



Southern California RLS Support Group

under the auspices of the

RLS Foundation

In search of a good night's sleep



October 2018 Agenda

- **1:00 Welcome and Announcements**
- **1:15 Various Topics, including Support Group Input Survey and Highlights from the RLS Patient Symposium**
- **2:00 Special Presentation: “Medications: Dopamine Agonists, Impulse Control Disorder, Augmentation and Alpha-2-Delta Ligands”, Speaker: Mark Buchfuhrer, M.D.**
- **3:15 Adjourn**



Nature of Support Group Should We Change or Supplement It?

Current Model:

- **People directly affected by RLS and their caregivers, friends and family**
- **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: Details

- **Limited resources: Foundation reimbursement limited to \$100/year**
 - In the past, venues were provided at no cost, some had parking fees
 - Refreshments were donated by SGLs, costs defrayed by attendees
- **The Montecito Center charges \$30/hr, \$90 for the afternoon: how would you feel about paying an admission fee?**



Nature of Support Group Revisited

- **We currently meet twice a year**
 - **Should it be more frequent?**
 - **If so, would an informal arrangement without a medical advisor be satisfactory, e.g. meeting at a restaurant where reservations may be necessary?**
 - **Other ideas? Please fill out the survey**



Membership in RLS Foundation

- **Goals: Increase awareness, improve treatments and find a cure**
- **Nightwalkers Newsletter – four issues/year; access to archives, including webinars**
- **Discussion board/chat group**
- **www.rls.org (Our minutes are at rlshelp.org)**
- **\$35 Membership fee; Funding needed NOW (more about that in Symposium Highlights)**



RLS Patient Symposium

- **First symposium held in over ten years**
 - **Big Pharma sponsorship virtually eliminated due to settlement over off-label marketing**
 - **Karla Dzienkowski, RN, BSN, Exec Director: “already working on another one on the East Coast”**
- **Held in La Jolla at Scripps Green Hospital over one and a half days**
 - **Presentations by clinical and research experts**



From the RLS Foundation Executive Director...

- **Discussion Board/Chat Room at bb.rls.org is often untapped resource for assistance**
- **New series of webinars for Physicians Only for doctors who want to learn more about RLS**
- **Use RLS Symptoms Diary and Doctor Visit Expectations to prepare prior to exam**



Karla's remarks (continued)

- **Urged to participate in the National RLS Opioid Registry if you are currently taking an opioid**
 - **Phone interview and brief online survey with info stored anonymously to gather data**
 - **John Winkelman, MD, PhD, Massachusetts General Hospital**
 - **Contact:** Julia Purks, (617) 643-2082 or email RLSregistry@partners.org
 - Visit:** www.massgeneral.org/rls-registry



RLS Patient Symposium

- **Just because you've tried a medicine before and did not get a response does not mean that this medicine will not work to treat your RLS**
- **We have made major strides in RLS compared with Parkinson's, ALS and Alzheimer's (Christopher Early, Johns Hopkins)**



RLS Patient Symposium

- **Sleep study is often recommended even after RLS diagnosis is made because many patients also suffer from sleep apnea.**
 - **Most telling part of sleep study may be what patients do in non-sleep hours (crawling, pacing, etc.**
- **RLS Severity Scale (0-40) is a rating scale used by several doctors.**
- **Circadian nature of disease is still not understood.**



RLS Patient Symposium

Drugs that show promise?

- **Dipyridamole (treats peripheral arterial disease) off label – promising studies**
- **Ecopipam – small trial treating augmentation funded by the Foundation (Wm. Ondo, M.D.)**
- **Buprenorphine is a newer opioid. Taken sublingually; easily cut into smaller doses; less respiratory depression; withdrawal may be less severe**



RLS Patient Symposium: Alternate therapy issues

- **Newly-identified triggers: Melatonin can worsen RLS (inhibits secretion of dopamine); also St. John's Wort**
- **Magnesium glycinate may be helpful for pain**



RLS Patient Symposium

Drugs that show promise?

- **Dipyridamole (treats peripheral arterial disease) off label – promising studies**
- **Ecopipam – small trial treating augmentation funded by the Foundation (Wm. Ondo, M.D.)**



RLS Patient Symposium

Cannabis-related

- **Startling revelation: content of THC in marijuana: was 7% in the 60's, now 20%**
- **Epidiolex, a non-synthetic form of CBD with THC less than 0.1% now approved for seizures, moved from schedule 1 to schedule 5 drug, dosage max. 10 mg two times daily.**
 - **First FDA-approved drug to contain a purified extract from the cannabis plant**



RLS Patient Symposium Cannabis-related

- **Bottom line: Majority of doctors present at the Symposium expressed reservations about the addition of cannabis to regular meds**
 - **They emphasized getting these products from reputable dealers/dispensaries. “Go low and slow.”**



