

RESTLESS LEGS SYNDROME



Causes, diagnosis and treatment

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



RESTLESS LEGS
SYNDROME
FOUNDATION

RESTLESS LEGS SYNDROME FOUNDATION

www.rls.org

WHAT IS RESTLESS LEGS SYNDROME?

Restless Legs Syndrome (RLS), also called Willis-Ekbom disease (WED), is a neurological disorder 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. They should not be solely accounted for by other conditions such as leg cramps, positional discomfort or myalgia. Because RLS most often occurs in the evening, it can severely disrupt sleep and reduce quality of life.

If you have RLS, you are not alone. RLS is estimated to significantly affect two to three percent of adults. In the United States, 7.4 million adults are significantly affected by the disease.

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.

THE RLS FOUNDATION

The RLS Foundation is a 501(c)(3) organization that has been helping and supporting people that have RLS live better lives since 1992. 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 patients find the medical and social support they need, and provides the medical community with information on diagnosis and treatment. The Foundation's Medical Advisory Board includes renowned experts who author several publications, including the *RLS Medical Bulletin* and patient brochures. The Foundation's research grant program supports efforts worldwide that aim to understand the disease and find a cure.

Visit www.rls.org to learn more about RLS and the resources available for patients and their families.

This publication has been reviewed and approved by the RLS Foundation's 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 sponsor any products or services.



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WHAT ARE THE PRIMARY FEATURES OF RLS?

You may be diagnosed with RLS if your symptoms:

- Include a strong urge to move your legs or other limbs that you may not be able to resist. This need is often accompanied by uncomfortable sensations that might be described as creeping, itching, pulling, creepy-crawly, tugging or gnawing. Symptoms may also involve your arms and other body parts.
- Start or worsen when you are resting. The longer you rest, the more frequent and intense your symptoms will likely become.
- Improve when you move your legs or other affected body parts. Relief can be complete or partial, but generally starts very soon after starting an activity. Relief persists as long as you keep moving.
- Worsen in the evening, especially when you are lying down. Activities that bother you at night do not bother you during the day.
- Cannot solely be attributed to a medical or behavioral disorder (e.g., arthritis, leg cramps, vein disorders, habitual foot tapping).
- Cause significant stress on your relationships, work, family, education or other areas of life by impacting your sleep, energy/vitality, daily activities or mood.

WHAT OTHER SYMPTOMS MIGHT I EXPERIENCE?

A chief complaint among people who have RLS is difficulty in falling or staying asleep. Many individuals also 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. Sleep deprivation can seriously impact work, relationships, and health.

DO ONLY OLDER PEOPLE GET RLS?

While RLS is most often diagnosed in middle-aged individuals, the disease affects people of all ages. Patients can often trace symptoms back to their childhood and remember hearing things like “those are growing pains” or “quit wiggling so much.”

WHAT CAUSES RLS?

A single unifying cause of RLS has not been established, but extensive research is underway. In 2007, scientists discovered the first gene variant that contributes substantially to risk for RLS. This finding is the outcome of a study conducted by Dr. David Rye and deCODE Genetics in Iceland, and funded in part by the RLS Foundation.

Other research has established the following:

- RLS often runs in families. This is called primary or familial RLS.
- The disease sometimes appears to result from other conditions such as iron deficiency or renal failure that, when present, worsen symptoms. This is called secondary RLS.
- Approximately 20 percent of women develop RLS during pregnancy, but symptoms often disappear after childbirth.
- Anemia and low iron (ferritin) levels frequently contribute to a worsening of symptoms.
- 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.

HOW DO DOCTORS DIAGNOSE RLS?

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

Your doctor should:

- Listen to your description of symptoms and conduct a diagnostic interview checking the primary symptoms listed on the previous page.
- Review your medical history.
- Complete a thorough physical exam.
- Rule out other medical conditions that may be confused with RLS.

Your doctor might also:

- Check your iron (ferritin) levels.
- Ask you to stay overnight in a sleep study lab to determine other possible causes of your sleep disturbance.

WHAT ARE MY TREATMENT OPTIONS?

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. Creating your treatment strategy may also involve:

- Checking to see if you have an iron deficiency, and possibly supplementing your diet with iron.
Note: Iron supplements should only be taken under the supervision and care of a physician.
- Examining other prescription drugs, over-the-counter medications or herbal remedies you may be taking. For example, drugs commonly used to treat high blood pressure, nausea, colds, allergies and depression can trigger RLS symptoms.
- Identifying any habits or activities that worsen your symptoms.
- Reviewing your diet to ensure it is healthy and balanced.
- Finding activities that help you cope. These might include walking, stretching, taking hot or cold baths, massage, acupuncture or relaxation techniques.
- Finding ways to keep your mind engaged with activities like discussions, needlework or video games while you are sitting.
- Implementing a program of good sleep habits (see below) and coping strategies.

