



# eNcouragement

The Newsletter for the Minnesota Neuropathy Association  
Volume XIV – No 1 Winter 2017

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

Wednesday, February 22 – Open Board meeting – everyone invited – 2:00 pm – see below
<i>March meeting: Saturday, March 25 – 10:00 am at St Michael’s, 9201 Normandale Blvd flyer will be sent in March with details</i>
<i>Possibly a speaker about medical cannabis</i>
<b>Website: <a href="http://www.neuropathy-mn.org">www.neuropathy-mn.org</a></b>

As your Board of Directors, we want to send a friendly message to the MNA membership:

### **WE NEED NEW BOARD MEMBERS**

A rather small group of us have been keeping this organization going for twenty years, and some of us are "aging in place," others are running out of energy and/or ideas. We need some additional members to help carry the load. We would like to ease the new Board members into their jobs to keep it easy for them and have a smooth transition for all. No experience necessary. We are a group that meets in an atmosphere that is informal, relaxed and comfortable. People are involved and interested. There is usually a fair amount of discussion. Board members are committed. We try hard to really listen to each other. Differences of opinion are honored and thoroughly explored before decisions are made. People are encouraged to express their feelings as well as their thoughts.

Would you like to learn more about MNA? On Wednesday, February 22nd at 2:00 pm, we will be having an Open Board meeting. Everyone is invited. It will be held at 8100 Russell Avenue South in Bloomington (Applewood Pointe). Please RSVP to Lois at 952-941-5372 if you wish to attend, and for directions. Attend with no commitments.

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MNA had a request from the Multiple Myeloma support group for a speaker from MNA, and Michael Boland graciously volunteered to speak to the group on January 14.

Here is the response we received from the support group leader: *Michael did a wonderful job representing himself and the Minnesota Neuropathy Association. Neuropathy certainly seems to be a popular subject with Myeloma sufferers. We average about 30 attendees per meeting but 42 came to see Michael’s presentation. He didn’t disappoint. As there is no ‘silver bullet’ cure for neuropathy I found his presentation to be realistic yet positive and I’ve heard nothing but favorable feedback from our support group members.*

Thank you for suggesting that Michael speak to the Twin Cities Multiple Myeloma support group.

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*\*\*\*\*\*/I am not short. I am built low to the ground for speed and accuracy!*

Right now, we just need a few more souls to help with the work, and help generate new ideas. Our meetings occur less often than once each month. We are contemplating the idea of cutting back the number of membership meetings to 8 or 6 each year, which will also cut down on the work required. It will depend upon attendance, the enthusiasm of our members for the meetings, the number of good ideas we have for speakers, etc.

So, if you want to volunteer to join the Board, please do! If you have questions, please contact Lois Martin at 952-941-5372

P.S. We thank Ron Marien and Mary McLeod for volunteering to be Board members, but we need more MNA members to participate. We need YOU!!

## Twelve Tips to Ensure Access to Healthcare this Winter

When we think of winter, we think of chilly days, getting cozy under a soft fluffy blanket, or curling up with a warm drink and a good book. Maybe we should also consider a safety plan that will assure access to the healthcare we need.

Those of us who live with chronic pain or illness have learned to expect the unexpected. We know that our symptoms can escalate without warning. Some of us experience a worsening of symptoms during the cold and dry winter months. We may need additional medications to manage our symptoms or make more frequent visits to the doctor than usual. We need to do something to make sure our needs are met.

The following are some suggestions to make the winter months less intimidating:

1. Know what's in your medicine cabinet. Take an inventory of medications, including prescriptions and over-the-counter drugs.

2. Dispose of outdated prescriptions, vitamins or supplements by following the Food and Drug Administration's guide on "How to Dispose of Unused Medicines".

3. If a replacement prescription is needed, ask your doctor or pharmacy for a refill now.

4. Know your insurance company's policies on early refills *before* a winter storm hits.

5. If transportation or road conditions interfere with your ability to obtain a prescription, a substitute medication may be needed. Be sure to clarify with your pharmacist any differences in the medications or things to watch for.

6. Most medical practices have a cancellation policy, sometimes imposing a fee if you don't give 24-hour notice. Ask your doctor's staff about their policy when a winter storm prevents you from keeping an appointment.

7. Identify your support network in case someone needs to pick up a prescription for you or provide transportation to the doctor.

8. Get to know your pharmacist so they can help you anticipate your needs. Ask for their business card and keep it where it is readily available, especially if you are not the one picking up your prescription.

