NIGHTWALKERS

In search of a good night's sleep

Feeling Well is the Goal:
WED/RLS Treatments
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Summer 2014

WILLIS-EKBOM DISEASE FOUNDATION

formerly known as the RLS Foundation

NightWalkers *is the official publication of the Willis-Ekbom Disease (WED) Foundation*

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Representing You at SLEEP 2014

Karla M. Dzienkowski
Executive Director

SLEEP is the name of the annual meeting of the Associated Professional Sleep Societies (APSS). At the three-day meeting, leading experts in sleep medicine present and share their research findings with others in the field. Board Chair Jacci Bainbridge and I had the opportunity to attend this year's meeting in Minneapolis, and I would like to share some of my observations with you.

At today's medical conferences, a common way of sharing information among participants is through a "poster session" of new research. Typically, posters are displayed in a large room, and presenters stand near them to give brief speeches or answer questions. On each day of the SLEEP conference, posters were exhibited on a variety of sleep topics. It was exciting to view over 30 posters in the WED/RLS Treatment, Course and Comorbidities section. Three posters presented by Medical Advisory Board members Dr. Ondo and Dr. Becker highlighted results from the Patient Odyssey Survey of WED Foundation members. These posters generated much interest and many questions from fellow researchers, often validating what others had seen in their own patient populations.

Other posters in the WED/RLS section included topics such as problems with diagnosis and referral in Japan, clinical characteristics and effectiveness of treatment in children, benzodiazepines and opioids for treatment, WED/RLS evening undergraduate students, and many others. Two posters addressed the change in heart rate and heart rate variability associated with periodic limb movements. Overall, the poster session reflected the effect that WED/RLS has on multiple systems in the body and the need for continued research to study the causes and possible treatment options.

The SLEEP conference included nearly nine hours of postgraduate and general courses devoted to WED/RLS – many taught by members of our Medical Advisory Board and Scientific Advisory Board. This is roughly three hours per day on WED/RLS-related topics such as augmentation, treatment options, children, and pregnancy; and even a course on serum ferritin threshold for iron supplementation in pediatric populations with restless sleep. It was not so long ago that our researchers encountered skepticism among their peers when discussing the topic of WED/RLS in children. We have come so far in the last 22 years, and yet so much more needs to be done.

The SLEEP meeting gave us the opportunity to learn from and network with leading researchers in the world while sharing information with them about the WED Foundation and our competitive grant program. We are proud of our Medical Advisory Board and Scientific Advisory Board members' work and the impact it is having on the scientific community. The WED Foundation continues to represent your interests in the world of science and medicine and to promote research and education that will improve the lives of individuals with WED/RLS.

To view the WED Foundation posters presented at SLEEP, visit our blog at wedinfo.blogspot.com.

Best Wishes,

Karla M. Dzienkowski
Executive Director
Willis-Ekbom Disease Foundation

Feeling Well is the Goal

Interview with Birgit Högl, MD, on WED/RLS Treatments

Many people with Willis-Ekbom disease (restless legs syndrome, or WED/RLS) share common challenges in their treatment journey: a lengthy stretch of time – often years – before being diagnosed, treatment that falls short of meeting their needs, medications with unpleasant side effects, and the need to switch or increase medications as the disease progresses.

The good news is that with the help of a knowledgeable healthcare provider, most patients can achieve control of their disease, relief from their most troubling symptoms, and better quality of sleep. A wide range of treatment options is available, (For a comprehensive list, see page 7.) The WED Foundation continually works to improve treatment by educating patients and providers, funding research to develop new therapies, and coordinating the WED/RLS Quality Care program. (See page 13.)

Birgit Högl, MD, is the newly elected chair of the WED Foundation Medical Advisory Board and director of the Sleep Lab and Sleep Disorders Outpatient Clinic in the Department of Neurology at Innsbruck Medical University (a WED/RLS Quality Care Center). In her practice, Dr. Högl and her colleagues treat approximately 800 WED/RLS patients who are primarily from western Austria and northern Italy. We asked Dr. Högl to share her perspectives on treatments for the disease.

What are the main treatments you offer patients who have WED/RLS?

Basically the dopaminergic agents, mainly nonergot dopamine agonists (pramipexole, ropinirole and the rotigotine patch) on the one hand, and the alpha-2-delta ligands (gabapentin, gabapentin enacarbil and pregabalin) on the other. Another option is treatment with opiates, both strong and weak.

Which of these we choose depends on whether the patient needs steady treatment or not, if their WED/RLS is more mild or severe, if there is current augmentation or not, and many other factors. Recommended treatment also depends on whether the patient had previous treatments, and if so, why they were stopped – for example, if they were ineffective or not tolerated well.

What challenges do patients face in finding effective treatment?

Sometimes WED/RLS is not diagnosed in a timely manner. This has gotten better, but it still happens that people are treated for only the insomnia and it is not recognized that the insomnia is due to WED/RLS. Or if there is a comorbidity (simultaneous occurrence of two or more health conditions) – for instance, polyneuropathy – this may delay diagnosis. Also, sometimes people tend to think that this is something they imagine by themselves, perhaps because of nerves, and it doesn't deserve treatment. So they will criticize themselves for suffering from symptoms like dyskinesia (involuntary movements). Sometimes patients are ashamed to say they have it.

Birgit Högl, MD
Chair, Medical Advisory Board

There is a problem in general with people acknowledging that this can really be severe because some patients are only mildly affected and will never need treatment or seek treatment. This is not right, because as we all know, WED/RLS can range from very mild to very severe.

Another challenge we face is that many doctors still tend to mainly think that WED/RLS is not a serious disorder, because if you have it you won't end up in a wheelchair, be severely disabled, or die. This kind of thinking really discriminates against patients with severe WED/RLS. Unfortunately, even neurologists sometimes think this way, perhaps because they are used to very progressive and severe, life-threatening disorders, or those that they can identify from a brain scan or lumbar puncture or through a routine neurological exam.

Once a patient is diagnosed, what are the obstacles to effectively managing symptoms?

One challenge is that once they are correctly diagnosed, there should be a basic laboratory check for iron levels and ferritin levels, and this is not always done. If their ferritin levels are low, then iron supplementation should be tried as a first step.

Another major challenge is related to medication dosing with a dopamine agonist. For WED/RLS, doses are much lower than for Parkinson's disease, and usually a dose once in the evening is enough. But in our clinic we sometimes see patients who have been treated with the same dose as Parkinson's disease (three times per day, for example) at the beginning of their treatment, although this is not necessary and may increase the risk of experiencing side effects and developing augmentation over time.

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What should WED/RLS patients expect from their treatment?

Treatment expectations are important for our patients to understand, and we discuss these with each patient extensively. Treatment should not aim at abolishing 100 percent of the symptoms, 24/7. Because this may sometimes lead to higher than necessary dosing and may precipitate the development of augmentation. If the patient needs daily treatment, then the main goal is not to abolish every minor, non-bothersome symptom, but for the patient to feel well and for their overall WED/RLS to be well controlled. If they have minor symptoms that do not bother them, this is something one would tolerate and not necessarily push the dose upwards.

Can all patients hope for effective treatment?

Unfortunately, this is not straightforward in all cases. We all know that at least at the beginning of treatment, WED/RLS can be very well controlled for most patients. But for patients who are treated for a long time and perhaps even decades, it can be more and more difficult to find adequate medications or a combination of medications to control their symptoms. This is something that really concerns us, because sometimes the medication itself can contribute to making long-term WED/RLS so difficult to treat.

How important are alternative therapies and lifestyle changes?

I would advise doctors not to push anyone into drug treatment if he or she does not yet need it. If a patient says it helps enough when they massage their legs, for example, or walk on a nice cold floor in bare feet, we tell them that if their symptoms get worse and at some time in their life these activities are not enough, then medication is also available.

Many of our patients say they respond to things like dietary changes or by avoiding certain substances. We think they may indeed be affected by such things, and it will be important to study this and find better evidence beyond anecdotal reports. Physical activity can also be an issue. In our area of Austria, people play a lot of sports. Many patients find that when they run the marathon or do some very heavy exercise, their symptoms may get worse.

If they've found that something worsens their symptoms, they should avoid it. We encourage everyone to respect their experiences.

FDA approves device for treating WED/RLS

The U.S. Food and Drug Administration (FDA) has cleared the first nonpharmacological approach for patients suffering sleep loss due to WED/RLS. The Relaxis Pad, a device made by Sensory Medical, provides vibratory counterstimulation to the area of the body where symptoms are experienced. The device has been clinically shown to relieve symptoms, allowing patients to return to sleep without having to get out of bed.

