



# eNcouragement

The Newsletter for the Minnesota Neuropathy Association  
Volume XIV – No 4 Fall 2017

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

## **Save the date**

*Our next meeting will be Saturday, January 27<sup>th</sup> at St Michael's in Bloomington – details will be mailed in January.*

## **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.

**We need your help! The Board is looking for someone who would be willing to write the MNA quarterly newsletter. Compensation will be based on experience. Contact loismemartin@gmail.com if you or someone you know, might be interested.**

## **Moving or Snowbirds?**

When you move, please call or email us with your new address. If you go somewhere else in winter, please let us know, and we will send your MNA mail to that address at the appropriate time. Because we use standard mail (not first class), your mailing is returned to us and NOT forwarded, and we need to pay a fee for that service. Help us save that expense. Contact Lois Martin 952-941-5372 or loismemartin@gmail.com.

## **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](http://foundationforpn.org)>

## **MNA Updated Web site**

John Bishop and members of the Board have worked on a new, updated web site. John has spent many hours in revamping the web site. Take a look. The web address will stay the same: **[www.neuropathy-mn.org](http://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. See Dr Scott's and Nick Rich's information on this page and page 4.

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.



GO VIKINGS!!!

## 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.

### 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.

## Excerpts from the brochure of the Lake Elmo Pharmacy. Nick Rich, the pharmacist was our speaker in May.

"Pain is one of the most common reasons people consult a physician, yet it is frequently inadequately treated, leading to a enormous social cost in the form of lost productivity, needless suffering, and excessive healthcare expenditures."

Compounding combines an ageless art with the latest medical knowledge and state-of-the-art technology, enabling special trained professionals to prepare customized dosage forms that are just what the doctor ordered.

The optimal dosage form depends upon the specific needs of each patient. Options include:

*Transdermal and topical* administration are increasingly popular methods of drug delivery. Creams and gels can be formulated to provide high local concentrations at the sight of application, for trigger point application (e.g. combination of medications for neuropathy pain), or in a base that will allow the systemic absorption. Transdermal medications utilize the skin or mucosa to facilitate absorption. Studies suggest that there are no great restrictions on the type of drug that can be incorporated into a properly compounded transdermal gel. Other transdermal dosage forms include buccal troches and sublingual preparations.

*Oral* dosage forms also can be customized to meet the specific needs of each patient. We can combine numerous compatible medications into a single-dose for ease of administration or simplification of a confusing dosage schedule. We can compound medicated lollipops, freezer pops, "gummy bears", solutions and suspensions, flavored to suit the individual.

*Rectal* formulations include suppositories, solutions, gels, and enemas. "Rectal rockets" facilitate simultaneous internal and external application of medication for hemorrhoids and other problems.

*Nasal* preparations (spray, gel, drops, etc) may be used as a method of delivering many types of medication.

Note: if you feel you could benefit from the services of a compounding pharmacist, Nick Rich is available at 651-773-0889. [www.LakeElmoPharmacy.com](http://www.LakeElmoPharmacy.com). It is full service retail and compounding pharmacy.



## Energy boost

### Don't let fatigue get you down. These six strategies can help you manage it:

If you've been diagnosed with a neurologic condition and find yourself feeling tired, you've got lots of company. Fatigue is a common symptom of many neurological conditions.