9. Check to see if a pharmacy in your area delivers. If it's not in your insurance network, check to see if your insurance carrier will make an exception under special circumstances.

10. Have information on an alternate pharmacy handy in case yours does not have the medication you need. Pharmacy inventories can also be affected by winter weather.

11. Consider using a mail order prescription plan. Paperwork from your physician may be required.

12. If you already use mail delivery for your medications, contact the supplier. Ask them how they protect your medications from extreme temperatures during shipment. Frigid temperatures can alter the potency and stability of certain medications. Even if you live in a temperate area, your medications may travel through areas that are not.

Let your doctor and pharmacist know you have an action plan and ask them for any suggestions that will assure your access to medication this winter.

Consider how you will manage your healthcare needs. If you are prepared, you can enjoy a healthier and safer winter.

From Pain News Network

*Celeste Cooper, RN, is an advocate, freelance writer and author. She is also a person living with chronic pain. Celeste is lead author of Integrative Therapies for Fibromyalgia, Chronic Fatigue Syndrome and Myofascial Pain, and the Broken Body, Wounded Spirit: Balancing the See-Saw of Chronic Pain book series.*



## Questions to ask your doctor when trying new medications:

1. How long should it take to evaluate the effect of this medication?
2. Will this medication take effect with the first dose, or does it need to build up in my system, and if so, what is the expected time frame?
3. What side effects might I experience?
4. How long should it take for side effects to subside?
5. What should I do if I begin to feel uncomfortable with this medication?
6. What is the best way to communicate with you during this trial period if I need assistance?

From FPN e-tips January 2016

### ***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.

### ***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.

## Caregiver Tips

Being a caregiver – or needing a caregiver – will affect most of us at some point in our lives. If you are chronically ill or disabled, what can you do to find the right caregiver – for yourself or a loved one – and what can you do to keep from getting ‘burnout’ if you are the caregiver?

### **Finding a Caregiver**

Be as independent as possible. But, if you are struggling with everyday tasks, getting some help can help you. Here are some general guidelines to consider before you arrange for a caregiver:

Decide if you will rely on family members or hire a caregiver. If you decide to hire someone, consider whether they are licensed and have liability insurance.

Find someone you are comfortable with. Do they communicate well? Are there language barriers? Do you enjoy their company? Form a tag team. If extensive care is needed, more than one caregiver may be needed. It can also be helpful to have a back-up in case of emergency.

Set clear expectations. Will the caregiver cook? Clean? Run errands? Make sure you have a list of duties and keep the relationship professional if you have hired someone.

### **Being a Caregiver**

Many caregivers, especially family members, report symptoms of depression, increased stress and the general feeling of being overburdened when caring for a chronically ill or disabled patient. Here are some tips to help you avoid the emotional and physical strain of care giving. There are many resources and tools available to help you provided care for your loved one

- Find a caregiver support group.
- Reach out for help in the family or community.
- Learn to prioritize your tasks so your load is manageable.
- Take care of your health. Make sure to eat healthy, get some exercise and enough sleep.
- Incorporate joy into your life. Do things you enjoy on a daily basis: listen to music, garden, go see a movie, or take a walk.
- Start a journal. Writing will help you express emotion and regain perspective.

Being a responsible patient or caregiver means taking care of yourself first. If you are the patient, your caregiver will know how to give you the most freedom possible. If you are the caregiver, you will provide compassion and healthy support for the patient as you meet your own needs.

Source: FPN – July 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.

## Another exciting opportunity

Information was sent to you about an opportunity to help Dr Kennedy at the University of Minnesota in his, and his colleagues research project. This is phase 3 of the 'bumps' test and also a continuation of the 'sweat' test that some of our members were connected with a couple of years ago.

### Test procedure:

The testing takes two hours.

There are three parts to the testing:

1. "Bumps" touch sensory testing on the finger pads. The subject locates tiny bumps on a flat surface. The smallest bump felt becomes the "threshold" value. People with neuropathy have a higher threshold than people without neuropathy.
2. Stimulated sweating is visualized, via a starch-iodine reaction, on small areas of skin with a custom-made video camera. From this video, we can determine the number of sweat pores and the rate of sweating from each pore. People with neuropathy have fewer active sweat glands that produce less sweat.
3. "Speed Bumps" sensory testing measures flutter sensation at the toes and foot and the finger pads. Like highway speed bumps, but much smaller, our "Speed Bumps" are used to determine the smallest ridge size that can be felt. When people develop neuropathy, their ability to feel the smallest ridges diminishes.

