



eNcouragement

The Newsletter for The Minnesota Neuropathy Association
Volume XV No. 2 Spring 2018

“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 Thursday, May 24 at 7 p.m. Watch your mail for flyer with details.



The MNA thanks all of you who have so faithfully sent in your membership contribution each year. Without, we would not be able to offer the programs, activities, 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 contributions (not when it is due). You want to see a 2018 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.

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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: www.foundationforpn.org

Minnesota Neuropathy Association (MNA)

Visit our website: www.neuropathy-mn.org

My Move to One-Level Living

by Mary McLeod, MNA Board Member

This past August, I sold my home in Highland Park and moved to a high-rise condo between Lowertown and downtown St. Paul. There was really one primary motive for this: I thought I might have some difficulty walking eventually, due to my neuropathy, and wanted one-level living, to make it easier. And I wanted to choose where to move before my kids stepped in and chose it for me! (Well, that may be an exaggeration, but it's a possibility.)

I was really only considering the move, and hadn't yet made up my mind to do it, but when I saw this condo, I leapt at the chance to buy. I'm high above the city action, on the 31st floor. This condo has about the same number of square feet as my house, so I wouldn't have to give up any living space -- although I would be one double-bay garage lighter, and also wouldn't have a basement in which to throw extra stuff! But I lightened my load, so to speak, and made the move. And don't you know, I haven't missed any of the things I gave away and threw away. In fact, I could have done nicely without some of the "stuff" I still have, because I haven't even looked at it since August. We live and learn.

And the view! I have a glorious view of the state capitol, my favorite building in the whole world, where I had held two jobs. Our capitol, newly refurbished, is lit all night long, so if I wake during the night, that's the first thing I see. It's calming and healing to me. I hadn't realized that I already knew three of the people who live there, and have made new friends here just since moving in. One of them is 102 years old, but there are young couples also, and grandchildren seen coming and going.

What do I miss, and what am I glad to be rid of? I certainly don't miss mowing and shoveling! And I had gotten a love of gardening out of my system, so I haven't missed that, either -- perhaps when tomato season is here, I'll give it a passing thought,

but the Farmer's Market is only 2 blocks away. I do miss my neighbors, but have seen one couple when they came to an open house, and another couple several times. We email, also, and I'll have lunch with one of the women in March, so they're as close as ever, in every meaningful way.

If I'm very lucky, walking will never become difficult for me, but the development of neuropathy is impossible to predict. And either way, I think I'm in a good spot for my age. I can walk in the skyways during the winter, and the out-of-doors around here is endlessly interesting in the summer. The YMCA is on my block, and my Medicare insurance will cover the cost, so there are many ways here to get some exercise -- in fact, more than I had in my house. Paradoxically, there is little to no shopping in downtown St. Paul, so I have to go to the suburbs for anything I can't buy online.

The bottom line: Am I glad to be here? Absolutely!

Socks!

(Tips from the Foundation for Peripheral Neuropathy)

It seems that comfortable socks for painful, tender feet are rare to find, and when something works, our Facebook friends stay loyal to that brand.

Here are some tips that came from our FB followers:

- Very super fine gauge and seamless work is best
- Bombas were also recommended as expensive, but worth it for comfort
- Acorn fleece socks at night
- Ducks Unlimited socks for warmth and fluff at night.
- One of our Facebook friends recommended cutting off the tight elastic top of socks, and overcast the edges on a sewing machine for additional comfort
- For soft comfort at night, a soft sheepskin throw does the trick as a resting spot for sensitive feet.

February Meeting

At our meeting on February 24, the focus was a Circle of Conversation. People shared strategies and opinions. Below are some highlights.

Susie from Plymouth told the group she's researched offerings by the Mayo Pain Rehabilitation Center, which offers both 2-day and a 17-day programs. She noted that the longer program costs \$42,000 and is held Monday - Thursday for 4 weeks. Susie said that her insurance will assist with the cost and she plans to begin the longer program later this year. We will be anxious to hear from her after she has completed this!

Although Realief didn't help the first person who brought it up, another member told the group that Realief stopped the progression of her neuropathy.

