risk factors and take gabapentin (Neurontin, Gralise, Horizant) or pregabalin (Lyrica, Lyrica CR).

These risk factors include taking drugs that depress the central nervous system, such as opioids; and conditions that reduce lung function, such as chronic obstructive pulmonary disease (COPD). Elderly individuals are also at higher risk.

The FDA will require new warnings on packaging for gabapentin and pregabalin drugs. If you are taking these medications and have concerns, please contact your medical provider. Seek medical attention immediately if you or someone you are caring for experiences respiratory problems.

## RLS Membership: A Gift That Shows You Care

*Know someone who suffers from RLS?*

*Want to share RLS resources with your physician?*

*Want to promote RLS education and awareness?*

*Want to advocate for finding an RLS cure?*

Consider giving an RLS Foundation membership to someone in your life. Your gift will share support, knowledge and resources with someone who needs them.

The recipient will receive full access to valuable member benefits:

- Subscription to *NightWalkers*, the Foundation's acclaimed quarterly member magazine
- *RLS Medical Bulletin*, a comprehensive RLS resource to share with their healthcare provider
- Medical Alert Card and Special Accommodations Card for travel
- 24/7 online access to the Member Portal at [www.rls.org](http://www.rls.org) for RLS publications, webinars, *NightWalkers* archives and more.

The recipient will also receive a letter acknowledging your gift. To give a membership, visit [www.rls.org/gift-of-membership](http://www.rls.org/gift-of-membership), or call 512-366-9109.

*Don't have a recipient in mind?* A \$35 Pay It Forward gift will provide all of the membership benefits to someone in need. Most importantly, your gift will give someone comfort in knowing they are a part of a caring community. To gift a Pay It Forward membership, visit [www.rls.org/pay-it-forward](http://www.rls.org/pay-it-forward), or call 512-366-9109.

RLS Foundation members: You are part of a growing community searching for a cure. Your membership and other contributions directly support efforts like advocating for RLS in Washington, growing our network of RLS Quality Care Centers and funding the only dedicated RLS research program that seeks new treatments and a cure to improve the lives of men, women and children who struggle daily with RLS. Thank you for your support!

*All gift memberships, including Pay It Forward, are tax deductible to the full extent permitted by law.*

## On-Demand Healthcare Provider Education

The RLS Foundation offers free, on-demand webinars exclusively for healthcare providers, available online to professionals with a provider registration (DEA or NPI) number.

"RLS Diagnosis and Treatment Overview" – Shalini Paruthi, MD

"Dopamine Agonists, Impulse Control Disorder and Augmentation" – Mark Buchfuhrer, MD, FCCP

"Augmentation Treatment and Alpha-2-Delta Drugs" – Mark Buchfuhrer, MD, FCCP

"Augmentation: Treatment Case Study of Challenging RLS Cases" – Christopher J. Earley, MB, BCh, PhD, FRCPI

"RLS & Iron Overview and New Recommendations" – Christopher J. Earley, MB, BCh, PhD, FRCPI

"RLS Comorbidities and Management" – William Ondo, MD

"RLS, PLMD and Cardiovascular Implications" – Brian B. Koo, MD

"The Genetics of RLS" – Lynn Marie Trotti, MD, MSc

"Complexity and New Directions in Pediatric RLS" – Shalini Paruthi, MD

"RLS and Depression" – John W. Winkelman, MD, PhD

"RLS in the Surgical Patient: Management Considerations" – William Ondo, MD

"RLS, Sleep, and Technology in the Bedroom" – Jeffrey S. Durmer, MD, PhD

**Help increase RLS knowledge in the medical community! Refer your healthcare providers to [www.rls.org/PhysicianEd](http://www.rls.org/PhysicianEd). RLS Foundation Healthcare Provider Membership fees are waived after viewing the first six webinars, allowing the provider a listing on [www.rls.org](http://www.rls.org).**

## Stepping Up to Support the RLS Foundation

By Carla Rahn Phillips, Chair of the RLS Foundation Board of Directors

For those of us with RLS – and that includes me – it's easy to think we already have enough challenges without taking on something outside of our personal concerns. Nonetheless, many of us still volunteer our time or money, or both, for causes we believe in. Although I have struggled with RLS for more than 25 years, I only learned of the RLS Foundation a few years ago. After discovering the Foundation's website, I became a member to take full advantage of the information that the Foundation provides. Apart from becoming a member, however, it never occurred to me to volunteer my time. That changed due to an unexpected chain of coincidences.

As you may recall, August of 2017 marked a spectacular total eclipse of the sun that was visible across a wide swath of the continental United States. In the run-up to that eclipse, two of my college classmates started organizing a class get-together in Wyoming in the middle of the "path of totality" of the eclipse. It was shaping up to be a major event for our class, with five days of lectures from experts in astronomy and related fields, and the chance to visit with old friends. We were slated to virtually take over a remote mountain resort in Wyoming on the edge of Grand Tetons National Park, far from a major town. My husband and I were excited about attending, but, with my RLS, I began to worry about the meals we would be served. It sounds trivial, but if those meals were to have lots of salt and sugar, I knew I would not be able to sleep at night, because those are two of my triggers for RLS.

I was reluctant to raise my private concerns about the menus, even though attendance, lodging and meals had to be prepaid. Then one of the organizers asked if any of us had any special dietary requests, so I responded that it would be very helpful to have the option of low-sodium food, because I suffered from restless legs syndrome. It turned out that one of the organizers, Lew Phelps, also has RLS, and had already planned for low-sodium meals! Moreover, Lew had been a stalwart member of the RLS Foundation for decades, and in 2017 he had already chaired its Board of Directors for several years. The eclipse event was a great success. Even better, I was able to sleep well thanks to the foresight of Lew and his brother Chuck.

Long before memories of the eclipse faded, Lew suggested that I volunteer for the board of the Foundation. Unlike corporate boards of directors, nonprofit boards almost always serve without pay, and

the members of the RLS board pay their own transportation and hotel costs for the annual face-to-face meeting, as well as all their other expenses. In other words, it truly is a voluntary and financial commitment. Several members of the board are busy professionals in healthcare or other fields.

Nonetheless, they volunteer their time to the Foundation because of their passion to educate patients and healthcare professionals about RLS, support scientific research into its causes and management, and ultimately find a cure. I had recently retired from the University of Minnesota after four decades as a professor of European history, and Lew persuaded me that it was time to give back. I joined the Board of Directors in 2017 as one of the "civilian" members of that body – that is, a non-healthcare professional. Since then, by attending meetings of the board and its committees – nearly all online or by phone – I have learned an incredible amount about RLS and about the important work of the Foundation. When individuals make a major donation to the Foundation, members of the board thank them personally. As a board member, I have enjoyed writing to let major donors know how much we appreciate their support.

Lew just stepped down as chair of the Board of Directors after a long and distinguished tenure. One of his final acts as chair was to persuade me to succeed him as chair. Although I do not plan to replicate his long tenure, I hope I can make a useful contribution to the Foundation's work. It's the least I can do to thank the Foundation for helping me cope with my RLS.

As members, we receive *Night Walkers* and have access to webinars and the full library of the Foundation's publications. Thousands of nonmembers also benefit from free information that the Foundation provides, and it costs time and money to produce that information. The best thing that members can do is to persuade everyone they know with RLS to become members of the Foundation, which does so much for us all.



Carla Rahn Phillips, PhD

## Get the Latest on RLS Research and Treatments

For the latest updates on research, treatments, and living with RLS, visit the RLS Foundation blog at [rlsfoundation.blogspot.com](http://rlsfoundation.blogspot.com).

You can also receive monthly news through *eFriends*, the Foundation's e-newsletter. To request a subscription, visit [www.rls.org/subscribe](http://www.rls.org/subscribe).

For 24/7 connection to the RLS community, visit the online RLS discussion board at [bb.rls.org](http://bb.rls.org), or follow the RLS Foundation on Facebook, Twitter, YouTube, Instagram and LinkedIn.





## Why Your Voice Matters

Your advocacy efforts have been paying off! In October 2017, the RLS Foundation launched an advocacy initiative to inform federal policy makers about restless legs syndrome (RLS) with three main goals in mind: increasing funding for research, protecting appropriate access to opioid therapy, and expanding physician education and public awareness.

Many members of the RLS community have done their part in pursuing these goals by reaching out to their federal and local representatives via email, letter or phone – as well as joining the Foundation in Washington, DC, last May for RLS Advocacy Day on Capitol Hill. As a result, Congress continues to highlight RLS medical research at the National Institutes of Health (NIH) through report language in annual appropriations bills; and the Department of Defense continues to pursue important research on sleep disorders.

You may be wondering, “How does this affect me?” Educating legislators about the concerns of RLS patients puts necessary pressure on Congress to continue funding major research institutions, which in turn allocate resources to further research on RLS and sleep disorders in general – bringing scientists closer to finding better treatments and ultimately, a cure.

The proof is in the grant allocations that have been awarded to key researchers in the field, including members of the Foundation’s very own Scientific and Medical Advisory Board. **Brian B. Koo, MD**, who is the director of the Yale Center for Restless Legs Syndrome (an RLS Quality Care Center), recently received a grant from the Department of Defense for his work on RLS and hormones. Dr. Koo and his team at Yale University are investigating whether the levels of melanocortin hormones are increased in the blood and cerebral spinal fluid of people with RLS. (If you are interested in participating, see page 21.)

