

PainPathways Magazine Magazine FB Chat: Sleep Insights For Those With Fibromyalgia or Chronic Pain

*Transcripts highlights from Facebook chat
hosted by Dr. Rosenfeld: and Rae Marie Gleason on April 29,
2015*

Welcome! Thank you for joining us today for “Sleep Insights for Those with Fibromyalgia or Chronic Pain.” This Facebook chat will be hosted by Dr. Victor W. Rosenfeld and will cover topics such as:

- common sleep issues for Fibromyalgia sufferers
- recommendations for getting better sleep
- managing symptoms and sleep
- And more



Dr. Rosenfeld: is Board Certified in Neurology and Sleep Medicine. He is currently Neurology Department Head and Medical Director of the Sleep Center at SouthCoast Health in Savannah, Georgia.

He has numerous medical Sleep Medicine, Sleep Electrophysiology, Migraine, Neuro-Oncology, Huntington's Disease, Guillain-Barre Syndrome, and Fibromyalgia and is a frequent medical lecturer on a broad range of disease states including Sleep Apnea, Restless Legs, Narcolepsy, Fibromyalgia, Alzheimer's, Epilepsy, Neuro-virology, and Migraine, Chronic Fatigue, Stroke, Ataxia, Neuroendocrinology, Neurotoxicology, and Insomnia. His current research interests include Chronic Pain and Fatigue and their relationship to sleep.



Rae Marie Gleason is also on the chat tonight. Rae is the Medical Education and Research Director at the National Fibromyalgia & Chronic Pain Association. She has 25 years of experience in the Fibromyalgia advocacy and research field. She will also be answering your questions.

Now, please join us in welcoming Dr. Victor Rosenfeld and Rae Gleason!

Dr. Rosenfeld: Hello everyone and welcome!

Rae NFMCPA: Hello Everyone! So glad we are all together to learn more about sleep and fibromyalgia from Dr. Rosenfeld.

Jodi: Thank you Dr. Rosenfeld: for coming and participating in a Facebook chat on the importance of sleep when living with chronic pain. I have Full Body RSD/CRPS for over 25 years and have had problems with sleep. I'm looking forward to reading and learning new ideas that might help me with getting the

Yvonne: I have FM and I use a C-pap. Question is how often should I be retested for a setting change if any for my machine?

Dr. Rosenfeld: Good question, Sleep Apnea (OSA) is seen in almost half of the patients I treat with FMS. However, treatment is based on severity. I only recommend CPAP in severe cases (AHI >30). In mild (5-15) and moderate (15-30), I recommend an Oral Appliance made by a dentist with knowledge in the area. For CPAP users a recheck every 5 yrs. is appropriate or earlier if there has been significant weight gain or loss.

Cindy: I would like to know about any breakthroughs made in the research of fibromyalgia. Is there any chance of finding a cure?

Dr. Rosenfeld: Yes, actually I just had some original research published in the Journal of Clinical Neurophysiology looking at sleep dysfunction in FMS. I found that many patients with FMS have Sleep Apnea. Also using qEEG we were able to identify patients with FMS.

Dr. Rosenfeld: Alpha intrusions were seen during sleep in folks with FMS a kind of awake like brain frequency. This may answer why folks with FMS do not have restful sleep and why they are so fatigued.

Terri: I can't recall if it was my sleep study or the EEG but I was told that this was the case with me, that my brain literally never shuts down and takes any quiet time Plus I do the whole sleep walking/talking, acting my dreams out stuff

Cheryl: Turning in bed is so painful at night I must wake to turn because I have chronic migraines also, I am told to only use NASIDS 3 times a week. I use no narcotics, or sleeping pills. I do use icy hot type products & rice socks. Any other suggestions? Would it be OK in your option if I took a NASID Nightly for help in controlling of my Fibromyalgia pain? Any suggestions?

Dr. Rosenfeld: Chronic pain can interfere with sleep, so a medication which helps with both pain and sleep should be considered. Also if one is having more than 4 migraines a month, the American Headache Association strongly recommends a preventative medication taken daily to reduce the frequency of the headaches. It sounds like a tricyclic like Elavil (amitriptyline) 25-50 mg could help sleep, pain, and act as a migraine preventative. No, taking NSAIDS daily is bad as it is bad for the kidney, stomach and promotes analgesic rebound.

