

“Providing hope and a better quality of life through educating and connecting members to medical resources and emerging technologies”

Save the dates

Thursday, June 29, 1:00 pm – see enclosed flyer
Speaker from Pinnacle Foot and Ankle Clinic

Thursday, July 27, 1:00 pm
Speaker: Lars Oddsson:
Co-founder of Walkasins

Thursday, August 31, 1:00 pm
Dr Jeffery Allen, speaker
Researcher at U of M with Dr Walk

Saturday, September 23, 10:00 am
Dr Leland Scott, speaker
More information to follow



Have you heard of the SNF 3-day rule?

You may have had a friend or relative who suddenly discovered they needed to make an upfront payment of thousands of dollars to a Skilled Nursing Facility (SNF) even though they've been in the hospital for three days. While in the hospital, they may have been on "observation status" for a day or two, and not officially admitted as an inpatient until the following day. Medicare has this to say: beneficiaries must have a prior inpatient hospital stay of no fewer than three consecutive days in order to be eligible for Medicare coverage inpatient SNF care. This requirement is referred to as the SNF 3-day rule.

Check with your insurance company to determine if they waive the three-day rule. Your insurance coverage should state: no prior hospitalization required.

What is observation status?

Hospitals may keep Medicare patients in "observation status" in reaction to possible penalties for inappropriate admissions. A 2015 law requires hospitals to notify patients who are in this status for 24 hours or more that they are in fact an outpatient and potentially subject to the three-day rule.

Prime Time – Spring 2017 issue

Thank you for your support!

The MNA thanks all of you who have so faithfully sent in your membership contribution each year. Without you, we would not be able to offer the programs, activities, monthly mailings, and newsletters that we have done in the past, and will continue to do. Remember that our Board members are all volunteers; we have no paid staff.

Look at the mailing label on the envelope in which you received this newsletter. The **yellow highlighted area** indicates when the last year you made your contribution (not when it is due). You want to see a 2017 in that highlighted area by the end of this year. Mail your contribution, payable to MNA, in the enclosed envelope to Myron Martin, 8100 Russell Avenue South, #127, Minneapolis, MN 55431. The suggested yearly contribution is \$25.00 (or more, if you can). Since we are a 501(c)(3) organization, your contribution is tax deductible. If you feel that your mailing label's date does not reflect your most recent membership contribution, please call Myron Martin, treasurer, 952-941-5372 to verify your information.

Too much sun, too many bugs?

Picture you and your family relaxing at the lakeshore, soaking in the sun and polishing off some quickly melting ice cream. Ah, Summer. Oops, you forgot the sunscreen, you aren't drinking enough water and the temperature is rising. And, there are a lot of mosquitoes out there. Ouch, summer

Heat-related illness and severe sunburn are preventable; and mosquitoes, biting flies and ticks can be held at bay. The following are general tips for everyone to enjoy the outdoors, but take these precautions:

The heat is on – drink plenty of fluids, but limit alcoholic, caffeinated and too sugary beverages. Staying hydrated can keep your body cool. Carry bottled water if you'll be outdoors for a long stretch.

Be generous with sunscreen – the most effective products will be labeled with "broad spectrum" or "UVA/UVB protection". Apply sunscreen liberally about 30 minutes before going into the sun. Consult the packaging for when to reapply but generally do so after rigorous activity, swimming or being in the sun for several hours.

Wear the right clothing – wear lightweight, light-colored and loose fitting clothing. Don't forget a brimmed hat and sunglasses.

Stop bugging me – don't let biting insects drive you back inside. Wearing insect repellent is one way to help protect you from the bite of pesky, and sometimes dangerous, insects that may transmit disease. In addition to wearing long sleeves and long pants and avoiding bug friendly places like tall grass and standing water, apply insect repellent to skin can keep bugs from landing on you.

Thank You

Our thanks to The Foundation for Peripheral Neuropathy (FPN) for permission to reprint the articles that are part of this issue of the MNA newsletter. Some are a bit technical, but still contain valuable information. There are many helpful articles from time to time on their website.

