Points of interest

- Your continued donations have kept this Newsletter and NEMSN alive. Please keep those donations coming no matter how large or small. Our thanks.
- We do appreciate all the letters to the Editor and hope that you keep writing. We look forward to your letters and comments.
- We are interested in your story. Please take the time to write it and send to us for our newsletter.
- If you have not seen our web site yet, it is very informative.
- CHECK OUT WWW.NEMSN.ORG

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National EMS Network Newsletter

NEMSN is extremely pleased to announce the addition of another physician to our Medical Advisory Panel - Kim Sing Lo, D.O. of New York City. He is a clinical doctor who has experience treating EMS patients. Welcome, Dr. Lo.

Kim Sing Lo, D.O., is board certified in Osteopathic Manipulative Medicine (OMM) by the American Osteopathic Association. He has been in private practice in New York City from 1994 until his recent retirement in 2015.

Kim Sing Lo, D.O. has also held several teaching positions. He served as Assistant Professor of Osteopathic Manipulative Medicine at the Kirksville College of Osteopathic Medicine in Kirksville, Missouri (the world’s foremost institution of osteopathic medicine) from 1991-92. From 1992-94 he was Assistant Professor at the New York College of Osteopathic Medicine. Besides that, he has taught osteopathic intern physicians and students at Lutheran Medical Center in Brooklyn, NY.

Dr. Lo was a recipient of a 1990 research grant from Burroughs Welcome and Mead Johnson to study the effects of Osteopathic Manipulative Treatment on patients with fibromyalgia.

To find other physicians who have been trained in the same way that Dr. Lo was, he recommends this website: www.cranialacademy.org

Note from NEMSN: Dr. Lo treated one EMS patient during epidemic times, and this person’s symptoms improved under his care. More recently, for the past 15 years he regularly treated one more EMS patient, who credits him with saving her life and giving her back some of the functionality that was taken away by EMS. Dr. Lo has treated many others with conditions that have overlapping symptoms with EMS, such as fibromyalgia, and various autoimmune and musculoskeletal conditions.
From the Editor

New Article on EMS by Dr. Gleich

Gerald J. Gleich, M.D. has just written a new informational article on EMS, which will soon be published online at http://apfed.org/, website of the American Partnership For Eosinophilic Disorders (APFED). The article is a result of recent connection between NEMSN and APFED. Dr. Gleich has encouraged this cooperation. Besides being a member of NEMSN’s Medical Advisory Panel, he is on APFED’s Board of Directors. The APFED website itself is an excellent resource for anyone suffering from eosinophilic disease. It is a place to get up-to-date, relevant information and even to find doctors.

Dr. Gleich’s new article sets forth the history of the 1989 EMS epidemic. It summarizes the disease itself – what is known about EMS and the kinds of issues that remain unknown. It describes the similarity to another disease that appeared as an epidemic in 1981, the Spanish toxic oil syndrome (TOS), which was caused by contaminated cooking oil. Dr. Gleich states that the contaminant which caused EMS has never been identified, and he quotes a paragraph from an article by Edward Belongia, M.D. (also on our Medical Advisory Panel), which agrees that there is hence no awareness of the cause and effects of the disease similar to EMS/TOS will recur. Hopefully some of the lessons learned will be remembered by physicians/scientists at that time and the path of investigation resumed."

APFED’s Executive Director, Mary Jo Strobel, says that Dr. Gleich’s article will appear on the organization’s website in early 2016. We hope that this is the first of many cooperative projects between NEMSN and APFED. We’ll keep you posted.

We are missing addresses for many of our members as they have moved and not let us know of their new address. If you know of anyone who is not getting our newsletter, please let us know their new address, phone numbers and e-mail addresses.

Mission Statement

The National Eosinophilia-Myalgia Syndrome Network, Inc., is a non-profit organization dedicated to helping EMS survivors and their families by offering educational information and peer support. NEMSN is also committed to encouraging research to improve treatment for L-tryptophan-induced EMS and to increasing awareness of the cause and effects of the disease.

