

Magnesium for EM...Who Knew?

An amazing breakthrough has been found by our members Dr. Jay Cohen and Karl Granat. They both have realized great results in taking magnesium as a supplement to their other medicines. While the trials on this treatment are still underway, it's important to note that taking this mineral is not without side effects, and as for all treatments, it should be used under the supervision of a doctor.

So far, it has been noted that by taking large doses of Magnesium daily, both Karl and Jay have realized enough relief that they are both back on their feet and have regained normal activities to some extent. However, it has only been through their searching for magnesium types, amounts, and methods to take them, that they were able to work up to the larger doses that made the difference. And this took several months. They are both under the care of their EM savvy physicians, and are carefully undergoing this trial treatment for now. As this breakthrough develops keep an eye on the egroups conversations to follow the progress more closely. It's exciting, but caution must be used whenever considering additions to your daily régime of medications or treatments.

Introducing the Una-Boot

One of our egroup participant's has tried, and recommends, another interesting therapy for the relief of EM... the "Una Boot." This is a new therapy used in the relief of sores caused by diabetes, but is found to be helpful in other needs of aiding the circulation in the feet. While it's not actually a "boot," it is a layering process of zinc-oxide cream and bandages, applied by medical professionals. Check with your doctor about it, if you are interested. However, in addition to this applied wrap, there is another type available that can be used by the patient at home: the CircAid Thera boot. You can find more information about this product at: <http://www.circaid.com/products/Thera-Boot.htm> This wrapping process is similar to the use of support stockings for aiding in easing the swelling caused by EM, and is not just for treating open sores. Many of our members have found that the elastic properties of the tight stockings provide great relief from some of our EM symptoms. If you are interested in learning more about it, please visit the egroups site <http://www.egroups.com/group/EM> and search our EM archives for the "una boot." OR... write to us and we will be happy to help you find the information.

Traveling The Globe With EM

How many times have you canceled a trip or turned down an opportunity to even try to travel because of the symptoms of EM? You are not alone. Many of us have, wishing later that we had tried to go along. Read on to hear about how some of our member's "survive the trip..."

- Take along devices to help you cool down: small ice packs, personal sized fans (battery operated), umbrellas, sun hats, etc. There are cooling garments available that fit the hands or feet, as well as the whole body. There are several members that rely on these on a daily basis as well as during travel.
- Drink plenty of cool water. Not only will the hydration help you feel better, the cool liquid helps keep you cooled off.
- Plan plenty of breaks for exercise, to help aid the circulation. This is easy while in a plane, since you can usually get up and stroll around the plane's cabin. While driving, you may need to pull over for these breaks.
- Plan for relaxation. This may sound a little silly when you are planning a vacation... yet, how many of us try to cram as much into our limited vacation time as possible only to arrive home exhausted! Learn to say "no" when the event of the day is not possible for you. It may be hard to miss out on something fun, but not as hard as facing the pain of an attack.
- Bring along plenty of "props" to help elevate the affected limbs. Pillows and cushions work well, but don't rely on the airlines to provide them, bring what you will need. Airline pillows are usually very small, and there is a limited supply of them. If you are planning to watch an event and need to elevate while sitting, small camp stools are handy to use and small to pack along. While riding in the car, I sit sideways on the seat so that my feet are elevated.
- Make prior arrangements with the airlines or travel mode company to help you on or off the vehicle. Many provide wheel chair service to help you make it through the large terminals.
- Spread out the amount of travel to be done in one day if possible. Plan your trip with reasonable expectations in mind. If walking is a problem, reserve an electric wheelchair (this wonderful device truly saved the day for me at Disney World!). If sitting with the legs in a dependant position is a problem, plan time for having them elevated. Plan to deal reasonably with jet lag, it's a very real problem and can ruin a trip if not handled well.
- Plan to pack your medication with you at all times. You don't want to be left "stranded" and without your medications while the airline is searching for your lost luggage. Write down what medications you are to take, and when, so that the people with you can help remind you. Take copies of your prescriptions along with you and keep them with the medications at all times. It is not only a measure to insure accurate replacement should you need more, but some countries require copies of your prescriptions in order to allow you to transport them in their country.
- If visiting a foreign country, watch out for foods that cause vascular constriction or dilation, exacerbating your EM. Pack along some safe snacks and drinks.

If you are fairly new to having EM, don't be shy to ask us for help! There are many TEA members around the world with travel experience that would be happy to offer help or

advice in planning your trip. Don't forget that stress can exacerbate EM, and while the physical stresses of a trip are a factor, the mental ones are just as important... so don't hesitate to ask.

The Research Fund is Growing!