Likewise, RLS Foundation advisory board member **James Connor, PhD**, at Penn State University received a grant from the National Institute of Neurological Disorders and Stroke to investigate iron deficiency and the RLS brain, in collaboration with **David Rye, MD, PhD**, and **Lynn Marie Trotti, MD, MSc**, both of Emory University. Dr. Trotti is the director of the Emory Sleep Center – an RLS Quality Care Center. Together, these researchers have developed models that will help to determine how cerebral spinal fluid from RLS patients affects the iron transport at the blood brain barrier.

Also funded by the NIH are RLS Foundation advisory board member **Kathy Richards, PhD, RN, FAAN**, of the University of Texas; and **Christine Kovach, PhD, RN, FAAN**, of the University of Wisconsin. They received a large grant from the National Institute on Aging to improve the treatment of nighttime agitation in people with Alzheimer’s disease. The researchers hypothesize that RLS may be a cause for nighttime agitation and sleep disturbance in these individuals.

These experts have made significant advances in the field of RLS research. Dr. Koo is one of the world’s foremost experts on the epidemiologic research that links periodic limb movements during sleep and cardiovascular disease. Dr. Connor is a leader in

*“The RLS Foundation’s presence in Washington, DC, has been very important in enhancing visibility of the name and the disease. This gives us a fighting chance for competitive grant money.”*

– Dr. Christopher Earley

understanding the cellular and molecular mechanisms by which cells regulate iron. Dr. Rye was part of an international team that identified the first gene variant associated with RLS. And, Dr. Trotti is a two-time recipient of the American Academy of Sleep Medicine Foundation Strategic Research Award for her work on central disorders of hypersomnolence, RLS and sleep in neurodegenerative disease. (For more on Dr. Trotti’s accomplishments, see page 12.)

In addition to their work in research, these experts also work directly with the RLS Foundation to increase their impact on the RLS community. Drs. Connor, Koo and Trotti are all members of the RLSF Scientific and Medical Advisory Board. Dr. Koo and Dr. Trotti serve as the directors of the Yale Center for Restless Legs Syndrome and the Emory Sleep Center, respectively. Dr. Rye is a certified RLS provider at the Emory Sleep Center. Finally, Dr. Koo and Dr. Trotti play a significant role in educating the public, as the medical editor of *Night Walkers* and the author of the “In the News” column, respectively.

RLS Foundation Scientific and Medical Advisory Board member **John W. Winkelman, MD, PhD**, of Harvard University; and board member **Jeffrey Durmer, MD, PhD**, of Fusion Health; have attended numerous meetings with policy makers to advocate the needs of RLS patients.

**Christopher Earley, MB, BCh, PhD, FRCPI**, also adds a powerful voice to RLS advocacy in Washington. Dr. Earley is not only the chair of the RLS Foundation’s Scientific and Medical Advisory Board, but also the director of the John’s Hopkins Center for Restless Legs Syndrome, an RLS Quality Care Center. He has joined the RLS Foundation in Washington on multiple occasions to advocate for the needs of RLS patients, healthcare providers, and researchers. Dr. Earley is conducting an NIH-funded study to evaluate epigenetic changes in DNA from blood (lymphocytes) and from brain autopsy in individuals with and without RLS.

Here is Dr. Earley’s take on the recently funded research projects: “The truth is, restless legs syndrome is something that most people don’t know about, and definitely very few people understand. When it comes to competing for grant-based money whether through the National Institutes of Health, National Science Foundation, or Department of Defense, name recognition is important. The RLS Foundation’s presence in Washington, DC, has been very important in enhancing visibility of the name and the disease. This gives us a fighting chance for competitive grant money when measured up against heart disease, cancer, and neurological conditions like Alzheimer’s disease. Further work is needed. Another visit to Washington is planned in February to address the possibility of giving RLS higher visibility on grant-supported initiatives.”

## Eating with RLS: Diet Makes a Difference

Diet can have a significant effect on the symptoms of many chronic conditions, and RLS is no exception. While there is no specific “RLS diet,” your dietary choices can make a difference – and may even help avert a night of unwanted “night walking.”

For many people with RLS, the optimum diet boils down to avoiding four common ingredients: caffeine, alcohol, sugar and salt. Pay close attention to your diet and RLS to determine if any of these ingredients trigger RLS symptoms.

Research studies have shown caffeine to be an RLS trigger. In addition to avoiding coffee and caffeinated tea, be sure to check ingredient lists for hidden sources of caffeine in soda, chocolate, energy drinks and other convenience foods. Another common RLS trigger is alcohol, which disrupts sleep, and in turn exacerbates RLS. Watch for hidden sources of alcohol in products such as mustard, extracts, sauces (e.g., bearnaise or bordelaise) and fondue.

Anecdotally, many people report that sugar, artificial sugars (such as those found in reduced-calorie and weight loss products) or salt increases their RLS symptoms. With salt, it is thought that excess fluid retention may stimulate sensory components in the legs that trigger RLS sensations.

If your healthcare provider determines that a vitamin deficiency is contributing to your RLS, then you may be directed to supplement your diet with iron, vitamin B12 or folate.

In fact, all patients with RLS should have their iron stores checked. Iron is vital to the functioning of the brain's dopamine system. In addition, brain iron deficiency is a known contributing factor to RLS. For someone with RLS, it's important to maintain a serum ferritin (blood iron) level above 75–100 micrograms per liter (as measured by a serum ferritin lab test). Lower iron stores correlate to greater severity of RLS symptoms.

If your ferritin level is low, your doctor may ask you to increase your dietary intake of iron through supplements or food. You can find heme iron (animal-based) in beef, poultry, seafood and fish; and non-heme iron (plant-based) in foods such as tofu, beans, fruits, vegetables, and enriched cereal, rice and pasta. To absorb the most iron, avoid supplements or eating foods high in calcium (for example, calcium supplements, dairy products) for two hours before or after taking iron. The tannins in coffee and tea also reduce the absorption of iron. On the other hand, consuming foods high in vitamin C, such as strawberries or orange juice, may enhance your iron absorption.

Your doctor may also recommend intravenous iron therapy or oral iron supplements to treat your RLS. Iron supplements should only be taken under the care and supervision of a healthcare provider.

Another dietary element to consider is magnesium. Magnesium plays a role in regulating protein synthesis, nerve and muscle function. It is vital for the function of gamma aminobutyric acid (GABA) receptors in the brain, which initiate sleep. Low magnesium can cause a variety of health issues, including numbness, tingling, muscle twitching, cramps and muscle soreness.

The recommended daily allowance for magnesium is about 400 mg for adults. You can find magnesium in green leafy vegetables, cereals and, to a lesser extent, foods containing fiber. Foods that interfere with magnesium absorption include carbonated beverages, sugar, high-carb foods, caffeine and alcohol. However, there is little research to show that increasing magnesium via supplement intake improves RLS. Please consult with your healthcare provider before taking any supplements, as moderate amounts of some minerals can cause toxicity.

If you suffer from gastrointestinal symptoms such as gas, bloating, abdominal pain, intermittent diarrhea and constipation, or anemia, then your provider may evaluate you for two disorders that impair iron absorption: small intestinal bacterial overgrowth (SIBO) and celiac disease. The common link between these disorders is gluten. While there is little evidence suggesting that gluten causes or exacerbates RLS, limited research has shown a link between gluten ingestion and changes in bacteria in the gut, which may result in SIBO. For people who have SIBO, the small intestine does not absorb nutrients as it should.

Celiac disease is an immune disorder in which ingestion of gluten can damage the small intestine and limit the absorption of nutrients. If you have persistent low iron levels on lab tests and are taking oral iron supplementation as directed, your doctor may order a specific antibody blood test to check for celiac disease.

If you are diagnosed with SIBO or celiac disease, your doctor may recommend a gluten free diet to increase absorption of nutrients, and iron in particular.

When making dietary changes or starting supplements to improve RLS symptoms, keep in mind that obesity is associated with RLS, and maintaining a healthy weight in general can help to alleviate health issues. Ask your doctor about dietary changes you can make to improve your health – such as following the Mediterranean diet or a gluten-free diet. Be sure to avoid fad diets, which are difficult to maintain and may even cause weight gain in the long run. By taking steps to a healthier lifestyle by getting moderate exercise and eating right, you can make strides toward improving your RLS.



