

# NIGHTWALKERS

*In search of a good night's sleep*

**Fall 2020**

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SYNDROME  
FOUNDATION

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**NightWalkers** is the official publication of the Restless Legs Syndrome (RLS) Foundation

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*From the Director*

## Working Together for a Common Cause

The common theme underlying our work during the fall focuses on the importance of advocacy – several opportunities allowed Restless Legs Syndrome Foundation members to serve as advocates for themselves, others and the greater RLS community.

On RLS Awareness Day, September 23, we invited you to participate in the RLS Patient Odyssey Survey II. The survey offered an opportunity to share important information regarding RLS treatments, and the effects of RLS on emotional well-being, relationships and overall health. By investigating the burden of disease, the RLS Patient Odyssey Survey II will help to uncover areas for future education and research, such as barriers to receiving adequate care. Study results also provide current RLS data to support our advocacy outreach in Washington. I thank everyone and their partners from across the globe who took the time to take the survey. Our next step is to present the survey findings to over 5,000 healthcare providers and researchers in attendance at the Seattle SLEEP 2021 conference, which will be held in June 2021.

RLS Awareness Day culminated on September 23 with a call to action. Members were asked to contact their congressional legislators and share their personal RLS story. Your advocacy helps to expand our reach to make all congressional legislators RLS-aware. I thank everyone who took part in this RLS advocacy outreach to raise awareness and consideration of our needs among lawmakers when it comes to policy or legislation.

RLS Foundation members are a unique cohort of advocates. Our strength in numbers amplifies the needs of the men, women and children who live with this often-devastating disease. By advocating at the national level, we hope that legislator awareness and support for RLS research through funding will advance our goals for new treatments and a cure. The glue that makes our advocacy efforts an effective binder is you.

As always, we do this together.

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



Karla M. Dzienkowski, RN, BSN  
Executive Director

## NightWalkers has a New Medical Editor

The Restless Legs Syndrome Foundation is happy to announce that Mark J. Buchfuhrer, MD, FRCP(C), FCCP, FAASM is the new medical editor for *NightWalkers* magazine!

Dr. Buchfuhrer, a prominent member of the Foundation's Scientific and Medical Advisory Board, is a sleep specialist and pulmonologist in Downey, California. He is affiliated with multiple hospitals in the area, including PIH Health Hospital-Downey and the Restless Legs Syndrome Clinic at the Stanford Center for Sleep Sciences and Medicine, a certified RLS Quality Care Center. Dr. Buchfuhrer received his medical degree from University of Ottawa Faculty of Medicine and has been in practice for more than 38 years. He also serves on the Foundation's Medical Bulletin Committee, the Opiates Committee and the Revised Treatment Consensus Committee.

"The RLS Foundation welcomes Dr. Buchfuhrer's return as Medical Editor of *NightWalkers*," said Karla Dzienkowski, the Foundation's Executive Director. "Dr. Buchfuhrer's decades of experience as a clinician and researcher will ensure scientific accuracy and completeness of all articles published in *NightWalkers*. Dr. B, as the patient community prefers to call him, is a fan-favorite for webinar presentations and is always willing to lend a hand to RLS Foundation staff to keep projects that benefit the RLS community moving forward. We look forward to working with Dr. Buchfuhrer as we continue our goals to educate and inform the RLS community through *NightWalkers*."

### Thank You, Dr. Koo!

The Restless Legs Syndrome Foundation also gives a big thanks to Dr. Brian Koo for serving as *NightWalkers*' medical editor over the last five years. His medical expertise has allowed us to provide our members with

trustworthy, accurate health information in every *NightWalkers* issue. Dr. Koo, also a member of the Foundation's Scientific and Medical Advisory Board and director of the Yale Center for Restless Legs Syndrome, a certified RLS Quality Care Center, always made time in his busy schedule to share his knowledge and guidance

"The RLS Foundation is thankful for Dr. Koo's five years of service to the organization as Medical Editor of *NightWalkers*," said Dzienkowski. "He reviewed countless articles over the years to ensure accuracy and alignment with current treatment guidelines. Dr. Koo's knowledge and editorial experience has been instrumental in making *NightWalkers* a trusted educational resource for the RLS community. We are grateful for his contributions and expertise, which enhanced the quality of life for those living with RLS."

Dr. Brian Koo, chief medical director of Sleep Medicine at the Connecticut Veterans Affairs Healthcare System, is also an assistant professor of neurology at Yale University. He will continue as chair of the Foundation's Medical Bulletin Committee and serve on the Revised Treatment Consensus Committee.



Mark J. Buchfuhrer, MD,  
FRCP(C), FCCP, FAASM



Brian Koo, MD

## Honor Roll

*The Restless Legs (RLS) Foundation is sincerely grateful for the donations we received in memory and in honor of the following individuals from July 1, 2020 through September 26, 2020:*

### In Honor of:

Your daddy  
Your mother, who also suffered  
with RLS  
Betty M. Brockington  
Dr. Mark Buchfuhrer  
Gail Buckley  
Zibby Crawford  
Ali Dzienkowski  
Dr. Christopher Earley  
Dana Evans  
Mary Fluri  
Maddie Lionberger  
Jason & Ben Moore

Lew Phelps  
J Steven Poceta, MD  
Clara Schlemeyer

### In Memory of:

A beloved brother-in-law  
Our beloved uncle, Dave  
Carole J. Adams  
Gerda A. Berndt  
Thelma E. Bradt  
Elsie F. Brown  
David J. Correia  
Thad Cox  
Steve Crnkovich

Dan Daly  
George M. DeRoche  
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Margaret Gibson  
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Rob Kaplan  
Shirley Ruth Kibler  
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Debbie Kunze and Carl Willis  
Virginia Main  
Irene Mokrzycki

Dr. Roland Roberts  
Helen M. Shedenhelm  
Mary Ellen Strupp  
Barbara Thiele  
Elizabeth "Bill" Tunison  
Frances Robert Williams

### Ekbom Heritage Society\*:

Anonymous (3)

*\*The Ekbom Heritage Society includes the loyal supporters who have included the RLS Foundation in their estate planning. We extend our gratitude and deepest sympathy to their families.*

# Foundation Board Member Publishes New Research on the Dangers of Dopamine Agonists

New research from John Winkelman, MD, PhD, a member of the RLS Foundation's Scientific and Medical Advisory Board, and director of the Massachusetts General Hospital certified RLS Quality Care Center, was featured in the August issue of *Sleep Review* magazine! The article, "Are Dopamine Agonists Doing More Harm Than Good for Restless Legs Syndrome Patients?" features a study that Winkelman, a researcher at Harvard Medical School, conducted, which found nearly 20% of restless legs syndrome (RLS) patients are prescribed doses above the FDA recommended maximum.

The article notes that while clinicians who prescribe their patients higher doses of dopamine agonists (DAs) may find symptoms quickly disappear, that result is usually temporary and can even lead to worsening RLS, also known as augmentation – or as Winkelman describes it, "putting out fire with gasoline." Research indicates that augmentation occurs in 50% to 70% of patients who use DA medications for 10 years.

"When the dopamine agonists have made the RLS worse, the response of most doctors, unfortunately, is to increase the dose, which just makes it even worse," said Winkelman, whose study was published in the medical journal, *Sleep*. "Then they increase it again and they get into this vicious cycle."

The research found that roughly 20% of RLS patients prescribed dopamine agonists, out of a large data sample, were prescribed doses higher than the upper limit of what the Food and Drug Administration (and RLS expert guidelines) recommend. Even more worrisome is that half of those patients (10% of those given a dopamine agonist) are prescribed these medications at doses greater than 150% of the FDA recommended maximum for RLS.

"This doesn't happen overnight. This happens over years and years," said Winkelman.

Dr. Mark Buchfuhrer, also on the Foundation's Scientific and Medical Advisory Board and the new medical editor for *Night Walkers*, commented on Winkelman's research. "For most doctors this is still first line treatment," said Buchfuhrer, who practices at the Restless Legs Syndrome Clinic at the Stanford Center for Sleep Sciences and Medicine, a certified RLS Quality Care Center.

Dr. Winkelman concluded that prescriber education on the risks of high-dose DA prescribing for RLS is especially important. The Foundation offers a free twelve-part on-demand educational webinar series to educate healthcare providers about the care of RLS patients. The series is located at [www.rls.org/PhysicianEd](http://www.rls.org/PhysicianEd).



John Winkelman MD, PhD

## Sleep Review

To access the full article online, visit <https://www.sleepreviewmag.com/sleepreviews/pharmaceuticals/prescription-drugs/dopamine-agonists-harm-restless-legs-syndrome-patients/>.

