

Non-Medication Treatments & Partnering with Doctors - Patients' Perspectives -

Beth Fischer, Steve Smith

RLS Foundation Discussion Board Moderators (Volunteers)

Beth.RLSFmod@gmail.com, Stephen.RLSFmod@gmail.com
Visit us at: bb.rls.org

Patients' Perspectives

Disclaimer

We are patients, not physicians. Although we have consulted the published literature, our main source of information is the collective experiences of patients who post on the RLS Discussion Board, including ourselves.

Patients' Perspectives

Part 1 - Non-medication therapies for RLS

- Therapies that may provide relief
 - When it's happening (physical activities, distractions)
 - Physical devices or treatments
 - Overall health & diet therapies
 - Botanicals (where legal)
- Therapies that usually do NOT work

We will address two aspects of the patient's perspective.

In Part 1, we will cover Non-medication therapies for WED/RLS symptoms

- (Note we're not talking about therapies for insomnia, anxiety, and other problems that tend to co-exist with WED/RLS – only therapies for the sensorimotor symptoms of WED/RLS itself)

These will include

techniques that help when the symptoms are active

various physical devices

BRIEFLY, therapies related to overall health & diet

& also VERY BRIEFLY herbs & their derivatives

We'll also give you a list of Therapies that usually do NOT work.

Patients' Perspectives

Part 2 – Partnering with Doctors

- How to approach a doctor who doesn't have enough experience with RLS or augmentation
 - A. Personalities
 - B. Before the appointment
 - C. At the appointment
 - D. How to bring up the topic of opioids
- Finding a new doctor

In Part 2, we'll discuss how to approach a doctor who is ignorant of RLS, or of augmentation.

- We'll include how to present your doctor with scientific information
- How to bring up the topic of opioids, and
- How to find a new doctor

Patients' Perspectives

Part 1: Non-medication Therapies

- We've all tried one at some point
- No therapy works for everyone
- What works for mild symptoms might not work for severe symptoms
- Success can be hard to measure (symptoms vary so much)
- Some therapies (e.g. diet) require a long-term commitment that may be hard to sustain

although most of the people who post on the disc board use pharmaceuticals, virtually everyone has at one point or another tried an alternative or non-medication therapy.

- Sadly, none of the non-medication therapies work for everyone, but many are useful to some people .
- RLS severity varies, and what helps a person with mild symptoms might be inadequate for someone with severe symptoms.
- the success of any non-medication therapy can be difficult to quantify, since it varies so much from day to day.
- Some alternatives, like changes in diet, require a long-term commitment that may be difficult to sustain for a sufferer wanting fast results.

Part 1: Non-medication Therapies

Therapies that May Help

When it's happening

Physical activities

- walking, squats, stretches
- immersion in very hot or cold water

Distractions

- Sudoku, puzzles, a good novel (often doesn't help sleep)
- active listening to music (e.g. imagine dancing)
- passive listening to familiar music: "Songs I know by heart, played just loud enough to hear the words"
- frisson: listening to music that provokes intense emotion tinged with nostalgia

The first group of therapies are ones you can try while the symptoms are active.

Physical activities include

- walking, squats, stretches – the urge to move defines our disease., and we've all been forced to do these things whether we wanted to or not.
- And immersion of the legs or feet in hot or cold water - some people crave it very hot, others crave it icy - do what works for you .

Distractions are mentally or emotionally engaging activities:

- Solving puzzles, reading an absorbing book, anything that requires sustained mental alertness .

Unfortunately, this involves being awake. Like the physical activities, these techniques often can't help you sleep.

The next three therapies have been used to fall asleep:

- active listening to music: becoming fully absorbed in the music, or imaging the exact moves you would make while dancing
- passive listening to familiar music: "Songs I [know] by heart played just loud enough to hear the words" – the patient who used this method thinks that maybe auditory input is needed to keep the brain distracted from the symptoms, but the input should be a familiar, well-liked song, so that the brain doesn't have to work

so hard that it keeps you awake.

- listening to music that gives you the chills - a complex suite of physiological and emotional responses, including goosebumps and a profound absorption in pleasurable emotions. Not everyone gets musical chills, but for those who do, WED/RLS seems to be excluded during the experience, and it becomes a route to falling asleep.