Nerve Cells Can Be Switched on to Repair Damage

Scientists at the University of Wisconsin have found a way to coax peripheral nerve cells into repairing damaged axons. Peripheral cells extend outside the central nervous system into the arms and legs and are responsible for sensation. They contain long fibers known as axons that transmit impulses from the brain. They can be damaged in diseases such as diabetes, causing pain.

The axons are surrounded by a protective sheath called myelin, a fatty insulation that speeds electrical signals from the brain. Myelin is created by Schwann cells, but researchers have discovered that Schwann cells can also stimulate nerve regrowth.

They conducted an experiment in mice with both intact axons and axons which had been cut. Using a method for switching on genes, they saw Schwann cells become more active, but only in the injured rodents. They went into a repair mode that stimulated nerve regrowth. This clean-up, as researchers call it, began within days of the injury.

As part of the clean-up process, the Schwann cells send signals that enlist blood cells to help in the repair. During this time, the myelin begins to dissolve to make room for the axonal repair. After the axons are on the road to recovery, a new myelin sheath begins to form over the regenerated fibers.

The scientists identified a particular pathway that switches the Schwann cells on or off. They suggest drugs may some day be available to activate the repair program.

A report on axonal regeneration was published in *The Journal of Neuroscience*.

Lead researcher John Svaren, a professor of comparative biosciences at the University of Wisconsin, says it's not clear that this single on-off pathway works to regenerate all axonal nerve cell damage. But he's hopeful that it's a key repair mechanism, not only within the peripheral nervous system but for nerve damage within the brain.

Until now, Svaren says scientists have thought of the Schwann cell as a "static entity," with only one function: producing myelin. But he is excited that the cells can be coaxed to become "first responders" in helping to repair the peripheral nervous system.

Vitamin B3 Prevents Nerve Pain Caused by Cancer Drugs

A new study in rats suggests that nicotinamide riboside (NR), a form of vitamin B3, may be useful for treating or preventing nerve pain (neuropathy) caused by chemotherapy drugs. The findings by researchers at the University of Iowa were published recently in the *Journal of the International Association for the Study of Pain* (PAIN) and lay the groundwork for testing whether this nutritional supplement can reduce nerve pain in cancer patients receiving chemotherapy.

Although chemotherapies have improved cancer survival rates, many of these drugs also cause debilitating side effects that decrease the quality of life of patients and survivors. In particular, many anti-cancer drugs cause chemotherapy-induced peripheral neuropathy (CIPN)—nerve damage and pain.

“Chemotherapy-induced peripheral neuropathy can both hinder continuation of treatment and persist long after treatment has ended, severely affecting the quality of life of cancer patients,” says Marta Hamity, UI assistant research scientist and first author on the study. “Our findings support the idea that NR could potentially be used to prevent or mitigate CIPN in cancer patients, resulting in a meaningful improvement in their quality of life and the ability to sustain better and longer treatment.”

A recent report from the American Society for Clinical Oncology states that there is an unmet need for treatments that can alleviate CIPN. The new study, led by Hamity and Donna Hammond, UI professor of anesthesia and pharmacology at the UI Carver College of Medicine, tested the effect of NR in female rats that were treated with paclitaxel, a chemotherapy commonly used to treat breast and ovarian cancer.

The researchers found that paclitaxel given at doses that mimicked the amount a human patient would receive caused peripheral neuropathy in the rats, and the effects lasted at least five weeks beyond the end of the chemotherapy treatment.

The team used a standard test to assess the pain caused by CIPN. They measured the rats’ increased sensitivity to a light foot poke. Untreated rats did not withdraw their foot when light pressure was applied. However, treatment with paclitaxel made the rats hypersensitive to this light touch and caused them to withdraw their foot.

NR boosts levels of an important cell metabolite called nicotinamide adenine dinucleotide (NAD+). Previous animal studies, including work from the UI lab of study co-author Charles Brenner, have shown that increasing NAD+ levels with NR can protect against many types of nerve damage. The new study found that the NR supplement increased levels of NAD+ in the rats’ blood by about 50 percent.