## Thank You for Taking the RLS Patient Odyssey Survey

In September, the RLS Foundation conducted a research survey to gain new insight into how RLS impacts daily life. The online survey opened on Sept. 23, and more than 1,300 RLS patients and their partners responded within the first week! The survey closed on Oct. 23, and the Foundation's Scientific and Medical Advisory Board Committee is now analyzing the data. Results will be shared next year with researchers, clinicians, policymakers and the public. Thank you to everyone who took the time to participate – your input will help identify focus areas for future education and research. Watch for more news with survey results and analysis in upcoming issues of *Night Walkers*.



# Support and Connection Are Just a Click Away

At the start of the COVID-19 pandemic, the Restless Legs Syndrome Foundation had to quickly adapt and make changes to some of the ways in which it serves the RLS community.

Face-to-face support group meetings were no longer safe, so we decided to try a new way of meeting using the Zoom platform. At first, only a handful of support group leaders were interested in switching to Zoom. But once we began to realize that this would be the new norm – at least for now – more and more groups were glad to have a way to safely connect with others while physical distancing at home. In fact, some of our support group leaders love the convenience of travelling to the couch for a meeting instead of across town!

"After using Zoom for a few virtual meetings, I felt excited because I'm able to attract more attendees from a wider geographical area," said Bill Becker, one of the first support group leaders to hold a virtual support group meeting. "The support group also likes the tool, so we will be continuing to use this venue moving forward."

After many successful gatherings of local groups over Zoom, the Foundation decided to host meetings open to anyone who wanted to attend, regardless of their location. These virtual support group meetings were so popular that we now have four standing meeting times every month: one meeting per week at varying times and days of the week to accommodate different time zones. Participants from all over the world, including Australia, Ireland, UK and South America have joined.

Many people who participate in these support group meetings had never spoken to another person with RLS until they found us – and you. Although it is unfortunate that we had to suspend face-to-face meetings, switching to a virtual support group platform has been a great and much-appreciated resource for the RLS community and Foundation staff, because it allows us to keep learning about people's experiences and hear their stories.


During this time of physical distancing, stress and uncertainty, we found a way to come together, and one thing is certain: virtual support group meetings are here to stay! Moving forward, we have created a new volunteer position for virtual support group leaders.

If you are interested in joining a virtual support group, visit [www.rls.org/vsg](http://www.rls.org/vsg) and sign up for a time that works best for you. If you are interested in becoming a virtual support group leader, email [clara@rls.org](mailto:clara@rls.org) or visit [www.rls.org/volunteer](http://www.rls.org/volunteer).

We look forward to meeting you!

## How to Join a Virtual Support Group Meeting

1. This is an example of the email reminder you will receive with login information before the meeting starts. Click the circled link to open a Zoom window.



Thank you for registering to attend a Virtual RLS Support Group Meeting on:

**Date: Thursday, September 17**

**Time: 12 pm PT | 1 pm MT | 2 pm CT | 3 pm ET**

If you are joining a ZOOM meeting for the first time, please login early to test your sound and video. If your computer, tablet or smartphone is not compatible, or you don't have a video camera, we recommend you dial-in using the phone number below to participate.

**Join Zoom Meeting**

<https://us02web.zoom.us/j/82444673005?pwd=eVlxUGFHUnl4U0J2eExBdUM1azhPdZ09>

Meeting ID: 824 4467 3005  
Password: 901514

**To join by phone only, dial by your location**

- +1 346 248 7799 US (Houston)
- +1 669 900 9128 US (San Jose)
- +1 253 215 8782 US (Tacoma)
- +1 646 558 8656 US (New York)
- +1 301 715 8592 US (Germantown)
- +1 312 626 6799 US (Chicago)

2. When you see the Zoom screen, click the word "allow."
3. You should now be in Zoom! In the top right-hand corner, you can switch from speaker view (in which you only see the person speaking) to gallery view (where you see everyone that has selected "start video"). In the bottom left-hand corner, you can mute yourself (in large meetings it may be necessary to mute yourself when not speaking) and turn your video on or off. The chat bubble allows you to send messages to the group or to individuals privately.

## Advocacy in a Virtual World

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

For over 40 years, I taught European History at the University of Minnesota. In 1991, the University of Minnesota developed the Gopher system of searching for information by computer – five years before the World Wide Web. Even so, I avoided using the Gopher system – or even email – until it became embarrassing not to be connected. For those same 40 years, I struggled to define, and then to manage, my restless legs syndrome (RLS). Even my doctors at the university's teaching hospital knew little about RLS or how best to treat it, but somehow we worked together to manage my symptoms. These days, I'm on the internet several hours every day, and sometimes more, especially if I'm involved in a research project that requires specific data that would take a considerable amount of time to find otherwise. And it was through the internet that I finally located the RLS Foundation and the wealth of resources that it provides about RLS and its treatment.

In these difficult times, with restrictions on our normal human interactions because of the COVID-19 pandemic, the internet has become even more important to all of us. I participate in academic meetings online that had originally been planned as face-to-face gatherings in distant cities and abroad. I use Skype and Zoom and other platforms to touch base with people I know; in fact, I'm in closer touch with family and friends than I've been in years. Several weeks ago, my cousin, who lives in Santa Fe, New Mexico, celebrated her 75th birthday. Her husband arranged a Zoom party that brought together a big group of well-wishers, including her brother in Paris, friends in England, and many of us in the United States. During the party, I connected with a cousin I hadn't seen in more than 20 years and met some of my cousin's friends whom I had heard about but didn't know. It was a wonderful occasion, all because of the internet and the creative ways that we can use it.

Through the internet, we can also follow the activities of organizations we support. As you know, the RLS Foundation had planned a major Patient Symposium in Baltimore, MD for October of this year, following the successful symposium held in La Jolla, California, in 2018. Because of COVID-19, we had to postpone the in-person symposium until 2021 rather than risk the health of our members. Instead, we held an RLS Virtual Summit on Saturday, October 17. Unlike an in-person summit, there was no limit on the number of persons who could attend, and 125 registered for the one-day event. I was delighted by the attendance and by the chance to hear directly from RLS experts at many of our RLS Quality Care Centers.

For the RLS Foundation, advocacy efforts are crucial, and the internet has also given a huge boost to those efforts. We considered it a great success when our RLS Awareness Day on September 23, 2019, inspired several dozen members to take

the time to schedule at-home visits with their members of congress. Those meetings were extremely useful in helping key members of Congress understand what RLS is and why it is so important to continue funding research about it. One Foundation member was successful in having restless legs syndrome mentioned in the Extension of Remarks in the Congressional Record dated September 18, 2019.

In 2020, our September 23 RLS Awareness Day took place in cyberspace, with vastly more individuals participating than we could ever have imagined or organized in person. We still aimed to educate and advocate for RLS Awareness and research in our government's healthcare and legislative structures, but our impact was substantially greater and more far-reaching than any in-person effort could achieve. I am personally grateful to everyone who participated in making this year's RLS Awareness Day a success, including those who participated in our RLS Patient Odyssey Survey II, both patients and partners. Because you took the time to fill out the survey, researchers will have a clearer idea of the impact that RLS has on the quality of daily life. In addition, people without direct experience with RLS will be able to find out more about the disease when the results of the survey are published.

The Summer 2020 issue of *NightWalkers* was devoted in large part to the Foundation's connection to the virtual world. In addition to announcements about opportunities to advocate for RLS goals from the comfort of our homes, there were notices about new initiatives such as the creation of online "virtual support groups" for RLS. I read the issue from cover to cover and learned from reading about current research and about the daily struggles that our members face in managing their RLS.

Long after the current COVID-19 crisis passes, our intense connection with the virtual world of the internet is likely to continue. For me, the perfect image of that connection is the picture on the cover of the Summer 2020 issue: a woman sitting at her computer with a big smile on her face, obviously enjoying the opportunity to connect with the virtual world of the internet. The RLS Foundation, and all of us who share its goals, will benefit from that connection. Stay tuned for information about how we can all help achieve our shared goals.

## RLS, COVID-19 and Our Superpower

By Linda Secretan, Secretary, RLS Foundation Board of Directors, and Support Group Leader

Does COVID-19 present unique challenges to people with restless legs syndrome? You may have had a quick, almost automatic response to that question. Was it yes or no? As I started to unpack my own answer, I wondered what we know about staying healthy in the unique environment of a global pandemic, and how that stacks up with strategies to live our best life with RLS. It surprised even my optimistic self to find that those who live with RLS also have a superpower. To tell the story of that discovery is to explore our differences and our similarities.

People with RLS mostly find that we do better with understanding and connection. When observing a person new to a support group, I am always, always reminded of my own wonderment at finding myself in a room of people who *got it*, to whom I didn't need to explain myself, who understood what it was like to be a nightwalker. Whether we are introverts or extroverts, whatever our challenges, we are relieved to find that we are not alone.