Part 1: Non-medication Therapies

Therapies that May Help

Physical devices or treatments

- Pneumatic compression devices



- pneumatic compression devices – wide range of models and prices
 - tend to be good for mild symptoms
 - commonly provide some relief for moderate symptoms -
 - some also provide heat or infrared

Part 1: Non-medication Therapies

Therapies that May Help

Physical devices or treatments

- Pneumatic compression devices




- Near-infrared therapy

- handheld devices
- hands-free pads
- saunas



Hands-free pads

The study used a beefed-up version of this pad system




2011 study:

- 30-minute treatments 3x per week for 4 weeks
- Reduced severity score from avg 24 to 11
- Symptoms slowly returned after treatment ended


Handheld devices

\$50




Infrared saunas

\$1000




Handheld devices

\$6700



Handheld devices

\$3000



Near-infrared therapy – studies show that NIR helps to reduce symptoms; these studies used hands-free pads, in-clinic; not sure how expensive these systems are- - see pictures

There are also handheld devices BUT

not practical to use while falling asleep;

the shape of available devices is not always appropriate for administering to the body part in need;

saunas

expensive




many are full-spectrum IR whereas studies were done only with Near IR

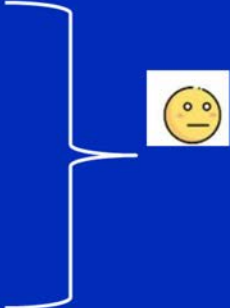
need more studies!

Part 1: Non-medication Therapies

Therapies that May Help

Physical devices or treatments

- Pneumatic compression devices 
- Near-infrared therapy
 - handheld devices 
 - hands-free pads 
 - saunas
- Compression stockings
- Heat pads
- TENS (great for PLMS – mixed, poor for RLS)
- Acupuncture
- Vibration pads
- Weighted blankets
- Elevating the head end of the bed



The therapies in this next group – work for some people, other people hate them or get no benefit.

- compression stockings –some people find them somewhat helpful sometimes 😊 - some people cannot stand them
- heat pads - - - dry heat (eg electrical heat pad) is not as good as hot water, but much more practical in bed 😊.

Can be helpful for some people, especially those prone to chills which seem to bring on the WED/RLS.

- TENS – remarkably good results for a few people, others seem to have felt no effect;
 - recent study indicates that TENS can reduce PLMs
 - effectiveness may depend on electrode placement, frequency patterns, and type of WED/RLS (lower back and lower leg have both worked for PLMs)
- acupuncture - a dozen people say it doesn't work, 2 or 3 said it worked fairly well;

perhaps the difference was placement of needles (many acupuncturists would target the legs, the successful one might have targeted the lower back);

note that repeat treatments were necessary for the successful person, spaced a few months apart iirc

- vibration pads (e.g. Relaxis) – based on counter-stimulation- - generally no
- weighted blankets – not for everyone, & probably not always for anyone, but worth a try to see if it's useful for you
- Elevate the head of your bed

Part 1: Non-medication Therapies

Therapies that May Help

Overall Health & Diet



- Exercise – Don't do too much too quickly
 - Don't make sudden changes
 - Replenish vitamins or minerals that you're deficient in
 - Drink enough water
 - Manage other health issues – SIBO, MS, OAS, kidney disease, etc.
 - Diet – each of these has given relief to a handful of board members:
 - Gluten free
 - Wahls/Paleo/Keto
 - Low Oxalate
 - Low Histamine/Tyramine
 - avoiding "trigger foods" (which differ for everyone)
- Nutrition is a complicated subject. More research is needed!

- - exercise - Don't try to do too much too quickly. Next day soreness is an indication you did too much. Some of us have found that intense exercise is fine if we build up to it gradually; that it is not the intensity of the exercise but *sudden changes in the intensity*, that seems to bring on symptoms.
- - replenish any vitamin or other substance you're depleted in (e.g. vitamin D; Mg; water!) –after reading thousands of discussion board posts, the moderators wonder if symptom severity might be increased by deficiencies in vitamins and minerals that are not directly related to WED/RLS. Correcting those deficiencies seems to relieve symptoms to some degree. There are no studies to support or refute this

-this includes water. Stay hydrated !