## Walking for Awareness in the EU

*Inspired by a desire for the world to know that RLS is a real diagnosis, in 2018 Lucy Hoekstra decided to walk to raise awareness for RLS. "Walk" is a simple word for her incredible journey. Hoekstra first attempted to walk from her home in the Netherlands to her sister's home in Denmark but did not succeed. Nevertheless, she persisted with help from the European Alliance for Restless Legs Syndrome, and the European Federation of Neurological Associations (EFNA). On August 28, 2019, Hoekstra started a 356-mile journey from Hurdgearyp, Netherlands, to Krusbjerg, Denmark. Over 26 days, she walked the entire way, carrying her necessities and stopping for rest. Along the route she met supporters, blogged about her experience, and educated strangers about RLS. Hoekstra completed her trek on September 23, International RLS Awareness Day, inspiring people whose lives are affected by RLS, and others.*

*Joke Jaarsma, who is the vice chair of the Restless Legs Foundation in the Netherlands, and the president of EFNA, says, "In 20 years of patient advocacy, I have not seen this much press attention in just a couple of weeks. People like Lucy can make the difference!"*

*The RLS Foundation would like to thank Hoekstra for her work to raise awareness about RLS. Amber Arellano, RLS Foundation membership coordinator, recently interviewed Hoekstra about her incredible journey.*

### **What inspired you to promote RLS, and why did you choose to walk?**

I have had RLS symptoms since I was a teenager but only received my diagnosis about three years ago. It took so long because my former doctor didn't recognize it. After I got my diagnosis, I noticed that a lot of people don't know anything about RLS. This was frustrating at times, and I wanted the world to know that it is a real thing.

Last November, I went to Brussels for a workshop given by EFNA. This was for young neurological patients to learn how to advocate in a digital world of social media. After the great workshop, I decided to walk to raise awareness for RLS.

### **How did you prepare mentally, physically and emotionally for your 356-mile journey?**

I started training in January and walked almost every weekend – sometimes twice. During these training walks I could test a lot of things, like shoes, my bag and clothes; and what, when and how much I would need to eat. I learned a little bit more every weekend, and in the end, it was perfect for my trip.

Mentally and emotionally I didn't really prepare. I talked about it with family and friends but tried not to make a big thing of it. When I had my walking idea, I went to Joke Jaarsma, who is vice president of the Dutch RLS patient organization. She has connections with the German and European patient organizations. Together they organized the whole trip – press releases, website, hotels, etc., thanks also to an EFNA award (#BrainLifeGoals) that we had won. This took a lot of pressure off of me, and I'm really thankful for all the work they did.

### **How did it make you feel when people joined you as you walked?**

It was great to have people with me to support me. Most of them were complete strangers, but when you walk and talk, you get to know people. During my trip, my pace slowed down a little, so at times like that it was good to have people with me, to get me through some hard moments.



Lucy Hoekstra

### **What were some unexpected obstacles you experienced on your journey?**

The first week I had some blisters. That was painful, but luckily after a week it went better. I also almost got lost a few times, but I was always able to find my way. Luckily, I have Google Maps on my phone, and sometimes people would show me the way. So I had a few obstacles but overcame them all.

### **What was the most surprising thing that happened to you while you were walking?**

There were a lot of funny things and surprises. A few times people were offering me food and drinks – that was really nice. One time I was eating lunch in a cafe, and I talked to the people next to me about my trip and RLS. When I ordered, they said they would pay for me; that was a nice surprise!

When I was halfway, I needed to cross a river on a ferry. A lot of truckers and people on holiday also use this ferry. I had a flag on my bag, so people recognized me and waved and cheered. It had been a hard day that day, but that cheer squad made it so much better.

Another great thing was that a radio station followed me all the way and regularly interviewed me "live" on their program. On Christmas Day, they featured my walk when looking back on memorable events in 2019.

### **What advice do you have for others about raising awareness?**

Don't be afraid to tell your story. When I had my diagnosis of RLS about three years ago, I didn't tell a lot of people. It was because on the one hand, people can react in an unsupportive way; on the other hand, I didn't want people to know that something is wrong with me.

I now know that it is necessary to tell people about RLS so that more people, including doctors, know more about RLS and can react in a positive way. My legs may be weird sometimes, but that doesn't mean that I am. Telling my story and raising awareness brought me a lot of good things, and I met a lot of nice people.

### **Do you plan to advocate for RLS again? If so, how?**

My plan is to keep advocating for RLS, but at the moment I don't know what form this will take. I think there is still a lot of work to do to raise awareness and do research about RLS. Luckily, there are some great people and organizations that work hard as advocates for RLS.



## RLS and Disability Benefits

If RLS has left you unable to work, you may want to consider applying for government disability benefits. The Social Security Administration (SSA) offers monthly financial support to people with serious illnesses whose conditions prevent them from working. While not everyone with RLS will qualify, you may be eligible for aid if you have a severe case of RLS.

### Medical Qualifications and Disability Benefits

The SSA uses its own medical guide (the “Blue Book,” which may be viewed online) to evaluate applications for disability benefits. You must have one of the listed impairments or an equivalent combination of impairments to qualify for benefits.

Although RLS is not specifically listed in the Blue Book, you still may qualify if symptoms listed under other conditions accurately describe your symptoms. For example, many people with RLS may have depression and exhaustion due to the condition. To qualify for Social Security benefits with depression, you must prove you experience any five of the following:

- Depressed mood
- Diminished interest in nearly all activities
- Change in weight
- Difficulty sleeping
- Noticeable physical agitation
- Less energy
- Feelings of guilt or worthlessness
- Difficulty concentrating
- Thoughts of death or suicide

In addition, you must have challenges in at least one of the following areas:

- Understanding, remembering, or applying new information
- Interacting with others in the workplace
- Concentrating and completing tasks
- “Adapting” oneself, (i.e., controlling your emotions in the workplace)

Other examples of RLS-related conditions included in the Blue Book are other mood disorders, heart disease, and vision problems.

### Medical Evidence Needed to Qualify

In addition to having a collection of symptoms listed in the Blue Book, the condition must make it impossible for you to earn a living (currently defined as making less than \$1,260 per month).

If you feel that your RLS symptoms might qualify you to receive disability benefits, you should ask your doctor to fill out the Residual Functional Capacity (RFC) form on your behalf. The RFC is available on the Social Security Administration website. After you apply, your physician also may be asked to submit relevant medical records.

The RFC describes exactly how much physical labor you’re able to do, from lifting weights to standing for extended periods of time. The physician’s assessment is given weight in making the determination. Factors considered may include:

- Any medications you’re taking and their side effects
- The jobs you’ve had in the past and the exact physical activities you can no longer perform
- How long you’ve been undergoing treatment for RLS
- Any other conditions you have that contribute to your inability to work
- If you perform sedentary/desk work, a physician’s statement describing the limitation on this type of job

### Starting Your Application

Although most people will find it convenient to apply online, you can also make an appointment for a face-to-face meeting at any of the more than 1,300 Social Security Administration offices in your community.

While approval rates are low, especially for conditions that are not listed in the Blue Book, a thorough appeals process is available for any denied claimants. Once you are approved for disability, you can focus on what’s important: your health.

### Resources

- RLS Foundation: [www.rls.org](http://www.rls.org)
- National Sleep Foundation: [www.sleepfoundation.org/restless-leg-syndrome/about-rls](http://www.sleepfoundation.org/restless-leg-syndrome/about-rls)
- Social Security Administration: [www.ssa.gov/disability](http://www.ssa.gov/disability)

*Article courtesy of Disability Benefits Center. The RLS Foundation does not endorse or sponsor any products or services, nor is it qualified to provide legal advice as to potential benefits. To learn more or apply for disability benefits, please contact the Social Security Administration.*

### Upcoming Patient Education Webinars

“Basics of RLS” • February 7, 2020

J. Andrew Berkowski, MD

“Genetics and Epigenetics of RLS” • March 12, 2020

Christopher J. Earley, MB, BCh, PhD, FRCPI

“Iron and RLS” • April 2020

James R. Connor, PhD

*Webinar schedule is subject to change. Visit [www.rls.org](http://www.rls.org) for final details and further information on attending these free educational webinars.*

## Webinar Q&A: Basic RLS Pathophysiology

*Finding better treatments and a cure for RLS starts with understanding how the disease affects the body. What causes RLS symptoms? What processes deep within the brain and body are characteristic of RLS – or changed by RLS?*

*In July 2019, researcher James R. Connor, PhD, of Pennsylvania State University, shared some answers. Dr. Connor presented the RLS Foundation webinar “Basic RLS Pathophysiology.” A member of the RLS Foundation Scientific and Medical Advisory Board, Dr. Connor is an internationally recognized expert on RLS and the field of brain iron metabolism.*

*Below are answers to questions from webinar participants. Recordings of this and other webinars are available to RLS Foundation members in the Members Only section of [www.rls.org](http://www.rls.org). Nonmembers can view webinar recordings by joining the Foundation for \$35 annually (\$45 international). Scholarships are available. Contact the RLS Foundation at [info@rls.org](mailto:info@rls.org) or 512-366-9109.*

**Q: How close are we to definitively stating the cause of RLS?**

**A:** We know that RLS is not a neurodegenerative disease. This is hugely important, because it guides therapy and means that we are not trying to rescue cells with RLS treatments. In terms of a definitive cause, we have some way to go. We have a profile of RLS, and we know what an RLS brain looks like. But in terms of how those anatomical, structural and functional changes come together to be a disease, we don't have the smoking gun yet. We think that iron deficiency of the brain may be an underlying cause of RLS. The question is, how did the brain become iron deficient?

**Q: Is all RLS connected to our genetics? Or are there other causes?**

**A:** There are certainly causes beyond genetics. It's true that if a family member has it, the odds increase that you will also have it. You don't make iron in your body; you have to get it from your diet. If your RLS symptoms are associated with iron deficiency, then your RLS might be more related to dietary than genetic issues. There is certainly an interaction between genes and RLS, but also there is a significant component that is not genetic.