Also, we are not surprised to find that people with RLS are not all the same. We have different manifestations and frequency of symptoms, different remedies and different triggers. Some feel that familiar creepy, fizzy feeling in the legs, some in the arms, some even in the face. Some of us kick our partners out of bed with periodic limb movements in sleep (PLMs), some have pain, some do not, some may suffer night and day, some occasionally and some only with pregnancy. And the triggers! Those are almost as idiosyncratic as fingerprints – from ice cream or alcohol to salted nuts and minor abrasions. Indeed, what sets off our symptoms seems to be a work in progress as we may discover variations of our own triggers with each passing year.

We are all learning in our own way how to manage our RLS. The question here is how to incorporate current, wise thinking about staying healthy during a global pandemic into our RLS coping solutions. We know the usual precautions. What more can we as individuals do?

**Exercise matters:** A recent article from the Exercise is Medicine initiative shows exercise improves immune function and response to viral infections, reduces stress, helps treat pre-existing conditions, and would enhance the effect of an eventual vaccine. The documented benefits of exercise are not news, and even though exercise science hasn't caught up with the global pandemic, its protective role is widely known, particularly for older adults who are less effective in responding to vaccines by producing antibodies.

Many of us have learned the benefit of exercising above and beyond the kicking, tapping, fidgeting and squirming that come with the territory. Regular activity is a key to well-being. Some Foundation resources include: *Can an Active Lifestyle Prevent or Improve RLS Symptoms?* (see page 15) and the webinar from Dr. Norma Cuellar, *RLS and Coping Strategies*, both available at [www.rls.org/webinars](http://www.rls.org/webinars).

The difference for people with RLS is that we may need to be especially careful about timing and intensity. I crave vigorous regular exercise, but over (and under) exercising are sure triggers for increased symptoms. Some find that in contrast to the usual stricture against exercise before

bed, a late-night walk may prevent an even later night, unintended walk!

**Resilience matters:** Positive emotion and optimism can be built and are protective. There is no formula, but research points to some simple ways to develop resilience. Psychologist Dr. Rick Hanson of the Greater Good Science Center at the University of California Berkeley suggests three keys: first, through mindful breathing with longer exhalations, return to the present and away from worries about the future. Next, remember times when you have endured and connect with your strengths. Finally, connect with other people.

Again, check out the *RLS and Coping Strategies* webinar as well as the publication *Complementary/Alternative Medicine and RLS*. Both refer to mindfulness and breathing techniques. Connecting with one's strengths reminds me of the absolute joy I felt the evening I sat in the middle-row and listened to a string quartet without moving an eyelash – thanks to the right treatment at the right time. When I breath into that memory and hold on to it, it helps in times when nothing seems to work. We can turn past experiences into inner resources to increase resilience in hard times.

Resiliency may also be tied to how we restore a sense of agency. Through acting on our behalf and that of others, we develop a sense of being in control during a time when so much seems beyond our control. For those of us with RLS, that path is clear and well-marked. The Advocacy page on [www.rls.org](http://www.rls.org) provides expert guidance as does the webinar *How You Can Raise Awareness*, online at [www.rls.org/advocacy](http://www.rls.org/advocacy).

**Connection matters:** Tied to resilience, this strategy is one you will have heard about, joked about with someone you love from a six-foot distance, and sometimes despaired of – wondering when you'll ever hug someone in greeting again. Yet, you may also have found yourself reaching out to friends you haven't talked to for years. I surprised myself by picking up the phone the other day and having a long and satisfying talk with a childhood friend from decades ago. Human connections are soul-restoring.

There is a reason we declare often that “you are not alone.” We each have our own story of relief when we found the RLS Foundation – frantic searching for help online in the middle of the night, a chance conversation on an airplane, an article in the local paper about a support group – and we can turbocharge the connection that leads to resiliency by sharing our stories with friends, family, community and our elected representatives.

Is there magic in all this? Yes. These suggestions for coping are as close as our own well-researched publications and webinars and they all have solid evidence behind them. But for people with RLS, there is more. A recent theme emerging from our virtual support group meetings is that we are all so very different and each have our go-to ways of taking care of ourselves. They are as individual as our triggers and as varied as “soap under the sheets” to low total daily dose opioids. The uncertainty, dread, and darkness of COVID-19 are equal to the effects we sometimes recognize from having RLS. Our superpower is that we already know how to deal with them. Our superpower is we've got this!



## Yuqing Li, PhD, 2015 RLS Foundation Grant Recipient, Awarded NIH Funding

The National Advisory Neurological Disorders and Stroke Council (NANDSC), a division of the National Institutes of Health (NIH), has awarded a new grant to Yuqing Li, PhD, a professor of Neurology and Neuroscience at the University of Florida. Dr. Li and his team will further investigate the genetic mechanisms that are involved in the development of restless legs syndrome.

Dr. Li will build on his previous research concerning the role of the MEIS1 gene in RLS, which was made possible with an RLS Foundation grant he received in 2015. Li's work involved exploration of an animal model in which he and his team performed a detailed analysis of MEIS1 mutant mice to determine whether they showed RLS symptoms. They also examined the brain's dopamine system to identify areas affected by the MEIS1 mutation.

"I want to take this opportunity to express my gratitude for the Foundation grant in 2015," said Li, who published three papers on MEIS1. "The funding allowed us to collect the necessary preliminary data to apply for this NIH grant."

Li says the Foundation grant allowed him to identify changes in the dopamine and cholinergic systems in the brains of the mutant animals, which suggests that they could be important in causing RLS.

"With the new NIH grant award, we are going to develop animal models with MEIS1 altered only in dopaminergic or cholinergic systems," said Li, who received the NIH grant in

September. "This will allow us to determine the relative importance of the two systems in causing the RLS. We may find out that both systems are important, or one is crucial and leads to the changes in the other. This kind of knowledge will allow us to have a better understanding of how RLS can develop in patients and develop better-targeted therapies for RLS patients."



*Yuqing Li, PhD*

The support of the Foundation members has led to the funding of 47 grants totaling over \$1.8 million in funding. "The RLS Foundation is excited by the news of this NIH award to Dr. Li. This study will help to expand our knowledge and understanding of the disease leading to development of targeted therapies and, hopefully, a cure," said Dzienkowski, RLS Foundation executive director. To support the RLS Foundation Research Grant Program go to [www.rls.org/donate](http://www.rls.org/donate).

## Patient Webinars

### Safe Treatment of RLS with Opioids

John W. Winkelman, MD, PhD  
Recorded: May 6, 2020

### sIRLS: Self-Administered International Restless Legs Syndrome Severity Scale

Denise Sharon, MD, PhD, FAASM  
Recorded: June 10, 2020

### Cannabis and RLS

Jacquelyn Bainbridge, PharmD  
Recorded: July 14, 2020

### Painful RLS: Do You Have It?

Elias G. Karroum, MD, PhD  
August 19, 2020

### Ask the Doctor

Mark J. Buchfuhrer, MD, FRCP(C), FCCP  
September 9, 2020

### Using Light to Increase Alertness and Improve Sleep

Mariana G. Figueiro, PhD  
October 8, 2020

### Genetics and Epigenetics of RLS

Christopher J. Earley, MB, BCh, PhD, FRCPI  
November 12, 2020

*Webinar schedule is subject to change. Visit [www.rls.org/webinars](http://www.rls.org/webinars) for final details and registration information on attending these free educational webinars. All webinar recordings are available to view in the member portal section of our website.*



## Kratom: Helpful or Harmful?

In recent years, some people have been turning to kratom in an attempt to control withdrawal symptoms and cravings caused by addiction to opioids and other substances. Some companies market kratom products as a “natural substitute for opium,” but are now receiving warning letters from the Federal Drug Administration (FDA) for making unsubstantiated claims. Seeking a natural or alternative treatment to pharmaceuticals may be of interest to some people with restless legs syndrome, but there is no scientific evidence that kratom is an effective or safe alternative treatment.

The ongoing debate regarding the risks and benefits of kratom centers around reports of its stimulating effects, increased alertness, physical energy, and talkativeness at low doses, as well as its supposed sedative effects at high doses. The chemical substances, mitragynine and 7-a-hydroxymitragynine, found in the kratom leaf, interact with opioid receptors in the brain, causing sedation, pleasure and decreased pain when consumed in large amounts. Instances of psychosis with symptoms of hallucinations, delusions and confusion have also been reported. Because kratom acts on the brain in ways that are like the effects of morphine, it exposes users to the risks of addiction, abuse and dependence, according to the FDA.

Kratom – a tropical tree native to Southeast Asia – may appeal to those who are seeking an herbal alternative to traditional medical treatment. Opium is similarly considered as an “herbal” product since it is made from poppy flowers. The leaf of a kratom tree is usually chewed, brewed or crushed into powder. In the US, kratom tends to be sold in a processed form (e.g., pills, capsules or extracts). However, there is no uniformity of strength, and similar mg doses from different sources may contain vastly different amounts of active drug, making it difficult to know how much a person is actually taking.