One member told the group that "Realief" did nothing and he also found it to be costly. He reported that he saw Dr. Kelm and that he had 14 treatments (the amount recommended by the clinic) at a cost of \$191 each.

Lois reported using a machine made by Zopec every morning. This involves electrical stimulation, and she believes it is helpful because she noticed a difference when she didn't use it.

Steve said that laser treatments didn't work for him, and, in fact, his symptoms worsened after starting laser treatments. He also said that he thinks exercises may help symptoms, and he believes very strongly that sugar is bad for neuropathy.

Phyllis told us that she has success with Biofreeze and Lidoderm patches. She noted that patches containing 5% Lidocaine require a prescription, but that 4% patches are sold over-the-counter.

Someone made the comment that drinking lots of liquids during the day makes leg cramps better for them.

Lois reminded us that nerves regenerate very slowly, so it may be hard to tell what is actually helping, and hard to know how long a fair trial (of any treatment) should be.

Mary reminded the group that it is possible to have two medical problems at once, so just because someone has neuropathy and some other medical issue, doesn't mean that the second issue has anything to do with neuropathy.

Mary also suggested that we use our "invisible disability" as an opportunity to bond with others who also have one, and gave the example of bonding with her son, who has schizophrenia. She pointed out that many invisible disabilities draw stigma, disbelief, doubt, minimizing, etc.

Two videos were shown featuring Vietnam Veteran Gene Richards, who developed disabling neuropathy as a result of exposure to Agent Orange. The first video's subject was the importance of patient support groups. Patients who are suffering know things -- and can share information (that doctors may not).

The focus of the second video was "Anger as Energy." Mr. Richards advised patients to believe in themselves, and remember that the problem "is not the doctor -- the problem is the disease!" He went on to say that when you feel you are not getting the acknowledgement and support you deserve from providers or others, you should use your anger to drive your feelings, which will lead to ACTION.



It is Real

By Andy Wilcox



Deep inside, it burns,
Cutting deep as glass turns,
Into bone cutting on bone,
No solution, going home.

Feel the constriction,
This is my world, not fiction.
Gasping for new air,
Relief is nowhere.

Stabbing razors in my mind,
Cut my resolve, they bind.
Take it away I scream,
What is it, asks the team.

Bend, turn and lying down,
That smile you see is a frown,
But on the outside all you see,
Is an image, a stronger me.

Is it broken, is it on fire,
Is it spasms and a cutting wire?
It is in my head, it really is,
Yet it manifests like this.

Take a step, fall to the ground,
It's what started this go-round.
The aching should have stopped,
But, I'm learning to stay on top.

Fusing, cutting, say I'm better,
I will push even harder,
My body says it's done,
But the pain has not won!

Our bodies may be broken,
But our hearts are open,
With prayers that you will see,
No matter what, I am still me.

The agony beneath my smile,
Is merely coping for a while,
Trying to master a new way,
And, yes, trying to stay sane.

No one sees the glass rug below,
The cracking from moving so.
My humor will be my sign,
When it's gone, I've run dry.

Look deeper, in my eyes,
See the weariness, the tears I cry.
An embrace, a hand, a tear,
Share with me so this, too, I can bear.

Stay with me, I do pray,
I'm not alone at least today.
You are my foundation, my mattress,
My firm footing, my longing rest.

No matter the agony, I will stand,
Knowing they can't see the sand,
Which I am walking against each day,
Trying to explain why it's my pain.

Ignore that blue card in my car,
It's not who I am, it's not my star.
I am right here, look in my soul,
I'll fight, even if I'm alone.

*Andy Wilcox (MNA Member)
– Canton, S.D., January 2018*



The way you start your day determines how well you live your day. - Robin Sharma

Did you know that the first hour of the morning is crucial? How you start your day from the moment you wake up will set the precedence for how the rest of your day will go. And how your days go will ultimately affect how the rest of your life will go.

How did you start your day today? When you woke up, what were your first words that came out of your mouth? Did you complain? Did you think about what wasn't working in your life?

The words you speak have power. They can hurt or help, encourage or discourage, build up or tear down.

Consider the language you use in your own life. Is it positive, proactive, and possibility-driven? Or is it filled with doubt and fear?