**Q: At this point in time does lack of iron in the brain appear to be the crux of the problem?**

**A:** Yes. We also find underlying dopaminergic problems; RLS symptoms will respond to dopamine agonists as a treatment. But the crux of the problem is brain iron deficiency, and the data supports this assertion.

**Q: Do we know how iron is involved in causing RLS?**

**A:** Probably in multiple ways. Iron is needed to create dopamine in the brain. Looking at the structural and functional changes that are going on in iron deficiency, we see a decrease in the dopamine receptors, so that's one way. Another change we see in iron deficient brains is that the adenosine is elevated. There seems to be a protein or chemical that regulates glutamate and dopamine. That protein is responsive to iron status, and since basic energy is responsive to iron status, this protein has an effect on basic energy.

One of the things we look at that has not been explored much in RLS is myelin. Myelin is a fatty substance that goes around the nerve axons, serving as an insulation to help them conduct messages faster. Think of an axon as sort of an electrical cable, and you have to wrap the cable with some type of insulation for it to work well. That's what myelin does for you in the brain. The best example of myelin not working correctly is multiple sclerosis. One of the things that we know happens in restless legs brains, is that there is less myelin. That's consistent with less iron in the brain. In RLS research, much of our focus is on the dopaminergic system in the substantia nigra because we see changes there, but how much of the restless legs brain has a broader change or deficit? Myelin is something that is still an open area for exploration, because it might help us to look more broadly at therapeutic strategies.

**Q: How are serum ferritin levels and dopamine related in the pathophysiology of RLS?**

**A:** They don't seem to be. One of the things we have learned over time is that often, what's going on in the blood does not inform us at all about what is going on in the brain. For example, serum ferritin [measurement of how much iron your body stores] really has not predicted dopamine receptors or dopamine levels in the brain. A lot of that is because of the physiology. The endothelial cells of the brain forming the blood vessel have tight junctions, so they don't allow free communication between the blood and the brain. There has to be a transport system. The brain is really acting to some extent independently of what's going on in the serum, although it's clearly being informed by what's going on in the serum.

**Q: Do RLS pathways change over time, making symptoms worse, or is it just augmentation that makes symptoms feel worse?**

**A:** Great question. Are there really structural changes over time that change the responsivity of RLS? At this point, we don't know. In other disorders, perhaps even opioid addictions, there do seem to be structural changes that occur over time, so it would not be surprising if there are changes over time in RLS. We just don't have the data to support it.

**Q: Do you consider RLS and periodic limb movement disorder (PLMD) two sides of the same coin, in a way?**

**A:** Not really. When Richard Allen\* first recruited me to help in the RLS field, that was one of the things that he strongly argued for. I don't know how much they are related functionally, but from the symptomatic standpoint they're very different. I know that periodic limb movements are responsive to the dopamine agonists, so at some level there is probably a biological similarity. But the symptoms of RLS and PLMD are very different.

*\*Richard P. Allen, PhD, is a renowned RLS researcher at the Johns Hopkins Center for Restless Legs Syndrome.*

**Q: How do researchers explain the hyperarousal symptoms that are a feature of RLS?**

**A:** I think that has to do with the chemical changes going on in the brain in RLS: the elevated dopamine, and probably glutamate and adenosine relationships. In basic brain physiology, this is the arousal system that we all use when we need to be aroused and alert. There are very appropriate responses going on in the brain when you are in a situation where you need to be hyperalert; the problem in restless legs syndrome is that the system is coming on at the wrong time, when you are trying to go to sleep. The challenge is in understanding the neurotransmitters in the brain associated with arousal, and why they're elevated at the wrong time in restless legs.

**Q: What are some practical implications of your findings regarding brain structure and function for severe RLS?**

**A:** The practical implications are in understanding why some of the treatments we have are working. The bigger question is in trying to understand what happens much earlier, before the structural and functional changes of RLS happen. When we study patients with RLS symptoms, we want to understand whether symptoms first happened as an iron deficiency that occurred during development. For example, changes may have occurred when the individual was a preschooler and the brain was developing and growing quickly, but maybe without enough iron. It may have gotten to a certain point where there was a disruption in the dopaminergic system and other neurotransmitter systems, which were more apparent as the individual became older.

The practical standpoint is understanding how important the iron balance is in the brain. We understand that in Parkinson's and Alzheimer's, too much iron promotes neurodegeneration. On the other end of the spectrum we have restless legs syndrome that suggests there is not enough iron, but the individual still has these sensory sensations. How do we find that balance of iron that puts us somewhere between restless legs and Parkinson's?

Understanding uptake in regulation of brain iron is a key part of this. We need to understand how iron gets into the brain, and once we do that, we can regulate to get more iron into the brain in RLS patients. We can keep iron out of the brain in Parkinson's patients. I think those are the basic practical aspects of what we are trying to do.

**Q: Is anything in the pipeline that will relieve RLS symptoms without making the condition worse in the long run?**

**A:** I am not sure that there is at this time, but we keep looking and studying. Once we understand what's wrong or what's different in the RLS brain, then we can target that issue rather than targeting the symptoms. A drug intervention at that point is going to be able to make things better without inserting itself into the middle of a tightly regulated system that's gone awry. When you start messing with a system that is already a little askew, that's where the

augmentation problems begin. We need to understand the fundamental cause and target that.

**Q: Are there any new therapies on the horizon, oral or intravenous, that will help to maintain ferritin levels and, ultimately, iron levels in the brain?**

**A:** There are products available, such as intravenous iron compounds that aim to maintain ferritin levels. But there's no guarantee that keeping ferritin levels up is going to increase brain iron uptake. There are certainly plenty of iron supplements out there; the question is, how much are they going to impact what's going on in the brain? Other types of products are under development that may help with this.

**Q: Is there any research that could use the brain as a contribution for study?**

**A:** The understanding that there is brain iron deficiency in people with RLS came directly from autopsy studies, as did the understanding that RLS does not have a neurodegenerative component. As we continue to refine the questions that we are asking, we continue to need brain donations to evaluate those questions within the RLS tissue itself.

*Editor's note: If you are interested in donating your brain tissue for research, call 1-800-BRAINBANK for information.*

**Q: Tell us the direction of your latest research.**

**A:** At Penn State, we have models in place now to really understand regulation of brain iron uptake, including follow-up studies with cerebral spinal fluid. We are conducting research\* in close collaboration with Dr. David Rye and Dr. Lynn Marie Trotti at Emory. The idea is to really understand the signal in the brain that's informing the blood to increase transport of iron into the brain, and what happens to that signal in RLS. Is there a wrong signal? Is the restless legs brain telling the blood that it has enough iron when it doesn't? Or is the signal just not there? We have some pretty good ideas of how we can look at that, and we hope that over the next few years, we can answer these questions.

*\*This study was recently funded by the National Institutes of Health, thanks in part to advocacy for increased research funding by the RLS Foundation and other groups. See page 6 to learn more.*

*Editor's note: It is the policy of the Restless Legs Syndrome Foundation in all cases to disclose any relationships that might be perceived as conflicts of interest. Dr. Connor is a co-founder of Sidero Bioscience, a biotechnology company that is developing a medical food product to alleviate iron deficiency. The Foundation makes no recommendations or endorsements; members should consult their own healthcare providers for guidance.*



## Meet Dr. Lynn Marie Trotti

Every quarter, the RLS Foundation brings important research updates to *NightWalkers* readers, thanks to the contributions of Lynn Marie Trotti, MD, MS, author of the “In the News” column.

Dr. Trotti has made many contributions to the RLS community, both clinically and through research. Since 2014, Dr. Trotti has served on the RLS Foundation Scientific and Medical Advisory Board. She is the director of the RLS Quality Care Center at the Emory Sleep Center, and an associate professor of neurology at Emory University School of Medicine.

Dr. Trotti treats patients with all sleep disorders, including RLS. Her research focuses on the central disorders of hypersomnolence, such as narcolepsy, idiopathic hypersomnia, and Kleine-Levin syndrome; on parasomnias, such as rapid-eye movement (REM) behavior disorder and sleepwalking; and on the overlap of sleep and movement disorders such as Parkinson’s disease. Dr. Trotti has been awarded federal grants for several projects, including “Genotype-Phenotype Correlations in Restless Legs Syndrome and Periodic Limb Movements of Sleep (PLMs).” Her contributions to research articles on the genetic risk factors for PLMs, and the association between elevated C-reactive protein with PLMs in patients with RLS, have been published in the

*New England Journal of Medicine*, and in *Brain, Behavior, and Immunity*, respectively.

Dr. Trotti holds leadership roles as a committee member of the American Academy of Sleep Medicine, the National Sleep Foundation and the Hypersomnia Foundation. In 2011, she received the American Academy of Sleep Medicine Movement Disorders Section Investigator Award and the Sleep Research Network Diversity Travel Award. Dr. Trotti is also an active participant in community outreach, providing her expertise to various platforms such as the Narcolepsy Network annual meeting and the American Parkinson’s Disease Association education meeting.