Also, processed kratom is not regulated by the FDA and may contain other harmful substances. In 2019, the FDA conducted laboratory testing of 30 different kratom products from a variety of sources and found significant levels of lead and nickel at concentrations that exceed

safe exposure for oral, daily drug intake. Long-term use could lead to heavy metal poisoning, including nervous system or kidney damage, anemia, high blood pressure and/or increased risk of certain cancers.

Although kratom remains a legal substance, it is not legally marketed in the US as a drug or dietary supplement. The FDA warns the public not to use kratom, and the Drug Enforcement Administration (DEA) has listed kratom as a Drug and Chemical of Concern. Some of the negative side effects as reported by the DEA include nausea, itching, sweating, dry mouth, constipation, increased urination, tachycardia (increased heart rate), vomiting, drowsiness and loss of appetite. Former FDA Commissioner, Scott Gottlieb, stated, “at a time when we face an opioid epidemic of devastating proportions, manufacturers should not be allowed to mislead consumers into believing kratom products are a ‘safe’ alternative to prescription opioids.” Using products with unproven claims may prevent those addicted to opioids from seeking safer, more effective treatments, such as methadone and buprenorphine. The FDA prioritizes reducing the rate of Americans who are addicted to opioids by promoting more widespread innovation and access to opioid addiction treatments, continues to warn against the use of kratom and encourages more research to better understand kratom’s safety profile and long-term health effects.

If you are considering kratom and are experiencing any change in RLS symptoms or are thinking about pursuing any new treatment or supplement, consult with your doctor prior to initiating a change to your current treatment plan.

*This publication has been reviewed and approved by the RLS Foundation Scientific and Medical Advisory Board. Literature distributed by the RLS Foundation, including this publication, is offered for information purposes only and should not be considered a substitute for the advice of a healthcare provider. The RLS Foundation does not endorse or sponsor any products or services.*

## New, Novel Treatment Method for RLS

Stefan Clemens, an East Carolina University (ECU) associate professor at the Brody School of Medicine’s Department of Physiology, was awarded a US patent for his novel method of treating restless legs syndrome (RLS), which could lead to more effective care over a longer period of time for patients.

RLS is frequently treated with dopaminergic drugs to replace or prevent the loss of dopamine. While these drugs can deliver a high initial effect, they often lose their effectiveness over time and symptoms can worsen, a side effect known as augmentation. Classic RLS treatments act on a dopamine receptor known as D3, which has a suppressive effect in the nervous system.

Clemens’ animal models show that over time the medication leads to an increase of a different, excitatory receptor subtype, D1. This increase of the D1 receptor might be the cause of augmentation. Clemens’ patent, which he received in late August, targets the increased D1 receptor levels in RLS patients suffering from augmentation, leading to reduced activation of D1 receptors while providing traditional therapy relief from RLS.

*continued on page 11*



Stefan Clemens

## Webinar Q &A: Ask Dr. B

*In early September, the Restless Legs Syndrome Foundation hosted a webinar featuring Foundation Scientific and Medical Advisory Board member Mark Buchfuhrer, MD, to answer questions about RLS. Indeed, he received a wide and interesting variety of inquiries about different treatments, lifestyle issues, disease progression and more. Dr. Buchfuhrer — or Dr. B. as his patients like to call him — is from Downey, California and is affiliated with multiple hospitals in the area, including PIH Health Hospital-Downey and Stanford Health Care-Stanford Hospital. The following Q&A is based on the “Ask Dr. B” webinar. To view the recorded webinar, visit the member Portal at [www.rls.org](http://www.rls.org).*

**Q: Do you have any suggestions for using homeopathic or natural ways to deal with RLS, other than a TENS unit?**

**A:** Helpful strategies to avoid exacerbation of RLS symptoms include avoiding triggers. The most common trigger is alcohol. Sugar, refined carbohydrates and gluten are also RLS triggers but are less common. Moderate forms of exercise are beneficial in managing RLS symptoms, whereas very vigorous/strenuous exercise can lead to an increase in symptoms. Hot or cold showers are helpful for some individuals. Devices that vibrate or wrap around the leg and foot may alleviate aggravating symptoms. The key is to determine your personal RLS triggers and avoid them. It is also important to identify alternative treatments to cope with troublesome symptoms. Hot or cold showers, massage, exercise and mentally engaging activities such as crossword puzzles or video games are examples of coping methods to manage symptoms.

**Q: Are there any new promising treatments for RLS?**

**A:** There are no new game-changing treatments on the horizon. It is important to remember that it takes time from research and development of a drug until it is approved for medical use. Support for the RLS Foundation's Research Grant Program and Public Policy Advocacy Program in Washington help to raise awareness of RLS and need for research funding.

**Q: At what level of ferritin do you recommend iron infusions for RLS?**

**A:** Ferritin levels 100 mcg/L or less is the new recommended parameter for iron infusion. It is important to avoid ferritin testing when ill. Ferritin is an acute phase reactant that is elevated during an infection or inflammation process. If you are ill or have any inflammatory condition, wait at least six to eight weeks to test your ferritin level.

**Q: Do people with RLS get addicted to opioids? If so, what is the percentage?**

**A:** Addiction is a psycho-social term. The correct terms to evaluate the potential for problems with opioid use are dependence and tolerance. Tolerance is the body's adaptation to the use of a drug to function with a diminished response to a drug that requires a dosage increase to achieve the desired response, and dependence is withdrawal symptoms occurring when the drug is stopped. When opioids are prescribed appropriately, the risk for development

of opioid use disorder (OUD) is minimal. The low total daily doses prescribed for management of RLS symptoms lessens the likelihood for the development of dependence and tolerance. The Mayo Clinic Proceedings article, “The Appropriate Use of Opioids in the Treatment of Refractory Restless Legs Syndrome” provides guidelines for physicians and patients to follow to minimize risk associated with treatment.

**Q: Do you think that dopamine agonists permanently damage the dopamine receptors for many individuals with RLS?**

**A:** There is no definitive answer to this question. In the Borreguero study, RLS patients who were not augmented but on long term dopamine agonist drugs and stopped taking dopamine agonists and were then prescribed an alpha-2-delta ligand were compared to RLS patients who only took an alpha-2-delta ligand to manage RLS symptoms. The RLS patients who previously took dopamine agonists did not respond as well to gapentinoid (alpha-2-delta ligands) drugs. It has been hypothesized that the dopamine agonists left permanent damage, preventing them from getting back to their baseline symptoms prior to dopamine agonist administration.

**Q: Does RLS always progress as a disease? Can it be stabilized with the correct medication?**

**A:** RLS does not always progress as a disease. Some individuals may experience a spontaneous remission that lasts for months, years or forever (especially those with milder disease). RLS symptoms can flux and dissipate over time. In my practice, the majority of patients who are not on dopamine agonists are extremely stable over the years. Patients prescribed opioid therapy to manage refractory RLS take low daily doses that remain unchanged or only minimally increased —over a time span of two to three decades.

**Q: Even though my sleep time has increased with opioids, has a definitive link been established between intestinal disease and RLS?**

**A:** Dr. Weinstock has studied the relationship between SIBO (small intestinal bacterial overgrowth) and RLS. It may be that a gut issue leading to a malabsorption of iron triggers the occurrence of RLS symptoms in genetically predisposed people. Anecdotally, patients have reported a benefit to treating SIBO, but over time, results tend to be diminished. More research into the gut-RLS relationship is needed.

**Q: How can I compensate for methadone's negative impact on testosterone levels and all sexual functions?**

**A:** Side effects of methadone treatment include diminished libido and erectile dysfunction in men. If this side effect occurs, the physician needs to consider another treatment option to manage RLS symptoms. The RLS Foundation's new consensus treatment guidelines, which will be published later this year, discuss alternative therapies such as buprenorphine (Belbuca). Research by

*continued on next page*



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Dr. Rye has found these alternative therapies successful in managing RLS. Problems such as decreased libido are rarely experienced on buprenorphine, especially when low doses are used.

**Q: How effective are iron infusions? Do they eliminate the need for medication?**

**A:** Iron infusions are an effective treatment for individuals with iron deficiency. Surrogate markers, such as serum iron or ferritin levels, measure iron levels in the body and do not provide a measure of iron levels in the brain. The majority of individuals respond well to therapy and there is a good chance of having medication doses decreased or discontinued with a positive response to intravenous iron treatment.

**Q: If you have poor circulation, can blood thinners have a positive impact on RLS symptoms?**

**A:** Blood thinners do not have an impact on RLS. Ferré's adenosine study evaluated dipyridamole as a potential RLS therapy, but the effect on RLS most likely was not due to making platelets less active but rather due to its effect on the adenosine system. Further studies are needed to replicate study findings.

