

eNcouragement

The Newsletter for the Minnesota Neuropathy Association
Volume XIII – No 2 Spring 2016

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

Upcoming Meetings

Thursday, May 26th, 1:00 pm – see enclosed flyer
Speaker: Dr Adam Locketz
Thursday, June 30th, 1:00 pm in Bloomington
Thursday, July 28th

Family and friends encouraged to attend.

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.

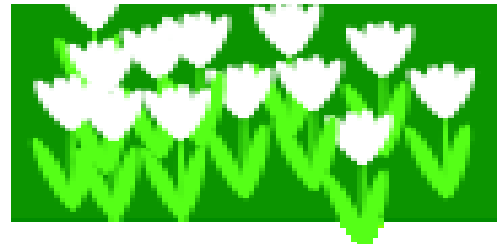
Thank you for your support!

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 2016 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 amount 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.

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 continues to look for several members to add to the Board to be in ‘training’ to oversee the Association into the coming years, and for MNA to continue to be an effective support group for our members. If this is of interest to you, please contact any of the Board members. Unless some individuals come forward to help, some other plans may need to be made.



Therapy Pools

My name is Laurie Sparks and I am the Director of Wellness at **Summit Place** Senior Campus. I am contacting you regarding your list of therapy pools on your website and I am interested in having Summit Place added. We have two pools. Our large pool has depth up to 4.1 feet and is 91 degrees. Our second pool is called a HydroWorx pool. This pool has an elevator floor reaching a depth of 6 feet and is 94 degree temperature. Contact Laurie at 952-995-1022 for details. 8501 Flying Cloud Drive, Eden Prairie

Silver Creek on Main in Maple Grove has a wellness center open to the public for people 55 years of age or better that features a 91-degree pool. Membership is \$50.00 per month plus tax and a couples membership is \$80.00 per month plus tax. There is a \$45 plus tax joiner fee, however we can waive that if the referral comes from MN Neuropathy. Contact information:

The Club at SilverCreek on Main 763-955-1758
8200 Main Street North, Maple Gove, MN 55369
cshidla@silvercreekonmain.com
www.silvercreekonmain.com

Park Shore Senior Community, 3663 Park Center Blvd, in St Louis Park – pool is 91 degrees – call Heidi at 952-848-5840 for information and monthly memberships

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MTM (Medication Therapy Management) What is it??

Doctors prescribe drugs, and pharmacists only filled prescriptions in the past. But who is looking at the big picture? Who is making sure all the drugs you take are working for you and interact well? The Medication Therapy Management pharmacist reviews all the medicine you take – including prescriptions, over-the-counter drugs and supplements.

Be safe -- you meet with the pharmacist who will confirm that the medicine you're taking is safe and effective. The pharmacist can also confirm that your medicine has no negative side effects or interactions.

Feel good--you know the medicine you take is right for your lifestyle. You don't need to worry about the long-term effects of taking several prescriptions or whether the meds you currently take have side effects.

Save money -- there are several ways you may be able to save money on your medicine. Pharmacists may recommend taking fewer drugs, find generic alternatives, or create a plan to help you get off some medicines

There are 13 MN Health systems with MTM programs, in various stages of development. Some just have one or two pharmacists providing the service, while others have more than 10. The MTM leaders of these MN health systems get together once a month and collaborate on many projects together. Here are the systems and a little about their Mission and Objectives.

Editors note: after calling a number of health systems/clinics, here is what I have learned. All the larger health systems have an MTM pharmacist/s, but it may take a bit to find him/her. He/she may work at several clinics on alternating days, or 'float' between clinics. Some of the following may work with you even if you are not a patient at their clinic. If you are a patient at one of the smaller health systems, call your primary doctor, and ask what is available, or ask for a referral.

These are the organizations that participate in the Health System Alliance for Integrated Medication Management (HAIMM) Collaborative.

Allina Health

call your Allina clinic and they will advise you as to which clinic provides this service

Essentia

Fairview

612-672-7005 or toll free 866-332-3708

First Light

Health East

HealthPartners

their program is called RxCheckup -- call 952-967-7969

Hennepin County Medical Center

Mayo Clinic

North Memorial

Olmsted Medical Group

Park Nicollet Health Services

call your clinic's family practice or internal medicine department, and ask for the MTM pharmacist.