- - repair or treat any other health issues (e.g. sleep apnea; SIBO; MS) – Similar to vitamin and mineral deficiencies, if you have other unresolved health issues, your WED/RLS may be worse. Addressing those issues with proper treatment might reduce the severity of your symptoms.
- diet – many people have had improvement in symptoms from altering their diet. Not trying to be all-inclusive here, but various board members have had such success with the following diets (a handful each):

gluten-free

Wahls/paleo/keto

gluten free, but also dairy free, high in a variety of vegetables, low carb, no sugar, no highly processed foods

low oxalate

no high-oxalate foods (e.g. spinach, soy products, nuts, potatoes, dates), and low-oxalate foods in moderation (e.g. tomatoes, apricots, sardines); some people even avoid substances like gelatin that cause the body to create oxalic acid endogenously

low-histamine/tyramine

some people have a histamine intolerance

eliminate the many foods contain histamines (e.g. mushrooms, chocolate, soy products, nuts, beer)

Avoiding “trigger foods” – some people notice worsened symptoms after eating certain foods – ice cream, sugar, etc. What is a trigger for one person is not necessarily going to be a trigger for the next person.

Part 1: Non-medication Therapies

Therapies that May Help

Botanicals

- Kratom – a plant with opioid-like properties
 - Used by some to treat RLS
 - Content varies and may be cut with other agents
 - Illegal in many places
- Chinese Herbs – e.g. Yi Gan San, Paeonia radix
 - Anecdotal reports of success
 - Needs more work!
- Marijuana and its derivatives (e.g. CBD oil)
 - helps very few people with symptoms
 - helps many with sleep
 - Illegal in many places



Issues: Legality, Strength variations between batches, Impurities (insecticides, herbicides, heavy metals, etc.), Lack of research

- kratom –
 - a plant with opioid-like properties
 - where it is legal, people use it successfully to treat WED/RLS.
 - Needs more work.
- Chinese herbs –
 - some promise; anecdotal evidence for:
 - a mixtures of herbs called Yi Gan San
 - a substance called Paeoniae radix, which was not studied by itself but as a component of two different herbal mixtures given to a patient, whose 60 years of WED/RLS was resolved in under 2 months
 - needs more work – could be a whole talk itself
- marijuana & its derivatives including CBD oil –
 - Helps very few people with the actual symptoms, helps many more people with sleep
 - could be a whole talk itself

Part 1: Non-medication Therapies

Therapies that Usually Don't Help

Some people say they were helped by these, but the benefit turned out to be transient.
Was it due to a placebo effect?

- Soap under sheets
- Stand-on vibration devices
- Chi swing machine
- Foot wraps
- Magnesium oils (external use) and Epsom salts
- Tonic water (quinine is banned in US)
- Homeopathic remedies



- soap under sheets (perhaps originally was lavender soap, and came about because lavender is soothing, however, it soothes the mind, not WED/RLS)
- foot wraps e.g. Restiffic- - a few people reported a little bit of relief, but the help was transient.
- tonic water/quinine—apparently some GPs still recommend quinine to new RLS/WED patients.

there is no evidence that it helps, except a few anecdotal reports that may indicate a placebo effect.

- Quinine has been banned in the U.S. for RLS since 2006,

because of the potentially lethal side effects and lack of evidence that it helps RLS.

- (homeopathic remedies (e.g. Hyland's cream) - homeopathy has been proven over and over in scientific studies not to work. Regardless, quite a number of people on the board have tried the Hyland's product over the years, yet no one reported sustained relief.

people often report that some cream or rub works, but the effect wears off after a few minutes. Probably it was the rubbing that worked, not the cream, but possibly it was the moisturizing, since dry, itchy skin can trigger symptoms.

Patients' Perspectives

Part 2: Partnering with Doctors

How to approach a doctor without RLS experience

A. Personalities

- No doctor knows everything
- Doctors are people too
 - They have good and bad days
 - Their personality may not mesh well with yours
- Be knowledgeable yourself!
- Most doctors genuinely want what is best for their patients
- Some doctors are not willing to learn from patients

most of us have had to explain some aspect of RLS to a health care professional at some point, because they didn't know

maybe we've had to explain what augmentation is
or that RLS is not just about the legs, despite the name.
we've struggled to convey just how disruptive the disease is

It can be frustrating, can drive us to despair, when our doctor doesn't understand the fundamentals

PERSONALITIES The first thing we should realize in approaching a doctor who doesn't know enough about our disease is that

No doctor knows everything - it's not humanly possible. Your doctor's lack of knowledge about WED/RLS is not a reflection of his competence.