The RLS Foundation is grateful for Dr. Trotti’s many contributions: her knowledge, her impact on the lives of countless patients, and her dedication to understanding and finding a cure for RLS through research.



Lynn Marie Trotti, MD, MS

## Honor Roll

*The RLS Foundation is sincerely grateful for donations received from October 1, 2019, through December 31, 2019, in memory and in honor of the following individuals:*

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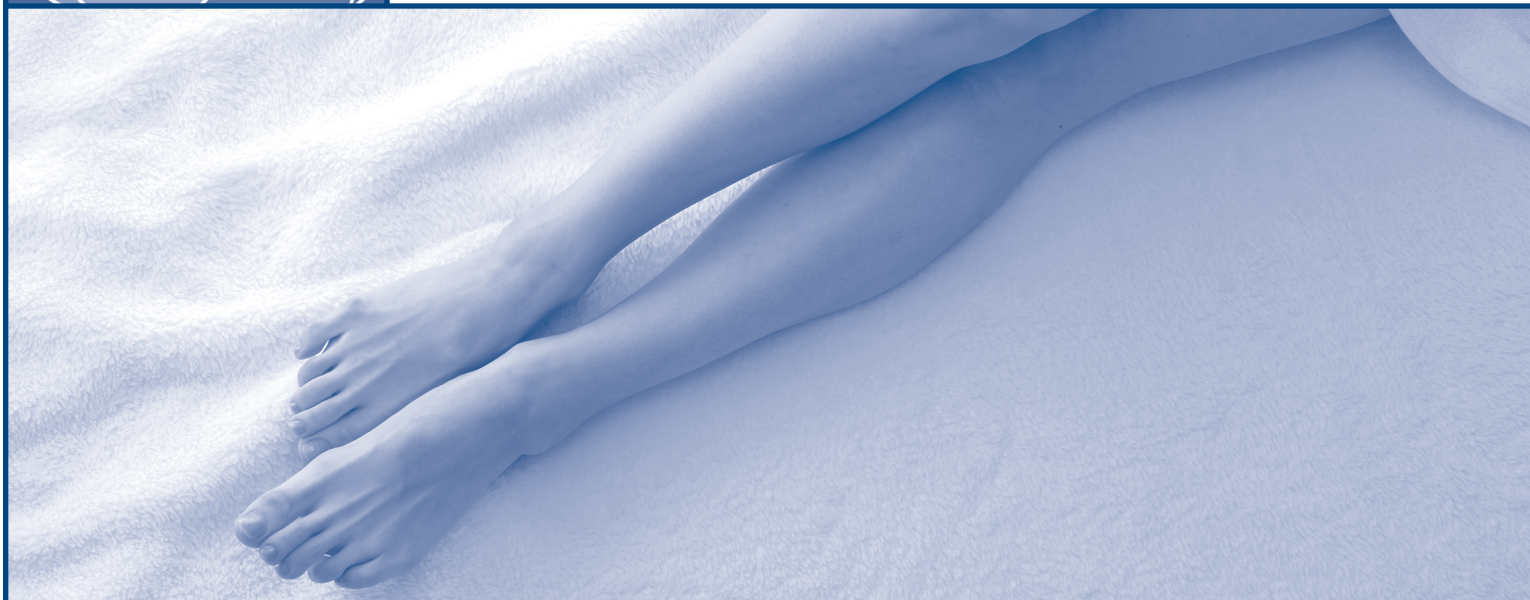
All those suffering with no cure	Rhondda Grant
All those who suffer and are not understood	Charles D. Hamilton
Dr. Avinash Aggarwal	Jeffrey Jones
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# RLS and Periodic Limb Movements in Sleep



Periodic limb movements in sleep (PLMS) are recurrent movements of the feet and legs that usually occur every 20 to 40 seconds while a person is asleep. In severe cases, these movements can number into the hundreds over the course of a night.

PLMS is not a diagnosis or a disease, but rather a motor phenomenon that occurs during sleep. PLMS often happen with restless legs syndrome (RLS), as up to 90% of people with RLS also have PLMS. But PLMS also commonly occur with other conditions such as sleep apnea, narcolepsy, Parkinson's disease, neuropathy and multiple sclerosis, and are even present in healthy people, especially if they are elderly. They are commonly caused by the most antidepressants or antipsychotic agents.

## The motor phenomenon

Individual movements that constitute PLMS consist of flexion of the foot, largely through the contraction of a muscle called the anterior tibialis. Other muscles that are involved include the gastrocnemius (calf), quadriceps, hamstrings, and small muscles of the foot.

Most commonly, movements consist of flexing of the foot at the ankle and fanning of the toes, but sometimes a larger amplitude movement of the upper leg can also occur. To a nearby bed partner, these movements, even if only of the foot, can be disruptive, as they are often brisk and powerful.

## Effects on sleep and wakefulness

As the name implies, PLMS occur during sleep, so people who have PLMS may not know that they move their legs during sleep. Often it is the bed partner who makes them aware of these movements.

Periodic limb (or leg) movements can also occur when people are awake, as is often the case for those who have RLS, and may take place right before sleep. Their legs and feet will move and “jump” involuntarily. This, in addition to the uncomfortable urge to move the legs caused by RLS, often results in delayed sleep.

Individual movements associated with PLMS can also be associated with very brief arousal from sleep. These arousals may occur without the person being aware of them or may result in more prolonged awakening.

## Severity of PLMS

PLMS are most often detected during a sleep study, during which the frequency of movements is reported in an index called the periodic limb movement index, or PLMI. This is expressed as the number of individual movements per hour of sleep, and ranges from zero to about 120 per hour. Some physicians would consider a PLMI of greater than 5–10 as abnormal, and perhaps a PLMI of greater than 30 as severe. But this is not a hard and fast rule for determining the clinical importance of these movements.

## Relationship to RLS

As previously stated, PLMS occurs in up to 90% of people who have RLS. It is also true that the severity of RLS correlates to the PLMI, and that both RLS severity and PLMI tend to increase with age. Medicines that treat RLS, especially dopaminergic medications, also suppress PLMS.

## What is the significance of PLMS?

The significance of PLMS in relation to physical health is an area of investigation. It is known that individual limb movements making up PLMS are associated with discrete increases in blood pressure and heart rate. This has led some scientists to hypothesize that these movements may link RLS and PLMS to high blood pressure, heart disease and stroke. Although epidemiologic studies suggest that this might be true, it is not clear if PLMS are causal to this increased risk of cardiovascular disease or simply a marker of cardiovascular disease.

## What is PLMD?

Periodic limb movement disorder (PLMD) is a condition in which PLMS have been demonstrated, usually by polysomnography, and at the same time the patient experiences poor sleep or daytime sleepiness.

The thought behind PLMD is that frequent PLMS results in recurrent arousal, poor sleep, and thus sleepiness or tiredness during the day. A patient can take medication to suppress the PLMS, thus also improving sleep quality and daytime functioning.

In diagnosing PLMD, it is very important to rule out other causes of poor sleep and fatigue. PLMD can only be diagnosed when other conditions, including RLS, have been ruled out or treated adequately.

## Should PLMS be treated?

Treatment for PLMS may be recommended in some, but not all, cases. For someone who has RLS that is sufficiently severe to warrant medical treatment, the good news is that often this treatment will decrease PLMS, especially if the medicines are in the dopaminergic or alpha-2-delta ligand medication classes.

Someone who does not have RLS, but rather has PLMS with poor sleep or daytime fatigue, may want to consider treatment options if PLMS symptoms are severe enough to offset the risk of medication side effects. There is no evidence that treating PLMS with medicine decreases cardiovascular risk, and most RLS and PLMS experts do not advocate treating these movements in isolation when there are no symptoms of RLS.

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*The RLS Foundation is dedicated to improving the lives of the men, women, and children who live with this often devastating disease. The organization's goals are to increase awareness, improve treatments and, through research, find a cure for restless legs syndrome.*

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*The RLS Foundation is unable to respond to individual medical or treatment-based questions due to liability issues. Your personal healthcare provider knows you best, so please contact your provider with specific questions related to the ongoing management of your RLS. We welcome your general-interest medical questions, which may be submitted to [info@rls.org](mailto:info@rls.org) with "Ask the Doctor" in the subject line. Select questions on areas of common interest will be published in a future issue of Night Walkers. Questions will be edited as needed and published anonymously.*

**Q:** I suffer from RLS almost all the time. It is very difficult to rest, sleep or nap. The meds I am taking are pramipexole and gabapentin. I would consider my RLS severe. I am not sure what to do from here. I am desperate for relief.

**A:** Severe and chronic forms of RLS that become resistant to typical treatments over time, are common. Successful management of these cases requires much more information and a careful medical evaluation. The best strategy is to consult a specialist who has expertise in RLS, such as a provider at an RLS Quality Care Center. In general, one of the issues to be clarified is whether or not a patient is experiencing augmentation. Also, it is important to check for adequate iron stores, comorbidities, and medications that are contraindicated in RLS. Based on this medical evaluation, different strategies can be considered: to modify the dose and time of administration of the current therapy; to switch to, or combine with other medications like rotigotine or pregabalin; or in very severe cases, to consider the use of opioids.