Good Sleep Habit Tips:

- Maintain a cool, dark, quiet and comfortable sleeping environment.
- Go to bed at the same time every night.
- Get up at the same time every morning.
- Get enough sleep to feel well rested.
- Consider going to bed later and rising later.
- Get moderate and regular exercise.
- Find the optimal time of day to exercise.

SYMPTOM DIARY

A symptom diary is useful for helping to diagnose RLS and identifying triggers. By keeping the diary on the next page for 7–14 consecutive days, you may discover patterns to discuss with your doctor. For a complete symptom diary, visit www.rls.org or call the RLS Foundation at 512-366-9109.

RESTLESS LEGS SYNDROME FOUNDATION PATIENT SYMPTOM DIARY

<i>To be completed after waking up for the day:</i>	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>							
<i>To be completed just before your bedtime:</i>							
<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>							

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 undergone clinical studies in RLS patients. Medications fall into four major classes:

DOPAMINERGIC AGENTS are also used to treat Parkinson's disease (PD). These drugs are generally started at low dosages and increased gradually. One side effect may be augmentation (see opposite).

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

SEDATIVES are most effective for improving sleep quality.

<u>Generic name</u>	<u>Brand name</u>
eszopiclone	Lunesta [®]
temazepam	Restoril [®]
zaleplon	Sonata [®]
zolpidem	Ambien [®]

ALPHA-2-DELTA LIGANDS are particularly effective for patients with severe insomnia, painful RLS symptoms, or a previous impulse control disorder (ICD).

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

PAIN RELIEVERS are used when RLS is severe and relentless.

<u>Generic name</u>	<u>Brand name</u>
codeine	none
hydrocodone	Vicodin [®]
methadone	none
morphine	none
oxycodone	Percocet [®] , Roxicodone [®] , OxyContin [®]
tramadol	Ultram [®]

Always talk to your doctor about potential side effects and medication interactions.

WHAT IS AUGMENTATION?

Augmentation occurs when a dopaminergic agent successfully relieves symptoms at night, but eventually, symptoms start to develop earlier in the day, and symptoms spread from the legs to the arms and trunk. In this case, increasing the dosage usually worsens symptoms. If augmentation occurs, you and your doctor can work together to find a new treatment strategy that will work for you. Be sure to talk with your doctor before making changes to your regimen.

LIVING WITH RLS

Although there is not yet a cure for RLS, you can do many of the things you enjoy. By learning all 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.
- *Keep a symptom diary.* If you can't sit still to write, dictate into a tape recorder. Keep track of your medications and coping strategies and share these with your physician.
- *Occupy your mind.* Keeping your mind actively engaged may ease your symptoms. Find an activity you enjoy to help you through troublesome times.
- *Rise to new levels.* You may be more comfortable if you elevate your desktop or bookstand to a height that will allow you to stand.
- *Stretch out your day.* Begin and end your day with stretching or gentle massage.
- *Reach out.* Support groups throughout the U.S., Canada, and Internationally help RLS patients and their families. Consider joining our discussion board, our Facebook page, read our blog or follow us on Twitter to share your ideas and experiences.

Visit www.rls.org to learn more about RLS, find a support group, or join an online discussion today!

WHAT CAN I DO TO HELP?

Join us in our efforts to increase awareness, improve treatments, and through research, find a cure!

The work of the Restless Legs Syndrome (RLS) Foundation is made possible by the generosity of individuals like you. Your tax-deductible gift in any amount will help disseminate information about RLS disease, and fund vital research to improve the lives of individuals and families who live with the disease.

MEMBER BENEFITS

For \$35 a year (\$35 in Canada and \$45 internationally), you can become a member of the RLS Foundation. 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 newsletter that includes treatment updates, feature stories, clinical trials information, support group listings and more.
- A medical alert card.
- Membership and special accommodations card.
- RLSF magnet.
- Access to Members Only section on www.rls.org.
- The satisfaction of supporting education 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.

Thank you for your support!

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 U.S. and Canada; \$45 for international).
- I have included an additional tax-deductible donation of \$_____.
- I would like more information about planned giving (estate gifts and/or including the RLS Foundation in my will).

Step 2 - Please provide your contact information.

The RLS Foundation does not share or sell any information.

Name _____

Address _____

City _____

State _____ Zip code _____

Country _____

Telephone _____

Email _____

Step 3 - Payment Information

- I have included a check
(in U.S. dollars, drawn on a U.S. bank) 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
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Austin, TX 78746



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