Think of your doctor as a respected colleague. Not a god. And not someone who's out to get you.

Doctors have good and bad days, and they come in multiple flavors – of personality. Some of those flavors might not agree with you. If your personality don't mesh with your doctors', it can be hard to work together.

It helps if you're as knowledgeable as possible yourself.

But no matter what you do, some doctors are **simply not willing** to learn from anyone without medical training. Most doctors, genuinely want what's best for their patients.

The fact that so many patients are tortured by augmentation is not an indication that our doctors want to torture us. It is a sad commentary on how slowly knowledge diffuses through the medical system.

So let's cover BEFORE, During, and After an appointment.

Part 2: Partnering with Doctors

How to approach a doctor without RLS experience

B. Before the Appointment

1. **Write down the purpose of your visit** - *pick the problem that is most important;*

describe your symptoms and their impact on your life; and
what you want done about it !

EXAMPLE

Problem: My treatment is not effective anymore

Symptoms: I feel horrible sensations in my legs and arms that I can't even describe. I cannot sleep

Impact: I can't think clearly and I make poor decisions. My productivity at work has gone way down

Goal: To get treatment that will stop the sensations and allow me to sleep well enough to return some quality of life

It's always best to prepare for an appt. First,

Write down the purpose of your visit –

don't try to cover everything in one visit, there won't be time. Pick the problem that is most important –

be sure you

describe your symptoms and their impact on your life; and

write down what you want done about it !

Let's say your treatment for RLS symptoms is not effective anymore.

You can write: I feel horrible sensations in my legs and arms that I can't even describe. It starts every day right after work, and it goes on all night. I want to sleep, but I have to stand up and walk around. I never get a break and I'm exhausted.

or whatever is true in your case. Those are the symptoms.

Now write the impact: Maybe: I've become stupid. I can't think clearly and I make poor decisions. My husband's impatient with me. My productivity at work has gone way down. I'm afraid I might be fired!

Then for your sake as much as the doctor's, write down what the Goal of your appointment is: For example: To get treatment that will stop the unbearable sensations and allow me to sleep thru the night **and get back some** quality of life.

It might seem obvious that that's your goal, but at the end of an appointment, it will be good to ask yourself, **has something been proposed that will help** me achieve that goal? **DID I GET WHAT I CAME FOR?**

Part 2: Partnering with Doctors

B. Before the Appointment (continued)

2. Carefully select printed information to bring.

EXAMPLE:

- You're augmenting.
- You suspect your doctor will recommend a dose increase.
- You're already at 1 mg pramipexole (2x recommended max. dose)

PRINT:

- Management of RLS: Updated Algorithm (download free: mayoclinicproceedings.org)

3. Highlight what you want your doctor to know (*only the most important!*)

4. Practice summarizing the highlighted points



There are many useful brochures in the members section of the RLS Foundation website www.rls.org

The second part of preparation, BEFORE an appt, you don't always have to do this, but if your doctor is ignorant of WED/RLS, doesn't know about augmentation, isn't aware that iron therapy is a front-line treatment, any of those things-

then you should Carefully **select some literature** to bring.

I'll give you a list of the most useful publications in a bit

FOR EXAMPLE: Let's say you're augmenting but your doctor has never heard of augmentation. You're pretty sure he'll recommend an increase in your pramipexole dosage, and you're already at 1 mg – which you know is twice the recommended max daily dose

The best paper to print would be this one

called **The Management of Restless Legs Syndrome: An Updated Algorithm**, published this year

It's available for free, thanks to the Foundation

Ideally, you would read it yourself.

Or at least the parts that address your situation.
and then go thru it with a highlighter
In this case, there's a table where you would highlight *the max daily dose of pram is .5 mg- half*

And HERE, highlight *a description of augmentation*:

“The single and by far most common problem [with using dopamine agonists] is disease augmentation – which is ONSET of RLS symptoms earlier in the day, spread of symptoms to the arms, etc.”