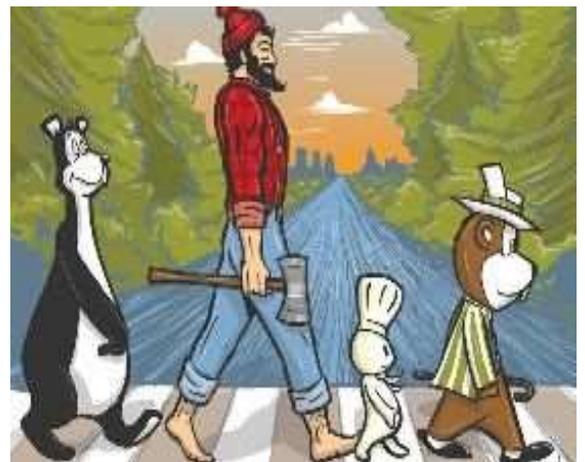
Prophylactic treatment with daily doses of NR (200 mg/kg) for seven days before chemotherapy and maintained for 24 days after chemotherapy ceased prevented the hypersensitivity to touch in the rats. This protective effect lasted for at least two weeks after the NR supplementation stopped

FPN – April 2017

Suggestion from our member:

Frankincense and Myrrh Neuropathy Rubbing Oil - 2 fl oz

Take a look at this rubbing oil---I get almost immediate relief from it---first thing to really work for me. My wife rubs it onto my feet and whalla--I feel much better. I bought it at Walgreens.



Who are these icons?

Answers on last page

How to Sleep With Neuropathy

Sleep is an essential part of living—sleep helps us avoid major health problems and it is essential to our mental and physical performance. It affects our mood and stress and anxiety levels. Unfortunately, sleep disturbance or insomnia is often a side effect of neuropathy pain. It is a common complaint among people who live with chronic pain.

It's no surprise that about 70 percent of pain patients, including those suffering from PN, back pain, headaches, arthritis and fibromyalgia, report they have trouble sleeping according to the Journal of Pain Medicine.

Pain can interfere with sleep due to a combination of issues. The list includes discomfort, reduced activity levels, anxiety, worry, depression and use of medications such as codeine that relieve pain but disturb sleep.

Most experts recommend a range of seven to nine hours of sleep per night for adults, regardless of age or gender. This may seem impossible to people with chronic pain, but there are steps you can take to improve your sleep, which may lead to less pain and lower levels of depression and anxiety. First, talk with your doctor to see if there are medications that may lessen your sleep disturbance. You should also check with your doctor to make sure your current medications aren't causing some of your sleep disturbance.

Beyond medication, there are several things you can do yourself to improve your sleep. Here are some methods to try and help you fall asleep more quickly, help you sleep more deeply, help you stay asleep, and ultimately help keep you healthy.

Following are tips for improving your sleep:

- Reduce your caffeine intake, especially in the afternoons
- Quit smoking
- Limit and/or omit alcohol consumption
- Limit naps to less than one hour, preferably less
- Don't stay in bed too long—spending time in bed without sleeping leads to more shallow sleep
- Adhere to a regular daily schedule including going to bed and getting up at the same time

- Maintain a regular exercise program. Be sure to complete exercise several hours before bedtime
- Make sure your bed is comfortable. You should have enough room to stretch and turn comfortably. Experiment with different levels of mattress firmness, foam or egg crate toppers, and pillows that provide more support
- Keep your room cool. The temperature of your bedroom also affects sleep. Most people sleep best in a slightly cool room (around 65° F or 18° C) with adequate ventilation. A bedroom that is too hot or too cold can interfere with quality sleep.
- Turn off your TV and Computer. Many people use the television to fall asleep or relax at the end of the day. Not only does the light suppress melatonin production, but television can actually stimulate the mind, rather than relaxing it.
- Don't watch the clock – turn your alarm clock around so that it is not facing you
- Keep a note pad and pencil by your bed to write down any thoughts that may wake you up at night so you can put them to rest.
- Refrain from taking a hot bath or shower right before bed; the body needs to cool a degree before getting into deep sleep
- Try listening to relaxing soft music or audio books instead, or practicing relaxation exercises.