RLS Patient Symposium

Iron Therapy

- **Over 13 research studies have shown brain iron deficiency in RLS patients**
 - **Ferritin level used as measure of iron status**
 - **Less iron equals more leg movements on MRIs and Ultrasound**
- **“Evidence-based and consensus clinical practice guidelines for the iron treatment of restless legs syndrome/Willis-Ekbom disease in adults and children: IRLSSG task force report published in Sleep Medicine journal (4 authors present at Symposium)**



RLS Patient Symposium

Iron Therapy

- **Hemoglobin, not serum ferritin, may function as a systemic predictor for brain iron uptake**
- **Hemoglobin (< or = to 11 g/dL) is a predictor of RLS when pregnant**
- **All the following (fasting!) tests should be taken to measure brain iron deficiency: ferritin, iron, TIBC and transferrin saturation**



RLS Patient Symposium

Iron Therapy

- **Ferritin testing in AM after at least 12 hours of fasting; having a cold, etc., may elevate levels**
- **Trying to push ferritin level to upper 300s; repeat IVs as needed; some patients getting 1-2 years of relief from symptoms; works in about 60% of those treated**
- **Not officially approved by FDA for RLS treatment**



RLS Patient Symposium

- **To help cover ferritin blood test for insurance, use Diagnostic Code E83.10 Iron Disorder**
- **Use physician-recommended oral iron with 100 mg Vitamin C once daily for twelve weeks before considering IV iron therapy**
- **Oral iron supplements: Ferroglycine sulfate (better tolerated) vs Heme iron**



RLS Patient Symposium

- **Limited effectiveness from oral iron supplements because they are not well absorbed and do not cross the blood brain barrier**



RLS Patient Symposium

- **Certain compounds (iron gluconate & iron sucrose) are not recommended for IV iron therapy, nor is premedicating (R. Allen)**
- **It can take from four weeks to two months for a response from IV iron**
- **Undergoing IV iron therapy doesn't necessarily eliminate meds but can reduce the need for them**



RLS Patient Symposium

- **Most hematologists are unfamiliar with IV iron infusions for RLS**
- **For oral iron, take at least one hour before or two hours after food. Especially zinc and calcium block iron absorption.**
- **Zantac can disrupt oral iron absorption**



RLS Patient Symposium

- **Iron patch (e.g.PatchMD) doesn't make sense as there are no transporters for it (C.Earley**
- **Similar low blood iron levels in RLS are found in Migraine, Ataxia and Alopecia patients**
- **In order to go off any Dopamine Agonist (DA), you need to go drug free for a minimum of 12 days after tapering (C. Earley, Johns Hopkins)**



RLS Patient Symposium

- **RLS fits the definition for pain in Merriam-Webster dictionary**
- **Methadone is FDA approved for Chronic Pain Syndrome**
- **Muscle relaxants can make you sedated while worsening RLS; however, Baclophen has helped one patient with fibromyalgia (C. Earley)**



RLS Patient Symposium

- **Airplane-like walkway lighting available for the home**
- **CBTi app (free) is a good insomnia coach**
- **Try office chair vibrator on Amazon**
- **Pneumatic Compression Devices good for kids, too!**
- **All experts agreed that they were unaware of any practices that use telemedicine for RLS**



RLS Patient Symposium

- **In terms of frequency in various ethnic populations, blue-eyed French Canadians have highest frequency, slightly lower in Asians. Well-known study found less than 1% in Nigerians. Iron in diet may have impact. In general, more prevalent in Northern Europeans, decreasing in Mediterranean with African continent lowest.**
- **23andme incorporates questions on RLS**



RLS Patient Symposium: RLS Foundation Needs Funding!

- **Plea from Lew Phelps, RLS Foundation Board Chair: We need your donations!**
- **Lobbying firm in D.C. tasked with Opioid Advocacy –funding dries up after December**
 - **Need \$50K more for another year**
- **Direct mailing lists for membership building**
 - **Need more \$ to purchase**
- **Consider tax advantages for 401k with MRD's**



Break

**Refreshments and
Networking**

Please return by 2 PM



Presentation

**“Medications: Dopamine Agonists,
Impulse Control Disorder,
Augmentation and Alpha-2-Delta
Ligands”**

Mark Buchfuhrer, M.D.



Questions for Dr B

- **Each table has at least one index card per person for writing questions for Dr. Buchfuhrer**



Meeting Adjourns

- **Please help us clear the building by 3:15**
- **Next meeting: Currently planned for April 2019 - Attendees will be notified by email so for those who are new, please ensure that we have your email address. If you don't have an email address or prefer a post office mailing, please send Mary Cuseo a self-addressed stamped envelope.**



Backup Slides *(or If There's Time)*



Breakout Groups

- **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 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?**