Ridgeview Medical Center

University of Minnesota Physicians

(continued on next page)

A bit about us:

Our Mission: Advancing a culture that values pharmacist contributions within team-based care models to ensure safe and effective use of medications across our population.

Objectives:

- Support collaboration among health-systems to advance comprehensive medication management integrated into team-based care models.
- Promote policy that ensures patient access to integrated, comprehensive medication management services.
- Develop and demonstrate measurable quality standards for integrated, comprehensive medication management services.
- Disseminate our findings, efforts and experiences.

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From ANDY MOORE, of Dynatronics

Dynatronics was the first therapeutic laser company in the USA. I have worked with LLLT for over 25 years. We do not make any claims for PN, but have seen some success. You are familiar with Anodyne - they used LED's and had success with a percentage of users. They did make claims for PN and eventually got in trouble with the FDA. I have sold hundreds of LLLT devices in the area, not one had a "true laser".

We use two professional consultants-Chukuka Enwemeka and Stephen Guffey. I feel it is a disservice to your members to omit anything but "lasers" for PN. Dr. Enwemeka once told me "buying a laser, is like buying a black & white TV". It is wavelength (600-1000nm) and dosage (joules) that produced results in all the studies, not the source itself. Early studies used lasers, because that was what was available to produce light in a specific wavelength. Today, Diodes can produce the same results with greater power, safety and in greater spectrum of wavelengths. LEDs, SLDs and now surface mount diodes, create the most powerful and safe treatments.

For more information, contact Andy Moore, regional sales manager, at 1-800-874-6251.

SOLVING THE HEALTHCARE PUZZLE: THE IMPACT OF CONCIERGE NURSING!

Our April speaker, Denise Nelson

Today's healthcare system is more complicated than ever. As our population ages, individuals are living with more chronic health conditions such as heart disease, diabetes, high blood pressure, high cholesterol and chronic pain conditions. People not only want to live longer, but they are demanding better care, better health, and lower costs.

VIP Expert Nurse Consulting is a unique service making the difference in people's lives by providing one-on-one guidance where there had been a void previously between patient and care provider. A customized care program is more crucial than ever with shortened doctor appointments, the increased use of prescribing medications, and increased cost of health insurance and medical care.

As the owner of VIP Expert Nurse Consulting, LLC I have a record of achieving results such as reduction in medications, decrease in procedures and doctors appointments, reduction in pain, and improved health and wellbeing for the individual. As an experienced Registered Nurse and healthcare expert with over 20 years experience in a broad range of nursing within hospitals, clinics, and as a healthcare champion and leader, I can draw on that expertise to help the individual address personal challenges and achieve their healthcare goals.

In meeting with a client an individualized profile is created along with a plan and we work together to restore the individual to "Restored Health". Acting as a patient advocate at the individual's medical appointments critical information is communicated with your provider, important questions are asked, and the doctor is able to make timely decisions in your care plan. After the appointment, the individual is able to review with an expert nurse the key information shared at the appointment and changes to be addressed. A written report is provided. This results in increased clarity to the individual and reduced confusion with the treatment and plan. With an experienced concierge nurse VIP Expert Nurse Consulting, LLC can bring you to a higher level of health.

For a complimentary consultation, please visit "www.vipnurseconsulting.com" or contact Denise Nelson, RN - principal and owner of VIP Expert Nurse Consulting, LLC at 612-387-5532

In February we had a **Circle of Conversation** meeting, and the following are some reports

received about discussion in small groups from our 'recorders':

Recorder Ellen Lane:

1. What's the worse thing about neuropathy?
 - The loss of abilities and activities.
 - Pain which prevents sleep
 - Sensitivity to cold temperatures and feet feeling cold all the time
 - Problems with balance
 - Poor circulation causes sores on toes
 - Pins and needles and pain in feet after working all day standing and walking
2. Something good that comes from neuropathy?
 - Loss of excess weight due to medication and also as a result, greater attention to nutrition
 - Learn to swallow your pride: don't feel bad about using aids, like a cane, or asking for help
 - Acceptance of what you can and can't do. Meeting others who suffer from neuropathy at meetings like this one
3. If you could tell your doctor to change something, what would it be?
 - Have a more understanding attitude to patients and their concerns, be better listeners
 - Find a way to slow the progression of the disease
 - Do more research
 - Why do medications lose their effectiveness

Recorder Connie Schramm

- Each person in our group has experienced neuropathy for different periods of time, which range from two to over fifteen years. Each has had different and similar experiences with pain and treatments.
1. What are the worst things about our neuropathy?
 - All stated they have pain, burning, sensitivity, numbness, or balance problems.
 - Being unable to get a good night of sleep is difficult for most.
 - All are not able to be as active as in they were prior to having neuropathy.
 - Finding the correct medication and correct dosage is a problem to control pain.
 - When one has found some comfort, whether it be medication or another treatment, it has not been consistent.