Visualize a peaceful, restful place. Close your eyes and imagine a place or activity that is calming and peaceful for you. Concentrate on how relaxed this place or activity makes you feel.

Some patients find comfort from a pillow between their legs that keeps their knees from touching. And there's an added benefit: A pillow between your legs at night will prevent your upper leg from pulling your spine out of alignment and reduces stress on your hips and lower back.

It may take three to four weeks of trying these techniques before you begin to see an improvement in your sleep. During the first two weeks, your sleep may actually worsen before it improves, but improved sleep may lead to less pain intensity and improved mood.

NIH Provides Two Grants for Peripheral Neuropathy Research

This past August, 2016, The National Institutes of Health (NIH) provided two separate grants supporting peripheral neuropathy research last month. This is excellent news as it demonstrates recognition of the need for funding in this area.

MDI Biological Laboratory Conducting Peripheral Neuropathy Research

The MDI Biological Laboratory has announced that it has received a grant of \$456,500 over two years from the National Institute of Neurological Disorders and Stroke to support research conducted by assistant professor Sandra Rieger, Ph.D., on chemotherapy-induced peripheral neuropathy.

The grant will allow Rieger to focus her research on the molecular mechanisms underlying peripheral neuropathy induced by paclitaxel, a common chemotherapy agent. She believes the mechanisms leading to paclitaxel-induced peripheral neuropathy may also underlie other types of sensory neuropathies, such as those caused by diabetes or treatment with antibiotics. Her lab has identified two drug candidates with the potential to prevent or reverse the effects of sensory nerve degeneration in zebrafish.

The grant funding will be used in part to assess the efficacy of the drug candidates in mammalian models.

Dr. Rieger recently attended the Foundation for Peripheral Neuropathy's 2016 International Research Symposium in Chicago.

JAX Resource for Research of Peripheral Neuropathy

The second grant will provide four years of funding, totaling \$1,219,140, to The Jackson Laboratory to develop mouse models for inherited peripheral neuropathies and neurodegenerative diseases including Charcot-Marie-Tooth disease (CMT).

The new grant establishes the JAX Resource for Research of Peripheral Neuropathy to accelerate the creation, distribution and use of high-priority mouse models for CMT research. Burgess, JAX Mouse Repository Director Cathleen Lutz, Ph.D., and Research Scientist Kevin Seburn, Ph.D., are the principal investigators of the grant.

FPN – September 2016

A Note from MNA

*Our newsletters contain a variety of information, and in each article we have identified the source, **but the views and opinions of the articles do not necessarily represent the views of MNA, nor do they infer an endorsement of any product or service.** They are not intended to replace medical or other professional advice and counsel.*

The Foundation for Peripheral Neuropathy (FPN)

Mission:

Dedicated to Reversing the Irreversible

Visit their website: <foundationforpn.org>

MNA Updated Web site

Currently John Bishop and members of the Board are working on a new, updated web site. John has spent many hours in revamping the web site, and it should be ready for 'roll-out' soon. The web address will stay the same: www.neuropathy-mn.org. Thank you John!

Presenters' notes

Periodically we receive requests for information that a speaker presents when members are unable to attend a meeting.

If a presenter uses a handout or power point that is informative, we share that with our members when we send our monthly flyer.

We also encourage our speakers to write an article for our newsletter. We do not have any way of doing a video or audio recording of our speakers.

FIBROMYALGIA: A PERIPHERAL PAIN DISORDER?

Fibromyalgia is a common, debilitating condition that has long confounded researchers — the syndrome has had no demonstrable pathology or definitive diagnostic test. Now, new research suggests that fibromyalgia may have a neuropathic basis in some patients.

In a study published in the October issue of *Seminars in Arthritis and Rheumatism*, researchers found that women with fibromyalgia exhibited corneal nerve atrophy consistent with neuropathic pain. The findings suggest that some patients with fibromyalgia may actually have small fiber polyneuropathy (SFPN), a disease with potentially treatable causes.