When experiencing WED/RLS symptoms, the patient places the Relaxis Pad at the site of the discomfort and chooses a vibration intensity. The device provides 30 minutes of vibratory counterstimulation, gradually ramping down and shutting off without waking the patient.

Two clinical research studies published in a peer-reviewed journal article found the device superior to placebo pads for improving sleep quality in patients with primary WED/RLS. The Relaxis Pad has not yet been tested for improving symptoms other than sleep disruption.

The product will be released and available by prescription starting in September. To learn more, talk with your doctor

or visit www.sensorymedical.com.

Dr. Silber Receives Ekbom Award

On June 2, 2014, WED Foundation Board Chair Jacci Bainbridge, PharmD, presented Michael Silber, MB, ChB, with the prestigious Ekbom Award in recognition of his leadership and achievements in WED/RLS medical education and research. Dr. Silber's work has gained him international recognition and the respect of his peers in the field of sleep medicine.

Michael Silber, MB, ChB

Dr. Silber has been involved with WED/RLS Foundation since 1999. He has served on the Medical Advisory Board for 11 years (from 1999 to 2005 and from 2009 to present) and as chair for the past three years. He has presented the results of his numerous research studies on the pathophysiology, diagnosis and treatment of WED/RLS at professional meetings and in peer-reviewed publications. Dr. Silber was the lead author of both the original 2004 treatment algorithm for WED/RLS and the 2013 revised consensus statement on managing the disease, both published in *Mayo Clinic Proceedings*. As Dr. Silber's career clearly demonstrates, he has embraced and supported the WED Foundation's goals to increase awareness, identify new and better treatments, and ultimately find a cure for WED/RLS.

The Foundation is pleased to have Dr. Silber join the distinguished group of individuals who have received the Ekbom Award. Past recipients include Arthur Walters, MD (1998); Richard P. Allen, PhD (2000); Cate Murray (2001); Bob Balkam (2003); Sheila Connolly (2005) and Bob Waterman (2008).

Congratulations and thank you, Dr. Silber!

About the Ekbom Award

The WED Foundation established the Ekbom Award in 1998 to honor individuals who make significant contributions to the WED Foundation and toward enriching the lives of people with WED/RLS. Swedish neurologist Karl-Axel Ekbom, MD, for whom this award is named, published early reports on the disease and first named it *restless legs syndrome*. The WED Foundation is grateful to the Ekbom family for allowing their name to be used for this distinguished award in honor of Dr. Ekbom and his work.

Past Ekbom Award recipients shared the following congratulatory notes, which were read by Chair Jacci Bainbridge at the Ekbom Award ceremony.

Please do give my very warm congratulations to Dr. Michael Silber. Michael is an exceptionally worthy recipient of the Ekbom Award. Although it has been some years since I have seen him, I well remember his calm and friendly way of listening, contributing and making any discussion fruitful.

The Foundation and each of its goals have definitely benefitted from his words, always well informed and expressed with both humility and wisdom.

Bob Balkam

Dear Dr. Silber,

I, along with millions of people affected with WED/RLS, have great admiration for the many years of work you have accomplished nationally and internationally, work which has impacted our treatment enormously. In 1989, I was one of the eight people with WED/RLS, who began sharing letters and discussing our "rare" condition. Your leadership as chair of the Medical Advisory Board distinguishes your impact for our now "common disorder"! Thank you especially for the development of and recently revised treatment algorithm for the management of WED/RLS. It is a marvelous comprehensive medical publication for healthcare providers, support group leaders and contact people.

Congratulations, Michael, as you receive the 2014 Ekbom Award this evening. I join your colleagues and the WED Foundation in celebrating you.

Warmest Regards,

Sheila C. Connolly
June 2, 2014

Medical Advisory Board Elects New Chair and Members

The WED Foundation is pleased to welcome several new members to the Medical Advisory Board and to announce the election of Birgit Högl, MD, as chair effective July 1, at the completion of Dr. Silber's term as chair. Daniel Picchietti, MD, has been elected vice chair. Joining the Medical Advisory Board are Suresh Kotagal, MD; Clete Kushida, MD, PhD, RPSGT; Lynn Marie Trotti, MD, MSc; and John Winkelman, MD, PhD.

Dr. Birgit Högl is an associate professor of neurology, a senior board-certified sleep specialist and director of the Sleep Lab and Sleep Disorders Outpatient Clinic (a WED/RLS Quality Care Center) in the Department of Neurology at Innsbruck Medical University in Austria. Dr. Högl is an active member of the European Section of the International RLS Study Group (IRLSSG) and has collaborated with Julianne Winkelmann, MD, on the genetics consortium research project. Dr. Högl has served on the WED Foundation Medical Advisory Board for the past six years.

Dr. Suresh Kotagal is a professor of neurology at Mayo Clinic College of Medicine. He is board certified in sleep medicine, sleep disorders medicine, and psychiatry and neurology (ABPN) with special qualifications in child neurology. In 2013, Dr. Kotagal received the Excellence in Education award from the American Academy of Sleep Medicine. He is a physician provider at the Mayo Clinic Center for Sleep Medicine, a WED/RLS Quality Care Center.

Dr. Clete Kushida is a professor of psychiatry and behavioral sciences at Stanford University Medical Center. The clinical focus areas of his practice include sleep medicine, sleep disorders and neurology. Dr. Kushida is president of the World Sleep Federation, medical director of the Stanford Sleep Medicine Center, and past president of the American Academy of Sleep Medicine. He previously served on the Medical Advisory Board from 2003 to 2009.

Dr. Lynn Marie Trotti is an assistant professor of neurology at the Emory University School of Medicine and is board certified in both neurology and sleep medicine. She was a co-investigator on the WED Foundation-sponsored genome-wide association study of periodic limb movements in sleep and WED/RLS (published in the *New England Journal of Medicine* in 2007). In addition to conducting research, she serves as chair of the RLS section of the American Academy of Sleep Medicine Task Force on Quality Metrics.

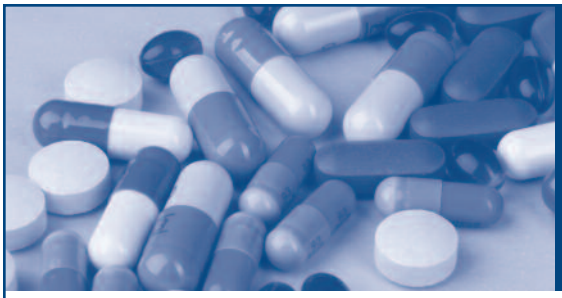
Dr. John Winkelman is an associate professor of psychiatry at Harvard Medical School and is board certified in psychiatry and sleep medicine. In 2005, He served as chair of the Scientific Committee, Fourth International Scientific Symposium on Parkinson's Disease and Restless Legs Syndrome. Dr. Winkelman previously served on the WED Foundation Medical Advisory Board from 1999 to 2005 and from 2006 to 2012.

With the changing of the guard on the Medical Advisory Board, the Foundation bids farewell to three members: Philip M. Becker, MD; Mark Buchfuhrer, MD, FRCP(c), FCCP; and Christopher J. Earley, MB, BCh, PhD, FRCPI, who completed their terms on the Board on June 30, 2014. (Dr. Earley will continue to serve on the Scientific Advisory Board.)

The three were presented with WED Foundation recognition awards by Dr. Silber at a reception in Minneapolis. Executive Director Karla Dzienkowski says, "I thank Dr. Becker, Dr. Buchfuhrer and Dr. Earley for their outstanding leadership and contributions to the WED Foundation as members of the Medical Advisory Board. The Foundation is grateful to these individuals for their work on behalf of the WED/RLS community."

Dr. Silber presenting recognition awards to Dr. Buchfuhrer, Dr. Earley and Dr. Becker

Thank you, Dr. Becker, Dr. Buchfuhrer and Dr. Earley!



Medications for Willis-Ekbom Disease/ Restless Legs Syndrome

A Guide to Help You Control and Manage Your WED/RLS

The following information was reviewed by members of the WED Foundation Medical Advisory Board. This document is offered for informational purposes only; no products are endorsed by the WED Foundation. This is not a complete list of medications that may be available.

It is very important to talk with your healthcare provider about potential side effects and drug interactions before making any change to your medication treatment plan.

Overview

There are many non-drug therapies that can help relieve symptoms of Willis-Ekbom disease (restless legs syndrome, or WED/RLS). But for individuals experiencing frequent or severe symptoms, medications may be an important part of their treatment strategy. If you need to take medication, your physician will work with you through careful trials to find a drug and dosage that works best to manage your symptoms.

The U.S. Food and Drug Administration (FDA) has approved four drugs for treating WED/RLS: ropinirole (Requip), pramipexole (Mirapex), gabapentin enacarbil (Horizant) and rotigotine (Neupro).