**Q: Is the treatment of RLS with methadone safe and effective? Also, is it mostly considered a drug of last resort?**

**A:** Methadone is a safe and effective treatment for refractory RLS when opioid guidelines are followed. The Mayo Clinic Proceedings article, "The Appropriate Use of Opioids in the Treatment of Refractory Restless Legs Syndrome," provides guidelines for physicians and patients to follow to minimize risk associated with this treatment modality. When RLS becomes unresponsive to first- or second-line therapies, a thorough assessment conducted by you and your healthcare provider should occur to rule out any factors contributing to a worsening of your RLS.

**Q: What are your thoughts about the use of magnesium to reduce nightly RLS symptoms?**

**A:** There are no credible studies that support the use of magnesium to alleviate RLS symptoms.

**Q: What do you think about topical CBD for treatment of RLS symptoms?**

**A:** CBD (cannabidiol) is the non-psychoactive chemical component of the cannabis plant. It is found in edibles and oil formulation. CBD promotes relaxation and sleep but is not a treatment for RLS. A product with a combination of CBD and low dose THC (tetrahydrocannabinol), is helpful in alleviating RLS symptoms when inhaled. The 2018 Farm Bill removed legal restrictions from hemp derived CBD, but the use and possession of cannabis is illegal by the US federal government.

**Q: Would a procedure to reduce varicose veins help to reduce RLS symptoms?**

**A:** There are no surgical procedures to reduce or eliminate RLS symptoms. A British study found that painful legs attributed to varicose veins did not improve with surgery. Cosmetic appearance and perhaps less swelling of the legs were the only benefits from the surgical procedure.

*continued from page 9*

"Our lab postulates that this new compound will maintain long-term efficacy for RLS," Clemens said. "If augmentation begins, we predict that we can reduce D1 receptor activation in patients and balance things back out, keeping the treatment effective."

Using a grant from the North Carolina Biotechnology Center, Clemens and a collaborator from the University of Houston will run a small pilot study of the new treatment method. His work also gained the attention of a company that has interest in establishing a partnership where ECU's patent rights may be used in combination with its existing drug formulation for treating augmentation. "The patent would not have been issued without their help," said Clemens, who is also working on medical treatments for opioid pain tolerance. "I now know that it can be very beneficial to have experts in other areas come from different angles that make us think of other ways to use our work." Clemens is a member of the Foundation's Scientific and Medical Advisory Board and is the Chair of the Research Grant committee.



## RLS Quality Care Centers Provide Superior Treatment

Restless legs syndrome (RLS) is a serious neurological sleep disorder affecting over 12 million men, women and children in the United States. Treatment for RLS is not a one-size-fits-all illness – it requires an individualized treatment approach. RLS is a common disease, yet many healthcare providers lack the experience of recognizing and treating the newly diagnosed and those with more complicated forms of the disease. On average, it takes nearly 13 years of needless suffering before an accurate diagnosis of RLS is made. Today, more than ever, individuals have more healthcare and treatment options to choose from to manage chronic diseases like RLS.

In 2013, the RLS Foundation committed to developing a network of certified RLS Quality Care Centers (QCCs) to improve diagnosis, treatment and management of individuals with RLS. Foundation QCCs allow patients to receive expert care from knowledgeable and experienced healthcare providers. To date, the RLS Foundation has certified 11 Quality Care Centers – nine are based in the US and two QCCs are located in Europe. RLS Quality Care Centers raise awareness of RLS's profile as a serious medical condition that is recognized by the renowned academic institutions where QCCs reside.

### Quality Care for Every Patient

QCC clinicians and researchers provide expert care and specialized disease management for every RLS patient in their care. These healthcare providers and institutions also undergo a rigorous review by the Foundation's Scientific and Medical Advisory Board. To receive provider certification, each applicant must demonstrate a high level of expertise and experience in managing a wide range of case complexities

that often coincide with other medical conditions. These providers must maintain current continuing medical education hours, which include RLS-specific coursework, and RLS consensus treatment guidelines.

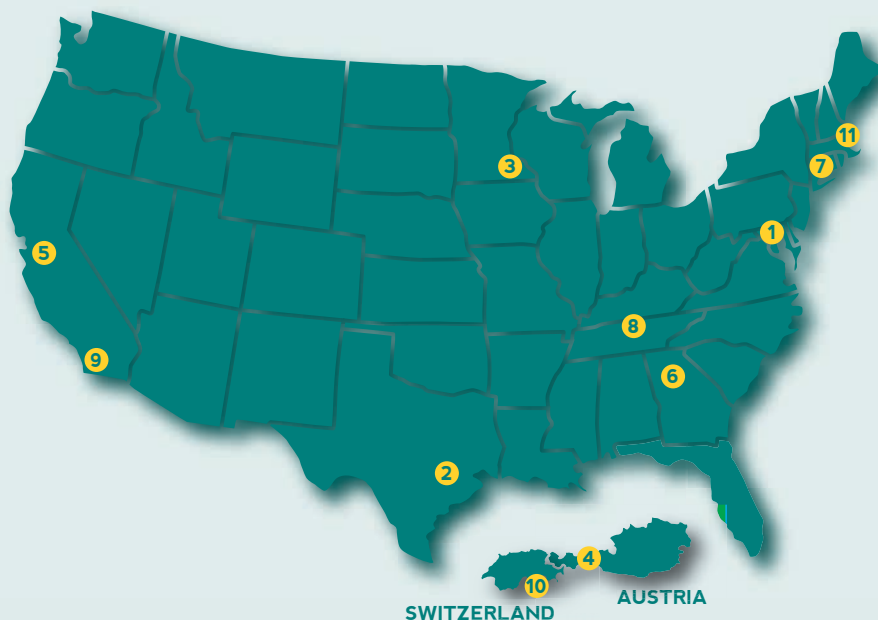
Each QCC must demonstrate organizational capabilities, including comprehensive diagnostic and therapeutic capabilities to manage RLS patients' healthcare needs. For example, QCC providers must have access to laboratory facilities, sleep study centers and healthcare providers specialized in pulmonology, psychiatry and hematology. Access to these specialty areas ensures a comprehensive treatment plan for the RLS patient.

The certified providers who practice at the Foundation's QCCs are recognized leaders in the field and often serve as presenters at physician conferences, scientific symposiums and industry events. Each of these speaking opportunities raises RLS's profile by educating, stimulating research and encouraging a broader interest in RLS within the medical community. Our hope is that through this type of outreach by the certified providers at our 11 QCCs, physicians in other academic institutions and hospital networks will aspire to provide this high level of care to the RLS patients they serve by becoming an RLS Foundation QCC.

Although patients often remark about the travel that is required to visit an RLS QCC that is outside of their local area or state, their only regret is that they did not make an appointment sooner! To make an appointment at an RLS Foundation certified RLS Quality Care Center, visit [www.rls.org/qcc](http://www.rls.org/qcc) to locate the contact information for a QCC nearest to you.

Staffed by RLS experts with extensive experience in treating individuals who live daily with the impact of the disease. For details on our current certified QCCs visit [www.rls.org/QCC](http://www.rls.org/QCC).

1. Johns Hopkins Center for Restless Legs Syndrome  
*Baltimore, Maryland*
2. Houston Methodist Neurological Institute  
*Houston, Texas*
3. Center for Sleep Medicine at Mayo Clinic  
*Rochester, Minnesota*
4. Innsbruck Medical University, Department of Neurology, Sleep Lab and Sleep Disorders Outpatient Clinic  
*Innsbruck, Austria*
5. Stanford Sleep Medicine Center  
*Redwood City, California*
6. Emory Sleep Center  
*Atlanta, Georgia*
7. Yale Centers for Restless Legs Syndrome  
*New Haven, Connecticut*
8. Vanderbilt University Medical Center  
*Franklin, Tennessee*
9. Scripps Clinic Viterbi Family Sleep Center  
*La Jolla, California*
10. Sleep Center, Neurocenter of Southern Switzerland  
*Lugano, Switzerland*
11. Massachusetts General Hospital  
*Boston, Massachusetts*





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 NightWalkers. Questions will be edited as needed and published anonymously.

**Q: I have had RLS for four years and it mostly affects my left leg. I also have severe osteoarthritis in my left knee, while my right knee is healthy. Are you aware of studies, if any, on the correlation between RLS and osteoarthritis, or on the effect of a full knee replacement on RLS?**

**A:** RLS can occur in either or both legs and even alternate from one leg to the other. I have seen patients who have pain in only one leg (due to arthritis, neuropathy or other conditions) that seem to trigger the RLS in one leg only. However, there are no studies demonstrating a relationship between osteoarthritis and RLS. There are studies showing increased RLS in patients with rheumatoid arthritis. It is possible that a total knee replacement could improve the left leg RLS symptoms if it resolves the knee pain. However, some RLS patients notice an increase in RLS after major surgery (my personal observation).