*Mauro Manconi, MD, PhD*

**Q:** After augmenting on Mirapex, I was prescribed the 2 mg Neupro Patch to be applied daily. During the first month of using the patch, my RLS symptoms were almost nonexistent; however, the first time I placed the patch on my abdomen, I experienced extreme RLS during the entire night. Following the patch placement guidelines, I tried placing the patch on my thigh and hip, on two separate occasions. I again experienced terrible RLS symptoms throughout the night. However, when placing the patch on my arms, chest and back, I get almost 100% relief from my RLS for the first time in almost a year. For some unexplained reason the patch does not work for me on the lower torso. Is there an explanation for my strange experience with the Neupro patch placement on the lower torso?

**A:** The effectiveness of any patch first depends on how well it is absorbed through the skin. Overall, Neupro Patch is absorbed slightly less effectively in the thighs compared to the shoulders and arms. In any individual, this may be more pronounced depending on a number of factors. For example, someone who rubs their thighs to improve RLS may develop callouses or inflammation that would reduce absorption.

*William Ondo, MD*

**Q:** I was on Xanax for anxiety for many years, but I got to the point where I could not take the drug anymore. I switched to Klonopin (1 mg, three times daily), which has worked great for the anxiety but not for my RLS. (When I used Xanax, only .25-.50 mg was enough to relieve my RLS when I got into bed.) I have RLS only once or twice a week, so I don't want to take a drug every day. I tried Requip, but that did nothing for me; it seems that Xanax is the only thing that works. I have been using any leftover Xanax as needed for my RLS, with no aftereffects or side effects, but it won't last forever. My psychiatrist and general physician won't prescribe just four or five .50 mg doses per month for my RLS. Any idea what I can do to get the Xanax that I have used for years and that has a proven track record of relieving my symptoms?

**A:** You describe a typical case of coexistence of anxiety and a mild form of RLS, where the patient is looking for one single drug to control both disorders. First, it is a bit unusual that alprazolam (Xanax) works better than clonazepam (Klonopin) in RLS. Both are benzodiazepines. The main difference between them is the duration of their effect, which is very long for clonazepam (more than 35 hours) and much shorter for alprazolam (8 to 11 hours). Therefore, clonazepam does not need to be taken three times per day. Also, data supporting the effectiveness of benzodiazepines to treat RLS is not convincing, and these drugs are no longer recommended for RLS. If there is a need to stay on benzodiazepines, then the only other compound that has been tested for RLS is temazepam, which has a pharmacological profile much more similar to alprazolam than clonazepam. One valid option might be to consider a complete shift from benzodiazepines to the alpha-2-delta ligands drug category (gabapentin, pregabalin, and gabapentin enacarbil), which can be very effective for both anxiety and RLS.

*Mauro Manconi, MD, PhD*

# In the News

By Lynn Marie Trotti, MD, MSc

## Can CPAP Treat RLS?

Lakshmanan S et al. “Impact of Positive Airway Pressure on International Restless Legs Syndrome Score in Sleep Disordered Breathing.” *Journal of Clinical Medicine*, December 2019.

### The Background

Obstructive sleep apnea is a disorder that results in repetitive collapse of the airway during sleep, which causes oxygen levels to fall, and sleep to be disturbed. Obstructive sleep apnea is very common in adults. It is not yet clear from studies whether people with RLS are more likely to have obstructive sleep apnea than people without RLS. However, because RLS and obstructive sleep apnea are both common, there is a large group of people who will have both disorders, even if the two disorders do not share a specific relationship. Both sleep disruption and low oxygen levels might worsen existing RLS symptoms, so treatment of sleep apnea might help with RLS symptoms in people who have both disorders. Continuous positive airway pressure (CPAP) is usually the first-line treatment of obstructive sleep apnea. It works by using pressurized air to splint the airway open, and requires use of a small machine and mask during sleep.

### The Research

The researchers reviewed clinic records to identify people with RLS who were diagnosed with obstructive sleep apnea over a 5.5-year period. RLS severity prior to and after sleep apnea diagnosis was measured using the International RLS Severity Scale – a 40-point scale that is commonly used to assess RLS symptoms and their effect on sleep and daytime functioning. People who used CPAP to treat their sleep apnea were compared to people who did not use CPAP. Records from a total of 434 patients were included in the study, of which 325 used CPAP and 109 did not. Nearly half of the patients were treated with RLS medications. The people who used CPAP tended to be older, had more severe sleep apnea, and were more likely to be male. The people who did and did not use CPAP had similar severity of RLS symptoms when sleep apnea was diagnosed. Sixty-two percent of people using CPAP used it regularly (i.e., at least 4 hours per night, at least 70% of nights). Although RLS symptom severity improved in both groups over time, it improved more in people in the CPAP group than those in the non-CPAP group.

### The Bottom Line

There are multiple reasons to treat obstructive sleep apnea. For people who have RLS and obstructive sleep apnea, treatment of sleep apnea with CPAP may reduce RLS severity.

### Further Questions

A placebo-controlled trial of CPAP would be very helpful to confirm a treatment benefit in people with RLS and obstructive sleep apnea. If indeed CPAP reduces RLS severity, what is the mechanism? Do people with more severe drops in oxygen benefit from CPAP more, in terms of RLS severity? Or do people with more severe sleep disruption benefit from CPAP more? For people who cannot tolerate CPAP, do other treatments for sleep apnea also reduce RLS symptoms to a similar extent?

## Why Do Children with Kidney Disease Develop RLS?

Riar S et al. “Restless Legs Syndrome in Chronic Kidney Disease: Is Iron or Inflammatory Status to Blame?” *Journal of Clinical Sleep Medicine*, November 2019.



Lynn Marie Trotti, MD, MSc

### The Background

Although the exact cause or causes of RLS are not yet known, research has identified a variety of factors that increase the risk of developing RLS. These include genetic factors (including nearly 20 different genes) and nongenetic factors. Major risk factors in the latter group include iron deficiency and chronic kidney disease. Inflammation has also been implicated as either a cause or consequence of RLS. Although chronic kidney disease is known to be a risk factor for RLS, it is not known how kidney disease, iron levels, and inflammation may be related in children with RLS.

### The Research

Children with kidney disease were recruited into the study (with permission from their parents). Three different groups were included; children who had previously had a kidney transplant, children who were receiving dialysis for kidney disease, and children with kidney disease who did not need a transplant or dialysis. RLS was diagnosed by questionnaire, completed by the parent (for kids ages 8–12) or completed by the teen (ages 13–18). Multiple measures of iron, anemia and inflammation were collected in a blood sample. RLS was present in 15% of the 124 children with kidney disease, similar across all three types of kidney disease. Iron deficiency was common in the children with kidney disease (present in 71%) but was not related to the presence or absence of RLS. Inflammation was also common in the children with kidney disease (present in 40%) and unrelated to RLS.

### The Bottom Line

Although iron deficiency and inflammation are both common in children with kidney disease, neither explains the relationship between chronic kidney disease and RLS.

### Further Questions

Measures of iron and inflammation in the brain and spinal cord may be different than measures of iron and inflammation in the blood. Because RLS is likely a disorder of brain and/or spinal cord, abnormalities of iron or inflammation within the nervous system might still explain some of the relationship between RLS and kidney disease.

## Sleep and Attention-Deficit Hyperactivity Disorder

Liu X et al. "Association of Sleep Problems with ADHD Symptoms: Findings from the Shandong Adolescent Behavior and Health Cohort (SABHC)." *Sleep*, December 2019.

### The Background

Attention-deficit hyperactivity disorder (ADHD) is a common neurologic condition that results in difficulties with attention, and impulsivity or hyperactivity. Children with ADHD frequently have poor sleep, and this poor sleep may both worsen ADHD symptoms and result from ADHD symptoms. Abnormalities in dopamine and iron have been implicated in both ADHD and RLS, and prior studies have shown that RLS and ADHD commonly co-occur. However, most studies investigating the potential relationship between RLS and ADHD have measured only a single point in time, rather than monitoring people over time for the development of ADHD.

### The Research

Adolescents were recruited from middle and high schools in China to participate in a study that required completing questionnaires at the beginning of the study and again one year later. The questionnaires evaluated RLS (using the four RLS diagnostic questions) and ADHD symptoms, along with sleep duration, insomnia symptoms, snoring, age, sex, tobacco and alcohol use, depression, other mental health problems, medical problems, economic status, and parental relationships. Over 8,000 adolescents were recruited into the study, of whom 7,072 completed questionnaires at both time points. Equal numbers of boys and girls were included, with an average age of 14.6 years. ADHD symptoms were present in 7.6% of the adolescents at the first visit and 6.7% at the second visit, and equally common in boys and girls. At a single point in time, adolescents with ADHD symptoms were more than twice as likely as those without ADHD symptoms to have RLS symptoms (17.4% vs 8.5%). The association between RLS symptoms and ADHD symptoms was not explained by differences in age, gender, smoking, alcohol use, mental health, physical health, economic status or parental relationships. Adolescents with ADHD symptoms were also more likely to have other sleep problems and short sleep times. Of the adolescents without ADHD symptoms at the first visit, 291 (4.5%) developed ADHD symptoms by the second visit. Those adolescents with RLS symptoms at the first visit were nearly twice as likely as those without RLS symptoms to have developed ADHD symptoms by the second visit, even accounting for the other substance, mental health, physical health and social/economic variables.