What do you say when you first look in the mirror? What do you say when you take a shower? What do you say when you get dressed? How do you leave the house for work? Do you just run out the door or do you say something nice first? What do you say when you get in the car? Do you slam the door and growl about the day or do you think positive thoughts?

Whether spoken out loud or quietly to yourself, you frame your world with the words you speak.

To cultivate a wellspring of language fueled by love and not fear, look inward. Your thoughts and

feelings directly impact what comes out of your mouth.

Adjust your focus to elevate your language.

This mental nourishment will equip you with faith-filled, life-affirming language to propel your growth and positively impact your life!

If you have a lousy way of starting your day, you're not going to have a good day. Develop an inspiring morning routine that sets in motion the best day possible and allows you to say something to yourself that makes you feel good.

- Adapted from Jack Canfield and Louise Hay



Buyer beware!

Have you seen encouraging ads in the newspaper, online and even on television, promising to be able to cure your peripheral neuropathy? The truth is there is no known cure for PN at this time. But there are a plethora of scammers out there trying to profit on your pain.

Do your homework, do not pay large sums of money on treatments making big promises.

First and foremost, check with your doctor before signing up for any new treatment, because no one understands your complete health profile like they do. Also, do research on the internet, ask to speak to former patients who have received such treatment, check with your support group leaders, and even check with us - we will be happy to share any information we have on available treatment options. *(From the Foundation for Peripheral Neuropathy "E-Tips")*

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.

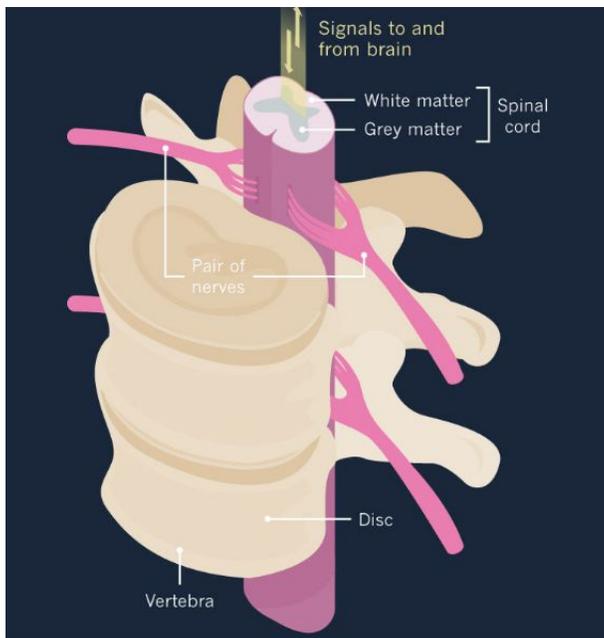
Possible good news for nerve growth?

(The following two articles are about spinal cord injuries. Though not about neuropathy, they explore the regrowth of nerves - something in which we are all interested)

Repairing the Neural Highway

By David Holmes

Nature Magazine, December 13, 2017



At present, there is no way to reverse damage to the spinal cord or to restore lost function. But regenerative therapies in the initial stages of clinical testing are offering hope.

Reconnecting brain and body

The key to restoring sensory and motor function to patients with spinal cord injuries lies in finding a way for signals to travel between the brain and the affected areas of the body once again. Some researchers are using electronics to bypass the damaged spinal cord, whereas others see promise in coaxing the body's own machinery to repair itself.

Rewiring

Advances in computer processing power, miniaturization of electronics and a growing understanding of the CNS are gradually enabling researchers to transmit signals from the brain to the

muscles without traversing the spinal cord. Neural activity in the brain can be recorded, processed outside the body and then used to induce contraction of the muscles. This bypasses the damaged spinal cord altogether, but it is still some way from clinical use.

Regeneration

There are no treatments approved for repairing spinal-cord injury or restoring lost function. However, a number of treatments are in the initial stages of clinical development. They are designed to coax damaged axons to regrow across the lesion caused by an injury.

Altered environment

The biochemical composition of the environment that surrounds damaged nerve cells affects the cells' ability to regenerate.

Introducing enzymes that break down CSPGs can help to trigger axon regeneration in mice.