*Mark J. Buchfuhrer, MD, FRCP(C), FCCP, FAASM*

**Q: I am 22-years-old and have had this creepy kind of feeling in my legs when sleeping for about five to six years. Whenever I sleep, even if it is daytime or nighttime, this sensation starts in my calves. My sleep pattern is majorly affected by this. I can't get to sleep until 3 am, even though I go to bed at 10 pm. I have done everything to try and get rid of this – stretching, walking, cycling, running, yoga, massage, hot pack, icepack, etc. – but it won't go away. I'm unable to bear this and my parents are worrying about me. Please help me. I want to sleep.**

**A:** It sounds like you have restless legs syndrome. The first thing to do, considering the severity at a relatively young age, would be to check several iron studies to see if there's any iron deficiency and supplement this aggressively, potentially even with intravenous iron. If that is not successful, then there are several medicines that are generally effective for RLS, but you need to see a doctor for these.

*William Ondo, MD*

**Q: I just read that amantadine might be helpful for RLS. I've not run across this before.**

**A:** Amantadine is an old drug most commonly used for dyskinesia (involuntary movements) in Parkinson's disease. There is one 20-year-old study which showed some modest benefit but was generally not as helpful as dopaminergic medications. Amantadine is a drug with multiple pathways of action, which has multiple mechanisms by which it works, including the release of dopamine, which is probably how it helps RLS modestly. Most RLS experts who have tried it have not had much success, so it is not commonly tried.

*William Ondo, MD*

**Q: I have been using a 2 mg per 24-hour rotigotine transdermal patch applied one hour before bedtime. It has worked well for me. Why haven't I heard more about this patch for relieving RLS?**

**A:** Rotigotine patches are one of the four FDA-approved medications for restless legs syndrome. It is fairly well-known by experts, but some people don't like the idea of treating symptoms that occur only in the evening with a 24-hour patch. Overall, it is the same class of medicine as pramipexole and ropinirole. The patent is expiring for the company that owns the drug and will be available in a generic formulation in the near future.

*William Ondo, MD*

**Q: I was diagnosed with RLS in August 2019. My doctor suggested I take 0.125 mg pramipexole and 0.25mg clonazepam every evening. How long should I continue this medication? Could you please suggest any alternate options to get relief from RLS?**

**A:** Dopamine agonists like pramipexole are usually very effective treatments for RLS over the short-term. Over time - usually one to five years - they can become less effective (requiring higher doses) and/or actually make RLS worse, with RLS symptoms emerging earlier in the day, more severe symptoms or extension of symptoms to the arms. For this reason, we suggest keeping doses of these medications as low as possible, and if symptoms do worsen in this way, immediately discuss it with your prescribing physician. Other medications, such as gabapentin, pregabalin, gabapentin enacarbil or iron (if iron is low or low-normal) may be better choices for the long-term. Clonazepam is usually not prescribed for RLS unless there is also an independent problem with anxiety or insomnia.

*John W. Winkelman, MD, PhD*

# 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 have suffered with RLS for many, many years. When people asked me what it feels like, it was hard to describe. Last night, I think I came upon the words to explain it better than I have been able to do before. If you take a can of soda, shake it up, and pour it into the veins in your legs, it will likely give you that tingly feeling that RLS does. Does that sound right to anyone else who suffers this disorder? I use over-the-counter lecithin to control the symptoms of RLS and it works for me. However, some people are allergic to lecithin and should not take it. – *Carol*

I had RLS for the first time when I was around 12. I am now 64 and have had it off and on throughout my life. When I married three years ago and moved to Boerne, TX, my restless legs immediately got worse. I was sleeping about four hours a night and was up and down. I found I could sleep in the upstairs bedroom with no problems. When I mentioned this to my environmental doctor, who I saw for allergies, he mentioned electric and magnetic fields (EMF). I talked to the engineer from our electric company who gave me a Gauss meter. When we laid it on our motorized bed it jumped up to six, which is very high, especially to sleep on. When we unplugged the bed, the meter dropped to zero. Unplugging was a big help but did not stop my RLS. Next, I hired a person to come in and check my entire house. The WiFi router is in the closet next to our bedroom. I learned that smart TVs emit an enormous amount of radiation/EMF. This includes the TV in the bedroom that has the Firestick. However, my safe bedroom upstairs has no WiFi or Firestick and interestingly, the readings in that room were almost all zero which proved to my husband (who thought it was just me) that there was something to this. Now we have all plugs on a switch that we can unplug at night. I am back to sleeping in our bedroom. I know without a doubt it has a huge impact on my RLS. I think people just don't realize how the environment may have a huge impact. Please take time to experiment. Cut the power to your bedroom and at least see if it helps. – *Susie*

I have suffered with RLS every night for almost 20 years. Although I was taking pramipexole, I had to increase the dose every two years. Then, in *NightWalkers*, someone said magnesium malate made their RLS stop completely. It has changed my life, too! I take one 425 mg pill three hours before bed. I still need to take the pramipexole, but at a lower dose. I cannot thank the person who shared their experience enough! – *Irene*

I have had a serious case of RLS for approximately 50 years. Like most, I went through the gamut of sleep studies over those years and many medications. For the past 30 years, I have been on some combination of methadone and pramipexole. About three years ago, the paradoxical effect known as augmentation set in and required moving off pramipexole and onto gabapentin. Within two years that combination was no longer working either and I began to get very worried. It seemed that my body had grown tolerant to methadone and no increase in dosage of either methadone or gabapentin made any difference. I was switched to oxycodone. I did not like the dopiness I felt with either oxycodone or hydromorphone; furthermore, they weren't very effective. Thank God for the RLS Foundation and the webinars that introduced me to Dr. Christopher Earley at Johns Hopkins. His work with a wide variety of opiate medications introduced me to buprenorphine. Unfortunately, none of the sleep specialists in Minnesota would prescribe it. But through a referral from my daughter-in-law, a palliative care doctor, I was able to see a pain doctor who, in collaboration with my sleep doctor, prescribed the medication. After the first night, I went from despair to elation. I was soon able to taper off gabapentin and am now sleeping better than I have in many years. I hope this article will encourage other sleep specialists to get certified (a very simple process) in the use of this excellent medication. And for tough-case patients like myself, who have also run the gamut of all the usually prescribed medications and find that nothing is working any longer – I know you are increasingly afraid that you may go crazy, or worse, before a solution is found – don't give up. Find a doctor who will work with your sleep specialist to evaluate your symptoms and determine the best treatment for your RLS. Give buprenorphine a try if other opioids are ineffective in managing your symptoms. Show them Dr. Earley's webinar on the RLS Foundation website. – *Glenn*

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





# Can an Active Lifestyle Prevent or Improve RLS Symptoms?

## The short answer is: Yes!

First, research demonstrates an association between lifestyle and RLS. Regular exercisers are 3.3 times less likely to have restless legs syndrome (RLS) than non-exercisers. Second, for those individuals living with RLS, one study suggests<sup>1</sup> that regular exercise reduces severity of the symptoms by an average of 40%.

It certainly seems logical that our bodies are more still at night after a physically active day. However, the exact mechanisms for how exercise prevents or reduces severity of RLS remain unknown. Other interrelated lifestyle factors may contribute. In addition to being an increasingly inactive population, we're also increasingly sleep-deprived. Television, computer activities, and other electronic temptations increasingly delay our bedtime. Sleep restriction, in turn, reduces daytime physical activity – inadequate sleep makes us too tired to exercise. These observations reveal how unhealthy lifestyles initiate vicious cycles that exacerbate or perpetuate diseases such as RLS. Sleep deprivation promotes inactivity, which in turn contributes to a worsening of RLS symptoms leading to development of insomnia. This lack of activity and exercise may lead to the development of anxiety, irritation and depression.

## What type of exercise is best for RLS?

Questions regarding what type and level of exercise is best for RLS is still being addressed carefully, although existing data indicates the benefit of exercise involving the legs. Clinical experience suggests that regularity of exercise is important. While many patients find that regular mild to moderate exercise helps their RLS symptoms, vigorous or extreme exercise often worsens RLS symptoms. One way to ensure regularity of exercise is to identify a variety of activities you enjoy. This prevents boredom with any one activity. Then, devote around 30 minutes of each day to one of your chosen activities. Make enjoyable physical activity a daily lifetime habit!

## When is the best time to exercise?

Some controversy exists concerning when to exercise – both for treatment of RLS and for sleep quality in general. It is probably best to avoid significant exercise within an hour or so of bedtime. On the other hand, some practitioners now prescribe mild to moderate evening activity up to an hour before bedtime to help treat insomnia. It is inconclusive that exercise within a few hours before bedtime helps promote sleep. Most articles suggest exercise typically has the best benefit for sleep when done in the morning to early afternoon. The best way for you to find out is to do the experiment yourself: Does the time of day when exercise is performed have an effect on your RLS? Is morning or evening exercise better?