Dr. Rosenfeld: This may open the avenue to focus on the sleep part of FMS not only to test for the condition but also as a key area for treatment

Chris: Are narcolepsy and fibro related somehow? I have been diagnosed with both. It's next to impossible to get a restful night's sleep.

Dr. Rosenfeld: Yes, there is a higher incidence of Narcolepsy and Idiopathic Hypersomnia in patients with FMS based on my research as well as a high prevalence of chronic pain in patients with Narcolepsy. One of the best medicines for Narcolepsy is Xyrem (Sodium Oxybate), which is actually a SLEEP medicine, and in a handful of folks can be life changing. It improves deep sleep and fatigue as well and was studied in FMS, of which I was one of the principal investigators. The data showed that it improved pain, fatigue, and sleep complaints, as well if not better than the three currently FDA approved medicines for FMS. Unfortunately the FDA scientific panel which acknowledged the superiority of the data turfed it to a "advisory panel" with little to no scientific expertise at all, some admitted not even reading the study, and so did not get its FDA approval. And so because of the horrific stupidity of the FDA, millions of fibromyalgia sufferers lack access to probably the most powerful medicine out there. But if you happen to have Narcolepsy, for which it is actually approved, I would strongly recommend a trial.

Carol: Does everyone with fibromyalgia have sleep problems? What is the connection?

Dr. Rosenfeld: Sleep is actually a critical part of FMS and was part of the original description of the condition called "Neurasthenia". My research and those of others has showed that the deep sleep dysfunction is probably a primary cause of the condition or at least a significant contributor. As mentioned this problem, alpha wave intrusions can now be tested. And there are also some experimental therapies for it.

Dr. Rosenfeld: as a follow up to Carols' question in a study of over 2000 pts with FMS Sleep and Fatigue rated higher than pain as the most important issues in FMS

Bridge for Pelvic Pain: Have you found a hereditary link to FMS patients where either fibromyalgia occurs in the same family or one family member has FMS while other family members have other chronic pain conditions?

Rae NFMCPA: There is some really good work being done on genetics and FM at the University of North Carolina as well as some other research centers. There have been familial studies done as well that all point to a genetic predisposition to developing fibromyalgia. There is lots of work still to be done, but results of some of these studies are very positive.

Pat: How do you find a dentist who makes the oral appliance? Does it have a specific name? And also about Klonopin and Ativan.

Dr. Rosenfeld: Many dentists make oral appliances, which can be used for mild and moderate Sleep Apnea and usually are better tolerated than CPAP which is typically used for more severe cases. Getting them covered by either the medical or dental insurance can be a nightmare, however. I use a dentist Doug Smith in Savannah who actually bills the insurance.

In terms of Ativan and Klonopin, they can slightly interfere with deep sleep. Ativan is short about an hour and Klonopin is longer about 7 hrs. Xanax is in the middle. The advantage is they are very affordable and I prescribe them a ton because they help sleep and are affordable.

: Mine is an Oral Orthotic by [Dr. Demerjian](#) - I LOVE it, it helped changed my life for the better. Helped not only with TMJ but also dystonia, burning pain, balance/coordination, vision... I highly recommend his particular techniques for

PainPathways Magazine: We have lots of questions coming in and Dr. Rosenfeld: is answering as quickly as possible. Thanks for your patience.

Melissa: My fiber started as a severe sleep disorder. I now take a mixture of meds and sleep medicine to sleep at night. Is there anything in the future that will replace sleep medicine for those of us with a severe sleep disorder?

Dr. Rosenfeld: yes I was a principal investigator for a medicine trial called Sodium Oxybate, a very powerful sleep drug that was shown to improve sleep, pain, and fatigue. It is absolutely the best-known medicine for FMS in my opinion that is available.

Terri: I have Narcolepsy and FMS both, is there a correlation between the two (as it seems I have several friends that do as well)?