DISCLAIMER

The NEMSN does not engage in the practice of medicine or law & does not claim to have legal or medical knowledge. All persons should seek the advice of their own lawyers & medical professionals. Opinions expressed by individual writers herein are those of the writers and not necessarily those of the NEMSN Board of Directors or its committee or subcommittee heads, nor of the Editor. Information is intended merely to inform readers. Drugs & treatments & legal issues should be discussed with readers’ own physicians & attorneys.
How Does Your Diet Affect How You Feel?

by Jinx Engstrom

Hippocrates said, “Leave your drugs in the chemist’s pot if you can heal the patient with food.”

Research has not provided a lot of facts about EMS to help us cope, but everyone agrees that it is an inflammatory illness. Nobody has a cure for EMS or inflammation in general, but I have been exploring the idea that the food we eat can make the inflammation worse. Theories abound about which diet is the best anti-inflammatory diet. I am not advocating one book over another but I would like to share with you some of the foods that many are claiming are pro-inflammatory so should be avoided by those of us with inflammatory illnesses.

1. Refined white sugar and high fructose corn syrup are two foods that should be avoided. Too much sugar can increase cytokines in the body, which increases inflammation. It is important to read labels because some processed foods have sugar or corn syrup added, which you would normally not expect. Vegetables and vegetable products like soups often have sugar added. Fruits and fruit juices often have sugar added even when the fruit is already sweet. Refined sugar and high fructose corn syrup are cheap and can be added to flavor a lower concentration of fruit juice.

2. Trans fats are another food to avoid. If a label says “hydrogenated” or “partially hydrogenated” fat, look for something else. The Mayo Clinic says that trans fats can induce inflammation by damaging the cells in the lining of the blood vessels.

3. White bread and other refined grains are digested rapidly in the body and turn into simple sugar, which in turn increases inflammation.

4. MSG (monosodium glutamate) is a flavor enhancer that causes inflammation, although how it causes inflammation is not understood. Since many people are trying to avoid MSG, the food industry has separated out the free glutamate and it appears in food as natural flavoring.

5. Cottonseed oil was originally developed as a way to use a waste product to produce machine and lamp oil. When the market for lamp and machine oil faded, the industry found a way to continue to sell the product for processed foods. Many people get an inflammation of the intestinal tract from eating foods containing cottonseed oil. Again, read the labels on your food. Many crackers, cookies and other commercially prepared foods are using cottonseed oil. I believe that as manufacturers received the message that people are avoiding trans fats, they have replaced them with cottonseed oil because it is cheap. Also the growing of cotton is not regulated as a food so chemicals which are not allowed for food, are used on cotton.

6. Gluten is a component of wheat that can cause inflammation for some people. The form of wheat that we have in this country is higher in gluten than it used to be. In the middle of the 20th century an American biologist named Norman Borlaug developed a higher gluten type of wheat in an effort to provide a higher protein diet for the poor people of the world. He received a Nobel Peace Prize for his research. He may have also created a food that our bodies cannot digest without creating inflammation. Some people claim that the sour dough process may make the gluten more easily digested.

7. Bovine hormones in milk and meat can cause inflammation. Some sources for meat and dairy are hormone free.

While trying to avoid these pro-inflammatory foods, what are the anti-inflammatory foods that will help us?

1. There is less agreement on this issue but all agree that four or five servings of fresh or frozen vegetables a day is helpful. Some say they should be eaten raw, others say they must be cooked and others say it is important to have some of each. You decide which is right for you.

2. Three servings of fresh or frozen fruits or berries per day is helpful.

Continued page 8...
Kim Sing Lo, D.O., an osteopathic physician who specializes in the hands-on treatment called Osteopathic Manipulative Therapy (OMT), has just joined our Medical Advisory Panel. It is welcome news to have this great clinical doctor as a NEMSN advisor. He joins our other distinguished panel members, EMS epidemiologist Edward Belongia, M.D. and eosinophilia expert Gerald J. Gleich, M.D. Dr. Lo has been my own clinical doctor for over 15 years and has treated each and every EMS symptom as they have come up. Early on in the 1989 epidemic he treated another EMS patient, and this person also improved under his care.