1. Identify the cause. Fatigue comes in different forms. Work with your doctor to determine the cause so you can get targeted recommendations. If the fatigue makes it hard to get to the doctor's office, call and set a time to chat. Your doctor may be able to suggest some things over the phone.
2. Tweak doses. Some medications can cause fatigue. Your doctor may be able to lower the dose so the drug remains effective but causes less fatigue. If not, talk to your doctor about changing the timing of your medication. For example, you may be able to take some drugs before bedtime, when a side effect of drowsiness could be of benefit. If you take multiple drugs, talk to your doctor about reducing that number and therefore the risk of tiredness as a side effect.
3. Get regular exercise. Exercise can improve your mood by releasing endorphins – hormones that make us feel good – and take your mind off the fatigue. Researchers have found that compared with the groups that did not exercise, the groups that did yoga and aquatic exercise three times a week had significantly less depression and fatigue. Check with your doctor before starting any exercise program to be sure it won't make you more tired or cause injuries, and to get recommendations for your condition.
4. Schedule occupational therapy. An occupational therapist can identify ways to conserve energy in everyday activities such as dressing, bathing, and reaching for things.
5. Use assistive devices. Canes, walkers, and wheelchairs can help you conserve energy, even if you only use them occasionally or for major events like travel or a trip to the mall.
6. Address sleep problems. Difficulty sleeping can exacerbate fatigue. Start with simple techniques such as avoiding caffeine and naps late in the day. If you're still having trouble talk to your doctor about adjusting your medication or participating in a sleep study.

Excerpts from *Neurology Now* – October/November 2017 issue

## Six Things To Know When Selecting a Complementary Health Practitioner

If you're looking for a complementary health practitioner to help treat a medical problem, it is important to be as careful and thorough in your search as you are when looking for conventional care.

Here are some tips to help you in your search:

1. **If you need names of practitioners in your area, first check with your doctor or other health care provider.** A nearby hospital or medical school, professional organizations, state regulatory agencies or licensing boards, or even your health insurance provider may be helpful. Unfortunately, the National Center for Complementary and Integrative Health (NCCIH) cannot refer you to practitioners.
2. **Find out as much as you can about any potential practitioner, including education, training, licensing, and certifications.** The credentials required for complementary health practitioners vary tremendously from state to state and from discipline to discipline.

Once you have found a possible practitioner, here are some tips about deciding whether he or she is right for you:

3. **Find out whether the practitioner is willing to work together with your conventional health care providers.** For safe, coordinated care, it's important for all of the professionals involved in your health to communicate and cooperate.
4. **Explain all of your health conditions to the practitioner, and find out about the practitioner's training and experience in working with people who have your conditions.** Choose a practitioner who understands how to work with people with your specific needs, even if general well-being is your goal. And, remember that health conditions can affect the safety of complementary approaches.
5. **Don't assume that your health insurance will cover the practitioner's services.** Contact your health insurance provider and ask. Insurance plans differ greatly in what complementary health approaches they cover, and even if they cover a particular approach, restrictions may apply.
6. **Tell all your health care providers about the complementary approaches you use and about all practitioners who are treating you.** Keeping your health care providers fully informed helps you to stay in control and effectively manage your health.

FPN E tips – June 2017

# Notes from Dr Scott's power point presentation in September

## Overview of neuropathy

- Review the fundamentals of neuropathy including underlying causes
- Understand the importance of differentiating neuropathy from other causes of numbness, weakness and pain.

Neuropathy is a symptom of an underlying condition. Effective treatment requires treatment of the underlying condition, not just treatment of the symptoms. The most powerful word in science: WHY? Why do you have neuropathy, or more specifically what is the underlying cause?

Nerve damage: Hereditary or Acquired?

Hereditary includes Charcot Marie Tooth, Fabry disease, SMA, hereditary SFN, celiac disease, and amyloidosis

Acquired could include: diabetes, B12 deficiency, B6 toxicity, Guillain-Barre, CIDP, multifocal motor neuropathy, botulism/diphtheria, hepatitis C virus infection, polio/leprosy, and beriberi.

Not all numbness is neuropathy. Other causes of numbness may be a stroke, multiple sclerosis, spinal cord damage (cervical stenosis myelopathy or thoracic stenosis myelopathy), nerve root impingement in the cervical, thoracic, or lumbar area, carpal tunnel syndrome, tarsal tunnel syndrome.

Neuropathy without pain?