Dr. Rosenfeld: Yes more folks with FMS have Narcolepsy and vice versa compared to the general population. Also as mentioned in my last post, Sodium Oxybate, which is FDA approved for Narcolepsy is probably the most powerful drug available for Fibromyalgia

Sandra: I have been reading a lot about Ehlers Danslo Syndrome, especially type 3. It sounds like a lot like fibromyalgia but with the precise pathophysiology as to why one sees a systemic 'invasion' on the body. Could it be that fibro is u diagnosed EDS? Or do you think they really are different diseases?

NFMCPA Rae: Hello Sandra, Actually Ehlers Danlos syndrome is yet another condition that overlaps with fibromyalgia. FM is an overlapping condition with many other illnesses including Lupus, Arthritis, IBS, TMJ, and many other disorders. When FM accompanies other illnesses patients are usually more hampered by all of the disorders by the pain and other symptoms of FM.

Sandra: Thank you for addressing my question.

Nancy: Is restless leg syndrome often found in people with FMS?

Dr. Rosenfeld: Yes, about 30%-50% of patients with FMS have RLS. Interestingly dopamine agonists like Mirapex and benzos like Klonopin help RLS and a lot of folks with FMS too.

Terri: A very low dose 300 mg of gabapentin has helped with my RLS, on the

Jan: If someone has restless leg syndrome, are there medications that make that worse for sleeping?

Dr. Rosenfeld: Yes, Jan (and hello!) TCA's like Elavil or OTC sleep drugs like Benadryl can help sleep but will worsen RLS. Also Savella and Cymbalta which are SNRI's that help FMS pain can worsen RLS.

Lisa: I am wondering if cortisol plays a role in either the insomnia or unrefreshed sleep of fibromyalgia patients. And IF so, what is the cause of

elevated cortisol besides the obvious cause in many being stress. And how would one combat high cortisol if stress isn't the cause?

Dr. Rosenfeld: Very good question. Yes, elevated cortisol is associated with insomnia, chronic pain, and fatigue, and high stress type personalities. Cortisol has a circadian rhythm, usually around 20 in the morning and 10 in the evening. Sometimes in FMS early cortisol is high all the time, or the curve is reversed and later in the course the whole curve flattens to zero, "adrenal fatigue."

The stress response thru ACTH released by the Hypothalamus is what controls the cortisol response. So yes, lowering stress and learning better coping skills and strategies can help that. There are medications, steroid genesis inhibitors, such as mitotane, cyadren, or neuromodulatory agents such as Ocreatide or Bromocriptine that can blunt the Cortisol levels. More often than not, patients will come in at the adrenal fatigue point with low levels and I will try and boost them with adrenal support vitamins and extracts usually found at a high quality health food store.

In terms of testing one should get an AM and PM cortisol level and there are salivary type tests that will evaluate it over a 24-hour period. Also to round out the panel I usually check DHEA-sulfate.

Kelly: Is there any side effects from long term use of mid sleep medication such as Ambien? Also, how effective is taking melatonin (10mg) nightly for achieving deep sleep?

Dr. Rosenfeld: long-term use of most sedatives tend to worsen deep sleep and some interfere with REM sleep (most antidepressants). But if there is no sleep at all, that is even worse

Melatonin helps circadian rhythm (early bird/night owl) but not really the best sleep aid per se. Some folks who are very sensitive to medications may do better with melatonin. Dose ranges from 3 to 10 mg usually.

Regina: I'm currently taking Savella 100 mg 2x a day for my fibromyalgia and this drug works pretty good for me. I also have a Neurostimulator in my spine to help with the pain, do you think there will be any new medications developed for fibromyalgia that are not as expensive as Savella? I can't take Lyrica or Cymbalta.

Dr. Rosenfeld: no major trials for new classes of drugs are being looked out. Sodium Oxybate would be nice to have a FDA approval but right now it is

>\$5000 a month! There is some work in other countries on THC and derivatives which could translate into affordable therapies. Also gabapentinoids (Lyrica) and SNRIs (Cymbalta) are generic classes now. Tramadol is generic and a good pain killer that is generally safe.

Regina: Thank you for answering my question!!!

Gina: I'm definitely asking my doctor about a neurotransmitter for my chronic back pain this may be the thing I've been hoping for, I've lived with chronic severe pain for twenty years.