And you would **highlight this**:

The risk of augmentation is dose dependent, thus the great importance of not exceeding recommended max doses.

If possible, you should be ready to summarize each point. Practice summarising each point out loud.

Part 2: Dealing with Doctors

B. Before the Appointment (continued)

xi- the day (typically at least 2 h earlier) and return sooner after
with taking the medication and may spread to other parts of the
en- body. With time, the RLS symptoms can become extremely
np- severe, causing severe insomnia and preventing the patient
rm from remaining sedentary for more than a few minutes.
om Increasing the medication provides relief for weeks or
07] months, but ultimately just “adds fuel to the fire,” which

Using a quote from an authoritative source can help your doctor understand the devastating impact on your life.

From Buchfuhrer, 2012, Neurotherapeutics

There are many useful brochures in the members section of the RLS Foundation website www.rls.org

Sometimes we have trouble describing the effects of WED/RLS on our lives.

Using a quote from an authoritative source can help your doctor understand.
Like this one: ”

With time, the RLS symptoms can become extremely severe, causing severe insomnia and preventing the patient from remaining sedentary for more than a few minutes.”

preveneting the patient from being still for mor than a few minutes!

From doctor to doctor – maybe it will have more impact.

Part 2: Partnering with Doctors

B. Before the Appointment (continued)

The Big Four –Literature for your Doctor

1. The 2021 Updated Algorithm paper
"The Management of Restless Legs Syndrome: An Updated Algorithm", free at mayoclinicproceedings.org
2. The little blue book
"Clinical Management of Restless Legs Syndrome" 2nd edition, by Lee & others, about \$US 30
3. The 2018 consensus paper on opioids
"The Appropriate Use of Opioids in the Treatment of Refractory Restless Legs Syndrome", free at mayoclinicproceedings.org
4. The 2018 consensus paper on iron
"Evidence-based and consensus clinical practice guidelines for the iron treatment of restless legs syndrome/Willis-Ekbom disease in adults and children", free at www.sciencedirect.com/journal/sleep-medicine vol 41)

Here are four important pieces of WED/RLS literature. **Any one of them** is a good thing to give to **any doctor** who **seems willing to learn**.

ONE a copy of the Updated Algorithm that I already mentioned

TWO a copy of the little blue book, It's a bit dated now, but still a wonderful reference for patients **and** doctors. **It costs** about \$30, **but if you give** one of those to your doctor, **it will help not only** you but also her other patients.

THIRD the **consensus paper on opioids** in treating RLS – also available for free from the Mayo Clinic

and FOURTH the consensus **paper on iron treatment** of RLS – available free from the journal sleep medicine.

These are publications you should become familiar with, if you have enough energy to, because you might need to know them well enough to share with your physician some day.

Part 2: Partnering with Doctors

How to approach a doctor without RLS experience

C. At the Appointment

1. Review your purpose, your symptoms & their impact. "Can I review my symptoms with you?"
2. Share your printed information: "Can I get your opinion of this?"
 - *Don't start off with "I found this on the Internet" !*
 - Let her see the title page
 - Open to your first highlight – either summarize or let her read
 - Move her to the next highlight
 - Sit back and wait for her opinion

DURING the appt. FIRST. Review your purpose – **Describe your symptoms & their impact** - **read your written summary** if you have to, to be sure you get that message across

don't assume that your doctor knows this already. **Refresh her memory .**

Just say ““Can I review my symptoms with you?”

SECOND Share your printed information – **don't leave this** for the end!

NOW, There are ways to share information - -

–**don't start off with** “ I found this on the internet” Your doctor is going to want to know that it came from an authoritative source.

– **don't think in your head** “You should know this already” because -
- as we've said, no doctor can know **the ins and outs of every** disease.

instead, Ask “Can I get your opinion on **something?**”

Show her the title page **so she can see it's from a reliable source**

Open to your first highlight, and either summarize it - like you practiced - or let her read it

Move to your next highlight. And so on.
sit back and wait for her opinion.