In addition, a neurologist will perform a neurological examination.

All tests are non-invasive. No blood is drawn.

Both individuals, with and without neuropathy, are needed for these tests. You go to the U of M Medical Center-East Bank Hospital, (500 Harvard St SE) where there is free valet parking and an escort will meet you to take you to the lab. Please call to make an appointment or for more information:

**612-626-6148**

PLEASE use this opportunity to further research!!

## Three types of peripheral nerves

- Motor
- Sensory
- Autonomic

**Motor nerves** send impulses from the brain and spinal cord to all of the muscles in the body. This permits people to do activities like walking, catching a baseball, or moving the fingers to pick something up. Motor nerve damage can lead to muscle weakness, difficulty walking, or moving the arms, cramps and spasms.

**Sensory nerves** send messages in the other direction - from the muscles back to the spinal cord and the brain. Special sensors in the skin and deep inside the body help people identify if an object is sharp, rough, or smooth; if it's hot or cold; or if it's standing still or in motion. Sensory nerve damage often results in tingling, numbness, pain, and extreme sensitivity to touch. Larger sensory fibers enclosed in myelin (a fatty protein that coats and insulates the nerves) registers vibration, light touch and position sense. Damage to large sensory fibers decreases the ability to feel vibrations and touch, resulting in a general sense of numbness, particularly in the hands and feet. Loss of position sense often makes people unable to coordinate complex movements like walking, holding a pen, and fastening buttons. Smaller sensory fibers without myelin sheaths transmit pain and temperature sensations. Damage to these fibers can interfere with the ability to feel pain or changes in temperature.

**Autonomic nerves** control involuntary or semi-voluntary functions, such as heart rate, blood pressure, digestion, and sweating. When the autonomic nerves are damaged, a person's heart may beat faster or slower. They may get dizzy when standing up; sweat excessively, or have difficulty sweating at all. In addition, autonomic nerve damage may result in difficulty swallowing, nausea, vomiting, diarrhea or constipation, problems with urination, abnormal pupil size, and sexual dysfunction.

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*\*\*\*\*\*I never make the same mistake twice. I make it five or six times just to be sure.*

## The Foundation for Peripheral Neuropathy (FPN)

### Mission:

**Dedicated to Reversing the Irreversible**

### Get Involved.... Donate today!

The mission of the Foundation can only be sustained through the generosity of people who share our vision to advance research and provide and improve quality of life to those living with neuropathy. All gifts, large or small, are important.

For a donation of \$30.00 (or more) per year, you are eligible for a complimentary premium membership. Our membership options offer flexible ways to get the latest peripheral neuropathy information while supporting the cause.

You may send your donation via their website: <foundationforpn.org>, or by mail to:  
The Foundation for Peripheral Neuropathy,  
485 Half Day Road, Suite 350  
Buffalo Grove, IL 60089

### 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.

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*FYI -- Our meetings in 2016 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. Our next meeting will be in March, in Bloomington.*

### 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.



*\*\*\*\*\*If you don't cut the cake in pieces, and just eat the whole cake, you had only one piece.*

### Board Members

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     |
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| Treasurer: Myron Martin   | 952-941-5372     |
| myronmartinmn@gmail.com   |                  |

The following Tips are taken from FPN E-news:

Dear Friends,

*After ten years as co-founder, President and Executive Director of the Foundation for Peripheral Neuropathy, and watching it grow into the leading neuropathy organization it is today, I announce my departure effective January 31st to pursue other opportunities.*

*Helping those living with peripheral neuropathy has been a deeply meaningful opportunity for me. During my time here I have been fortunate to meet so many wonderful folks who have shared their stories with me and who have allowed me to walk along with them in their journey; for that I am most grateful. FPN is about people living with peripheral neuropathy and we have for over 10 years made it our mission to provide the most reliable and comprehensive educational resources, raise awareness, and aid in the development of scientific innovation through our Peripheral Neuropathy Research Registry and our very successful International Scientific Symposia. The foundation remains committed to these goals and will continue under FPN's new Executive Director, Marlene Dodinval. Marlene has been with FPN for nearly two years as Sr. Program Manager, please help me welcome her to her new role.*

*The success of the FPN could not have been possible without all of you. Please continue to help us raise awareness of peripheral neuropathy, advocate for your own healthcare and participate in our fundraising campaigns so the Foundation can continue to support all of you!*

*It has been a pleasure to serve as your President and Executive Director during the last ten years.*

*With gratitude, Pam (Shlemon)*

*Editor's note: Pam was one of the speakers at our September 20<sup>th</sup> anniversary celebration!*

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*\*\*\*\*I am great at multi-tasking. I can waste time, be unproductive, and procrastinate...all at the same time.*

**Compression stockings**

Members of our community have written to us that some of them find relief from wearing compression socks/tights or even pantyhose (yes men and women). Compression stockings or socks may also provide a cushion for your feet against sudden injury.

