

# Guide to Living with RLS

## What is RLS?

Restless legs syndrome (RLS) is a disruptive neurological disorder that significantly affects 3% of the adult population.<sup>1</sup> RLS results in an irresistible urge to move the legs, and is often accompanied by unusual or unpleasant sensations in the legs that may be described as *creeping*, *tugging* or *pulling*. RLS most often occurs during the evening and nighttime hours severely disrupting sleep, causing daytime impairments and reduced quality of life.

## How is RLS diagnosed?

To be correctly diagnosed with RLS, you must meet these five diagnostic criteria:<sup>1</sup>

Urge to move the legs associated with unpleasant leg sensations.

Rest induces symptoms.

Gets better with activity.

Evening and nighttime worsening.

Sensation not solely caused by another medical or behavioral condition.

If you think you are experiencing RLS symptoms, schedule an appointment with your physician. Your provider will review your medical history, complete a physical exam, listen to a description of your symptoms, complete a diagnostic interview, and rule out conditions that may be confused with RLS. In addition, your doctor should check your iron levels as low brain iron plays a role in the development of RLS. If another sleep disorder is suspected, you may be asked to stay overnight for a sleep study in a sleep lab. Your physician will consider all of these factors in determining whether or not you have the disease. There is no diagnostic test available or biomarker available to confirm RLS diagnosis.

## What causes RLS?

RLS is due to a combination of genetics, environmental factors and comorbid conditions. RLS can be easily triggered in patients with a strong family history of RLS. Several studies have shown that there are multiple small variations across multiple genes that are associated with an increased risk of developing RLS. However, the “causal” relationship between these gene variations and the disease expression is less clear.<sup>2,3</sup> A substantial number of women develop RLS during pregnancy. Additionally, anemia, low iron (ferritin) levels, end stage renal disease with dialysis, and peripheral neuropathy are all associated with RLS.

## What treatments are available?

While there is currently no cure for RLS, there are many pharmaceutical and nonpharmaceutical therapies that help ease RLS symptoms. In addition to iron supplementation, there are three common drug classes that offer relief from RLS symptoms:<sup>4</sup>

**Iron therapy** (oral or intravenous) increases available brain iron, as low brain iron plays a role in the development of RLS. Consensus based clinical guidelines published in 2018, provide direction for appropriate iron management of RLS.<sup>5</sup>

**Alpha-2-delta ligands** (gabapentin, gabapentin enacarbil and pregabalin) are thought to relieve discomfort by changing the excitability of nerves that carry RLS sensations or pain.

**Dopamine agents** are no longer recommended due to risk of augmentation with long-term use.

• These medications include pramipexole, ropinirole, rotigotine and carbidopa/levodopa (which when used no more than three times weekly, the risk of augmentation is low).

**Opioids** (codeine, oxycodone, methadone) in low-total-daily doses are used when RLS symptoms are moderate to severe and other treatment options are no longer tolerated or effective.

To develop an RLS treatment plan, you and your provider can:

- Check for iron deficiency (an iron panel and ferritin level). It is important to note both lab tests as they are two separate check boxes on a lab requisition.
- Look at eliminating over-the-counter medications that contain first-generation sedating antihistamines (diphenhydramine), and some antidepressants that are known to worsen RLS symptoms. See the RLS Medical Alert Card for a complete list of medications.
- Develop a daily schedule of exercise and/or physical activities.
- Identify and eliminate activities that worsen your RLS symptoms.



## In order to diagnose RLS your physician will:

- review your medical history
- complete a physical exam
- listen to your description of symptoms
- complete a diagnostic interview
- rule out other conditions



RAISE AWARENESS

PROMOTE ADVOCACY

IMPROVE TREATMENTS

SUPPORT RESEARCH

FIND A CURE

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## How do I cope with RLS?

Living with RLS can be challenging. You can lessen your symptoms through treatments and lifestyle strategies. You can also find coping practices that work for you.

**Talk about RLS.** Share information with family and friends.

**Don't fight it.** Don't suppress the urge to move. Get out of bed and find an activity to get your mind off of RLS.

**Keep a diary.** Keep track of your medications and strategies to discuss with your physician. Dictate a voice memo if you can't sit still to write. Download the *RLS Symptoms Diary* to record daily activities such as diet and exercise.

**Occupy your mind.** Find an activity you enjoy to keep your mind engaged and help you through troublesome times.

**Rise to new levels.** Elevate your desktop to a height that will allow you to stand as you work or read.

**Stretch out your day.** Begin and end each day with stretching or gentle massage.

**Help others.** Consider joining or starting a support group. There are over 70 RLS support groups and contacts throughout the United States and Canada.