In addition, several drugs approved for treatment of other medical conditions have undergone clinical studies with WED/RLS patients and provide symptom relief when used "off label." Off-label use is the prescribing of approved medications that show success in treating another medical condition other than its intended use, a practice permitted by FDA regulations.

Dopaminergic Agents

Dopamine agonists are a class of medications often prescribed as the first-choice medication for treating WED/RLS and are also used to treat Parkinson's disease (PD). Dopaminergic medications enhance dopamine activity in the brain. They are usually started at low dosages and increased gradually until patients experience relief from symptoms. One side effect may be augmentation. (See "Augmentation" at right.)

Side effects of dopaminergic drugs include nausea, daytime sleepiness, vomiting, orthostatic hypotension (a temporary lowering of blood pressure when standing up from a lying or seated position), hallucinations, augmentation, insomnia and compulsive behaviors (repetitive behaviors that are potentially devastating).

Requip (ropinirole)
- FDA approved for treating WED/RLS.
- Requip XL (ropinirole extended release) is not FDA approved for treating WED/RLS.

Mirapex (pramipexole)
- FDA approved for treating WED/RLS.
- Mirapex ER (pramipexole dihydrochloride extended release) is not FDA approved for treating WED/RLS.

Neupro Patch (rotigotine)
- FDA approved for treating WED/RLS in the lower 1, 2 and 3 mg/day doses.
- Comes as a 24-hour patch applied directly to skin that is clean, dry and free of irritation. The patch is applied at the same time each day to a new place on the skin.

Dostinex/Cabaser (cabergoline)

Sinemet/Restix (carbidopa/levodopa)
- This class of drugs may not be a first choice of treatment for many people due to the risk of augmentation.
- If Sinemet/Restix is an option for you, controlled release may be better than immediate release but should be used with extreme caution. No levodopa drug should be used on a daily basis due to a very high risk of augmentation.
- Immediate-release Sinemet can be very useful when used occasionally for people who have mild WED/RLS, as it works very quickly (within 15–30 minutes on an empty stomach) and may not cause augmentation when taken on an as-needed basis.
- May cause drowsiness, dizziness or lightheadedness. Effects may be worsened if taken with alcohol or other medicines.
- Long-acting but may induce heart valve damage.

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 medication may initially improve symptoms, but over a short period the symptoms will again worsen.

If augmentation occurs, you and your doctor can work together to find a new medication treatment plan that works for you. Be sure to talk with your doctor before making any changes to your WED/RLS medication regimen.

Alpha-2-Delta Drugs

Alpha-2-delta drugs are thought to relieve discomfort by modifying calcium channels on the nerves and thus change the excitability of nerves that carry WED/RLS sensations or pain.

Side effects of Alpha-2-delta drugs can include sleepiness, weight gain, edema, tremor, dizziness, depression, problems with thinking, rash, and blood count abnormalities. These symptoms can be prevented or reduced by slowly increasing the medication dose.

Horizant (gabapentin enacarbil)
- FDA approved for treating WED/RLS.
- Extended-release formula.

Neurontin (gabapentin)

Lyrica (pregabalin)

Sedatives

Sedatives are most effective for improving sleep quality.

Restoril (temazipam)

Ambien (zolpidem)

Sonata (zaleplon)

Klonopin (clonazepam)
- Generally not recommended due to the complex breakdown of drug components and a very long half-life of 40 hours. *Half-life* is the amount of time it takes for the drug to lose half its strength in the body.

Pain Relievers

Opioid and non-opioid medications relieve pain and are used when WED/RLS is severe and relentless. Side effects of opioids include constipation, dizziness, increased risk for falls, nausea, vomiting and sometimes loss of drug effectiveness over time. Ultram may have fewer side effects.

Codeine (generic)

Percocet/Roxicodone

OxyContin (oxycodone extended release)

Methadone (generic)

Vicodin (hydrocodone and acetaminophen)

MS Contin (morphine, controlled release)

Ultram (tramadol)
- Although tramadol is technically not an opioid, it is often classified with opioids. Tramadol starts out as a non-opioid pain reliever, but is converted to an opioid after metabolism in the liver.

What Can I Do?

Working with your healthcare provider, you may need to undertake a series of trials to find a medication that effectively manages your symptoms. You may also consider asking your provider about exploring complementary and alternative medicine therapies as part of your treatment plan.

Keep a symptom diary to track your symptoms, including the time of day they occur as well as the coping strategies that helped to alleviate them. Share this information with your provider. It is also important to note if you missed or were late taking any medication doses.

Ask you provider to check your iron (ferritin) level, as low iron levels have been associated with worsening of WED/RLS symptoms.

Maintain good sleeping habits such as going to sleep and waking at the same time daily. Caffeine in some individuals may increase WED/RLS symptoms. Get regular exercise and avoid alcohol, which is known to aggravate WED/RLS symptoms.

Together, you and your doctor can work to find ways to improve your symptoms by incorporating lifestyle changes, self-care and medications into your treatment plan.

Further Information

The following publications are available from the WED Foundation at www.willis-ekbom.org or by calling 507-287-6465.

Symptom Diary for WED/RLS

Understanding Augmentation

WED/RLS Triggers

Complementary/Alternative Medicine and WED/RLS

Activity and Exercise

Understanding Drug Action

Drug Holidays and WED/RLS

1530 Greenview Dr SW Suite 210
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Phone: 507-287-6465
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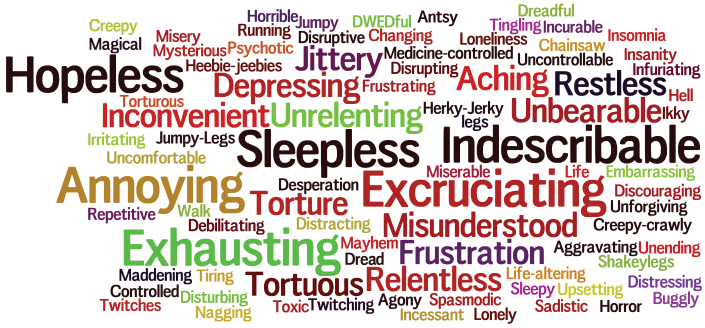
info@willis-ekbom.org
www.willis-ekbom.org

Words That Say "You Are Not Alone"

Kathy Page
2014 Development Committee Chair

Recently the WED Foundation created a word cloud – a graphic created from a list of words. The Foundation asked people to describe in one word what living with WED/RLS was like, then used those words to make a word cloud.



This word cloud is amazing. It is informational. It is truthful. Most of all, it is scary and depressing. Terms such as *herky-jerky legs*, *buggly* and *ikky* can make this disease sound trivial and bearable, but these words also describe what WED/RLS feels like. *Misunderstood* is a fact of life most of us have lived with for a long time. Historically, we have not been taken seriously, and in many, many cases this is still true.

Even when we get brave enough to admit that WED/RLS is *insanity*, *unending* and *tortuous*; friends, family members and medical professionals do not take us seriously. In their minds, having restless legs, arms or other body parts is minor – a small annoyance at best. I remember when fibromyalgia and chronic fatigue syndrome were considered maladies made up by people who were simply lazy. Now they are accepted and widely known as real conditions; the public at large knows exactly what they are.

I was thinking about what words might be used to create word clouds for other chronic conditions or diseases. Probably most of the words in our word cloud (such as *relentless*, *excruciating*, *unrelenting* and *incurable*) can be used to describe other diseases. Take out those words, plus the ones such as *heebie-jeebies*, and you are left with two that are major players in our world.

The first is *chainsaw*. While this may get chuckles, it is a deadly serious word. Too many people have said they would like to cut off their legs just to get away from the misery but are afraid of phantom restlessness. Name one other disease where you would think about cutting off part of your body rather than enduring the feelings. We are not talking about pain here (although many suffer pain along with the restlessness); pain is accepted in our society – having jumpy legs or arms is not.

The other word that makes this word cloud unique is *lonely*. I fully understand that every person at one time or another feels lonely. But this is a loneliness that comes when you are surrounded by people who have no clue what you are going through. Chemo patients, dialysis patients, people with dementia – all have enormous support networks, which is wonderful. WED/RLS affects from 7 to 10 percent of the population, and yet we walk the floors at night with no one beside us. We look out at the darkness without having anyone holding our hands.

This word cloud can be depressing – just like our lives can be when we are dealing with WED/RLS. But I prefer to look at it as something new and refreshing that can be used to create awareness, open conversations and best of all, remind us that we are not alone. I may not have the exact same symptoms as you, take the same medications or have the same outlook – but I know what you are going through.

The same moon shines over us all. So while we may not know each other personally, we can work together so that one night, if we find ourselves walking the floors, WED/RLS will not be the reason.

