



# *Causes, diagnosis and treatment*

*For the patient living with  
restless legs syndrome (RLS)*



RESTLESS LEGS  
SYNDROME  
FOUNDATION

[www.rls.org](http://www.rls.org)

## **RESTLESS LEGS SYNDROME**

Restless legs syndrome (RLS), also called Willis-Ekbom disease, is a neurological disease that causes an irresistible urge to move the legs, often accompanied by unusual or unpleasant sensations. Symptoms may also involve arms and other body parts. Because RLS most often occurs in the evening, it can severely disrupt sleep and reduce quality of life. RLS can cause significant stress on your relationships, work, family, education or other areas of life by impacting your sleep, energy/vitality, daily activities or mood.

While a cure for RLS has not yet been discovered, many treatments, coping strategies and support resources are available to help individuals and families living with the disease.

### **WHO IS AFFECTED BY RLS**

It is estimated that 10 million adults and 1.5 million children and adolescents in the US are significantly affected by RLS. It is most often diagnosed in middle-aged individuals, with women affected twice as often as men. Patients can often trace symptoms back to their childhood and remember hearing things like “those are growing pains” or “quit wiggling so much.”

### **CAUSES OF RLS**

A single unifying cause of RLS has not been established, but extensive research is underway. As the Foundation marked its 25th anniversary in 2017, nearly \$1.8 million in research grants were funded in search of better treatments and a cure. In 2007, Dr. David Rye, funded in part by the RLS Foundation, discovered the first gene variant that contributes substantially to the risk for RLS. Other research has established the following:

- RLS often runs in families. However, other medical conditions such as iron deficiency, renal failure or pregnancy may cause RLS to occur more frequently.
- Approximately 20 percent of women develop RLS during pregnancy, but symptoms often disappear a few days before or after childbirth.
- Brain iron deficiency (BID) is a contributing factor in the development of RLS. Treatment guidelines recommend iron replacement therapy when peripheral iron levels (measured by a ferritin lab test) are low.
- RLS is common in patients who require dialysis for end-stage renal disease.
- Damage to the nerves of the hands or feet (i.e., peripheral neuropathy) from any number of causes, including diabetes, often accompanies the disease.
- Attention deficit/hyperactivity disorder (ADHD) is common in children and adults with RLS.

## DIAGNOSIS AND TREATMENT

RLS is not diagnosed through laboratory testing, but rather through evaluation of symptoms.

Since 2012, there have been five required primary diagnostic criteria to support a diagnosis of RLS:

- **Urge to move the legs that is irresistible.** Sometimes the arms or other body parts are involved in addition to the legs.
- **Onset or worsening with rest.** The motor and sensory symptoms most often begin or worsen during periods of rest or inactivity, particularly when lying down or sitting.
- **Relief with movement.** RLS symptoms are partially or totally relieved by movements such as walking or stretching; symptoms are relieved for at least as long as the activity continues. Mental activity also reduces symptoms.
- **Circadian pattern.** RLS symptoms usually occur or worsen in the evening or at bedtime. Symptoms are usually dormant in the morning.
- **Exclusion of mimics.** Symptoms are not attributable to any other medical or behavioral condition (arthritis, leg cramps or swelling, habitual foot tapping, muscle pain, venous stasis).

RLS primary diagnostic criteria <sup>1</sup>
Urge to move the legs
Rest induced
Gets better with activity
Evening or night worsening
Sensation that is often hard to describe

1. Allen RP, Picchiatti D, Hening WA, et al. Restless legs syndrome: diagnostic criteria, special considerations, and epidemiology. A report from the restless legs syndrome diagnosis and epidemiology workshop at the National Institutes of Health. *Sleep Med.* 2003. 4(2):101-119.

Your doctor can help you explore ways to lessen your symptoms through lifestyle changes, self-care and medication. If you need medication, your provider will guide you through careful trials to find a drug and dosage that works best for you. To develop your treatment strategy, your healthcare provider should:

- Check to see if you have an iron deficiency, and possibly consider oral iron supplements or intravenous iron therapy. *Note: Iron supplements should only be taken under the supervision and care of a physician.*
- Examine other prescription drugs, over-the-counter medications or herbal remedies you may be taking. For example, drugs commonly used to treat nausea, colds, allergies and depression can trigger RLS symptoms.
- Identify any habits or activities that worsen your symptoms.

## PERIODIC LIMB MOVEMENTS IN SLEEP (PLMS)

A chief issue for people who have RLS is difficulty in falling or staying asleep. Eighty percent of individuals with RLS have periodic limb movements in sleep (PLMS). These movements occur every 20–30 seconds, on and off, throughout the night, causing partial awakenings that disrupt sleep. Treatment for PLMS may be recommended in some but not all cases. Medicines that treat RLS suppress PLMS. Research shows that PLMS may be associated with increased risk of cardiovascular problems.