- Neuropathy can cause numbness, weakness, tingling, imbalance, incoordination, cramps, or pain, or any combination
- Many forms of neuropathy don't cause pain
- Very chronic, slowly progressive nerve damage is more likely to cause numbness/weakness/imbalance without any associated pain or tingling.

Not all foot pain is neuropathy

Neuropathic pain: minimal morning pain, minimal pain walking, pain worse with feet up, pain bad in bed, worse if feet are elevated

Orthopedic pain: 'first step' upon arising, pain worse when walking, pain improved off feet, pain generally best in bed, better with feet elevated

Evaluation of neuropathy—nothing is irrelevant

History and examination: thorough history, family history, medical problems, medications, physical exam of motor, sensory, and reflexes

Laboratory testing: blood tests, genetic tests, EMG/NCS, MRI imaging, nerve biopsy

Treatment - symptomatic medication

Antiepileptics: Neurontin, Dilantin, Lyrica, Topamax, Tegretol

Tricyclic antidepressants: amitriptyline, nortriptyline, imipramine

SSRI's: lexapro

Atypicals: cymbalta

Narcotic analgesics

Topical compounded medications

Part two of Dr Scott's presentation

## Vitamins and Supplements

Vitamins (name, can cause, found in what foods)

Vitamin A carotenoids blindness  
cod liver oil, carrots, pumpkin, liver

Vitamin B1 thiamine beriberi  
brown rice, oatmeal, liver, eggs

Vitamin B2 riboflavin glossitis  
dairy, bananas

Vitamin B3 Niacin pellegra  
meat, fish, eggs

Vitamin B5 pantothenate tingling  
meat, broccoli, avocado

Vitamin B6 pyridoxine neuropathy  
meat, nuts, bananas, vegetables

Vitamin B7 biotin dermatitis  
leafy vegetables, peanuts, egg yolk

Vitamin B8 folate anemia  
leafy vegetables, cereals, liver

Vitamin B12 cobalamine dementia, neuropathy  
meat, fish, eggs, milk

Vitamin C Ascorbate scurvy  
fruits, vegetables, liver

Vitamin D cholecalciferol rickets, osteoporosis  
eggs, fish, liver

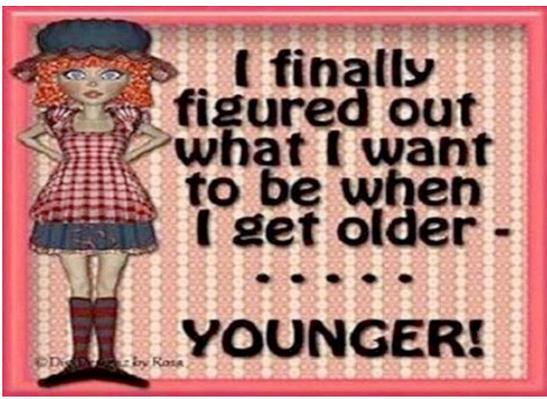
Vitamin E tocopherol sterility  
nuts/seeds, fruits, vegetables

Vitamin K phtloquinone bleeding  
leafy vegetables, egg yolk, liver

## Supplements

Biological supplements: creatine, CoEnzymeQ10, carnitine, fish oil, flaxseed oil

Herbal supplements: echinacea, saw palmetto, ginkgo biloba



## Neuropathic Pain: Navigating the Challenges of an Elusive Disease

The wide range of etiologies underlying neuropathic pain renders a particularly challenging condition to manage.

### Treatment Options and Pain Management

The three broad categories of pain management include medications, interventional therapies, and physical or psychosocial therapies. Generally speaking, a single medication will usually be inadequate to treat such a complex and intense condition, and typical analgesics such as acetaminophen, nonsteroidal anti-inflammatory drugs, or weak opioids are nearly always ineffective. "There is going to be some kind of rational polypharmacy instead of a single bullet," Dr Williams said. "The combination of medications and interventional treatments can be very effective with neuropathic pain."