Sincerely,

Kathy Page
2014 Development Committee Chair

Honor Roll

The Willis-Ekbom Disease (WED) Foundation is sincerely grateful for the donations we have received in memory and in honor of the following individuals:

Tributes
Georgianna Bell

Memorials
Charles Baggaley
Richard Carlton
Margaret Elizabeth Dane
Thomas Davis
Bud Dillihunt
Mabel Havrish
Dhanesh Sheth
Barbara Simko
Mary Vietto

April 7 – July 1, 2014

Mark Your Calendar: WED/RLS Awareness Day is September 23

On Tuesday, September, 23, 2014, communities across the globe will celebrate WED/RLS Awareness Day by engaging in activities that shine a spotlight on Willis-Ekbom disease (restless legs syndrome) as a serious, but treatable condition. This message is promoted by an international coalition of organizations representing patients, clinicians and scientists.

As a member of this coalition, the WED Foundation will raise awareness throughout the month of September on our website, blog and social media channels. Mark your calendar for September 23, and join us to raise awareness about WED/RLS!

About the international coalition

In 2012, an international coalition was established to jointly promote awareness about WED/RLS. These five organizations work tirelessly toward a common goal: improving the lives of the millions of people worldwide who are living with WED/RLS. To learn more, visit whatisrls.org or the organization websites listed below.

European Alliance for Restless Legs Syndrome (EARLS)
EARLS is a nonprofit, independent alliance of national patient organizations from various European countries. EARLS engages in activities that contribute to raising awareness of WED/RLS and raises important issues at a European level that are common to all members. *www.earls.eu*

European Restless Legs Syndrome Study Group (EURLSSG)
EURLSSG is a nonprofit association that brings together Euopean experts who are actively involved in WED/RLS research and dedicated to optimizing patient outcomes by continuously improving standards for diagnosis and treatment of WED/RLS. *www.eurlssg.org*

International Restless Legs Syndrome Study Group (IRLSSG)
IRLSSG is an organization of scientists and clinicians committed to advancing basic and clinical research on WED/RLS. Their mission includes the cooperative planning, implementation, analysis and reporting of multicenter studies with an international emphasis. To this end, the IRLSSG aims to advance knowledge about the causes, pathogenesis and clinical impact of WED/RLS and related disorders. *www.irlssg.org*

Willis-Ekbom Disease Foundation
The Willis-Ekbom Disease (WED) Foundation is a nonprofit, member organization based in North America that aims to help people who have WED/RLS live better lives. The goals of the Foundation are to increase awareness, improve treatments and through research, find a cure for the disease. *www.willis-ekbom.org*

World Association of Sleep Medicine (WASM)
WASM is an international member organization of healthcare professionals active in the field of sleep medicine. The fundamental mission of the WASM is to advance sleep health worldwide. WASM promotes and encourages education, research and patient care globally, and acts as a bridge between different sleep societies and cultures, supporting and encouraging worldwide exchange of clinical information and scientific studies. *www.wasmonline.org*

Top 20 ways to raise awareness for WED/RLS

1. Make a gift to the WED Foundation in honor or memory of someone special
2. Contact your local newspaper's health editor and ask him or her to write a piece about WED/RLS
3. Write a post on your Facebook page on September 23 using the words *WED/RLS Awareness Day*
4. Ask your city to add WED/RLS Awareness Day to the community calendar
5. Purchase WED/RLS apparel from the WED Foundation, or create your own, and wear it to a community event
6. Offer old issues of *NightWalkers* to your local library or to your doctor's office
7. Create your own WED/RLS fundraiser on www.razoo.com for the Restless Legs Syndrome Foundation (our official name on the site)
8. Download WED/RLS posters from www.willis-ekbom.org and post them in your community
9. Join our discussion board on bb.rls.org
10. Share one of our blog posts (wedinfo@blogspot.com) on Facebook or Twitter
11. Invite friends to "like" the WED Foundation Facebook page
12. Request a free WED/RLS awareness bracelet from the Foundation and wear it during the month of September
13. Ask your neighbors to leave their porch lights on overnight on September 23 to support the nightwalkers in your community
14. Hold a small fundraising or awareness raising event – for example, ask your employer to hold a "wear jeans or slippers to work" on a designated day and collect donations for the WED Foundation
15. Make and share a WED/RLS awareness video
16. Call a friend or family member with WED/RLS to find out how they are doing
17. Give the gift of a WED Foundation membership
18. Ask your WED/RLS healthcare provider to join our online directory at www.willis-ekbom.org
19. Ask your favorite sports team to announce or list WED/RLS Awareness Day on the Jumbotron on game day
20. Submit a personal story or image to share on our blog at wedinfo@blogspot.com

Acupuncture and WED/RLS

Norma G. Cuellar, PhD, RN, FAAN
Professor, Capstone College of Nursing, University of Alabama

Chinese medicine originated over 5,000 years ago and includes therapies such as acupuncture, nutritional and dietary supplements, and mind-body practices. Chinese medicine is based on the belief that a vital energy component called *qi* circulates throughout the body through 12 energy lines (meridians) that are associated with different organs. If there is imbalance in this energy, then illness or disease occurs.

In acupuncture, needles are inserted along the meridian lines in over 1,000 acupuncture points to restore balance. This intervention is believed to stimulate the release of pain-relieving endorphins, influence the release of neurotransmitters, stimulate circulation, and influence electrical currents in the body.

Acupuncture has been one of the most researched alternative medical practices. Once considered an experimental therapy by the U.S. Food and Drug Administration, acupuncture is now considered a medical device and is endorsed by the National Institutes of Health. An estimated $500 million dollars is spent annually on acupuncture, which is often covered by medical insurance.

What happens during a visit to the acupuncturist?

On your first visit, an acupuncturist will take your complete medical history and discuss your primary health concern as well as your lifestyle (eating, exercise, etc.). During this interview, he or she will also make an observational assessment, noting your face color, voice and tongue color and coating. The acupuncturist will palpate three pulse points at each of your wrists to determine the health of the 12 meridians.

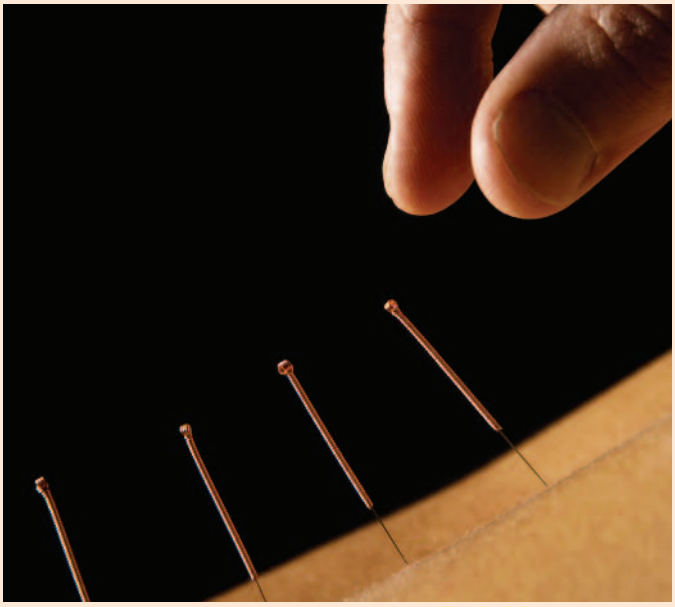
After the interview, the acupuncturist will give you a diagnosis and begin treatment using six to 12 needles in precise placement along the meridians. When the needles are inserted, you may feel a slight sting or prick; but after insertion, you should feel no pain. During the treatment, which may last up to 30 minutes, you should feel comfortable and relaxed. If you experience pain, numbness or discomfort, you should tell the acupuncturist.

How does Chinese medicine treat WED/RLS?

In Chinese medicine, acupuncture is the standard form of WED/RLS treatment. WED/RLS is considered a bi-syndrome resulting from obstructive problems in the leg meridians, rather than a disease with a single cause. The development of WED/RLS is associated with a qi disturbance inside the body.

The qi that flows during the day is called the yang; the qi that flows during the night is called the yin (which determines the sleep-wake cycle). In WED/RLS, there is believed to be a yin deficiency. As WED/RLS worsens, causing more disruption in nighttime sleep, the deficiency of yin gets worse as well. Acupuncture is used to balance yin and yang to break the cycle, calm down the legs, and promote peaceful sleep.

Specifically, acupuncture treatment for WED/RLS aims to 1) nourish and invigorate the liver and kidney, 2) regulate blood and qi activities and 3) unblock and promote the meridian flow in the legs. Acupuncturists will select the body points, or acupoints, based on an individual's symptom patterns, which usually focus along the meridians in the lower limbs.