As of July, we have a total of \$16,300 earmarked for research, between the two funds (N.O.R.D Fund, and our TEA dedicated account). The goal is to reach \$35,000 by the end of this year, but the truth is.... we actually need more than that to really get started. N.O.R.D requests proposals from the Medical Community at the \$35,000 amount, but there is no guarantee that the research could be done for that amount. TEA is looking for help in applying for grants or in fundraising. Unfortunately, we don't have the funds to employ someone to do this, as all positions are volunteer. However, all help is gratefully appreciated.

If all Else Fails, Try Plan "B?"...making a usable treatment plan

Few things in our lives require us to write out a detailed plan in order to follow, for a course of time. However, this is one of the best ways to ensure an accurate record of a progression of events. So why don't we do this more often? Especially in the case of our health and future welfare, why not have a good solid plan to begin with? Well, I'm as guilty as anyone, and seem to believe that my memory will suffice when it comes to remembering things I've tried and things I haven't... but who am I fooling? While I have a pretty good memory, I certainly don't have all the necessary components "logged" into my mind that could help my doctor understand my health situation and habits.

What I'm talking about is a good treatment plan for EM. I mean, "why do I expect success in eliminating my symptoms when I really don't have much of an idea about the exact path I'm taking to achieve it?" What would really be helpful to my doctor, and myself, is a detailed diary, and file, looking something like this:

- Record of meals, amounts of items eaten and drank, and noting the time of day.
- All medications taken, dose amounts, time of day taken. Include all "over the counter" medications, like aspirin and vitamins.
- Notes on any symptoms or reactions on a per day basis, including any allergic reactions.
- Records of any EM symptoms, including a recording of the types of pain, severity, and duration. Also record anything that helped terminate an attack, relieve a symptom, etc.
- Copies of all tests taken; i.e., blood tests, hair analysis, neurological exams, etc. If you keep the copies, then it's easier for you to refer to them in the future, rather than requesting them from the doctor's office each time they are needed.)
- Brief details on any environmental conditions, i.e., temperature, season, time of day, EM exacerbates, external stresses, etc.

- Brief details on any physical conditions, i.e., amount of sleep the night before, amount of rest, standing, sitting, working, walking, or any other physical activities.

After keeping an accurate and continual journal, not only will the doctor have an important tool to work with, but you should have a much better picture of your health and body. Not to mention the valuable record you will provide in the event that EM is hereditary. Once your daily pattern is established, you can then work with your doctor to introduce new medications, eliminate others, and just generally be able to create your own medical plan, along with having a good contingency plan at the ready. ...Then, if all else fails, you can always try Plan "B"... now that you have one, of course!

T.E.A. for Two

Meet Lennia Machen

FootSteps: Introduce us to your family.

Lennia: "My husband and my 2 children, are all my best friends and the people I most like to spend time with. In addition to these 2 kids that still live at home , we have 5 adult step-kids, 3 spouses, and 5 grand kids. Our family get-togethers are big and festive, and that doesn't even count Gary's 5 siblings and all their families, his parents, and my side too!"



FootSteps: Tell us something about yourself that is special to your life. What is your favorite way to spend time?

Lennia: "One of my favorite activities is writing, and reading... learning new things and Bible study. The next grouping of favorites all take me outdoors to ride horses, snowboard, garden, go boating and camping, and just generally anything in the wonderful playground that we live in here in Eastern Idaho. I have a view of the Grand Teton's out my office window, and Yellowstone Park 100 miles North. In between, there's thousands of acres of "backyard" for us to enjoy and play in... all beautiful, and all amazing. What more could I ask for?"

FootSteps: Tell us a little about your past, special skills, sports, hobbies, trips you've taken, or anything that you are glad that you did earlier in your life.

Lennia: "Ironically enough, I spent my youth in the cold. Being a competitive figure skater, 4 to 6 hours a day training in a 40 degree ice rink was an average day. Multiply that by 10 years of training, plus 12 years of teaching... it's no wonder I am dealing with flaring... my body had to heat up sometime! All kidding aside, I did spend a lot of my life learning to perform and teach ice skating in Portland, OR (yes, I knew Tonya Harding). My teaching career was very enjoyable but unfortunately was cut short by the logistics of needing a full time career after moving to Idaho. This turned out to be a tremendous blessing in disguise because the change in occupations ultimately led me to return to school and get my Bachelors degree this past Spring. I have returned this Fall to begin an MS in Human Resources, Training, and Development. My plan is to write class curriculum and lesson plans from home for either corporate or secondary education. I entertained going back to teaching, but had to face facts that standing in front of a class wasn't going to work too well with EM. Nevertheless, I really enjoy writing and hope I can become good enough at it to make a living.

More recently, I traveled to China to visit my step daughter who lives and works there. It was a true adventure and great fun. I'd love to go back and stay longer, everything was so very fascinating to me. The food was great, the people warm and friendly, and I loved seeing such a

different environment."