



# **Southern California WED/RLS Support Group**

under the auspices of the

## **Willis-Ekbom Disease Foundation**

In search of a good night's sleep

(Formerly known as the RLS  
Foundation)



# April 6, 2014

## Agenda

- **1:00 Welcome by Support Group Leader, Susan Schlichting**
- **1:10 RLS Basics**
- **1:30 Breakout Groups led by Mary Jo Enyeart**
  - **Groundrules and Introductions**
  - **Topical discussion**
  - **Develop questions for Dr. B.**
- **2:15 Break/Refreshments**
- **2:30 Q & A led by Dr. Buchfuhrer**
- **3:30 Adjourn**



# Sign in

- **Sign in table (Jim Crawford)**
- **Upon sign-in, each guest receives:**
  - **Agenda** for today's meeting
  - **Index card** for writing questions to ask Dr. Buchfuhrer
  - **Medical Alert Card**, developed by Dr. Buchfuhrer, which should be completed and shown to your health providers. Keep it with you, especially if you require hospitalization.



# Nature of Support Group

- **Made up of people directly affected by WED/RLS and their caregivers, friends and family**
- **Made up of volunteers and a medical advisor**
- **Not a therapy group or a 12-step program; purpose is to educate, share information and offer mutual support**
- **Attendance is voluntary.**



# Nature of Support Group

- **Minutes of all past meetings are on the So Ca RLS Support Group website: [www.rls-help.org](http://www.rls-help.org)**
- **Frequency of meetings – Twice annually**
- **Interest in carpooling**
- **Refreshments**
  - **Limited resources**
  - **Today's refreshments were donated by local volunteers**
  - **Your donation to cover costs sincerely appreciated**



# **Membership in WED Foundation**

- **Goals: Increase awareness, improve treatments and fund research to find a cure.**
- **Nightwalkers Newsletter – 4 issues/year**
- **Discussion board/chat group**
- **Membership is \$30 – \$5 discount if you join now.**
- **[www.rls-help.org](http://www.rls-help.org)**

# **2013 Patient Odyssey survey**

- 73% of patients report having symptoms daily.**
- Only 6 % say that their symptoms are completely controlled by their current medications.**



# RLS Basics

Questions





# Quiz

- **1. According to the National Institute of Neurological Disorders and Stroke, what % of the population may have RLS?**
  - a. 2
  - b. 3
  - c. 5
  - d. 10

# Quiz

- **2. About what % of the people with RLS experience a more common condition known as PLMS (periodic limb movement of sleep)?**
  - a. 10 - 15
  - b. 25 - 30
  - c. 50
  - d. 80 - 85



# Quiz

## True or False

- **3. Most people with PLMS experience RLS.**
- **4. People with PLMS that do not have RLS respond to similar treatments.**
- **5. Individuals with Parkinson's Disease often have RLS as well.**
- **6. Parkinson's Disease and RLS are both disorders related to dopamine.**



# Quiz

- **7. RLS appears to be related to certain chronic diseases (although researchers do not yet know whether such diseases actually cause RLS). Which one of the following diseases does NOT appear to be related to RLS?**
  - a. Kidney failure**
  - b. Diabetes**
  - c. Cancer**
  - d. Peripheral Neuropathy**



# Quiz

- **8. Which of the following are NOT one of the four criteria for diagnosing RLS?**
  - a. Symptoms worsen at night
  - b. Strong and overwhelming need or urge to move the affected limbs
  - c. Muscle cramps
  - d. Triggered by rest, relaxation or sleep
  - e. Relieved with movement



# Quiz

- **9. Which of the following is NOT a reason why some people with RLS avoid seeking medical attention:**
  - a. They believe that they will need surgery.**
  - b. They believe that their symptoms are too mild.**
  - c. They believe that their symptoms are not treatable.**
  - d. They believe that they will not be taken seriously.**



# Bonus Question

- **10. For people with RLS, a visit to the hospital can be especially stressful. Several things can go wrong if the hospital isn't fully aware of your drug sensitivities and medication schedule. Which of the following is NOT true:**
  - a. During surgery, your legs could move involuntarily, potentially interfering with a procedure.**
  - b. Pre- or post-surgery, the anesthesiologist could give you anti-nausea drugs that worsen your symptoms.**
  - c. If you are given Benadryl as a sleep aid, it will likely calm your need to move.**
  - d. If you experience breakthrough symptoms, your need for medication may be ignored or overlooked.**



# RLS Basics

Answers





# Quiz

- **1. According to the National Institute of Neurological Disorders and Stroke, what % of the population may have RLS?**
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# Quiz

## True or False

- **3. Most people with PLMS experience RLS.**  
*False.*



# Quiz

## True or False

- **4. People with PLMS that do not have RLS respond to similar treatments. *True***



# Quiz

## True or False

5. Individuals with Parkinson's Disease often have RLS as well. ***True. Twice the amount of PD patients have RLS than in the general population. (20% compared to 10% in the general population.)***

# Quiz

## True or False

- **6. Parkinson's Disease and RLS are both disorders related to dopamine. *True.***  
*Although PD and RLS both respond to dopamine, they are quite different in that PD patients have very low dopamine levels and high iron levels in their brains while the opposite is true for RLS.*



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# **Breakout Groups (Mary Jo Enyeart)**

- **Break out into smaller groups**
- **Introduce yourselves to one another: state your names and a little bit about why you were interested in coming today.**
- **Discuss the topics and report out.**
- **Before break, table captains from each of the groups collect questions for Dr. Buchfuhrer's Q&A and give them to Mary Jo, Jim or Susan.**



# Breakout Groups

## Ground Rules

- **Turn off your cell phone or put it on vibrate – step out of the room if you must answer it.**
- **Everything discussed in the group must be kept confidential.**
- **Make sure that each person has a chance to speak and that each person is heard.**
- **Only one conversation at a time.**
- **Don't interrupt. If you think of a comment or question while someone else is speaking, wait your turn. You can write it down so you don't forget.**

# Break out Topic

- **How does RLS affect your quality of life?**

# Break out Topic

- **What ideas have helped you cope?**



# Break/Refreshments

- **If there is anyone interested in volunteering for future support group meetings, please see Susan, Mary Jo or Jim after today's program. We need help with hospitality, publicity, membership or general assistance during the meetings.**
- **Dr. Buchfuhrer will be joining us starting at 2:30.**



# Q & A

- **Led by Mark J Buchfuhrer, MD, FRCP(C), FCCP, FASSM**





# Wrap Up

- **Next meeting is October 5th. Save the date!**
- **Attendees will be notified by email. If you don't have an email address or prefer a post office mailing, please send Susan a self-addressed stamped envelope.**
- **Special thank you to Mary Jo Enyeart, Jim Crawford and Juanita Wilson.**
- **Thank you for coming.**