Does research support acupuncture for WED/RLS?

While many people with WED/RLS find acupuncture beneficial in relieving symptoms (shortened duration, or decreased frequency or severity), research is lacking to show evidence of positive outcomes. In 2008, the Cochrane Library published a review on acupuncture in treating WED/RLS. Of 14 trials, only two met criteria for review, and both had poor methodologies.

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Swedish Association Changes Name to WED

WED-Förbundet, the Swedish association for people with WED/RLS, has changed its name to WED (Willis-Ekbom disease) in place of RLS (restless legs syndrome). WED-Förbundet is a nonprofit member organization established in the year 2000 to serve the interests of approximately 900,000 people in Sweden who have the disease. The organization educates patients, healthcare professionals and the public through online and print materials, public information meetings and member meetings all over Sweden. WED-Förbundet staff members recently answered a few questions about the name change.

What were your reasons for changing your name to WED?

Our reasons were the same as those we read about when the WED Foundation made the name change. Many of our members have experienced difficulty getting the right help when consulting a doctor about their WED/RLS. The former name, restless legs, spread wrong assumptions about the disease and sometimes even caused joking or trivializing comments from doctors, as well from the public. A change from *syndrome* to *disease* indicates that we are talking about something that is a serious illness that causes a lot of suffering.

Describe the process you used to make the name change.

The Board of WED-Förbundet made a decision to work toward the name change. After this decision we started an information and promotional campaign on our website and in our magazine. We also communicated through Facebook, where many of our members are active.

We described the misunderstandings caused by the name restless legs syndrome and that other countries had already made the change or were talking about doing so. We explained what we hoped the new name would accomplish and also introduced the significance of both Dr. Willis and Dr. Ekbom.

Our bylaws enabled us to make the name change in March 2014, two years after the Board's decision, and at our annual meeting there was full consent and approval. There have been very few comments or responses to the change from our members.

How has this benefited your organization and the people you serve?

Now that there is a serious name to a serious disease, we are able to communicate with the media, doctors, patients, members and the public in quite a different way than before. We have had success in media relations and there have been numerous articles about WED in recent months.

With the new name, we hope for greater willingness of doctors, especially general practitioners, to listen and be informed that the disease is something serious they all should know about.

It is too early to make an analysis of this, but we have received some very positive responses from doctors we collaborate with. At an annual meeting for sleep disorders, the papers presented were all referring to WED instead of RLS. One doctor commented, "Look what a patient organization is able to do!"

Acupuncture and WED/RLS continued from page 11

A literature search (Medline, PubMed and CINAHL) on acupuncture and WED/RLS identifies two articles published since 2008:

- In 2011, a retrospective chart review was conducted on 19 patients who had been diagnosed with WED/RLS and treated with acupuncture. Of the 19, 16 had not received drug treatment for WED/RLS before acupuncture, and three had taken either ropinirole or pramipexole. This review found that acupuncture was effective in the treatment of WED/RLS as an alternative to dopaminergics.[1]
- In 2008, 158 people with WED/RLS who received acupuncture and TDP radiation (a far-infrared heating therapy used to promote natural healing processes of the body) were compared with a control group treated with levodopa. After 30 days, those who received acupuncture with TDP radiation experienced effective relief of their WED/RLS symptoms compared with the control group.[2]

Summary

While the clinical evidence remains uncertain about the outcomes of acupuncture in persons with WED/RLS, there is promise that acupuncture does relieve some symptoms. More research is needed on this topic through studies that have scientific rigor with adequate sample sizes and methodologies. There is no research to show that acupuncture is not safe. As with any form of complementary and alternative medicine (CAM), acupuncture may be a beneficial therapy if it works well for you without any negative side effects. Always consult your healthcare provider before using acupuncture or any other form of CAM.

[1] Cripps M. 2011. "Acupuncture for restless legs syndrome in patients previously treated with dopaminergic drugs." *Acupuncture in Medicine: Journal of the British Medical Acupuncture Society* 29: 240–41.
[2] Wu YH, Sun CL, Wu D, Huang YY, Chi CM. 2008. "Observation on therapeutic effect of acupuncture on restless legs syndrome." *Zhongguo Zhenjiu* 28: 27–29.

Patients Share Their Quality Care Center Experience

Last year, the WED Foundation initiated a network of WED/RLS Quality Care Centers that are certified as providing expert care and specialized disease management. Quality Care Centers are recognized as leaders in the field, serve as liaisons to primary care providers and support groups, and are listed in Foundation materials so that patients and providers can use their services.

The Foundation recently conducted a brief online survey on the experience of patients who receive treatment from WED/RLS Quality Care Centers. We received 80 responses, 27 from individuals who had gone to one of the four certified Centers. Thank you to all who responded! We appreciate your input, both positive and constructive.

While the survey sample is small, this feedback helps take the pulse of how well Quality Care Centers are meeting the needs of our community. Nearly every person had a positive experience, and for many, the treatment they received was life changing.

Here are some survey highlights:

- All four of the certified WED/RLS Quality Care Centers were represented in the survey responses.
- People traveled as far as 2,800 miles to visit a Center.
- Individuals learned about Centers through a variety of channels: Facebook, *NightWalkers*, provider referrals, the WED Foundation website, online searches and other means.
- All respondents described their WED/RLS as severe or very severe.
- Of the 23 participants who answered specific questions:
  - 22 rated the quality of care they received as "very good" or "excellent"; one rated care quality as "fair"
  - 20 said their treatment plan changed as a result of the visit; three said it did not change.
  - 22 said their symptoms improved or stayed the same as a result; one said their symptoms worsened.

Sample comments:

"My symptoms are completely under control and my quality of life is better than it has been in many years."

"The treatment…has changed my life…. After years of searching for help, I can sleep now."

"Got my WED under control at my first visit."

"Really on the 'cutting edge' of WED/RLS treatments."

"Thank God you are there!"

WED/RLS Quality Care Centers

The Johns Hopkins Center for Restless Legs Syndrome
5501 Hopkins Bayview Circle • Baltimore, MD 21224

410-550-0574
Contact: Robin Fishel
rfishel2@jhmi.edu
Certified healthcare providers:
Christopher J. Earley, MB, BCh, PhD, FRCPI
Richard P. Allen, PhD

Mayo Clinic Center for Sleep Medicine
200 1st Street SW • Rochester, MN 55905

507-538-3270 (central appointment office)
www.mayoclinic.org/sleep-center-rsrt/appointments.html
Certified healthcare providers:
Bradley F. Boeve, MD
Suresh Kotagal, MD
Mithri Junna, MD
Melissa C. Lipford, MD
Michael H. Silber, MB, ChB
Erik K. St. Louis, MD
Maja Tippmann-Peikert, MD

The University of Texas Health Science Center at Houston (UTHealth)
6410 Fannin Suite 1014 • Houston, TX 77030

832-325-7080 (Department of Neurology)
Certified healthcare provider:
William G. Ondo, MD

Innsbruck Medical University
Department of Neurology, Sleep Lab and Sleep Disorders Outpatient Clinic
Anichstr. 35, 6020 • Innsbruck, Austria

+ 43 512 504-23890
Contacts: Maria Kuscher, Cesarie Ndayisaba, Manuela Oberlechner
schlaf-neurologie@i-med.ac.at
Certified healthcare providers:
Birgit Högl, MD
Birgit Frauscher, MD
Elisabeth Brandauer, MD
Thomas Mitterling, MD

In the News

RLS and Daily Physical Tasks

Restless Legs Syndrome Status as a Predictor for Lower Physical Function.
C. Zhang, Y. Li, X. Gao. *Neurology.* April 2014.

Background:
Research has shown links between WED/RLS and significant health conditions like heart disease and diabetes. Many of these health problems are associated with poor physical function. Physical function is defined as the ability to perform activities of daily life (for example, rising from a chair, walking, balancing, climbing stairs or lifting). In patients who have WED/RLS who experience decreased physical function, it has been unclear whether WED/RLS or the other diseases are responsible.

Research:
The researchers performed a longitudinal study where they followed a group of similar individuals over time. They followed 12,556 men who were part of the Health Professionals Follow-up Study, a Harvard School of Public Health study group consisting of male medical professionals. WED/RLS was diagnosed in participants at the start of the study based on the International RLS Study Group (IRLSSG) guidelines, and the men were followed for six years. Participants also completed the Physical Function (PF-10) survey at the beginning and end of the study.

The results showed that patients with WED/RLS had significantly lower PF-10 scores after six years than those without WED/RLS, even after adjusting for age and other possible confounding factors (for example, smoking and obesity). The drop in physical function for individuals who experienced WED/RLS symptoms 15 times a month or more was comparable to aging five years, being a moderate smoker, having high blood pressure or having depression.