Angie: Have you found that people who have Fibromyalgia also grind and clench their teeth? That just makes my ability to sleep worse.

Dr. Rosenfeld: yes some do, muscle relaxants such as Flexaril and Klonopin work the best for this in my opinion

Dawn: what are your thoughts on fibro and lupus using medical marijuana and cbd oil to help.

NFMCPA Rae: Hi Dawn. There hasn't been enough scientific studies to know for certain if medical marijuana and CBD oil are successful in the treatment of fibromyalgia. However, reports from patient testimonies seem to point to some people getting a lot of relief from these sources. Since marijuana does not work on opioid receptors it has a different pain pathway in the body. Hopefully, someone, somewhere will do the studies needed to know for sure how these work on FM.

Teri: Is the Cortisol Testing something that a Doctor must order?

Dr. Rosenfeld: No, you can order Cortisol "Salivary testing" online now pretty easily. It measures it over a 24 hr. period.

Emily: Are there different types of sleep studies? I had one with no findings. Should I continue to push the issue of sleeping for 10 hours and not being rested or just accept it as a part of fibro? My doctor put me on vyvanse for the fog and sleepiness. (I also have ADD) but it increases my pain. I get worsening tension in my neck. Every morning I wake up more tired than when I went to sleep. I have had sleep problems since birth.

Dr. Rosenfeld: Home sleep testing is very rudimentary and only really looks at sleep apnea. An in lab study is standardized and looks at apnea and leg movements. But only some places will go the extra mile and look for "Alpha intrusions in non-REM Sleep". This is a critical element for FMS. Many believe this

is a cause of the condition and answers why folks with FMS are so fatigued and have so much pain and cognitive impairment.

Anonymous: Have you found a hereditary link to FMS patients where either fibromyalgia occurs in the same family or one family member has FMS while other family members have other chronic pain conditions?

Dr. Rosenfeld: About 1/3 of folks with FMS have a genetic link. About 1/3 have early childhood trauma, and about 1/3 have spinal injury in their teens and 20s. About 10% have a severe midlife trauma like catastrophic surgery with complications and 10% have a Lupus like condition. Many folks have more than one risk factor.

Tori: My sleep study shows that I have 300+ spontaneous arousals in my sleep once my apnea is successfully treated. I supposedly have severe apnea that is very well controlled with a CPAP, but I noticed very little change in any of my symptoms even after a year and a half on CPAP so I believe this is due to the spontaneous arousals. I have CFS/ME, Fibromyalgia, and POTS as well as possible Ehlers Danlos and it is my understanding that is a common sleep pattern in these conditions. I am having trouble finding a sleep doctor that is familiar than this commonly occurs in these conditions. Do you have any suggestions on treating this sleep pattern?

Dr. Rosenfeld: Yes, please feel free to Google my research on alpha intrusions in patients with FMS. This phenomenon is also seen in CFS-ME. This is central element to all those conditions. A few doctors who treat FMS are willing to be very aggressive with this, probably 5-6 in the US actually. I would recommend looking at the research on Sodium Oxybate and FMS.

Terri: Is the Cortisol Testing something that a Doctor must order?

NFMCPA Rae: Hi Terri. Yes, a doctor needs to prescribe the test that needs to be done by a lab. Since cortisol is a hormone an endocrinologist is the one you should see. Since hormones in general can be out of balance in chronic pain conditions it is a good idea to have all of your hormone levels checked and each one that is out of balance should be treated. Check out the spring edition of the Fibromyalgia & Chronic PAIN Life magazine to learn more about hormone abnormalities and pain; plus you can read Dr. Rosenfeld's article about his study. <http://www.joomag.com/.../fibromyalgia-c.../0105718001425619808...>

Link for article: <http://www.joomag.com/magazine/fibromyalgia-chronic-pain-life-spring-2015-issue-11/0105718001425619808?short>

Liz: Is it true that vulvodynia is linked to fibromyalgia? I can't tolerate pregabalin, gabapentin, Amitriptyline, or Nortriptyline due to P.o.t.s. are there any other meds to help?? Also what's the best sleep meds?