In the United States, full-fledged doctors have either the initials M.D. (Medical Doctor) or the initials D.O. (Doctor of Osteopathy) after their names. M.D.s and D.O.s may go to the same medical schools and have the same specializations - internal medicine, obstetrics and gynecology, neurosurgery, cardiology, neuromusculoskeletal medicine, etc. They can both work in hospitals and prescribe medicine. D.O.s are trained to regard the body in a more holistic manner than M.D.s, with more emphasis on the consideration of the entire body and the whole person. A small percentage of American D.O.s, and a much tinier percentage of M.D.s, specialize in Osteopathic Manipulative Technique, "OMT", a hands-on way of treating illness and malfunction in the body. Certification in OMT requires a physician (who of course already has an extensive medical background) to put in a minimum of five years of extensive training in hands-on techniques, closely supervised.

By the way, osteopathic medicine is an American invention. In 1892, Dr. Andrew Still developed osteopathic medicine and founded the first osteopathic medical school, in Kirksville, MO. This institution continues to thrive today as A.T. Still University, Kirksville College of Osteopathic Medicine. According to the university website (www.atsu.edu), "Osteopathic medicine is a unique form of American medical care that was developed in 1874 by Andrew Taylor Still, M.D., D.O. Dissatisfied with 19th century healthcare, Still founded a philosophy of medicine based on ideas that date back to Hippocrates, the Father of Medicine, and which focuses on the unity of the body. Dr. Still pioneered the concept of wellness and identified the musculoskeletal system as a key element of health."

When fully trained, a practitioner of OMT can, with his or her hands, feel subtle movements within a patient's body. These include the constant rhythmic and cyclical motion of the cerebrospinal fluid in the central nervous system, and the movement of lymphatic fluid throughout the body, along with a lot more. When there are restrictions to these movements, there is detectable tightness in the body. Adverse effects to health can be profound. The physician trained in OMT can, with a very gentle manipulation of the patient's body or a gentle physical pressure exerted, relax and relieve tightness and pain. When the treatment's typical deep physical relaxation is achieved, healing is promoted. The body has a chance to work more normally again.

In my case, before meeting Dr. Lo I had gotten no help for my EMS symptoms from other doctors. My health had sunk far and seemed to be going down with increasing momentum, month by month, as more and more body parts malfunctioned. Finally, thanks to a family connection, I decided as almost a last resort to try something new and strange to me - osteopathy. I began having regular treatments by Dr. Lo. By this time I was experiencing such a myriad of difficult symptoms and I was in constant, great pain. Little by little, Dr. Lo's osteopathy helped me improve in many ways. I believe he saved my life. One example of a symptom from those days that was totally banished by osteopathy, was the shortness of breath that had been plaguing me for over a year, though no doctor had found anything wrong with my lungs. Osteopathy, however, relieved the tightness and clenching in my upper body, and this allowed the lungs to work normally because they were not being restricted anymore. The shortness of breath disappeared after a few treatments, never to return.

Over the years, as new or returning symptoms presented themselves, Dr. Lo, undaunted, worked on everything. I'll never forget how I (a composer/musician) despaired when suddenly, overnight and without warning, a great deal of hearing went out in one ear. Hearing tests by an ENT...

"Friends Supporting Friends"
Osteopathy - Help For Some EMS Patients  
*continued from page 6*

doctor confirmed the loss. This ear doctor ordered scans and other tests and really tried to figure out what had happened. He came up with nothing and advised me to get a hearing aid since I was having difficulty hearing even normal conversation. I didn’t do as he said but brought the problem to Dr. Lo. He worked hard to release the physical tightening of the soft tissue inside my head, near my ear. Right after the fourth treatment, my hearing popped back, in an instant. It has not gone out again. There are many examples like this I could give. The explanation from my osteopathic doctor as to what happens with my EMS body has always been pretty much the same, though. When the soft tissue (muscles, connective tissue, etc.) tightens up too much, right around a body organ, the organ itself may malfunction. Osteopathy can remove or lessen the tightening and clenching, permitting the organ to work right again.