- Side effects of the medication have been a problem. The doctor states there is no cure.
2. What are the good things about neuropathy?
 - All stated they have become more familiar with and careful about their bodies.
 - Exercise and diet are important.
 - Medication and treatment helps for many of our group.
 - We are not alone and have a wonderful support group with excellent speakers to educate us about resources and research.
 - We are allowed to be at the front of the line at security at the airport. (if we ask)
 3. What could we change or fix?
 - All would like to make neuropathy go away!
 - All would like to find a more trusted consistent treatment;/mediation, and better yet a cure!
 - More research!

Recorder Marilyn Martinson

1. What's the Worst Thing about Neuropathy?
 - Loss of what you use to be able to do.
 - A lot of complaints about pain, pins and needles feeling, numbness.
 - Feet were always cold. One of the ladies in our group ordered feet warmers called "Toasty Toes" or "Hot Hands" from Amazon. She showed us the little inserts she puts in her shoes to keep her feet warm. They also might have feet warmers at Cabela's or Fleet-Farm. She uses a heating pad under her feet in bed, under the bottom sheet, on low all night. She also has electric throws (small electric blanket) in every room in her house to throw over her feet and legs whenever she sits down.
 - It's hard to get to an accurate dose of pain pills such as Neurontin (Gabapentin). Everyone taking it seemed to feel his or her doctors were guessing at the amount of mg to prescribe. One doctor started patient out on low dose of 300 mg and kept prescribing higher, and because she still has so much pain, he keeps upping the dosage she takes, 3 times a day.
 - Another member was prescribed Neurontin 2500 mg 3 times a day. This was way too much for her, as side affects made her dizzy, headache and always sleepy. She told Dr. she wanted to lower dosage, and got herself down gradually to one 100 mg in the morning, one 100 mg at noon, and 300 mg

at night before bed. She was willing to handle some pain so as not get the brain fog side affects.

2. Anything Good about Neuropathy

- “Nothing” was everyone’s answer.
- Try to consider different fun things to do instead of long walks or runs, go on shorter walks and do lighter exercise until you get back in the habit again.
- Everything in moderation. Swimming, pool aerobics, playing cards, knitting, and needlepoint were a few suggestions.
- Meeting people that also have the same problems.
- Going out to lunch to keep in touch with friends. Call and talk to them on the phone.
- Doing errands earlier in the day before the pain gets worse as you get tired.

3. Change or Fix

- Partake in the research programs that the U of MN has from time to time. More research is always good and the more we can be involved in it, the faster there will be a cure. Come to the meetings when doctors and others talk about research and different help for us.
- Listen to helpful hints that we hear at each MNA meeting.
- Tell us when something helps you. Tell us about the supplements you are taking, to help you such as Vitamin B-12 to heal damaged nerves, Alpha Lipoic Acid, a vitamin-like antioxidant that slows premature aging of cells.

Thank you to all who attended this meeting, and participated in our small group discussion. And thanks to our three recorders. Wonderful reporting.

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.

See information about our February and April meetings on pages 3, 4, and 5

The following are items from the Foundation for Peripheral Neuropathy:



the FOUNDATION *for*
PERIPHERAL NEUROPATHY®

"Living with pain, I try to plan something enjoyable every day, because I find that distraction helps my pain.

I plan it as carefully as possible, considering any foods that are built into the plan, with whom I want to share the experience and as many other details as possible, because I find that the actual planning is another enjoyable distraction - as is remembering it afterwards."

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Many people living with chronic pain take prescription medication, which may cause fluctuations in weight and appetite.

- A decrease in appetite or symptoms like nausea or diarrhea, can lead to skipping meals, causing a missed opportunity to consume functional nutrients that play a role in decreasing inflammation.
- Pregablin (Lyrica), commonly used to treat neuropathic pain and fibromyalgia, can boost appetite, resulting in overeating.