Injecting mice with a combination of insulin-like growth factor 1 (IGF-1) and a protein called osteopontin can also promote nerve-cell regrowth.

Stimulating Regeneration

Factors that target damaged nerve cells directly can be introduced to boost the capacity of these cells to heal.

Next Steps

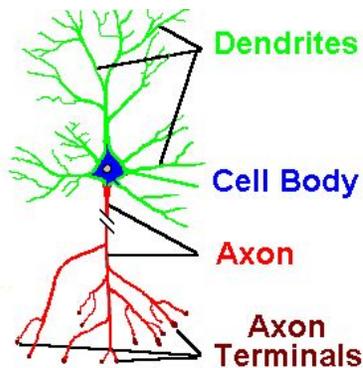
The ability to repair the spinal cord could lie in finding the correct combination of treatments to support healing across the scar — restoring or boosting the ability of nerve cells to regenerate while suppressing the inhibitory signals that are released after injury. Trials are underway — a small open-label trial of MSCs in people with spinal-cord injury was completed this year in Japan, and is expected to report its findings soon.

Spinal-Cord Injury: Spurring Regrowth

By David Holmes

Nature Magazine, December 13, 2017

The spinal cord rarely repairs itself when damaged, but ways of encouraging nerves to regrow are on the horizon.



As many as half a million people damage their spinal cord each year. For almost all of them, the injury will be life-changing. The spinal cord is an integral part of the central nervous system (CNS): nerve fibres of the peripheral nervous system project from it, relaying signals to and from muscles and organs — enabling us to move, and to feel heat and pain. But unlike their peripheral cousins, nerves in the CNS very rarely recover from damage.

As a result, injury to any part of the spinal cord can cause a permanent loss or reduction in bodily function below the site of damage. More than half of people with a spinal-cord injury have a 'complete injury': loss of function is total, with no motor or sensory function in areas of the body controlled by nerves that emerge from the spinal cord below the damaged site. The remainder of patients have an 'incomplete injury': they do retain or recover some function. In both cases, there are no approved ways of repairing the damage, and attempts to bypass the injury through implanted electronics are in their infancy.

There are signs, however, that researchers are on the verge of making crucial breakthroughs. As understanding grows about the complex interplay

between different cell types and the extracellular environment at the site of damage, researchers are increasingly optimistic that they will find a way to kick-start the regeneration that is suppressed in the CNS.

There are three broad approaches. The first focuses on altering the environment around damaged nerves in the spinal cord to remove molecules that are thought to restrict the ability of the nerves to regrow their axons — the long projections that thread through the cord and through which neurons connect to one another. The second aims to intervene in regulatory pathways within the damaged neurons themselves to take the brakes off the cells' inherent capacity to regenerate.

The third approach — and currently the closest to the clinic — deploys mesenchymal stem cells (MSCs). Preclinical studies show that MSCs injected into rats can home in on injured areas of a spinal cord. At the site of injury, the cells seem able to protect neurons from secondary damage caused by immune cells. They can also repair damage to the insulating layer of myelin around axons, promote axon regeneration and assist the formation of new blood vessels — and in so doing, restore some degree of function. They seem also able to differentiate into new nerve cells. The next challenge is to get this to work in humans. The results of a small trial of MSCs in people with a spinal-cord injury are due to be reported soon, and should give an indication as to whether this therapy can progress to larger trials.

The complex factors that prevent the spinal cord from repairing itself might mean that no one approach will be sufficient. It seems likely that a combination of treatments will be needed to support neuronal regeneration and restore function and independence to people with spinal-cord injury.



Hearty laughter is a good way to jog internally without having to go outdoors.

- Norman Cousins

Have you heard about corduroy pillows?

They're making headlines!

What do Alexander the Great and Winnie the Pooh have in common?

The same middle name.

I couldn't believe that the highway department called my dad a thief.

But when I got home, all the signs were there!

What did the left eye say to the right eye?

Between you and me, something smells!

Sometimes I tuck my knees into my chest and lean forward.

That's just how I roll!



Have ideas for the newsletter? Send to: kittywelter@yahoo.com.

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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.



How excited was the gardener about spring?
He was so excited he wet his plants!