## MEDICATIONS TO TREAT RLS

The FDA has approved four drugs for treating RLS: ropinirole (Requip), pramipexole (Mirapex), gabapentin enacarbil (Horizant) and rotigotine (Neupro). In addition, several drugs approved for other conditions have provided relief for RLS symptoms. Refer to the Foundation's *RLS Medical Bulletin* for dosing details.

---

**ALPHA-2-DELTA LIGANDS** are particularly effective for patients with severe insomnia, painful RLS symptoms, or a previous impulse control disorder. As a strategy to prevent RLS augmentation, alpha-2-delta ligands may be considered as a first line treatment in newly diagnosed patients.

<u>Generic name</u>	<u>Brand name</u>
gabapentin enacarbil	Horizant
gabapentin	Neurontin
pregabalin	Lyrica

---

**DOPAMINERGIC AGENTS** are also used to treat Parkinson's disease (PD). The lowest effective dose is used to manage symptoms while not exceeding FDA-approved dosages. Side effects include augmentation or development of impulse control disorders.

<u>Generic name</u>	<u>Brand name</u>
carbidopa/levodopa	Sinemet/Restix
pramipexole	Mirapex
ropinirole	Requip
rotigotine transdermal	Neupro

---

**IRON SUPPLEMENTATION** may be an effective therapy when peripheral iron levels are low.

<u>Type</u>	<u>Generic name</u>	<u>Brand name</u>
Oral	ferrous sulphate taken with vitamin C	none
Intravenous	ferric carboxymaltose	Injectafer
	ferumoxytol	Feraheme
	iron gluconate	Ferrlicit
	iron sucrose	Venofer
	low-molecular-weight iron dextran	INFed



**RLS FOUNDATION PATIENT SYMPTOM DIARY – Keep this diary for 7–14 consecutive days, you may identify triggers and discover patterns.**

*To be completed  
after waking up for the day:*

	Day 1	Day 2	Day 3	Day 4	Day 5	Day 6	Day 7
<i>Today's date:</i>							
<i>I woke up today at what time?</i>							
<i>I went to bed last night at what time?</i>							
<i>I woke up how many times during the night, if any?</i>							
<i>I slept how many hours last night?</i>							
<b><i>To be completed just before your bedtime:</i></b>							
<i>Today I experienced my RLS symptoms at what time(s)?</i>							
<i>From 1 to 5 (5 being the worst), my symptoms were how severe?</i>							
<i>My major stresses today were:</i>							

<p><i>I consumed any of these substances during the day: (include the time that you consumed each item)</i></p>	<input type="radio"/> Caffeine <input type="radio"/> Alcohol <input type="radio"/> Tobacco products <input type="radio"/> Over-the-counter medications <input type="radio"/> Other (please list)	<input type="radio"/> Caffeine <input type="radio"/> Alcohol <input type="radio"/> Tobacco products <input type="radio"/> Over-the-counter medications <input type="radio"/> Other (please list)	<input type="radio"/> Caffeine <input type="radio"/> Alcohol <input type="radio"/> Tobacco products <input type="radio"/> Over-the-counter medications <input type="radio"/> Other (please list)	<input type="radio"/> Caffeine <input type="radio"/> Alcohol <input type="radio"/> Tobacco products <input type="radio"/> Over-the-counter medications <input type="radio"/> Other (please list)	<input type="radio"/> Caffeine <input type="radio"/> Alcohol <input type="radio"/> Tobacco products <input type="radio"/> Over-the-counter medications <input type="radio"/> Other (please list)	<input type="radio"/> Caffeine <input type="radio"/> Alcohol <input type="radio"/> Tobacco products <input type="radio"/> Over-the-counter medications <input type="radio"/> Other (please list)	<input type="radio"/> Caffeine <input type="radio"/> Alcohol <input type="radio"/> Tobacco products <input type="radio"/> Over-the-counter medications <input type="radio"/> Other (please list)
<p><i>I exercised today for how long?</i></p>	<p>Times:</p>	<p>Times:</p>	<p>Times:</p>	<p>Times:</p>	<p>Times:</p>	<p>Times:</p>	<p>Times:</p>
<p><i>Additional comments:</i></p>							

## **AUGMENTATION AND IMPULSE CONTROL DISORDERS (ICDs)**

Augmentation is a worsening of symptoms that occurs over time (generally months to years) from taking a drug that acts on the dopamine system. Initially, the dopamine drugs markedly improve RLS symptoms but with time, many individuals will experience a worsening of their RLS symptoms. They will notice symptoms occurring earlier in the day, becoming more intense, not responding to previous effective doses of the dopamine drug and/or spreading to other body parts such as the arms and trunk. Increasing the dose of the dopamine drug will provide temporary relief (sometimes for months or longer) but will worsen the augmentation, making the RLS progressively harder to treat. Impulse control disorders (ICDs) are an adverse side effect of dopamine agonist therapy. Behaviors may include gambling, compulsive shopping or hypersexuality.

If you experience augmentation or an ICD, you and your doctor can work together to find a new treatment strategy that will work for you. Do not make any changes to your medications without consulting with your doctor.