## Exercise and medications

Unlike medications, the side-effects of regular exercise are all good. Use of daily, enjoyable physical activity to manage RLS offers many advantages over medications, and provides adjunct treatment for several diseases that often co-occur with RLS, such as diabetes and depression. Regular activity is especially beneficial for the management of RLS in children because of its developmental benefits. As always, patients should adhere to any activity limitations recommended by their healthcare provider.

It's common to hear people with RLS say, "It's as if my legs want to exercise after I lie down to go to sleep!" However, their legs may be telling them that they didn't get enough activity during the day. The good news is that regular enjoyable activity may reduce RLS symptoms, improve sleep quality and offer myriad other health benefits, including a possible reduction in symptoms and medications dose. For more information, please visit [exerciseismedicine.org](http://exerciseismedicine.org).

## Exercise/Activity Guidelines

- Daily is best! Make 30-60 minutes of enjoyable, physical activity a daily lifetime habit.
- Emphasize activities involving the legs, including both aerobic and resistance exercise.
- Avoid exercising to the point that muscles or joints ache or become painful, as this will very likely make the RLS symptoms worse and disrupt sleep.
- Exercise in moderation.
- Consider a variety of activities you enjoy. Variety prevents boredom with any single activity; however, some people prefer the routine of a daily walk or run.
- Yoga has been found to reduce RLS symptoms, severity and stress. Improved sleep and mood are benefits of yoga.<sup>2</sup>
- Do not engage in any activity or workload that a healthcare provider has told you to avoid.
- In addition to planned sessions, increase "incidental" activities such as taking the stairs, using distant parking places, performing physical chores with force and energy, etc.
- If time or motivation are problems, keep things simple and convenient (home gym instead of health club). A common strategy is to exercise by walking on a treadmill or riding an exercise bike while watching TV.

- Determine for yourself when to exercise for optimum relief of RLS symptoms; avoid significant exertion one hour before bedtime.
- Get adequate sleep to give you the energy required to be physically active.

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<sup>1</sup> Exercise and restless legs syndrome: a randomized controlled trial. Aukerman MM, Aukerman D, Bayard M, Tudiver F, Thorp L, Bailey B. J Am Board Fam Med. 2006 Sep-Oct;19(5):487-93.

<sup>2</sup> Effects of a 12-week yoga versus a 12-week educational film intervention on symptoms of restless legs syndrome and related outcomes: an exploratory randomized controlled trial. Innes K, Selfe T, Montgomery C, Hollingshead, N, Huysmans Z, Srinivasan R, Wen S, Hausmann M, Sherman K, Klatt M. J Clin Sleep Med. 2020 Jan 15;16(1):107-119. doi: 10.5664/jcsm.8134.

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Please become an RLS Foundation member and receive our quarterly newsletter, *NightWalkers*, as well as access to our library of handouts and brochures with the most current information available about RLS. Go to [www.rls.org/join](http://www.rls.org/join) to help us Find a Cure!



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

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## Different Journeys to a Common Destination

By Nelson Checkoway

If there is one silver lining that we have seen the restless legs syndrome (RLS) community discover over the course of the COVID-19 pandemic, it is the bonding together of more and more people who are joining our network through online support groups.

Since we were forced to “go virtual” as a safety measure, people who had been suffering silently – unable to travel or living too remotely to attend in-person support group gatherings – were suddenly able to share their stories, to give support to some, and to lean on others.

But well before COVID-19 struck, we have been following the journeys of RLS patients in our network. You can read some of their stories on our website and hear from some in our YouTube series “My RLS Journey.”

Caroline’s RLS started when she was in her 30’s and she tells of decades spent trying different remedies and being afflicted with augmentation. Her advice to fellow patients: “Keep an open mind and find the best neurologist you can.”

Donnie recalls his journey commencing when he was a teenager. “I didn’t think it was anything out of the ordinary, but it didn’t stop what I was doing so I lived with it.” He acknowledges that RLS affects your life every day, but he didn’t let his RLS deter him from flying gliders and SCUBA diving – things he loves to do.

Each storyteller has charted his or her own unique journey. Lori describes her symptoms as “not pain, but not a tolerable feeling” and says that what helps her cope is, “getting my mind on something other than my legs.” Janice says that the day she first heard about RLS was one of the most memorable in her life: “The day I found out I wasn’t crazy – that I had a disease!”

But what they all share is the realization that they not only needed help themselves, but that they also needed to help others. Donnie says: “The first time I talked to somebody else who had RLS, it gave me some solace, knowing that there are other people out there who know what I’m going through ... so the best thing you can do is, ‘let me help other people, let me help them get through it.’ ”

Janice agrees that of all the people she’s met over the years, the ones whose stories stick with her are the people who were suffering and who looked to her for advice: “I was so glad I could be one step ahead of them to help them ... and other people have been one step ahead to help me.”

All these journeys are unique. But they all arrive, hand-in-hand, at a common destination – a station-stop on the road to a cure, where caring, hope and compassion meet. There are many ways you can reach this destination, too. You can share your story. You can participate in an RLS support group. You can help us advocate for RLS research. And you can help the Foundation continue to bring our community together in the weeks and months to come, by giving to our Annual Fund when our appeal arrives in your mailbox this season.

As Janice concludes: “That’s part of the hope, that we’ll all just reach out and grab one another’s hands.”



# In the News

By Lynn Marie Trotti, MD, MSc

## Can Cognitive Behavioral Therapy Help People with RLS?

“Cognitive behavioral therapy for insomnia in restless legs syndrome patients.” Song, ML et al. *Sleep Medicine*. October 2020.

### The Background

People with restless legs syndrome may also have other sleep disorders, especially common ones such as sleep apnea and insomnia. Treatment of these other sleep disorders may be helpful in reducing symptoms of RLS. Insomnia can be treated with either medication or non-medication options. The major non-medication treatment is cognitive behavioral therapy for insomnia (CBT-I), a structured program designed to change thoughts and behaviors around sleep to reduce insomnia symptoms. For people with insomnia, CBT-I has been shown to be helpful in numerous studies. It is not known whether CBT-I works well for insomnia treatment in people who also have RLS.

### The Research

Twenty-five adult participants with both RLS and insomnia completed this study. They were all treated for RLS with a dopamine agonist but still had trouble falling asleep or staying asleep. They were randomly assigned either to receive CBT-I or to a control group, which received a single educational session on strategies for improving sleep. The CBT-I group attended weekly, one-hour, one-on-one sessions with a CBT-I provider for four weeks, during which time they were taught a variety of CBT-I techniques. These techniques were modified to make them more appropriate for people with RLS. For example, instead of being asked to sit quietly for a breathing meditation, participants were asked to move during this meditation. All participants completed symptom questionnaires and sleep logs and wore actigraphy (sensor worn to monitor rest/activity cycles) to estimate their sleep patterns. These evaluations were completed at the start of the study, after four weeks, and after three months. Most people who started the CBT-I program completed the study, while half of the people assigned to the sleep education group dropped out of the study. The group who received CBT-I reported significantly more improvement in their insomnia severity, time it took to fall asleep and ability to remain asleep than did the control group – both immediately after finishing CBT-I and eight weeks later. Anxiety symptoms were reduced in the CBT-I group after finishing CBT-I but had returned by eight weeks later. Neither group had significant changes in RLS symptom severity.

### The Bottom Line

For people who have both RLS and insomnia, CBT-I is helpful for insomnia symptoms, although it does not affect RLS symptoms. Some of the beneficial effects of CBT-I continue for at least two months after finishing CBT-I treatment.

## Further Questions

If CBT-I is part of the treatment for someone with RLS and insomnia, should CBT-I be started after RLS treatment (as it was in this study) or at the same time as RLS treatment? Would a different RLS medication, such as an alpha-2-delta ligand (such as gabapentin which promote sleep by causing sedation), be better than a dopamine agonist in combination with CBT-I?

## Who Gets the Most Improvement from Intravenous Iron Treatment?

“Patient characteristics predicting responses to intravenous ferric carboxymaltose treatment of restless legs syndrome.” Park, HR et al. *Sleep Medicine*. March 2020.

### The Background

Brain iron deficiency is known to be one factor involved in the development of restless legs syndrome. Some, but not all, forms of intravenous iron supplementation have been shown to be helpful for RLS in placebo-controlled trials. Ferric carboxymaltose is a type of intravenous iron that has been shown to reduce RLS symptoms, even among people who do not have iron deficiency based on blood testing. However, not all people with RLS who receive ferric carboxymaltose have an improvement in RLS symptoms, so it would be helpful to know if any features can predict who is most likely to benefit from this treatment.