Bottom Line:
Patients with WED/RLS have significantly decreased levels of physical functioning. This research study was well designed and included a large number of individuals; because of this, many news outlets have reported on the article.

New Questions:
What would be the change, if any, in physical function scores for women and men who are not medical professionals? Is WED/RLS the cause of decreased physical function by itself, or is another medical issue causing both WED/RLS and decreased physical function?

Oxygen in the Legs

Peripheral Hypoxia in Restless Legs Syndrome (Willis-Ekbom disease).
A. Salminen, V. Rimpilä, O. Polo. *Neurology.* May 2014.

Background:
Past research has suggested abnormal oxygen and carbon dioxide levels in the legs of patients with WED/RLS.

Research:
The researchers evaluated 15 patients with WED/RLS and 14 healthy individuals without WED/RLS as a control group. Each patient underwent two suggested immobilization tests (SITs) where they were able to quietly recline but did not need to fall asleep. During these tests, the patients had noninvasive oxygen and carbon dioxide monitors attached to the chest and legs. The patients with WED/RLS were tested another time after taking the medication pramipexole (Mirapex), a dopamine agonist.

The results showed that patients with WED/RLS had significantly lower levels of oxygen in their legs as compared with the control group. They had no differences in oxygen levels in the chest. They also had no differences in carbon dioxide levels in the legs or chest. Patients with more severe WED/RLS symptoms had a more significant drop in oxygen levels. In the patients with WED/RLS, after taking the medication, their oxygen levels increased but did not completely normalize.

Bottom Line:
Patients with WED/RLS had decreased levels of oxygen in their legs when they had WED/RLS symptoms, and oxygen levels were lowest in patients with more significant symptoms. Oxygen levels improved with a dopamine agonist medication.

New Questions:
A lot of research has studied iron and its relationship with WED/RLS. Hemoglobin is the iron-containing protein that is used to transport oxygen in the body. Are low oxygen levels a consequence of WED/RLS (maybe related to iron?), or are low oxygen levels partly the cause of WED/RLS? Would oxygen therapy help WED/RLS symptoms?

Vitamin D and WED/RLS

Possible Association Between Vitamin D Deficiency and Restless Legs Syndrome.
M. Oran, C. Unsal, A. Gurel. *Neuropsychiatric Disease and Treatment.* May 2014.

Background:
Although there remains no known cause of WED/RLS, researchers know the dopamine system likely plays a role. Vitamin D is produced in the skin with sunlight and can also be acquired through food. The major consequence of vitamin D deficiency is weak bones; however, there are numerous other medical problems, many of which we are just beginning to understand, that are caused or associated with low levels of vitamin D.

Research:
The researchers noticed that a few patients who were admitted to the hospital for neurologic diseases affecting the dopaminergic system also had low levels of vitamin D. Because of the association of the dopamine system with WED/RLS, the researchers designed a study to further investigate the relationship. The researchers evaluated 155 consecutive patients who were admitted with musculoskeletal symptoms to the internal medicine department of the hospital. Each of these patients underwent full neurologic and electromyography (EMG) evaluation. Vitamin D levels were obtained on all patients.

The results showed 36 patients with normal vitamin D levels and 119 patients with vitamin D deficiency. Both groups were similar in terms of average age, sex, body mass index (BMI) and blood levels of calcium, phosphate, alkaline phosphatase and ferritin (a protein that stores and releases iron in the blood). Of the 119 vitamin D-deficient patients, 60 (50.4%) had WED/RLS, but of the 36 patients with normal vitamin D levels, only 6 (16.7%) had WED/RLS.

Bottom Line:
Based on this study, people with vitamin D deficiency have significantly higher rates of WED/RLS.

New Questions:
Does WED/RLS increase vitamin D deficiency, or does vitamin D deficiency increase the risk of developing WED/RLS? Would replacing vitamin D in these deficient patients improve, or even cure, their WED/RLS? Would these results hold true for larger numbers of patients?

New: Canvas Prints with Word Cloud

Would you like to help raise awareness for WED/RLS? Canvas prints featuring the word cloud created by our community are now available at $20 for WED Foundation members and $25 for nonmembers. Shipping is included for U.S. addresses; for international mailing, please inquire.

To order your 8 x 10 canvas print, visit www.willis-ekbom.org or call 507-287-6465.

Coming in November: Give to the Max "Awesomeness"

"This is where awesomeness happens," declares givemn.org, the website for Give to the Max Day. On November 13, the WED Foundation will join over 4,000 Minnesota-based nonprofit organizations in Give to the Max Day. On this day each year, people from around the world come together virtually over a 24-hour period to make donations through givemn.org. Last year, the Foundation raised $20,834, thanks to matching gifts totaling $10,000.

How your donation is "maxed"

Every gift has the potential for helping the Foundation even more through matching donations and prizes. Last year, two generous supporters offered $5,000 each in matching gifts to the WED Foundation. Also, top fundraising organizations received prizes of up to $15,000, and individual donors were randomly chosen every hour for additional bonus gifts to their supported charity.

Mark your calendar for November 13, and consider planning a donation – all gifts, regardless of size, make a difference! Visit www.givemn.org to learn more.

giveMN.org
Click. Contribute. Change Your World.

Youth Art Contest Winner Announced

Congratulations to Bella, age six, who won the WED Foundation Youth Art Contest! Bella received a $50 VISA gift card for her winning entry.

What is WED/RLS and do I have it?

Webinar Q&A with Dr. Mark Buchfuhrer

The following questions and answers were shared during the April 2014 webinar "What is WED/RLS and do I have it?" with Mark Buchfuhrer, MD, FRCP(c), FCCP. For information on future WED Foundation webinars, visit www.willis-ekbom.org.

Symptoms and diagnosis

Q: Is numbness in the thigh common in WED/RLS?

A: Numbness in the thigh is reported often. It may be a sign of neuropathy in addition to WED/RLS and needs to be evaluated by a medical doctor. If both conditions are present, treating the WED/RLS will usually not resolve the thigh numbness.

Q: My legs don't jerk, but I constantly feel the need to move them. Circulatory causes have been dismissed. Can this still qualify as WED/RLS if there is no associated jerking?

A: The need to move your legs without the often associated leg jerking is compatible with a diagnosis of WED/RLS. Not all individuals with WED/RLS have the leg jerking/periodic limb movements (PLM), although over 85 percent do have these PLM.

Q: My sleep study indicated one symptom whereby my legs go up in the air like the shape of an L. Is this a symptom of WED/RLS?

A: This is a characteristic of PLM and may indicate the presence of WED/RLS. WED/RLS is based on patient-reported symptoms and less on leg movements/PLM found on a sleep study. Antidepressant use (among many other causes) may be the cause of PLM.

Q: Can you have WED/RLS without leg involvement – for example, just arms and shoulders?

A: WED/RLS must occur in the legs first, then progress to other body parts. Once it is present in the other body parts, occasionally the symptoms in the legs may be minimal or even absent.

Medications and WED/RLS

Q: Which drug has been the most effective in relieving WED/RLS symptoms?

A: All medication classes used alone or in combination with other medications are used to treat WED/RLS symptoms. Ninety percent of individuals respond to dopamine agonists, but these drugs make WED/RLS worse down the road, so I recommend using the lowest effective dose for treatment. The Neupro patch prescribed at FDA-approved dosages has shown lower rates of augmentation.

Q: I have been on Mirapex for seven years. WED/RLS symptoms are beginning earlier in the day. Why do my doctors want me to discontinue Mirapex, which I find impossible to do?

A: The reason that your doctors want you to stop Mirapex is that it sounds like the Mirapex is causing augmentation (a worsening of WED/RLS from taking a dopamine drug like Mirapex). If you increase the Mirapex to treat this worsening, your WED/RLS will temporarily improve, but each time the Mirapex dose is increased, this fuels the augmentation fire. Stopping the Mirapex should result in an improvement of WED/RLS symptoms. Symptoms will worsen temporarily, but in about two weeks to two months, WED/RLS symptoms will calm down. Special treatment should be given for those two months to control the temporary worsening of symptoms.

Q: What is considered a super high dose of Mirapex?

A: Although some experts still recommend higher maximum doses, I currently suggest that the maximum daily dosage is 0.25 mg for Mirapex (the drug is approved for WED/RLS up to 0.5 mg once daily) and 1 mg for Requip (approved for up to 4 mg once daily). Because of the risk of augmentation, it is best to use the lowest effective dose for treatment. If augmentation occurs and a change in therapy is needed, the transition will be less difficult for the patient when on a lower dose.