For the study, noninvasive corneal confocal bio-microscopy was used to examine corneal small fiber nerves in 17 women with severe fibromyalgia and 17 age-matched healthy women. Fibromyalgia patients had a mean Fibromyalgia Impact Questionnaire (FIQ) score of 69.

Compared with healthy controls, patients with fibromyalgia had significantly thinner corneal stromal, as well as diminished sub-basal plexus nerve density per square millimeter.

All but one patient in the fibromyalgia group had a Leeds assessment of neuropathic symptoms and signs (LANSS) score above the 12 cutoff point, suggesting a neuropathic component to their pain. Patients also had high Composite Autonomic Symptoms and Signs (COMPASS) tallies, reflecting prominent autonomic nervous system dysfunction.

Further analysis revealed a link between nerve slenderness and LANSS neuropathic pain symptoms questionnaire scores; similarly, an association was found between sub-basal nerve scarcity and LANSS score.

“We found an association between stromal nerve slenderness and neuropathic pain symptoms,” lead author Manuel Martinez-Lavin, MD, a professor of rheumatology at the Instituto Nacional de Cardiologia Ignacio Chavez in Mexico City, Mexico, told *Clinical Pain Advisor*.

Although symptoms of neuropathic pain are not uncommon in fibromyalgia, the syndrome has been primarily considered to be a central nervous system (CNS) processing disorder.

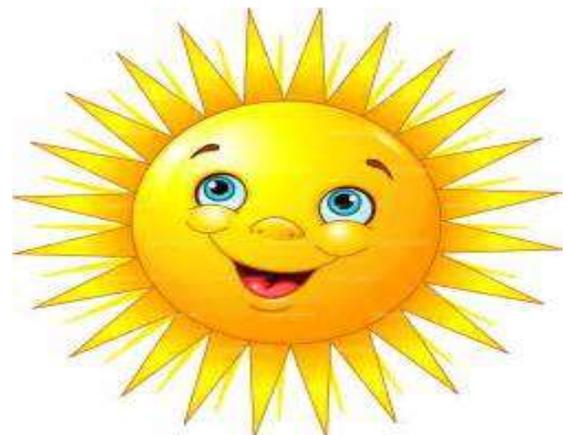
“Our group suspects that fibromyalgia is a neuropathic pain syndrome. We believe it is primarily a peripheral nerve disorder that causes central nervous system sensitization. We think that fibromyalgia is sympathetically maintained based on stress as a triggering event; heart rate studies suggest ongoing sympathetic hyperactivity,” Dr. Martinez-Lavin stated, noting that further studies are needed to confirm the controversial hypothesis.

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### MNA Handbooks Available

Our MNA Handbook is available for everyone who is a first-time member (i.e. makes a contribution for the first time). It has 70-80 pages of helpful information to help you in dealing with neuropathy. If you are a first-time member, and have not received your copy, please contact Lois Martin (952.941.5372), or [loismemartin@gmail.com](mailto:loismemartin@gmail.com).

If you have an MNA Handbook from several years ago, and would like to have the updated pages, we have good news for you! If you bring your complete Handbook to one of our meetings, we will exchange it for a new one.



knowledge and experience they have gained through conventional education or practice, using drugs, surgeries, or physical therapies.

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### **Shingles: What you need to know**

Herpes zoster, commonly called shingles, is an infection caused by the same virus that causes chickenpox. Only people who have had chicken pox can get shingles.

After a patient recovers from the chicken pox, the virus remains inactive in the body. Shingles develops when the virus becomes active again. People over the age of 50, or those with weakened immune systems due to diseases such as HIV or cancer, are at the highest risk for developing shingles.

Shingles usually appears as a painful rash, typically on only one side of the body. The rash generally lasts from one to fourteen days. However, some patients with shingles may develop postherpetic neuralgia (PHN), a condition in which the pain from shingles continues months or years after the rash has faded.