### The Research

The researchers reviewed medical records from all RLS patients who were treated clinically with intravenous ferric carboxymaltose over a three-year period. People who were already prescribed non-iron treatment for RLS were asked to keep this medication usage unchanged for four weeks after iron infusion. RLS symptoms were assessed immediately before iron treatment and again four weeks later. After excluding data from people with high iron values before the injection and those who had previously been treated with iron, the final data set included information on 189 people. 25 of these people did not complete a follow up assessment of their RLS symptoms, and so were assumed by the authors to have had no change in symptoms after intravenous iron treatment. Overall, RLS severity improved by at least 40% in just over half of the group (55% of participants) with 42.5% of subjects reporting improvement in severity to “mild” or “less.” People with iron deficiency or prior stomach surgery had much higher response rates of over 90%. Most clinical features, including gender, age, age of onset, family history of RLS, prior RLS medication, RLS severity and insomnia were not related to whether or not ferric carboxymaltose improved symptoms. For people with primary RLS, the best predictor of symptom improvement was a



Lynn Marie Trotti, MD, MSc

measure of iron stores called percent transferrin saturation, with lower values predicting better response to iron treatment.

### The Bottom Line

Intravenous ferric carboxymaltose has previously been shown to improve RLS symptoms, even in the absence of iron deficiency. However, this study suggests that people with iron deficiency, particularly as measured by percent transferrin saturation, may be more likely to benefit from this treatment.

### Further Questions

Blood markers of iron, including percent transferrin saturation, do not directly reflect brain iron levels. Is it feasible to use non-invasive measures of brain iron, such as ultrasound or brain MRI, to better predict which patients are most likely to benefit from treatment? Since it sometimes takes longer than four weeks to get a clinical response from IV iron, would a longer follow up study show even better responses?

### Does RLS Contribute to Poor Sleep in Children with Autism?

“Rethinking bedtime resistance in children with autism: is restless legs syndrome to blame?” Kanney, ML et al. *Journal of Clinical Sleep Medicine*. August 2020.

### The Background

Children with autism often have very poor sleep, which can cause problems for both the children and their caregivers. A number of studies have investigated insomnia in kids with autism, but few studies have evaluated RLS-type symptoms as a potential cause of sleep disturbance in these children.

### The Research

The researchers collected data from medical records of all children with autism who were sent to a pediatric sleep center for evaluation of insomnia, excluding those with sleep apnea. All children were assessed using a semi-structured interview, which included multiple questions about sleep habits and possible symptoms of RLS. When children had the verbal skills to participate, they answered questions about their symptoms; when they did not, their caregivers provided information on their behalf. A board-certified sleep specialist diagnosed RLS based on the International RLS Study Group pediatric criteria for “probable RLS,” “possible RLS” or RLS not fully meeting these criteria but strongly suspected on clinical grounds. Of the 103 children with autism referred for evaluation of insomnia, 39% were given a diagnosis of RLS. Caregivers more often reported nocturnal motor symptoms in children with RLS than those without RLS. The majority of children diagnosed with RLS who were able to undergo a sleep study were found to have periodic limb movements of sleep. More children with RLS than without RLS had iron deficiency. Children with RLS and iron deficiency were treated with oral iron. Ninety-two percent of these children had an improvement in their sleep. A smaller

number of children were treated with gabapentin, which was also helpful for sleep.

### The Bottom Line

RLS may contribute to poor sleep in some children with autism.

### Further Questions

For children with autism, insomnia and symptoms of RLS, does treatment of RLS improve child and caregiver sleep? Which RLS treatment is best in these kids?

### Is RLS a Risk Factor for Poor Pregnancy Outcomes?

“Maternal and neonatal outcomes associated with restless legs syndrome in pregnancy: A systematic review.” Steinweg, K. *Sleep Medicine Reviews*. July 2020.

### The Background

Some studies have suggested that people with RLS are at higher risk for certain medical disorders, including high blood pressure and depression, although findings of these associations have not been consistent across all studies. Fewer studies have assessed the association between RLS and disorders of pregnancy or pregnancy outcomes.

### The Research

The authors performed a systematic literature search to identify articles evaluating the relationship between RLS and any pregnancy related condition. They found 16 studies from 12 different countries. The most commonly evaluated pregnancy conditions were baby birthweight (eight studies), preterm birth (seven studies), Cesarean delivery (six studies), high blood pressure during pregnancy (four studies), and eclampsia (three studies). Most studies defined RLS using the International RLS Study Group criteria. For the studies assessing RLS and blood pressure (either high blood pressure or eclampsia), three of five studies showed an increased risk in those women with RLS compared to those without, leading the authors to conclude that there is a “plausible link” between RLS and these blood pressure disorders. Two studies found that women with RLS were more likely to experience depression either during pregnancy or postpartum. No consistent relationship was seen between RLS and Cesarean delivery, gestational age or birthweight.

### The Bottom Line

Pregnant women with RLS may be somewhat more likely to have certain pregnancy complications, but it is not clear whether RLS is the cause of these complications.

### Further Questions

What is the safest, most effective way to treat RLS during pregnancy? Would treatment of RLS during pregnancy lead to better pregnancy outcomes?



# 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 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 [rlsmods@rlsgroups.org](mailto:rlsmods@rlsgroups.org) for more information on how to get started.

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## Want to Join the Team?

We are looking for Volunteer Virtual Support Group leaders! If you are interested in volunteering for the Foundation but rather not travel or organize a physical meeting, this is for you. We will set up the Zoom video meeting and you will welcome the participants and lead the discussions.

If you are interested, please complete an application at [www.rls.org/volunteerapp](http://www.rls.org/volunteerapp) and we will get you started. For more information please email [clara@rls.org](mailto:clara@rls.org).

For a list of Virtual Support Group meeting go to [www.rls.org/vsg](http://www.rls.org/vsg).

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# Clinical Trials

*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.*

## Understanding the Role of Epigenetics in RLS

Researchers at Johns Hopkins School of Medicine, led by Christopher J. Earley, MB, BCh, PhD, are conducting a study designed to address the question of why does RLS have such a high inheritance risk. If you are a woman who currently has iron deficiency anemia then you may be eligible for this study. We are looking for women who do and do not (control group) have RLS symptoms.

Contact: Jessica at 410-550-1046

## Intravenous Iron Therapy in Patients with Anemia and RLS

Researchers at Johns Hopkins School of Medicine, led by Christopher J. Earley MB, BCh, PhD, are conducting a clinical trial to establish the effectiveness of intravenous iron in treating patients who have an anemia and who also have RLS symptoms. If you currently have an iron deficiency anemia and have frequent RLS symptoms then you may be eligible for this clinical trial.

Contact: Jessica at 410-550-1046

## Hormones and Their Role in Restless Legs Syndrome

RLS community: Brian Koo, MD, and his team of researchers at Yale have received funding from the Department of Defense to continue their study of hormones in RLS and are looking for RLS study participants.. 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: Abdalla Albanna, [abdalla.albanna@yale.edu](mailto:abdalla.albanna@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)

## Wearable Compression Vibratory Device

Are you experiencing bothersome RLS symptoms at least five days a week? Have you been experiencing these bothersome symptoms for at least three months? Have you been taking the same dosage of medication for RLS or no medication for at least two months?

If so, you may qualify to participate in a two-month investigational study to test a wearable compression vibratory device for patients (age 18 and older) with RLS who live in the San Francisco Bay area.

Qualifying participants will receive all study related materials at no cost and be paid for their time upon completion of the study requirements.

Contact: Ryan McCormick, CA Center for Sleep Disorders, [rmmccormick@sleepdx.com](mailto:rmmccormick@sleepdx.com) or 510-263-3331

## Is RLS Affecting Your Child?

Science 37 has a 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)



## 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 in part without prior permission from the RLS Foundation.

Quantity	Patient Handouts	Quantity	Patient Handouts	Quantity	Patient Handouts
	Augmentation: Diagnosis & Treatment		Drug Holidays and RLS		Research Grant Program
	Augmentation: A Quick Guide		Guide to Living with RLS		Surgery and RLS
	Augmentation FAQ		Healthcare and Your Child with RLS		Symptom Diary for RLS
	Can an Active Lifestyle Prevent or Improve RLS Symptoms?		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		
	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		
	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

## DONATION

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

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

## DONATION APPLIED TO

☐ Research  
☐ Where it is needed most

## PAYMENT METHOD

☐ I have enclosed a check in the amount of \$\_\_\_\_\_ in US dollars, drawn on a US bank, payable to the RLS Foundation.

☐ Please charge \$\_\_\_\_\_ to my ☐ American Express ☐ Discover ☐ MasterCard ☐ VISA

Card number \_\_\_\_\_ Expiration date \_\_\_\_\_

## CONTACT INFORMATION (Please make any changes to address on reverse side. We do not rent, sell or share our mailing list.)

Name \_\_\_\_\_ Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Email address \_\_\_\_\_ Phone number \_\_\_\_\_

**Restless Legs Syndrome Foundation | 3006 Bee Caves Road | Suite D206 | Austin, TX 78746**



RESTLESS LEGS  
SYNDROME  
FOUNDATION

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