The only drug classes with solid evidence of effectiveness are tricyclic antidepressants, such as amitriptyline and serotonin-noradrenaline reuptake inhibitors like duloxetine, which are considered first-line treatments. The antiepileptics pregabalin and gabapentin are also first-line, but best for peripheral neuropathic pain, although more recent research has produced negative results. Combining either of these antiepileptics with a tricyclic antidepressant can be more tolerable and effective than monotherapy, particularly for diabetic neuropathic pain.

Second-line treatments include lidocaine 5% patches (modest effect), capsaicin 8% patches (lacks long-term safety data), and tramadol (primarily for peripheral neuropathic pain), which work in some patients, but often modestly, and with low success rates.

BotulinumtoxinA as a third-line treatment has proven particularly beneficial for peripheral neuropathic pain and neuropathic pain resulting from diabetes, herpes, and trigeminal neuralgia. Opioids such as oxycodone and morphine are also considered third-line treatment for neuropathic pain, but are less effective and more prone to misuse, overdose, morbidity, death, and diversion.

Patients who do not show adequate response to medications may try interventional treatments such as nerve blocks, modulation of specific neural structures, or surgical procedures for targeted drug delivery, but risks for infection or other adverse effects are possible.

Neurostimulation to interfere with pain signals at different processing stages consist of cryoablation or the application of electrical, radiofrequency, or magnetic energy to pain pathways. Nerve blocks and steroid injections offer short-term relief (typically lasting a few months), and do not reduce the likelihood of later surgical intervention.

Spinal cord stimulation is ideal for patients not responding to other treatments, as it was shown to be relatively safe, reversible, cost-effective, and long-lasting (with results lasting a minimum of 24 months in several studies), particularly if burst- and high-frequency stimulation is used vs monophonic square-wave pulse. Although less evidence supports neurostimulation of afferent fibers outside the spinal cord as a viable option, this intervention has also shown relief for several neuropathic pain conditions, including occipital and postherpetic neuralgia.

Epidural motor cortex stimulation, repetitive transcranial magnetic stimulation, and transcranial direct current stimulation comprise the 3 types of epidural or transcranial cortical neurostimulation. An estimated 60% to 65% of patients experience at least a 40% reduction in pain intensity from epidural motor cortex stimulation, which requires surgery to place the electrodes. Meanwhile, repetitive transcranial magnetic stimulation and transcranial direct current stimulation are noninvasive and use magnetic coils or electrodes placed on the scalp to ease central, peripheral, and facial neuropathic pain for a minimum of 2 weeks. However, repetitive transcranial magnetic stimulation is contraindicated for those with aneurysm clips, deep brain electrodes, cardiac pacemakers, cochlear implants, or a history of epilepsy.

A more controversial approach is that of deep brain stimulation: whereas this intervention was found to be effective for some patients, it is associated with serious risks, including seizure during the procedure, lead fractures, and wound infections.

Intrathecal therapy to deliver morphine or ziconotide to specific nerves using an implanted, refillable pump is considered a last resort option. Dizziness, nausea, confusion, memory impairment, uncontrolled eye movements, and an increase in serum creatine kinase are the most common adverse events, but more serious morbidities and death are also associated with this treatment.

Of all psychological interventions, cognitive behavioral therapy is the only one supported by evidence; however, effect size is modest and varies across patients.

"People with chronic pain are not passive; they actively attempt to change the causes of pain and change their own behavior in response to pain," wrote review author, Luana Colloca, MD, PhD, an associate professor of anesthesiology at the University of Maryland School of Nursing, and colleagues. "However, for many patients, such change without therapeutic help is unachievable, and repeated misdirected attempts to solve the problem of pain drive them further into a cycle of pain, depression and disability." Further, it is not currently possible to reliably determine patients who will benefit most from psychological treatments or those most at risk for pain that is exceptionally difficult to manage.