Osteopathy is no cure for EMS. The EMS body can relax with treatment, but unlike the typically healthy body, it then tightens up again. For me, symptoms and attacks keep coming on. Osteopathy has been the only way I’ve found to get through whatever happens and then to also improve afterward. Osteopathy, along with the constant swimming/stretching I do, have also allowed me to get stronger in some ways over the years. Oh, and did I mention that when body tightness is relieved by osteopathy that pain goes way down? This part of treatment is just wonderful! The body is given a respite from pain and tightness. With this relaxation there sometimes is a chance for long term repair and healing, even with EMS.

There are websites that describe in detail what physicians trained in OMT can do and how they do it. You can have a look at the site of my current doctor, Junella Chin, D.O., another gifted physician, who took over Dr. Lo’s practice when he retired. Dr. Chin had already been doctor to about a half-dozen diagnosed EMS patients, before I came along. Her website contains, among much other useful information, a section on what a treatment session is like for the patient. Check out:

http://www.manhattanosteopath.com/treatment-sessions.html

For an in-depth explanation of hands-on osteopathy, see another site that Dr. Chin is connected with: www.osteohome.com

If you want to try hands-on osteopathy, make sure you find a real physician who is trained in OMT. There are others who know some techniques and may even call themselves osteopaths, but who are not doctors. Being treated by someone who lacks the extensive medical training that a physician has may set you up for ineffective or even harmful treatment.

To find a physician, hopefully geographically close to you, who is trained as Dr. Lo was trained, he recommends: www.cranialacademy.org

Dr. Lo has been known to consult with other osteopathic physicians about treating EMS patients. If you’re seeing an osteopathic physician and want him or her to communicate with Dr. Lo, please contact NEMSN. Likewise, if you have questions for Dr. Lo about osteopathy please contact us. If you don’t use the computer but would like more information, please phone or send a letter.

**In Memoriam**

Doris Elene Decker of Nida, Oklahoma  
12-03-31 - 11-27-15  
Our condolences to her family.
Letter to Dr. Oz Gone Unanswered

Even though there is evidence that the supplement 5-HP (which is chemically similar to L-tryptophan) is causing EMS or an EMS-like illness in some people who are taking it today, Dr. Oz continues advocating for its use. Here is one of his 5-HP web pages:

http://blog.doctoroz.com/is-this-right-for-you/5-htp-is-this-right-for-you

In June of 2015 NEMSN’s board sent the following letter to Dr. Oz to ask him to reconsider his position on taking 5-HTP. The letter was confirmed delivered by the US Post Office. NEMSN also made an attempt to follow up, re-sending the letter. Dr. Oz has not replied. Anyone who feels that Dr. Oz should not be advocating for using 5-HTP is urged to write to him, too. He is on the medical faculty at Columbia University in New York City at the address below.

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June 18, 2015
Mehmet Oz, M.D.
Columbia University Medical Center
Milstein Hospital Building
177 Fort Washington Avenue, Suite: 7-435
New York, NY 10032

Dear Dr. Oz,

The National Eosinophilia Myalgia Foundation respectfully asks you to stop endorsing use of the supplement 5-HTP, because there are continuing risks of developing Eosinophilia Myalgia Syndrome (EMS) from taking current 5-HTP and L-tryptophan supplements (chemically similar to 5-HTP).

In 2013 the medical journal Reactions Weekly published an article reporting several new cases of EMS from current 5-HTP:

http://www.atout-org.com/p2l2013/abstract_display?fr!!!!487a1a72-7fab-1030-b866-9251dd645b9d!bc9884ec-

d673-1030-b866-9251dd645b9d

In 2011 the medical journal Arthritis and Rheumatism published an article on a new case of EMS from current L-tryptophan supplements.


The NIH itself also warns of the risk of EMS from 5-HTP and that it is only "possibly safe”.