It's important to be aware of all of your medications' possible side effects.

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Proper lighting in your home is very important to your everyday safety:

- Make sure your rooms are well lit. Keep a flashlight with you or within reach to use when there is not enough lighting.
- Turn lights on before you enter a room.
- Floor lights that shine light up from the floor toward the ceiling or wall can help reduce glare.
- Turn on the lights outside of your home if you plan to go out, so your walk is well lit.
- Use a key chain with a light to help you see keyholes.

cure.

Dear Friends,

Pain, numbness, lack of balance and more. These are everyday experiences for those living with Peripheral Neuropathy.

Sure, there are a handful of drugs that are supposed to help minimize the pain; they don't seem to work for most of us. Diet and exercise are important and some of us find relief from trying different complementary therapies. The challenge is that they don't cure the problem or even relieve much of the pain, numbness or other symptoms. Nearly 16 years ago, I embarked on finding a cure and today, at the age of 87 years old, I am still on my quest.

Is there hope, a path forward to finding better treatments and a cure?

Yes, there is!

We at the Foundation for Peripheral Neuropathy, along with our scientific advisory board industry experts, believe there is a strong path we can follow to find a cure and better treatments.

It is the same path being used to find better treatments and even cures for cancer and many other diseases. We see hope in the development of the peripheral neuropathy research registry (PNRR). The PNRR is the first of its kind enrolling patients with peripheral neuropathy (PN), capturing their clinical history, physical exam, and laboratory testing as well as blood (DNA, serum and plasma).

The purpose of the registry is to provide data for genomic and biomarker analysis. It will also become a resource for recruiting patients in future research studies thereby reducing the time needed to conduct clinical trials. This data, when fully populated, will be used to advance clinical and basic research in different neuropathies. The PNRR is a partnership between patients, medical professionals and the Foundation for Peripheral Neuropathy working together to better understand the cause, develop effective treatment and find a


I pledged many years ago to help find better treatments and a cure and I have had the good fortune to be able to provide funding in support of the PNRR. However I cannot do it alone.

We are already halfway to our goal of enrolling 2000 patients! We need your help to make this a reality. It costs \$1000 to enroll one patient. I am asking each of you to take the pledge and join me and our Board of Directors by helping us raise \$1,000,000 to support the PNRR and help us add 1000 additional patients to the registry.

While some of us may not see new treatments or a cure in our lifetime that should not stop us. We all can play an important role; our efforts today will lead to a future without peripheral neuropathy.

Join our mission and become a force of hope in finding new treatments and a cure by making a tax-deductible contribution of \$25, \$50, \$100, \$250 \$500, \$1,000 or more.

Sincerely,



Jack Miller

Chairman and co-sufferer

If you would like to donate a tax-deductible gift you can send your check to:

The Foundation for Peripheral Neuropathy
485 Half Day Road, #350
Buffalo Grove, IL 60089

Or you may go online to www.foundationforpn.org, and send your gift via credit card.

Note from MNA Board of Directors: This is a legitimate organization, and is the organization that took up the 'cause' when The Neuropathy Association (TNA) folded last year.

Healthy lifestyle choices are important in treating and living with peripheral neuropathy. Smoking cessation is particularly important because smoking constricts the blood vessels that supply nutrients to the peripheral nerves and can worsen neuropathic symptoms.

Physical fitness is not the sole basis of being healthy; being healthy means being mentally and emotionally fit. Being healthy should be part of your overall lifestyle. Living a healthy lifestyle can help prevent chronic diseases and long-term illnesses. Feeling good about yourself and taking care of your health are important for your self-esteem and self-image. Maintain a healthy lifestyle by doing what is right for your body.

Power of Attitude

Attitude is a little thing that makes a big difference. – Winston Churchill

There's a direct correlation between a positive attitude and better relationships, superior health, and greater success.

Some studies show that personality traits like optimism and pessimism can affect many areas of your health and well-being. The positive thinking that typically comes with optimism is a key part of effective stress management. A positive attitude can boost your energy, heighten your inner strength, inspire others, and garner the fortitude to meet difficult challenges. According to research from the Mayo Clinic, positive thinking can increase your life span, decrease depression, reduce levels of distress, offer better psychological and physical well-being, and enable you to cope better during hardships and times of stress. And effective stress management is associated with many health benefits.