Q: I am trying to get off of Requip, and gabapentin has helped to reduce symptoms during the day, but I still can't get to sleep unless I take Requip. I have tried iron infusions but did not receive any relief.

A: There are several things that may be occurring. You could have augmentation, which would require a doctor who is knowledgeable in diagnosing and treating this problem. If you wish to completely stop the Requip without too much pain (discontinuing the Requip will typically cause a marked worsening of your WED/RLS symptoms), then you might have to consider substituting an opioid.

Q: When do you start gabenergics? Do you ever add them to dopaminergics or substitute them?

A: Use the lowest effective dose possible. Choose a gabenergic as a first-line treatment if you can't sleep at night. Gabenergics are known to help sleep and anxiety. They also work well in combination with or types of therapy such as dopaminergic or opioid drugs.

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Webinar Q & A

Continued from page 17

Q: Tell us your experience using the Neupro patch versus the oral dopaminergics.

A: I like the Neupro patch and am prescribing up to the 3 mg dose per day. Augmentation is limited even in the five-year studies that have shown it helps to manage daytime WED/RLS symptoms. The patch works around the clock and allows individuals to do anything they want to do at any time of the day. So, there are no limitations to participating in daytime sedentary activities. Since it is a 24-hour, slow-release medication, there are no peaks or troughs in delivery of the medication. According to studies, 70 percent of WED/RLS patients suffer from daytime symptoms in addition to evening/bedtime symptoms. I also use short-acting generic forms of Mirapex and Requip when appropriate but am prescribing them much less these days, due to concerns with the high rate of augmentation associated with the short-acting dopamine agonists.

Q: Opioids are known to lead to tolerance so the patient needs more. Why are these medications a good option for WED/RLS treatment? Also, don't they make one tired? Gaba drugs can cause weight gain. Again, these side effects from medications are not tolerable. What is a patient to do?

A: Opioids are a good treatment option for WED/RLS and due to sedating properties should be used at bedtime for the minority of patients who suffer from that side effect. However, the majority of patients who take opioids suffer little or no sedation and can take them during the daytime. Gabapentin (Neurontin) and gabapentin enacarbil (Horizant) can cause weight gain, so the trick is to use the smallest effective dose to manage WED/RLS symptoms.

Q: What is the dose for opioids like hydrocodone? I am trying to get off of Mirapex. What do you prescribe in addition to an opioid after discontinuing Mirapex?

A: I do not like to use hydrocodone since it also contains acetaminophen. Acetaminophen is an over-the-counter pain reliever that has no benefit in WED/RLS treatment. I prefer to use low doses of methadone, as it works best in WED/RLS patients and has the least side effects. I have also used oxycodone with success and will work with a patient to find an opioid medication that best manages symptoms and causes the fewest if any side effects. If additional help is needed, an alpha-2-delta drug (Horizant, gabapentin, Lyrica) may be added.

Q: Although not necessarily a primary treatment drug, tramadol (Ultram) often seems to work for many, including myself. It doesn't solve the problem or symptoms, but does seem to alleviate some of the leg symptoms. Does tramadol actually seem to work for many others?

A: Tramadol is not a true opioid, but the metabolites (the components of the drug when it breaks down in the body) may stimulate opioid receptors in the brain. It's the least potent medication in the opioid family and the least likely to cause tolerance or addiction. It is a good therapy for management of daytime WED/RLS symptoms.

Q: Will there be more work to raise awareness on the use of opiates in treating WED/RLS when the regular classes of medications do not work? Many doctors object to this treatment strongly and people cannot get help.

A: None of the companies that make brand name opioids is pursuing research or FDA approval here in the U.S., but there was one recent European study that demonstrates the effectiveness and safety of opioids for treating WED/RLS.

Q: Which antidepressant will *not* exacerbate WED/RLS?

A: Bupropion (Wellbutrin) is a moderately effective antidepressant that can be used by individuals with WED/RLS. It can worsen anxiety and insomnia. Trazadone is another WED/RLS-safe treatment option and may help depression when prescribed at the higher dose levels. Mixed results have been reported with the use of Abilify.

Q: When someone is on a selective serotonin norepinephrine reuptake inhibitor (SSNRI) medication; can he or she have periodic limb movements (PLM) while awake or while falling off to sleep?

A: Patients with PLM from selective serotonin reuptake inhibitor (SSRI) or selective serotonin norepinephrine reuptake inhibitor (SSNRI) medications have PLM only while asleep so are not aware of them (but their bed partners may be very aware of them). However, WED/RLS patients may have PLM while asleep or awake so may be quite aware of them.

Nondrug therapies

Q: Deep brain stimulation for refractory Willis-Ekbom disease is controversial. Do you know the outcome of surgeries that have been performed? What is your opinion?

A: Deep brain stimulation (DBS) is not always successful, so it is not a viable WED/RLS treatment.

Q: Are there any natural remedies or suggestions to try?

A: Everyone with WED/RLS needs to look at this type of option for him or herself. Other than iron supplements, no natural remedies have shown benefits in any scientific studies; only anecdotal information has been reported. Please note that iron therapy should only be used under the advice and care of a physician. Careful monitoring of iron levels is essential to prevent excess accumulation of iron in the body.

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A clinical trial is a research study that uses volunteers to investigate specific health questions. Below is a partial list of WED/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 (IRB) 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 or www.clinicaltrials.gov.

To learn more about clinical trials, download our Clinical Trials and Research *handout at www.willis-ekbom.org or request a paper copy using the publication order sheet on page 23.*

Have you been diagnosed with restless legs syndrome? Are you currently taking medication to treat restless legs syndrome (RLS)? Massachusetts General Hospital, Boston; and Spaulding Rehabilitation Hospital, Cambridge; are seeking men and women ages 20 to 65 to participate in a research study looking at the effects of restless legs syndrome on blood pressure. To participate, you cannot have diabetes, have high blood pressure or smoke. Participation will consist of three study visits for a total of up to seven hours. You will receive up to $300 for your participation. For more information and eligibility requirements, please call Laura at 617-643-6026 or email lschoerning@partners.org.

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Would your friend or family member (not a blood relative, if you have WED/RLS) like to make a lasting contribution to groundbreaking research? A Johns Hopkins team is recruiting healthy adult volunteers for a study on the role of glutamate in WED/RLS. In some cases, reimbursement may be available for time and travel expenses. To learn more, contact Tiana Krum at 410-550-1046 or tkrum1@jhmi.edu.

NeuroTrials Research in Atlanta, Georgia, is conducting a local study to examine the safety and efficacy of a new investigational drug for Willis-Ekbom disease (restless legs syndrome). Study-related care and study drug are provided at no cost. Qualified participants will be compensated for time and travel. To qualify, participants must be 18 to 70 years of age, have a diagnosis of WED/RLS for over six months, experience symptoms of WED/RLS for at least 15 nights per month, and otherwise be in good general health. If you are interested in learning more about this study, or to find out if you qualify, call 404-851-9934 or visit www.neurotrials.com.

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If you live in the New York City area, you may be eligible to participate in a new research opportunity. We are conducting a research study to determine whether there are changes in the retinal structure of the eyes of individuals with Willis-Ekbom disease (WED/RLS) compared to individuals with Parkinson's disease, individuals with multiple system atrophy, and healthy controls. The study will take place at the New York University Langone Medical Center and will require one visit, lasting approximately one to two hours. The visit will include an initial screening and an eye exam.

There is no direct benefit to you or expense reimbursement available from your participation in the study. It is hoped that the knowledge gained will be of benefit to others in the future. Studies done for this research study are not a part of your regular medical care and will not be included in your medical record. If interested, please contact Dr. Jose Martinez at Jose.Martinez@nyumc.org.

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Q: How many iron infusions does it take before you see improvement?

A: Some physicians prefer to give 250–500 mg of iron dextran, but many physicians now prescribe 1,000 mg of iron dextran for one infusion. Post-infusion, patients should expect to see a ferritin level greater than 200 mcg/L but not more than 300 mcg/L. The goal of intravenous (IV) iron is to get a good effect from the therapy but to not overload the patient. The increase in ferritin levels can last from three months to three years, with the average being 18 months for individuals who have received IV iron.

Q: Will over-the-counter iron bring up your ferritin level?

A: If you have a low ferritin level, less than 5 mcg/L, your body will absorb 20–30% of iron taken orally. However, when your ferritin level gets above 50–60 mcg/L, you may absorb less than 2%. Therefore, as your ferritin level increases, you will see diminishing returns from oral iron therapy.

WED/RLS Support Group Network

Across the United States and Canada, support groups bring people together to share their feelings about living with WED/RLS, discuss ways to communicate with their families, friends and healthcare providers, and learn about the latest treatments. The WED Foundation also maintains a network of contacts. Contacts are individuals who have volunteered to offer support by phone or email to people in their area who are looking for WED/RLS information, resources and support. They do not hold meetings, but they can assist you in finding help where you live.