Cognitive behavioral therapy would need to be part of an interdisciplinary approach, Dr Williams said, just as would biofeedback, acupuncture, mindfulness meditation, or other nonpharmacological approaches if any of those offer a patient some additional relief.

### **Looking Ahead:**

#### **Phenotyping and Personalized Medicine**

Although emerging, the practice of identifying specific phenotypes to better determine course of treatment is promising for a future of personalized medicine. For example, evidence suggests that patients displaying mechanical allodynia, but with intact nociceptive function, will be more likely to respond to systemic and topical sodium channel blockers, botulinum toxin A, and clonidine gel. "It would not be surprising if phenotyping has a great part to play in demonstrating the efficacy of

psychological interventions as it does for medications," the authors wrote.

Phenotype identification could also rely on genetic identifiers or certain combinations of symptoms or subjective descriptions of pain. For example, the voltage-gated sodium channel, Nav1.7, is established as an important pharmacological target, and identification of genetic mutations affecting this protein may inform treatment decisions.

Dr Williams told *Clinical Pain Advisor* that the field is headed in the direction of using genetics, phenotype identification, and personalized medicine, but it is still in the early stages.

"It's an approach that makes sense and that we're all endeavoring to get to, and sometimes we can do that, but we're still defining what those characteristics are," Dr Williams said. The neuropathic pain categories that present the biggest challenges for genetics-based stratification are acquired ones, such as neuropathic pain resulting from diabetes, stroke, cancer, trauma, shingles, or anything else that's polygenic or specific to an acquired disease. But eventually overcoming these challenges to offer personalized approaches to pain management will pay off in multiple ways.

"It's good medicine, it tends to be less costly, and people tend to have higher satisfaction, as opposed to starting treatment in a stepwise fashion," Dr Williams added. "Trial-and-error has dominated our approach for quite some time, but we're starting to be able to move out of that and have a more specific approach that's stratified and hopefully gives us a higher hit rate in terms of success sooner than that trial-and-error and stepwise approach."

*Note: the above article is a bit technical, but still contains much good information – from FPN website September 2017*



## Five causes of back pain

Not all injuries are created equal. Here, are some of the most prevalent conditions and symptoms.

**Muscle injuries** – overstretched or injured muscles, tendons, or ligaments can result in strains, sprains, or spasms. Poor posture, prolonged sitting, strenuous work, and repetitive action can stress so-called “soft tissues” in your back. This was the most common cause of back pain, affecting over one third of responses.

**Degenerative changes** – as you age, the gel-like discs cushioning the bones of your spine and the cartilage lining the joints, can begin to wear. That allows the bones to rub against one another, causing osteoarthritis. Some degeneration of this kind is harmless and unavoidable. Imaging studies show that almost everyone older than 60 has signs of spinal wear and tear. But most never reports significant pain.

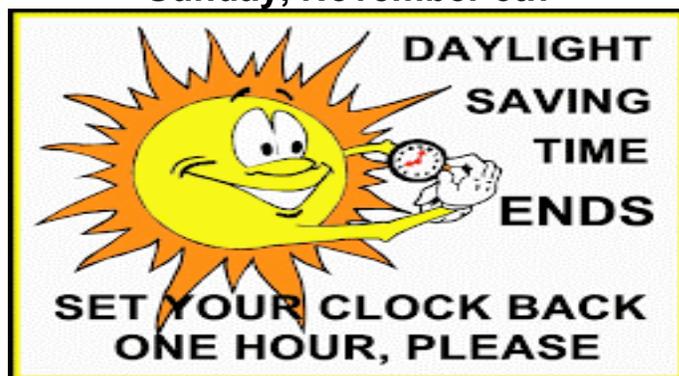
**Herniated, or slipped, disks** – lifting, pulling, bending, or twisting puts pressure on the discs. That pressure can cause them to bulge or slip. When a bulging disc in the lower spine irritates the sciatic nerve, sharp pain, called sciatica, is often excruciating and can radiate down a leg even when there’s no back pain. Slouching at the waist can worsen symptoms.