Part 2: Partnering with Doctors

How to approach a doctor without RLS experience

C. At the Appointment (continued)

3. Don't expect her to read it all right there.
4. Offer her the printout. "I printed this copy for you"
- Before you leave:
 5. Refer back to your Goal – what has she suggested to help achieve it?
 6. Were all of your questions answered?
 7. Ask for a follow-up appointment

3. She won't have time to read it all right there.
4. So Offer her the print-out to keep.

So, After you've gone over the information together,
and gone over her suggestions together, then

,5. REFER BACK TO YOUR GOAL. – Remember I told you to write it
down? Well, refer to that. And think:

what has she suggested to help achieve my goal?

Were all of my questions answered?

6. FINALLY make sure you get a follow-up appointment .**You'll need to review** the effectiveness of her suggestions.

We might have difficulty, if we have the idea that WE're suggesting changes
when it's the DOCTOR's job to do so.

That's why we DON'T recommend that you suggest changes. We only
recommend that you **provide access to the information** your doctor needs.

Then she'll **make a decision** about what to suggest

Part 2: Partnering with Doctors

How to approach a doctor without RLS experience

D. How to Bring up Opioids

- Don't ask for opioids. It is best to let your doctor bring it up
- Make sure your doctor understands your symptoms and their impact on your life
- Have a copy of the **consensus paper on opioids**
 - Highlight beforehand
 - Share as we discussed "Can I get your opinion on this?"
- Wait for his opinion.
- Remind him of your symptoms. "How will we get control of my symptoms?"
- Try what he suggests, if you can

The general approach we just outlined also applies to discussing opioids with your doctor, but

there are added concerns with opioids.

, because even doctors can have a gut-level reaction to the word.

Many of us have learned that opioids might give us a better quality of life, but we don't want to come across as addicts or our doctors aren't willing to prescribe.

First - as we've said - don't ask for opioids, or anything. It is best to let your doctor bring it up , after you've presented him with the right information.

Part of that info is your symptoms - make sure he understands your symptoms and their impact on your life, (which is why it's so important to have that stuff written down)

Second have a copy of the **consensus paper on Opioids in RLS** . that was on the Big Four slide

Share this paper in the way we've already discussed - **make highlights before the appointment, ask if you can get his opinion on it**

Then wait for his opinion.

If after all that he says that he won't consider opioids, ask him **"How will we get control of my symptoms? What do you suggest?"**. The idea here is to remind him of your symptoms and the impact they're having on your life. It is his job, as your doctor, to try to alleviate this suffering.

Then, **Try what he suggests**, if you can. **Maybe his suggestion will work**, even if it's not what you had in mind. **Or maybe that's what it takes** to convince him that you need a different kind of help.

Part 2: Partnering with Doctors

Finding a new doctor

When to find a new doctor

- If you can't function like a normal human being & your doctor hasn't been able to help
- If your doctor is unwilling to learn. This is usually obvious:
 - she won't even look at the material you bring
 - she shuts you down when you've just begun to speak
 - you ask her "Are you willing to learn about this with me?" and she says no
- Continue working with your current doc, but start the steps to find a new one

Sad to say

At some point a lot of us realize that we need a different doctor.

One who knows or is willing to learn more about WED/RLS.

You know you need a new doctor if

you can't function like a normal human being

and even though you've described it every way you can,
your doctor still can't recognize the severity of the impact on
your QoL,

or **she recognizes it** but is **unable** to improve your QoL,

you also need a new doctor **if your current doctor** has made it clear
that **she's unwilling to learn**. This is usually obvious, but some signs
are:

she won't even look at the material you bring;

she shuts you down when you've just begun to speak;

you outright ask her "Are you willing to learn about this
with me?" and she says no.

Even as you're working with your current doc, start the steps to
find a new one. IF any of that applies to you.

Part 2: Partnering with Doctors

Finding a new doctor

What type of doctor do you need?