### The Bottom Line

Adolescents with RLS are at increased risk for developing ADHD symptoms over time.

### Further Questions

Does treatment of RLS modify the risk of developing ADHD? In people with both RLS and ADHD, are dopaminergic or nondopaminergic medications better for the treatment of RLS?

## 'Tis the Season for RLS?

Liguori C. "Seasonality of Restless Legs Syndrome: Symptom Variability in Winter and Summer Times." *Sleep Medicine*, August 2019.

### The Background

RLS symptoms may vary over time, but the reasons for this variability are not fully understood. Some patients report an increase in RLS symptoms during the summer months, and a prior study demonstrated that Google searches for the term "restless legs" peak in the summer across multiple different countries. However, the possible seasonal variability in RLS symptoms has not been systematically studied.

### The Research

The researchers reviewed clinical charts to identify patients with RLS who had completed the International RLS Severity Scale during the hottest and coldest months in their region (either Austria or Italy). To be included, patients had to have had no changes to their RLS treatment between time points, no augmentation, and no causes of secondary RLS. A total of 64 patients were included, about two-thirds of them women, with an average age of 55.5 years old. For the group as a whole, RLS severity was significantly worse, by an average of 2.2 points, in the hottest summer months than the coldest winter months. However, this difference was only seen in the patients from Italy and among men.

### The Bottom Line

Among patients whose RLS treatment remains the same, RLS symptoms appear to worsen during the hottest months of the year.

### Further Questions

What explains the seasonal variability in RLS severity? The authors propose several hypotheses, including abnormalities of cooling driven by vascular or autonomic nervous system dysfunction, and fluctuations in iron. These hypotheses need to be tested in controlled studies.



# RLS Support Network

RLS **support group leaders** bring people together to share their experiences, gain coping strategies, learn from medical experts, and build a community of care. For a list of international support groups, visit [rls.org/internationalsupport](http://rls.org/internationalsupport). The Foundation also has a network of volunteer RLS **support contacts** who provide help by phone or email.

You can also find support at any time, day or night, on the RLS Foundation's **discussion board**. Visit [bb.rls.org](http://bb.rls.org) or email [rlsfmods@rlsgroups.org](mailto:rlsfmods@rlsgroups.org) for more information on how to get started.

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## Want to Join the Team?

We are always looking for volunteer support group leaders! Help is especially needed in the following states: **Alabama, Alaska, Arizona, Connecticut, Delaware, Georgia, Hawaii, Iowa, Kansas, Louisiana, Maryland, Minnesota, Mississippi, Missouri, Montana, Nebraska, New Mexico, New York, North Dakota, Oklahoma, Rhode Island, Utah, West Virginia, Wisconsin and Wyoming.**

If you are interested in starting a support group in your community, contact the RLS Foundation today! Visit [www.rls.org/volunteer](http://www.rls.org/volunteer) or email [clara@rls.org](mailto:clara@rls.org) for more information on how to apply.

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## New Support Group Leader

The RLS Foundation is pleased to welcome a new support group leader!

### Bonny Lepore

Prescott Valley, Arizona

*"I have suffered with RLS since 1980, severely since 2005. In my last stop to find an answer for my out-of-control RLS, a neurology clinic sent me home with little new information or hope. Since then I have begun looking for answers from other sources. I am personally interested in one-on-one contact with those in my area who are dealing with this difficult and sometimes debilitating syndrome. My experience, understanding and professional contacts will help me guide others to helpful resources."*



# Bedtime Stories

*Bedtime Stories are the opinions of the authors only and not of the RLS Foundation, its employees or its Board of Directors. Publication in NightWalkers does not imply endorsement by the RLS Foundation. Therapies and results described in Bedtime Stories reflect the experiences of individuals and cannot be generalized to everyone with RLS. It is important to talk to your healthcare provider and investigate concerns such as safety, efficacy and cost before making any changes to your treatment regimen. Stories may be edited for length or clarity.*

I had a fall in 2005 and twisted my ankle. My foot was stiff and swollen for a month; then the shaking, twitching and pains started. At the end of the day I would lay in bed with my legs shaking uncontrollably. I saw a neurologist, and he said it was RLS. I was prescribed medications but never took them because of the bad side effects. Shortly after my diagnosis, I went to Poland and my symptoms subsided, but came back when I returned to the US. I figured it was the Polish mineral water that helped, and I have been drinking it now for 12 years. It's high in magnesium\* and helps flush out excess sodium. I read a book by a naturopathic doctor who said you should limit your sodium to 2–200 mg per meal. The water is no cure, but my RLS is 80% to 90% better than before. I still have cramps sometimes, and wearing bad shoes, or standing or carrying too much weight for too long gets my RLS going. Swimming and biking are the best exercise for me, but I can't do too much of any exercise. I'd love a cure. I'm now 46 and have been dealing with this for 14 years. — *Stephanie*

Something that works for my restless legs syndrome is an over-the-counter supplement called lecithin.\* Years ago, I started to include lecithin every day with my regular vitamins. I had no idea that it would calm my restless legs. Every once in a while, I forget to take my vitamins along with the lecithin, and RLS strikes every time. As soon as I feel that uncomfortable feeling, I take lecithin and I'm comfortable again. Ask your doctor what he or she thinks. I hope for the best for all of you who suffer this uncomfortable disorder. — *Carol*

I have associated my RLS episodes with a combination of food and medication. An anticoagulant seems to sensitize me to foods that contain neuro-stimulants such as monosodium glutamate (MSG). I need to take the anticoagulant medication, but by avoiding highly processed foods that may contain glutamate, the incidence and severity of my RLS symptoms are diminished. Also, when I take the evening meds as early as possible and eat dinner early, this stimulates RLS earlier in the evening, when it can be overcome by activity. — *Pete*

I've experienced restless legs syndrome on and off for many years, but I've also had other symptoms such as sudden excessive tiredness, low mood, and irritability. My RLS seemed to be linked to eating particular foods and drinks (especially crisps and cheese, and sometimes alcohol). After many years of experiencing

symptoms I recently realized that all of them, including RLS, were being caused by histamine intolerance. This means that I am lacking the digestive enzyme DAO (diamine oxidase) to break down the histamine that many foods contain, so excess histamine builds up in my system and causes problems. I found that taking a DAO supplement\* before each meal helps to greatly relieve my symptoms, which is very welcome after having them for so long. I'm sure there may be many causes of RLS, but I just wanted to share my story in case it helps anyone else. — *Brett*

After all of my adult life with on-again, off-again RLS, I suffered devastating symptoms most of 2018, which provoked me to contact the RLS Foundation. I learned from your resources about augmentation from my meds.\*\* I approached my neurologist regarding this revelation, and my symptoms immediately ceased upon discontinuing my meds. I now also do not drink any wine, and I am symptom free! If on occasion I drink wine, then I experience relatively light RLS symptoms. — *Anonymous*

*\*\*Augmentation is a serious side effect of some RLS medications. If you are taking a dopamine medication and begin experiencing RLS symptoms that occur earlier in the day, increase in intensity, or spread to other parts of your body, then you may be experiencing augmentation. Contact your RLS healthcare provider promptly for guidance. To learn more, visit [www.rls.org](http://www.rls.org) or request RLS Foundation publications about augmentation, available on page 23.*

**Reminder:** Consult with your healthcare provider before making any changes to your treatment regimen, including dietary changes or supplements.

*\*Note: Research on supplements is limited. Before taking a supplement, it is best to seek the advice of your healthcare provider to ensure there are not interactions with other medications you may be taking.*



*A clinical trial is a research study that uses volunteers to investigate specific health questions. The RLS Foundation does not conduct clinical trials; however, as a service to our members we list clinical trial opportunities on [www.rls.org](http://www.rls.org) and in NightWalkers. Below is a partial list of RLS clinical trials currently seeking volunteers. Please contact the institution directly if you are interested in participating. All studies listed have received Institutional Review Board approval, which allows us to ensure that they follow established protocols. Please note: This is not a comprehensive list. To search for clinical trials in your area, visit [www.searchclinicaltrials.org](http://www.searchclinicaltrials.org) or [www.clinicaltrials.gov](http://www.clinicaltrials.gov).*

*To learn more about clinical trials, members can download the handout Clinical Trials and Research from [www.rls.org](http://www.rls.org) or request a paper copy from the Foundation.*

## Hormones and Their Role in Restless Legs Syndrome

RLS community: Brian Koo, MD, and his team at Yale University need your help. The researchers have received funding from the Department of Defense to continue their study of hormones in RLS and are looking for RLS patients to participate. The researchers are able to reimburse you for the cost of your travel (up to \$600) for a one-time visit to New Haven, Connecticut. The research aims to uncover the underlying biological mechanisms of RLS – an essential step to develop new, more effective treatments for RLS and to discover a cure.

Specifically, Dr. Koo's team is conducting the study to determine whether levels of specific hormones are increased in the blood and spinal fluid of persons with RLS. The research requires that participants undergo blood draws and a spinal tap. The researchers are looking for individuals with moderate to severe primary idiopathic RLS who do not have other disorders such as kidney disease, multiple sclerosis, Parkinson's disease, or severe neuropathy and who are not currently taking medicine for RLS. If you are taking medicine for RLS, you can discuss with Dr. Koo the possibility of temporarily coming off of your medicine. If you believe you are eligible or have any questions about the research, please contact the study team.