*NOTE: It is imperative that you check with your physician before using compression socks or tights because there are some conditions under which their use is not recommended and could be harmful.*

No remedy seems to work for everyone, but this could be something new to try!

**Use extra caution in the kitchen**

If you have loss of sensation in your hands, it's wise to use extra caution in the kitchen when handling hot, sharp, or heavy objects. Here are some tips to help keep you safe:

- When cooking, use potholders or oven mitts to remove hot pot lids, hold pots steady while stirring the contents, or move hot pots and pans around the kitchen.
- Install oven rack guards, and wear oven mitts when moving items into or out of the oven.
- Use both hands to lift hot or heavy items, or carry hot dishes on a tray or cart if that makes it easier.
- Keep knives in a butcher block, or use knife covers to help prevent accidental cuts.
- Set knives aside for washing separately, and use extra caution when washing them.
- Wear rubber gloves when washing dishes or using any cleaning products.

**Alpha lipoic acid**

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.

## **SCRAMBLER THERAPY**

*by Dr. Thomas Smith and Dr. Charles Loprinzi*

### **What is neuropathic pain, from the non-expert oncologist's point of view?**

The way we think of it, pain is about the most protective instinct and impulse known to humans! If you touch a hot plate, you retract your hand even before you actually feel the pain. Then, the pain comes – very localized – such that you can plunge the hand into cold water. After that, usually the pain goes away and you can then blame your son-in-law for leaving the hot plate on. But sometimes, the pain signal gets stuck in the “on” position, even though your hand has healed. There has been some damage to the nerve endings, and they are continuing to send the “pain” impulse when it is not doing you any good. The pain pathways in the spinal cord and the brain actually get bigger and more active; neurologists call this “wind-up.”

Pain has come to the attention of most oncologists because we CAUSE it with chemotherapy agents; we call it chemotherapy induced peripheral neuropathy (CIPN).

For the unfortunate 40-70% of chemo patients who get CIPN, it can range from being a nuisance to being life-destroying. Our patients describe constant burning or pins-and-needles pain, with numbness and tingling. It starts in the longest nerves that go to the hands and feet first, then progresses upstream. For many people it is just an inconvenience, and goes away in between chemo cycles and abates after treatment. But for others it persists, for years.

Preventing or treating CIPN has been frustrating. We both were part of the American Society of Clinical Oncology panel that made national clinical practice guidelines for CIPN. There are no drugs proven to prevent it, and alpha-lipoic acid, Vitamin A, natural products, L-carnitine – things that help in other neuropathies – were no better than placebo. Only one drug is proven to help, duloxetine (Cymbalta), with a reduction in pain of about 1 point on a 10-point scale.

Of course, there are other neuropathic pains that oncologists know all too well. The pain from a pinched nerve leaving a collapsed or damaged vertebra, shooting down the leg. The pain after shingles, “post-herpetic neuropathy” that can last for years. The pain after chest surgery, or mastectomy, or radiation.

## **What is Scrambler Therapy, and How Does it Work?**

Scrambler Therapy (marketed as Calmare™ therapy in the United States) is a new type of pain relief that uses a rapidly changing electrical impulse to send a “non-pain” signal along the same pain fibers that are sending the “pain” stimulus. We got interested in Scrambler Therapy because we thought it MIGHT help CIPN patients, and Scrambler Therapy appeared to be non-toxic. It had been cleared for safety by the FDA in 2009.

We were skeptical, but we did a trial of Scrambler Therapy. We treated 16 patients with refractory CIPN (present for at least 6 months, and refractory to medications); the group had a 60% reduction in their CIPN pain – in 10 days of treatment. Of the 16 patients we treated, essentially all reported some benefit, including 4 whose pain resolved to “0.” Function improved in most patients including less interference with walking and sleeping, for at least 3 months.