- Neurologists specializing in movement disorders
- Sleep specialists (who might also be psychiatrists or pulmonologists)
- Primary care providers (because anyone who is interested can learn about RLS)

You are seeking:

- Someone knowledgeable & experienced or
- Someone willing to learn

What type of doctor do you need? (1 slide)

It's true that WED/RLS is treated by:

- Neurologists specializing in movement disorders (because RLS is a movement disorder)
- It's also treated by Psychiatrists or Pulmonologists who've become sleep specialists (due to the prevalence of breathing and psychiatric issues in sleep medicine)
- It's also treated by Primary care providers in general medicine or internal medicine (because anyone who is interested can learn about WED/RLS)

Although a neurologist or sleep specialist ought to know the most, or at least be willing to learn, that's not always the case. The speciality doesn't really matter. What matters is, You are seeking

- Someone knowledgeable & experienced; or Barring that,
- someone willing to learn. That's the main criterion.

Part 2: Partnering with Doctors

Finding an RLS-savvy Doctor

1. Check if an RLS Quality Care Center is nearby www.rls.org
2. Check the RLS Foundation's list of Healthcare Providers
3. Ask members of an RLS Support Group or the RLS Discussion Board for recommendations
4. Check the Neurology department of the nearest major medical school
5. Call local neurologists who accept your insurance. Ask to speak with a nurse:
 - Does your doctor treat many RLS patients?
 - ... have experience treating augmentation?
 - ... prescribe opioids for chronic conditions?
 - Can you recommend another doctor in the area?
6. If there is a sleep clinic or sleep study center near you, call and ask their nurses the same questions
7. Call all primary care providers in your area and ask their nurses the same questions
8. Move

See the article by Steve in Nightwalkers, Spring 2018, p12

Finding a doctor (1 slide)

Steve wrote a wonderful little article in Nightwalkers, that's the Foundation's magazine for members. Steve's article is in the Spring 2018 edition– and I encourage you to look there, it's a good, personalized summary of his experiences in finding new doctors.

Basically this is what we've come up with

1. The ideal place to look is at an **RLS QCC** – These are certified by the Foundation. The CCs have to go thru an approvals process, convincing RLS specialists that they're capable of treating refractory, augmented RLS, and not just plain easy RLS. **So that's your best bet.**
- 2 If there's no QCC near you, **the Foundation** also maintains a list of providers **who have described themselves as knowledgeable** and asked to be on the list. This list isn't vetted – that is, the Foundation makes sure the providers have the certifications they say, but not that they are competent in WED/RLS care
- 3 You can also ask other patients for recommendations.
- 4 **One of the best ways - other than a QCC - is to look for Medical schools with teaching hospitals –**

You would Contact the **neurology dept or the sleep medicine** department.

The young practitioners at these schools are more likely to have received some training in RLS

so there might not be as much of a learning curve as with older professionals. Not always the case, tho.

5 If there's no medical school nearby, Call **all** the neurologists in your area.

We recommend that At each one, ask to speak with a nurse.

Ask the nurse if the doctor treats many WED/RLS patients

Does she treat refractory RLS?

What about augmented RLS?

Is she comfortable prescribing opioids for chronic conditions - - - like severe refractory RLS?

The nurses can be very candid and can save you lots of time. You can even ask a nurse for a recommendation for another doctor or clinic

6 If there's a sleep clinic nearby, call and ask their nurses the same questions.

Finally, Call all primary care providers in your area. and ask their nurses the same questions.

It can be a lot of work to do this. But balance that against how much more energy you'll have when your RLS is treated properly. It can be night and day. It is worth every effort to get the right treatment. Yes it costs a lot, in time, energy, and often in money, but getting the right doctor **can give you your life back.** What's that worth?

People have uprooted themselves and moved across the country to be near a good provider. I travelled 2,400 miles for one iron infusion. I have no regrets.

Best of luck in your efforts to find effective treatment !

Thank you to:

- The members of the Discussion Board, who have poured out their misery, frustration, experimentation, & successes over the years; it is largely their information we have shared today
- Our fellow moderators, Betty Rankin and Ann Battenfield
- The RLS Foundation for providing this opportunity to speak

Contact us: Beth.RLSFmod@gmail.com, Stephen.RLSFmod@gmail.com

Chat with us on the RLS Discussion Board: bb.rls.org

So we hope you've gotten some ideas from us today,

and we'd like to thank – all of you who post on the Discussion Board, for sharing so much of yourselves over the years... == it is largely your information that we've shared today

thanks also to our fellow moderators on the discussion board

and to the Foundation.

We welcome questions any time – you can see our email addresses there, or drop by the Disc Board

Thank you.