The Center for Disease Control (CDC) recommends that people 60 years old and older get the shingles vaccine to prevent shingles and PHN.

(Editor's note: having a family member with PHN for over five years with excruciating pain, I have been asking everyone to receive a shingles vaccine. Do it NOW!!

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## **Complementary + Integrative Therapies**

There are many different types of medicine being practiced today and we are often left wondering – what does each one do?

### **Conventional**

The standard form of care in the U.S., often referred to as Western medicine, practitioners hold M.D. (medical doctor) or D.O. (Doctor of Osteopathy) degrees. They work together with other licensed health professionals that provide the support services that are critical to patients. These professionals include registered nurses, anesthesiologists, physical and occupational therapists, and many others to provide the best possible care for patients. They determine diagnosis and treatment based on the medical

### **Complementary**

While complementary and alternative forms of medicine are often thought of interchangeably, there are differences. Complementary therapies are used together with conventional medicine. This might include a regimen of vitamins, supplements, herbs, and 'natural' substances to be used in conjunction with other medications.

### **Alternative**

Alternative therapies, on the other hand, are used in place of conventional medicine. One example would be if you choose to do yoga instead of a physical therapy regimen. Both complementary and alternative therapies (CAM) are referred to as Eastern medicine as many of the therapies originated in China

### **Integrative**

A total approach to health care, integrative medicine combines conventional and CAM therapies into a treatment plan where there is some high-quality evidence of safety and effectiveness

## **Complementary and alternative medicines (CAM) are divided into several broad categories:**

**Natural Products:** This category is the most popular form of CAM, used by more than 15% of the U.S. population. These include herbal medicines, vitamins, minerals, and products sold over the counter as dietary supplements.

**Mind and Body Medicine:** Using mind and body practices that focus on the interactions among the brain, mind, body, and behavior, to affect physical functioning and promote health. Examples are: Meditation, yoga, acupuncture, deep breathing exercises, hypnotherapy, progressive relaxation, and tai chi.

### **Manipulative and Body-based Practices:**

These practices focus primarily of the structures and systems of the body, including bones and joints, soft tissue, and circulatory and lymphatic systems. Spinal manipulation and massage fall into this category.

Energy medicine is among the most controversial of the CAM therapies. These therapies involve the manipulation of various energy fields to affect health. The most common practices include those involving

electromagnetic fields (magnet and light therapy).

Many of the CAM therapies have not been evaluated in rigorous controlled clinical trials, as has been the standard for pharmacotherapies utilized in Western medicine. In an attempt to address this limitation, the National Center for Complementary and Alternative Medicine, part of the National Institutes of Health, has developed an international presence in the field of complementary and alternative medicine. With a mission to explore and evaluate complementary and alternative therapies, it oversees many research projects in the United States – whether they are safe and whether they work.

As with any medical treatments, there can be risks with CAM therapies. And, while it is important to be aware of the risks, it is also encouraging to hear about the CAM therapies used by many PN sufferers. Just like conventional therapies, there is not one treatment that worked for everyone. Sometimes they had to try several different therapies, but some of them did find relief. It can be a matter of a little, short-lived relief, but when you live with the daily pain and symptoms of PN, it can be a welcome respite. The real goal is to find a treatment that is safe and will not do you any harm.

Complementary and alternative therapies should not replace your conventional care. The best approach is to integrate these therapies with your current treatments. FPN– 11/2016

### Is Alpha Lipoic Acid for you?

There is some clinical evidence supporting the effectiveness of alpha lipoic acid when taken orally or intravenously daily for treating the symptoms of peripheral neuropathy, but the evidence is limited by quantity, quality or contradictory findings. Taken alone or with other supplements, alpha lipoic acid seems to improve neuropathic sensory symptoms such as burning, pain, numbness and prickling of the feet and legs. FPN November 2016

### Have a safe and Happy Fourth of July



#### Board Members

Questions? Comments? Let your MNA Board know your thoughts and ideas! Contact information:

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*Answers: Hamm's Bear, Paul Bunyan, Poppin' Fresh, Fairchild (State Fair mascot)*