Contact: Nada Ahmed, [nada.ahmed@yale.edu](mailto:nada.ahmed@yale.edu) or 203-785-7393

## Investigational Nerve Stimulation Device

Researchers at SRI International (funded by Noctrix Health) are looking for people with RLS to test an investigational nerve stimulation device designed to reduce RLS symptoms. The study involves the evening use of small nerve stimulation devices attached to both legs, an actigraphy sleep assessment (a noninvasive method of monitoring rest and activity cycles), and daily electronic surveys for up to five weeks at home. There will be three, two-hour in-lab visits at the Human Sleep Research Laboratory in Menlo Park, California, scheduled in the evening at your convenience. You may qualify if you are 18 to 75 years old, have RLS, and live in the San Francisco Bay area. If you qualify to participate, you will be compensated up to \$400 for your participation.

Contact: 650-859-4532 or [sleep@sri.com](mailto:sleep@sri.com)

## Well-Being and Health in RLS

Restless Legs Syndrome (RLS) is a condition associated with significant lifestyle changes. Researchers at Yale University are conducting a study that looks at health and well-being in patients with RLS. The researchers are looking to study primary RLS, which is RLS that occurs in the absence of

diseases like Parkinson's disease, multiple sclerosis, severe neuropathy, end-stage renal disease, schizophrenia, terminal cancer, and others. The study is a one-time online questionnaire that takes about 10–20 minutes to complete. You will not need to talk to anyone to complete this study, and your response is completely anonymous. There is no way for the researchers or anyone to determine your identity, even after you have completed the questionnaire. To participate:

- Follow this link to the survey: [https://yalesurvey.ca1.qualtrics.com/jfe/form/SV\\_4I7rXK9CXrA7wwt](https://yalesurvey.ca1.qualtrics.com/jfe/form/SV_4I7rXK9CXrA7wwt)
- The first page contains information about how data is collected and stored. Selecting "I consent to participate in this research study" to initiate the survey.
- Please read all instructions carefully to ensure that questions are answered appropriately.
- Most of the questions require a response. Do not skip any sections unless instructed to do so. You will be informed if you accidentally skip a required question.
- The survey should be completed in one sitting.

Contact: Nada Ahmed, [nada.ahmed@yale.edu](mailto:nada.ahmed@yale.edu)

## Is RLS Affecting Your Child?

Science 37 has a new six-month research study for youth ages 13 to 17 affected by restless legs syndrome (RLS). The study explores whether a medication that is already approved for RLS in adults is also effective in adolescents with RLS. If it's a condition your child is struggling with, consider joining this research study. This study is open to those with RLS who are living in California, Florida, Illinois, New Jersey, New York and Texas. You can participate through an app from the comfort of your own home, and compensation is available.

Contact: 310-464-2190, [RLSstudy@science37.com](mailto:RLSstudy@science37.com)

Visit: [science37.net/rls](http://science37.net/rls)

## Adolescent RLS

Does your child have discomfort in their legs that may interfere with their sleep? They may describe their symptoms as throbbing, pulling, creeping, pain or other abnormal sensations in the legs when they are lying down or sitting. Your child may be suffering from RLS.

Worldwide Clinical Trials is conducting research studies to test an investigational medication for the treatment of adolescent RLS. You will receive the medication at no charge, an assessment by an RLS expert and compensation for participating. The studies will take place at the following locations: Amherst (NY), Columbia (SC), Indianapolis (IN), Nashville (TN), Philadelphia (PA), Redwood City (CA), and San Diego (CA). Qualified participants will be compensated for time and travel. To qualify, participants must:

- Be 13–17 years of age
- Have moderate-to-severe symptoms
- Be diagnosed with RLS
- Have parent/legal guardian consent

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## United We Stand



*RLS Foundation Board of Directors*

Is the nation as divided as network anchors and cable news pundits say we are? From the wall-to-wall coverage of today's political landscape, it might seem so – but at the RLS Foundation, we're grateful to say that our membership is a house united!

We all may come from varied backgrounds, faiths and ideologies, but when it comes to the disease we share, we stand firmly on common ground. Thanks to member support, we have begun to make our united voice heard and respected on both sides of the aisle in Washington.

Two years ago, we decided it was time to add a new pillar – public advocacy – to support the efforts that underpin so much of what we do in awareness-building, quality care delivery, and world-class research. In 2019, we learned just how powerful and effective our voices could be.

Our advocacy goals are incisive and laser-focused. We aim to press policy makers and stakeholders to support an increase in RLS research, to clear a path for improved education about RLS within the medical community and with the public, and to ensure patients with severe RLS continue to have access to low total daily dose opioid therapy, an important consideration as our nation grapples with the opioid crisis.

With the springboard of these clear objectives, expert counsel, and dedicated involvement from our staff and members, we set out in a quest to make significant headway.

- We held the first-ever RLS Advocacy Day on Capitol Hill in Washington on May 3, 2019, organizing a team of 30 participants to meet with 45 congressional offices representing 16 states.
- We educated key legislators, agency officials, and policy makers through a grassroots base of RLS patients and a group of congressional champions both on and off the Hill.

- We mobilized 350 public comments from the RLS community on federal rulemaking regarding the opioid epidemic to press the case for access to low total daily dose therapy.
- We coordinated grassroots meetings with local congressional offices throughout the country during the August recess.

In short order, our efforts began to bear fruit. We secured key congressional appropriations committee recommendations to support RLS research in the 2020 federal budget. We convinced Congress to continue to champion RLS research at the National Institutes of Health. The Senate Defense Appropriations committee once again included “sleep disorders” among the conditions eligible for funding through a Department of Defense medical research program. (For updates in these areas, including news of federally funded RLS research, turn to pages 3 and 6.)

And, at long last, we earned Congressional recognition of RLS Awareness Day on September 23!

Our members made the difference in two important ways. Membership dues and contributions to Foundation fundraisers helped pay for our presence in Washington and for experts who continue to guide us through the bureaucratic thicket and enable our voice to be heard. Moreover, some members strengthened our presence with their own personal voices and stories, through written comments and in-person meetings. To find out how you can make a personal difference, visit [www.rls.org/get-involved/advocacy](http://www.rls.org/get-involved/advocacy).

We enter a new year and a new decade with palpable optimism that a cure is finally within reach. We stand as a house united – not divided – as we continue to persuade policymakers across the political spectrum to more fully accommodate the needs of RLS patients, and to help deliver our ultimate goal of finding a cure for RLS.

## Publications

Most of the following publications are available for Foundation members to view and download at [www.rls.org](http://www.rls.org). Please note that all publications are copyrighted and may not be used in whole or part without prior permission from the RLS Foundation.

Quantity	Patient Handouts	Quantity	Patient Handouts	Quantity	Patient Handouts
	Active Lifestyle		Drug Holidays and RLS		Research Grant Program
	Augmentation: Diagnosis & Treatment		Guide to Living with RLS		Surgery and RLS
	Augmentation: A Quick Guide		Healthcare and Your Child with RLS		Symptom Diary for RLS
	Augmentation FAQ		Hospitalization Checklist		Triggers for RLS
	Clinical Trials and Research		Medication Withdrawal after Augmentation		Understanding Iron and RLS
	Complementary/Alternative Medicine and RLS		Medications for RLS		Understanding Possible Mimics of RLS
	Coping Methods		Pain and RLS		Your First Doctor Visit for RLS
	Depression and RLS		Periodic Limb Movements During Sleep		
Quantity	Patient Brochures	Quantity	Patient Brochures	Quantity	Patient Brochures
	Causes, Diagnosis and Treatment for the RLS Patient		RLS Guide for Children (nonmembers \$5)		
	Giving Avenues		RLS Guide for Teens (nonmembers \$5)		
Quantity	Healthcare Provider Brochures	Quantity	Healthcare Provider Brochures	Quantity	Healthcare Provider Brochures
	Pregnancy and RLS: A Guide for Healthcare Providers		RLS and PLMD in Children and Adolescents		
	Medical Bulletin: RLS Diagnosis and Treatment (nonmembers \$10)				

## MEMBERSHIP

☐ Yes, I want to join the Restless Legs Syndrome Foundation or renew my membership. (\$35\* US or Canada • \$45\* International)  
\*Amounts in US dollars

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☐ I would like to make an additional tax-deductible donation of \$\_\_\_\_\_.

☐ I would like to make a recurring monthly gift of  
 \$\_\_\_\_\_ Start date: \_\_\_\_\_ End date: \_\_\_\_\_.

## DONATION APPLIED TO

☐ research  
☐ where it is needed most

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# SAVE THE DATE:

The RLS Foundation is planning the next  
**National RLS Patient Symposium**  
**October 16-18, 2020 • Baltimore, Maryland**  
Mark your calendar, and watch for details in the next issue of *NightWalkers!*



## 2020 National RLS Patient Symposium

# MAKING RLS CONNECTIONS

OCT 16-18, 2020



BALTIMORE, MD