## **LIVING WITH RLS**

Although there is not yet a cure for RLS, most people with RLS, even those with severe symptoms, should be able to find a treatment regimen that provides adequate to excellent control of their RLS symptoms. If your RLS symptoms are not well controlled, you may consider consulting a specialist at a certified RLS Quality Care Center listed at [www.rls.org/qcc](http://www.rls.org/qcc). By learning all that you can and partnering with your healthcare provider, you can lessen your symptoms through treatments and lifestyle changes. You can also find coping strategies that work for you. Here are some suggestions:

- *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 that takes your mind off of your symptoms.
- *Stay active.* Find activities that help you cope, such as walking, stretching, taking hot or cold baths, massage, acupuncture or relaxation techniques.
- *Keep a symptom diary.* If you can't sit still to write, create a voice memo. Keep track of your medications and coping strategies and share these with your physician.
- *Occupy your mind.* Keep your mind engaged with activities you enjoy like discussions, needlework, crafts or video games.



- *Rise to new levels.* You may be more comfortable if you use a standing desk to work.
- *Keep good sleep habits.* Maintain a consistent sleep schedule, go to bed and wake up the same time every day.
- *Stretch out your day.* Begin and end your day with stretching or gentle massage.
- *Reach out.* Support groups throughout the US and Canada, and internationally, help RLS patients and their families. Join the Foundation's online discussion board, read the Foundation's blog or follow the RLS Foundation on Facebook, Instagram and Twitter to share your ideas and experiences.

## **THE RLS FOUNDATION**

The mission of the RLS Foundation is to improve the lives of the millions of men, women and children who live with RLS. The goals of the Foundation are to increase awareness, improve treatments and through research, find a cure.

Through its publications, website and support resources, the Foundation helps people with RLS find the support they need, and provides the medical community with information on diagnosis, treatment and management. The Foundation's Scientific and Medical Advisory Board includes renowned experts who author publications, such as the Foundation's comprehensive *RLS Medical Bulletin*. The Foundation's research grant program supports efforts worldwide that aim to understand the disease and find better treatments and a cure.

## **GET INVOLVED**

Join the RLS community in efforts to increase awareness, improve treatments, and through research, find a cure! The work of the RLS Foundation is made possible by the generosity of individuals like you. Your tax-deductible gift in any amount will help provide advocacy, education and support to patients and healthcare providers about RLS, and fund vital research to improve the lives of individuals and families who live with the disease.

## MEMBER BENEFITS

For \$35 per year (US and Canada) or \$45 internationally, you can become a member of the RLS Foundation. Scholarships are available to help cover membership dues. As a member, you will receive:

- The Foundation's *RLS Medical Bulletin*, which contains the latest treatment information to share with your healthcare provider.
- *NightWalkers*, a quarterly magazine that includes treatment updates, feature stories, clinical trials information, support group information and more.
- A Medical Alert Card that lists drugs safe for use and medications best avoided by RLS patients.
- Membership and special accommodations card.
- RLSF magnet.
- Access to the Member Portal on [www.rls.org](http://www.rls.org).
- The satisfaction of supporting education, advocacy and research to improve the lives of people with RLS worldwide!

The RLS Foundation is a 501(c)(3) nonprofit organization. Gifts made to the RLS Foundation are fully deductible to the extent permitted by law.

Become a member or make a financial gift today! Simply complete and mail the form opposite, or visit [www.rls.org/join](http://www.rls.org/join).

*Thank you for your support!*

---

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

## MEMBER/DONOR FORM

### Step 1 - Choose all that apply

- I want to become a member of the Restless Legs Syndrome (RLS) Foundation (annual rates: \$35 for US and Canada; \$45 for international).
- I have included an additional tax-deductible donation of \$\_\_\_\_\_.
- I would like more information about planned giving avenues (monthly giving, gift of stocks, estate gifts and/or including the RLS Foundation in my will).

### Step 2 - Please provide your contact information.

*The RLS Foundation does not rent, share or sell any information.*

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_

State \_\_\_\_\_ Zip code \_\_\_\_\_

Country \_\_\_\_\_

Telephone \_\_\_\_\_

Email \_\_\_\_\_

### Step 3 - Payment Information

- I have included a US check payable to RLS Foundation.
- Please bill \$\_\_\_\_\_ to my:  
 AmEx  Discover  MasterCard  Visa
- Please charge my credit card \$\_\_\_\_\_ each month for \_\_\_\_\_ month(s).

Credit card # \_\_\_\_\_

Exp. date \_\_\_\_\_

Name on card \_\_\_\_\_

### Step 4 - Mail your completed form to:

RLS Foundation  
3006 Bee Caves Road | Suite D206  
Austin, TX 78746



RESTLESS LEGS  
SYNDROME  
FOUNDATION

RLS Foundation  
3006 Bee Caves Road | Suite D206  
Austin, TX 78746

[info@rls.org](mailto:info@rls.org)  
[www.rls.org](http://www.rls.org)  
512-366-9109



INCREASE AWARENESS  
IMPROVE TREATMENTS  
FIND A CURE