The most up-to-date support group information is available on www.willis-ekbom.org. If you are unable to reach a contact or support group leader in your area, please contact the WED Foundation at info@willis-ekbom.org.

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Online Discussion Board Moderators

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Beth Fischer
rlsfmods@aim.com

Betty Rankin
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Stephen Smith
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Upcoming Meeting

Southern California
WED/RLS Support Group

Sunday, October 5
1:00–3:00 p.m.
St. Mary's Medical Center-
Health Enhancement
Center
1050 Linden Ave
Long Beach, CA

Speaker: Fred Burbank,
CEO, Sensory Medical, Inc.
Topic: Relaxis vibration pad
for sleep improvement
Contact: Susan Schlichting
310-792-2952
susan@rlsgroups.org

International
The following independent groups work in cooperation with the WED Foundation.

AUSTRALIA
Restless Legs Syndrome Australia
www.rls.org.au

AUSTRIA
Dachverband der österreichischen
Selbsthilfegruppen
www.restless-legs.at

BELGIUM
Association Belge du Syndrome
des Jambes sans Repos (Absjr)
www.absjr.be

DENMARK
Restless Legs Portalen
Restless Legs -Patientforeningen

FINLAND
Levottomat jalat RLSry (Finland)
www.uniliitto.fi

FRANCE
A.F.S.J.R, Association Française des
Personnes Affectées par le Syndrome
de Jambes sans Repos
www.afsjr.fr

GERMANY
Deutsche Restless Legs Vereinigung
www.restless-legs.org

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JAPAN
Osaka Sleep Health Network
www.oshnet-jp.org

THE NETHERLANDS
Stichting Restless Legs Nederland
www.stichting-restlesss-legs.org

NEW ZEALAND
Brain Research
www.neurological.org.nz

NORWAY
Foreningen rastlöse bein
www.rastlos.org

SPAIN
Aespi, Asociacion Espanola de sin-
drome de piernas inquietas Madrid
www.aespi.net

SWEDEN
WED-Förbundet
www.rlsforbundet.se

SWITZERLAND
Restless Legs Schweiz
www.restless-legs.ch

UNITED KINGDOM
Restless Legs Syndrome UK
www.rlsuk-esa.org.uk

Bedtime Stories

Bedtime Stories are the opinions of the authors only and not of the WED Foundation, its employees or its Board of Directors. Publication in NightWalkers *does not imply endorsement by the WED Foundation. Therapies and results described in Bedtime Stories reflect the experiences of individuals and cannot be generalized to everyone with WED/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 altered for length or clarity.*

I recently switched from Requip to Lyrica (100 mg at bedtime). I'm doing very well on it. I occasionally still need 0.25 mg Ativan for jumpy legs when I go to bed, but overall, I'm doing better than I was on Requip. I definitely experienced augmentation with Requip. The WED/RLS symptoms were getting worse and happening earlier and earlier in the day. Now that I'm off Requip and on Lyrica, the early afternoon symptoms have disappeared.
Lise P.

I finally have something that works without the terrible side effects I had previously on Mirapex (compulsive behavior, trouble breathing, augmentation, etc.). I take 2 mg Lunesta, 10 mg of OxyContin, and the Neupro 2 mg patch for two to three hours a night. Crazy, yes! But it works!! Hope it helps others.
Mary S.

Need Help? Visit the Online Discussion Board

Looking for help coping with WED/RLS? The WED Foundation online discussion board may be for you! This forum is a place for people to ask questions, exchange ideas and information, and encourage and support one another.

The board has several dedicated volunteers who moderate posts by over 4,000 registered users in topic areas like medications, nonpharmacologic treatments, special populations (pediatric, pregnancy, secondary, etc.) and help with relationships.

The forum is free and open to both members and nonmembers of the WED Foundation. Anyone can read posts, and registered users can comment or create new posts.

To the many volunteers who oversee the site comments and make sure users receive the response they need, thank you! Your dedication and caring make a profound difference in peoples' lives.

To join the online discussion board, visit www.willis-ekbom.org and click on "Connect with Others," or go directly to bb.rls.org. (Please note that even if you are a WED Foundation member, you must register on the portal to comment or create posts.)

Snapshot of recent discussion topics

Our discussion board is a very active community that creates new posts daily. Following is a snapshot of recent topics:

In the Pharmaceutical forum:
Published Research - Pharmaceutical
Pramipexole and serious side effects
Horizant
Neupro Patch
Warning: Drugs to avoid for RLS/PLMD patients

In the Just Joined forum:
Can't take much more of this
Help-exhausted mommy needs medicine...
Getting a doctor to understand
Going insane
Options? Feel I'm Out of Them

In the General WED/RLS forum:
Published Research - General Sleep and WED (RLS)
Important Links
Venting!
Getting Madder by the Minute
Who is your favorite doctor?

In the Special Populations forum:
Intravenous Iron Given prior to Pregnancy for Restless Legs
Ferritin Question
Useful info for parents with children

In the Relationships forum:
RLS is a sad condition
Does your RLS increase with human contact?

In the Non-Pharmaceutical forum:
Poppy seed tea - incredibly effective for me
amino acids...
Sleep position
Latest on TENS Unit Use for Nighttime Symptoms
The Foot Massage Fix
D-Ribose

Discussion Moderators Needed

Do you have a passion for helping others and enjoy interacting online? Are you knowledgeable about WED/RLS? If you have been actively participating on the discussion board and would like to become more involved, please consider becoming a volunteer moderator. Moderators must be reliable and able to communicate clearly in writing. To learn more, contact the WED Foundation at info@willis-ekbom.org.

Publication Order Sheet

Publications

Please note that most of our publications are available at www.willis-ekbom.org for viewing and downloading.

Quantity	Patient Brochures
	Causes, Diagnosis and Treatment for the Patient Living with Willis-Ekbom Disease/Restless Legs Syndrome. (©2013)
	Children and RLS: Restless Legs Syndrome and Periodic Limb Movement Disorder in Children and Adolescents: A Guide for Healthcare Providers. (©2007)
	Depression and RLS: Special Considerations in Treating Depression when the Patient has Restless Legs Syndrome. (©2011)
	Surgery and WED/RLS: Patient Guide. (©2014)
	WED/RLS in Cognitively Impaired Older Adults. (©2014)
	Medical Bulletin. Contains the latest WED/RLS diagnosis and treatment information for healthcare providers. (©2014) Free to members; $10 to nonmembers.
	"Revised Consensus Statement on the Management of Restless Legs Syndrome." Article in September 2013 issue of *Mayo Clinic Proceedings*. Provides a practical treatment approach for healthcare providers. Free to members; $5 to nonmembers.

Quantity	Patient Handouts	Quantity	Patient Handouts
	WED/RLS Triggers		*Activity and Exercise*
	Suggested Coping Methods		*Depression and WED/RLS*
	Understanding Augmentation		*Pain and WED/RLS*
	Elderly Population		*Clinical Trials and Research*
	Understanding Possible "Mimics"		*Your Child with WED/RLS*
	The Role of Iron in WED/RLS		*A Quick Guide to Living with WED/RLS*
	Medications for WED/RLS		*Understanding Drug Action*
	Drug Holidays and WED/RLS		*WED Foundation Research Grant Program*
	Symptom Diary for WED/RLS		*Complementary/Alternative Medicine and WED/RLS*
	Your First Doctor Visit for WED/RLS		*Hospitalization Checklist*

MEMBERSHIP

☐ Yes, I want to join the Willis-Ekbom Disease Foundation or renew my membership. ($35 U.S. or Canada • $45 International) (Please make any changes to address on reverse side.)

DONATION

☐ I would like to make an additional donation of $_____ for ☐ research ☐ WED/RLS Quality Care Center program ☐ education ☐ where it is needed most

☐ I would like to make a recurring monthly gift of $_____ for ☐ research ☐ WED/RLS Quality Care Center program ☐ education ☐ where it is needed most
Start date: _____ End date: _____

☐ I am setting up a monthly auto bill payment to the WED Foundation through my checking account. Please accept my monthly/quarterly gift of $_____ for ☐ research ☐ where it is needed most

PAYMENT METHOD

☐ I have enclosed a check in the amount of $_____ in U.S. dollars, drawn on a U.S. bank, payable to the RLS Foundation or the Willis-Ekbom Disease (WED) Foundation.

☐ Please bill $_____ to my ☐ American Express ☐ Discover ☐ MasterCard ☐ VISA

Card number_____ Expiration date _____

CONTACT INFORMATION *(We do not sell or share our mailing list.)*

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NIGHT WALKER