Dr. Rosenfeld: Yes, vulvodynia is seen in about 5-10%. Very difficult to treat. An urologist who does intra-bladder infusions of gabapentin can be helpful. Sleep meds I use include Xanax and other benzos, Elavil, Melatonin, Trazadone, Seroquel, Belsomra, and Sodium Oxybate

Sandra: I find myself tensing up my whole body frequently and randomly. It could be when I'm resting, reading, using iPad etc.... I have to consciously tell myself to loosen up. I believe I've been doing this for years and just thought it was normal or rather did not pay attention to it until different therapist would tell me repeatedly to stop tensing up, loosen my muscles, drop my shoulders, stop clenching fist etc....Have you come across this in other patients or in your research?

Dr. Rosenfeld: Yes, I've seen many like this. It is a hyper-vigilant or hyper arousal of the central nervous system, which is also why sleep is so disrupted. Biofeedback, relaxation, yoga and of course sedating medication are all approaches that can be tried.

Patty: What do you think about a possible connection to Dopamine levels? Another question regarding sleep, if there is a lot of dreaming does that show an interruption of deep sleep. I have FMS, RLS, Mild Sleep Apnea, and more and am having problems with waking every 1 1/2 - 2 hrs. but am very sensitive to medications so I don't take any prescription meds. What would help me sleep better?

Dr. Rosenfeld: Rae answered part of this, but yes some bench research by Patrick Woods has exposed a Dopamine link. People who are sensitive to meds can try Melatonin, Kava Kava, Chamomile, and L5HTP and Valerian Root

Kristina: Is there anything that will help with ambition? I have fibromyalgia and have no drive.

Dr. Rosenfeld: yes this could be a lot of things. I would certainly treat for depression if its there and look at meds such as painkillers and antidepressants which can also zap energy. Lastly and extensive look at hormones, Cortisol, Estrogen, DHEA and Testosterone are very important to look at when it comes to energy and motivation.

PainPathways Magazine: May 12 is Fibromyalgia Awareness Day and the [National Fibromyalgia & Chronic Pain Association](#) has information about local events during the month of May.

<http://www.fmcpaware.org/community/awarenessday2015.html>

Liz: Sorry I forgot to say I'm not sure if I have fibromyalgia but my diagnoses are M.E and POTS as well as vulvodynia.

Recently I attended physio and did squats, which worsened my condition. My thighs have been extremely tender to touch and burning at times. Also heavy like lead and achy. Does this sound like a fibro thing to you? I have also been having costochondritis. I've not been checked for fibromyalgia.

Dr. Rosenfeld: yes, could be. Tizanidine can be sedating but at 4-8 mg three times a day can reduce pain signal transmission. I would any activity including PT to reduce flaring up the condition till a good remedy can be found.

PainPathways Magazine: Here's a link to the [National Fibromyalgia & Chronic Pain Association](#). There are a lot of advocacy issues that are relevant to people with Fibromyalgia and other chronic pain conditions including public comments on the recently released National Pain Strategy.

Melissa: I have IC as well as fibro. It's my understanding that this is not unusual. Have you seen any research for a direct connection between the two?

NFMCPA Rae: Hi Melissa. As I mentioned in a previous post, fibromyalgia often accompanies other pain conditions such as IC. It is very important that your doctor separates the two conditions when addressing treatment. Sometimes taking care of overlapping pain conditions helps make fibromyalgia specific symptoms easier to treat. Whenever FM is part of a patient's symptomology it always has to be looked at as a separate entity and treated as such.

PainPathways Magazine: Everyone, our time is unfortunately up. We appreciate all of your thoughtful questions and our experts' informative responses. This has been a great dialogue, and we are excited to have another Facebook chat soon!

PainPathways Magazine: Hi everyone! This is Amy North, editor of PainPathways Magazine. On behalf of the magazine, we'd like to thank our expert and all those who participated in tonight's chat! We are excited to be offering this great forum for information and inspiration. We'll post transcripts of the chat to our website soon.

Have a good night everyone!

Dr. Rosenfeld: Thanks for all the great questions. I will also try and answer the ones we didn't get to, which should be posted tomorrow. Now y'all try and get a good night sleep!

Thank you PainPathways Magazine for having Dr. Rosenfeld: on tonight. He did

a fantastic job sharing information about sleep and chronic pain. I would love to

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