Here are several ways to adopt a positive mental attitude:

1. Positive thinking often starts with self-talk. Self-talk is the endless stream of unspoken thoughts that run through your head every day. These automatic thoughts can be positive or negative. Some of your self-talk comes from logic and reason. Other self-talk may arise from misconceptions that you create because of lack of information.
2. Surround yourself with positive people. Spend time with people who are positive, supportive, and who energize you. Remember, if you get too close to a drowning victim, he may take you down with him. Pick a positive person instead.

3. Be positive yourself. If you don't want to be surrounded by negative people, what makes you think others do? Learn to master your own thoughts.
4. Control your negative thinking. This can be accomplished in the following ways:
 - See the glass as half full rather than half empty.
 - Anticipate the best outcome.
 - Stay the middle ground. Don't view everything in extremes — as either fantastic or a catastrophe. This will help you reduce your highs and lows.
5. Consciously resist negative thinking. Be cognizant of and mentally avoid negative thinking. This will help you modify your behavior.
6. Be nice to yourself. Unfortunately, some people say the meanest things to themselves. If you criticize yourself long enough, you'll start to believe it. This negativity can drag you down over time. It may be time to fire the critic and hire the advocate.
7. Set realistic, achievable goals. There's nothing wrong with setting a high bar — unless you beat yourself up for not achieving your goals. The key is to build confidence by setting realistic goals and by hitting a lot of singles rather than swinging for the fences.
8. Keep it in perspective. Life is all about prioritizing the things that matter most in your life and focusing your efforts in these areas. This means that trivial things that go wrong every day shouldn't get you down. Learn to address or ignore small issues and move on. It's time to sweat the big stuff.
9. Turn challenges into opportunities. Instead of letting challenges overwhelm you, turn them into opportunities. (Rather than hitting the wall, climb over it or go around.)
10. Count your blessings. Be grateful and give thanks for the special things in your life rather than taking them for granted. Some people do this by giving thanks around the dinner table, keeping a written journal, or posting one special item each day on Facebook. Remember, some of the greatest possessions in life aren't material. Take every opportunity to make a wonderful new memory.

It's unclear why people who engage in positive thinking experience these health benefits. One theory is that having a positive outlook enables you to cope better with stressful situations, which reduces the harmful health effects of stress on your body. It's also thought that positive and optimistic

people tend to live healthier lifestyles — they get more physical activity, follow a healthier diet, and don't smoke or drink alcohol in excess.

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

Marty and Marilyn Beer	612-869-0295	mmbeer@q.com
Michael Boland	612-751-5800	obeollain@aol.com
Marilynn Martinson	952-933-5225	mj.martinson@comcast.net
Lois Martin	952-941-5372	loismemartin@gmail.com
Treasurer: Myron Martin	952-941-5372	myronmartinmn@gmail.com

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.

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.

FYI -- Our meetings this year have been in Bloomington. The reason for that is because the Board has changed a bit when planning speakers. We are now giving our presenters the option of an afternoon meeting (1:00 pm) or evening meeting (7:00 pm). We are also giving the presenters the option of having the meeting in Bloomington or Roseville, whatever fits their schedule. So both our May and June meeting will be at 1:00 pm in Bloomington. Mark your calendars.

The Board is still looking for individuals who can become part of the MNA Board, and are willing to be 'trained' for a position on the Board. If no one comes forward, the current Board will consider what changes need to occur to keep the organization viable.

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Comments from a member who attended the Circle of Conversation: I learned some new things about medication, shared some info, and recommended electric throws to anyone who can stand extra heat on their feet (it calms the nerves). In my group, there was a nice feeling of shared experiences, and common supportive feelings. It's a good thing to do yearly.

I have some info to add to the current list of therapies: For the entry on gabapentin, add this: Dr. Scott suggested I could take less medication in the morning, so I tried this and it worked well for me. (He also told me to add a bit in the evening if I need it, but you have already included that in the newsletter.) I was thrilled to be able to reduce the amount of medication I was taking! I was also able to reduce another med in the morning.

Electric throw: if you can tolerate extra heat on your legs and feet, then an electric throw might work well to calm your nerves. With socks on, I sit with one wrapped around my shins and feet while reading and watching TV, and it helps right away. Available online.

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