**Spinal stenosis** – the spine response to degenerative changes by growing new bones in the joints and thickening the ligaments to provide better support. But over time these bone spurs and thickening ligaments narrow the space around the spinal cord and can irritate nerves. Symptoms include numbness, weakness, or cramping in the back, buttocks, arms, or legs. Walking usually worsens symptoms; resting or sitting leaning forward tends to offer relief.

**Spinal instability** – when disks and joints wear, they don’t do a good job supporting the spine. As a result, vertebrae move more than they should. In some cases of bone slides forward, causing a condition called spondylolisthesis. Symptoms often come and go suddenly, sometimes shifting from one side of the body to the other, and can include a feeling of weakness in the legs with prolonged standing or walking.

Consumer Reports: June 2017

Sunday, November 5th



## The five most important questions to ask your doctor!

**Can you please repeat that?** If you are unclear about any information involving your treatment ask your doctor to go over it carefully. Make sure you’re especially clear on the dosage of any new medications, and possible side effects.

**Do you have printed materials available?** It’s not uncommon to shut down mentally as soon as you hear a diagnosis. Handouts about your condition can be extremely helpful. If your doctor doesn’t have printed materials, ask for a list of online resources.

**Can I have two minutes alone with you?** You may be less likely to broach tough topics if other people are in the room, so don’t hesitate to ask for privacy. Your doctor also may be more comfortable one-on-one, and may ask more probing questions.

**What if I know I can’t do what you’re suggesting?** When you are instructed to exercise five days each week and you know you can’t pull that off, tell your doctor so he or she has an opportunity to come up with an alternative course of action.

**Do you have a patient portal for questions?** If you’re embarrassed to address certain concerns live, find out if there’s an online patient portal through which you can send questions securely. That way you can ask and review the answers at home.

AARP Bulletin – January/February 2017

## Take care of your feet for a lifetime

Talk to your primary care doctor about your feet. The best way to start that conversation is to take your shoes and socks off when you go in for your regular checkup. Have the doctor take a look.

Check your feet every day. You may have serious foot problems, but feel no pain. Check your feet for cuts, sores, swelling, and infected toenails. Find a time to check your feet each day. Make checking your feet a part of your everyday routine. If you have trouble bending over to see your feet, use a mirror to help. Make sure to call your doctor right away if a cut, sore, blister, or bruise on your foot does not begin to heal after a few days.

Wear shoes and socks at all times. Do not walk barefoot—not even indoors—because it's easy to step on something and hurt your feet. A good pair of slippers around the house provides extra protection.

Always wear socks or stockings with your shoes to help avoid blisters and sores. Check the insides of your shoes for objects and be sure the lining is smooth before you put them on your feet. Wear shoes that fit well and protect your feet.

Tips for proper footwear when buying shoes.

- Make sure they're comfortable from the start and have enough room for your toes.
- Don't buy shoes with pointed toes or high heels. They put too much pressure on your toes.
- If your doctor prescribes special diabetic shoes and inserts, be sure to get comfortable styles you'll enjoy wearing. If you don't wear your shoes, you won't enjoy the health benefits your doctor intended.

Keep the blood flowing to your feet

- Put your feet up when you're sitting
- Wiggle your toes for five minutes two or three times a day
- Move your ankles up and down and in out to improve blood flow
- Don't cross your legs for long periods of time
- Ask your doctor or healthcare provider if compression wear might help improve your circulation
- Don't smoke. Smoking reduces blood flow to your feet

MNA Website

[www.neuropathy-mn.org](http://www.neuropathy-mn.org)



### Board Members

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

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*We are always looking for additional Board members. PLEASE consider volunteering to help. MNA may need to change some of its priorities unless we get additional help. Contact any of the Board members listed above for more information,*