**Find your triggers.** Consider eliminating caffeine, alcohol and nicotine. Download the *RLS Triggers* handout for more information.

**Implement good sleep habits.** Create a bedtime routine that incorporates relaxation techniques and reduces stimulating activities.

## What is the RLS Foundation?

The Restless Legs Syndrome Foundation is a nonprofit patient organization dedicated to improving the lives of the millions of men, women and children living with this devastating disease. The organization's goals are to increase awareness, improve treatments, and advance research to find a cure.

## Where can I get more information?

The RLS Foundation provides the most comprehensive and accurate RLS information at [www.rls.org](http://www.rls.org). The Foundation's website provides a list of RLS Quality Care Centers, a healthcare provider directory, a list of support groups in your area, as well as publications covering specific concerns like augmentation, medications, RLS and children, and much more. The Member Portal offers on-demand webinar recordings from RLS experts, current and past issues of our acclaimed quarterly magazine, *NightWalkers*, and publications covering RLS topics of interest. You can also contact the RLS Foundation at 512-366-9109 or by email at [info@rls.org](mailto:info@rls.org).

## How can I find a support group?

RLS support groups provide individuals with an opportunity to share their RLS experience and to offer support to others. The RLS Foundation offers weekly virtual support Zoom meetings. Go to [www.rls.org](http://www.rls.org) to find a support group or register to attend a virtual support group meeting. The Foundation's social media pages and online discussion board ([bb.rls.org](http://bb.rls.org)) also offer the opportunity to connect informally with people 24/7 worldwide who are living with RLS.

## How can I find a provider?

You will find a list of RLS Quality Care Centers on [www.rls.org/QCC](http://www.rls.org/QCC). These centers have expert RLS physicians with experience in treating mild to severe cases of RLS. We also offer a directory of healthcare providers who have indicated experience in treating RLS patients at [www.rls.org/find-a-doc](http://www.rls.org/find-a-doc).

## How do I become a member?

You can become a member of the RLS Foundation by visiting [www.rls.org/join](http://www.rls.org/join). Member benefits include:

- *NightWalkers* quarterly magazine subscription
- Medical Alert and Special Accommodations Card
- The RLS Foundation's *Medical Bulletin* (a comprehensive guide to diagnosis, treatment and management of RLS)
- 24/7 online access to RLS publications, past webinars and the *NightWalkers* archive

## What can I do to help?

Become a member of the RLS Foundation. Your membership not only entitles you to many benefits but also helps enhance awareness and educational outreach activities. The work of the Foundation is supported by individuals like you. Your tax-deductible gift in any amount will help support the Foundation's mission. Additionally, your support benefits the only RLS research grant program whose sole purpose is to fund research leading to new treatments and a cure for RLS.

## You are not alone!

One in 33 Americans require daily treatment for their RLS. Up to 10% of the population experiences RLS symptoms. Contact the RLS Foundation or your local support group for more information, to find help in managing your RLS or to make a difference for others who live with RLS.

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2. Schormair B, Zhao C, Bell S, et al. Identification of novel risk loci for restless legs syndrome in genome-wide association studies in individuals of European ancestry: a meta-analysis. *Lancet Neurology*. 2017;16(11):898-907. doi:10.1016/S1474-4422(17)30327-7

3. Schormair B, Zhao C, Bell S, et al. Genome-wide meta-analyses of restless legs syndrome yield insights into genetic architecture, disease biology and risk prediction. *Nature Genetics*. 2024;56(6):1090-1099. doi:10.1038/s41588-024-01763-1

4. Silber MH, Buchfuhrer MJ, Earley CJ, et al. The Management of Restless Legs Syndrome: An Updated Algorithm. *Mayo Clinic Proceedings*. 2021;96(7):1921-1937. doi:10.1016/j.mayocp.2020.12.026

5. Allen RP, Picchietti DL, Auerbach M, et al. Evidence-based and consensus clinical practice guidelines for the iron treatment of restless legs syndrome/Willis-Ekbom disease in adults and children: an IRLSSG task force report. *Sleep Medicine*. 2018;41:27-44. doi:10.1016/j.sleep.2017.11.1126

*The 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 advance research to find a cure for restless legs syndrome.*

This publication has been reviewed and approved by reviewers from the RLS Foundation Scientific and Medical Advisory Board.

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