EKG electrodes are used to transmit the electrical impulses from a colored electrode to a black one, back and forth. The treatment is given for 30-45 minutes for up to 10 days in a row (excluding weekends). Our patients report a feeling like being bitten by electrical ants, or bee-stings. If the treatment is working, the sensation will change to a “hum” in the nerve and go to the ends of the nerve. We have to start above the painful area – remember, we are trying to replace the pain with a “non-pain” stimulus, and sometimes can work progressively down the legs and arms as pain relief occurs.

Colleagues at Mayo Clinic were skeptical and repeated the study in a larger group of people with CIPN. Pacman, Loprinzi and colleagues at Mayo reported about a 50% reduction in pain, numbness and tingling lasting at least 3 months. Of note, there appeared to be a learning curve, with the later patients getting better and longer lasting pain relief.

We will be the first to note that Scrambler Therapy lacks the “Good Housekeeping Seal of Approval” of cancer treatments – the well-designed, large, high statistical power, randomized controlled trial. We are both doing randomized trials, comparing Scrambler Therapy to “sham” therapies: electrodes in the wrong place and to TENS (trans-cutaneous electrical stimulation).

That said, we are interested in treatments that might work and don't cause side effects. A recent review of at least 20 scientific reports noted no harm in any trial, with most reporting a substantial relief of pain. The two randomized trials comparing "sham" to real Scrambler Therapy showed a 50% reduction in low back pain, and a 91% reduction in pain from failed back syndrome, post herpetic neuropathy, and spinal cord stenosis. In all the trials, pain relief – if it happened – was obvious in the first 3 days, continued to get better, and usually lasted several months. There are additional reports of Scrambler Therapy having success in cancer somatic pain including bone and visceral metastases, complex regional pain syndrome, pediatric cancer chest wall pain, and others (see list below). The US Military has 17 Scrambler Therapy machines for treating both wounded warriors and civilians.

Some types of pain for which Scrambler Therapy has been used

- Pancreas and abdominal cancer pain
- Chemotherapy induced peripheral neuropathy
- Non cancer pain such as neuropathic back pain
- Post-herpetic pain (shingles pain)
- Bone metastases
- Spinal cord stenosis
- "Failed back syndrome" – after surgery, the back hurts worse
- Complex regional pain syndrome
- Post-mastectomy pain

**Is Scrambler Therapy Related to Anything Similar?**

Scrambler Therapy looks superficially like TENS therapy. TENS applies similar electrodes on the skin and passes a pulse of electrical current between them. TENS is a completely different type of on-off current, and, classically, the effect wears off as soon as the electrodes are removed. When Scrambler Therapy works, it seems to reset or reboot the system for an extended period of time. Spinal cord stimulation appears to have a same effect on pain that Scrambler Therapy appears to have. However, it involves putting electrodes on the spinal cord, and implantation of a pulse generator, similar to a pacemaker. It is also expensive – typically near \$100,000 for a trial, then surgery and the equipment. It can last for years.

**Is Scrambler Therapy Covered by Insurance?**

Quick answer, no, not very well yet. They are waiting for more traditional evidence (unlike the U S Military!) Some places are doing it for free on the

clinical trials listed on [clinicaltrials.gov](http://clinicaltrials.gov). There is a list of certified centers on the Calmare website. An increasing number of insurers are paying for Scrambler if the person and their doctor appeal with lots of evidence from the trials above.

The machines themselves are expensive (\$105,000 was the last quote we got) but can be used for a new person each hour, and last for years. The electrodes cost \$4-15 dollars per person for a course of treatment. A person with training can do the treatment supervised by a physician with knowledge of the nervous system.

**What research needs to be done before Scrambler Therapy is proven effective, and reimbursed if it is?**

We have been using Scrambler Therapy routinely at our centers, and believe there is benefit to some patients. At the same time, we are humbled by the many therapies that have shown promise in phase II trials only to be no better than placebo or sham in Phase III trials. We need bigger randomized trials, sponsored by the NIH or someone who is not trying to sell the machines.

*Dr. Thomas Smith is the Director of Palliative Medicine, Harry J. Duffey Family Professor of Palliative Medicine, Johns Hopkins Sidney Kimmel Comprehensive Cancer Center*  
*Dr. Charles Loprinzi is Regis Professor of Breast Cancer Research, Mayo Clinic*

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Sunday, March 12  
 Daylight Saving Time Begins