Besides all this, our organization receives regular reports from consumers who have newly come down with an EMS-like disease which they attribute to 5-HTP supplements or L-tryptophan supplements. The report on this group is that they are suffering anything from annoying symptoms to disability to death. Doctors themselves in general know little of EMS and so a diagnosis is difficult to come by. There are some very sick people we know about, who have been diagnosed with nothing at all.

Dr. Oz, one of your own web pages states that "5-HTP is mostly safe for short-term use. . ." and that EMS "comes from impurities in some L-tryptophan or 5-HTP supple-
ments", and that the way to avoid illness is to "make sure you’re taking good quality 5-HTP supplements".

http://blog.doctoroz.com/is-this-right-for-you/5-htp-is-this-right-for-you

Please contrast your statements with the following quote from epidemiologist Edward Belongia M.D., one of the chief epidemiologists who investigated the 1989 EMS epidemic. Dr. Belongia is currently Senior Epidemiologist/ Director of the Epidemiology Research Center, Marshfield Clinic Research Foundation in Marshfield, Wisconsin and serves on NEMSN’s Medical Advisory Panel. Dr. Belongia has this to say in an article he wrote in 2009:

*The specific contaminant that triggered EMS has never

Continued next page...
been proven, and we know it was present in extremely low concentrations. I don't think a manufacturer can determine that L-tryptophan is safe when there is no way to test for the causative agent. . . . Although it was Showa Denko L-tryptophan that caused the 1989 epidemic, we have no way of knowing whether the same contaminant might occur in the manufacturing process at another company. People who take L-tryptophan now are choosing to participate in a natural experiment on the safety of manufactured L-tryptophan. No company or government agency can verify the safety of these products."

http://www.nemsn.org/ems20.htm

ConsumerLab.com also refuses to certify that any particular brand of 5-HTP or L-tryptophan is safe to use:

"In contrast to ConsumerLab.com's Product Reviews, ConsumerLab.com did not test any L-tryptophan or 5-HTP supplements for this Review Article because their potential contaminants (which typically occur in minute amounts) are difficult to accurately test, making ConsumerLab.com uncomfortable with applying its 'Approved Quality' designation to a product."

https://www.consumerlab.com/reviews/L-tryptophan_5-HTP/tryptophan/

We realize there is much misinformation online about the supposed "safety" of current 5-HTP and L-tryptophan supplements, but much of that is driven by sellers of supplements taking advantage of the very incomplete investigation, to date, of EMS itself. Conclusions were drawn long before enough research had been done to understand the disease.

EMS is a painful, debilitating disease, sometimes fatal, and there is no cure. We know this all too well because our membership is made up largely of EMS survivors. Please stop helping to put more people at risk for lifelong pain and disability, also death.

We urge you, strongly, to act on this. You are a very influential person. If you do the right thing here, we are confident that others will follow you. Lives and health may be saved.

Sincerely,

[NEMSN]

Donor Honor Roll

Editor’s Note: A person’s name will be listed every time they donate to NEMSN. Thank you for your continued support.

Contributors (Regular) $5 - $49
Annette Jones
Good Shop

Contributors (Sustaining) $50 - $99
James Norris
Dr. Edward Belongia
A. Joy Hunter

Contributors (Friends) $100 - $249
Dr. Deborah S. Rose
Roger Bresnahan
Julie Ann Allender

Contributors (Benefactors) $250 - $499
Bernadette Zigalo

Contributors (Sponsors) $500 - $999
How Does Your Diet Affect How You Feel? Continued from page 3
by Jinx Engstrom

3. Ginger, turmeric, garlic, cinnamon, basil and rosemary are spices that are anti-inflammatory. Some say you would have to eat so much of these spices that this would not be practical. I myself am trying to add the spices I like to foods I already eat, to see if it helps. For instance, I discovered a little turmeric in an egg salad sandwich is very good, and cinnamon on my morning oatmeal is great.

4. Fish and seafood are high in omega 3 oils, which are anti-inflammatory. I take two Norwegian cod liver oil capsules daily and I feel it really diminishes joint pain.

5. Bone broth is a food which was consumed by almost everyone just one or two generations ago. It is made by cooking hormone free meat bones with water plus a few vegetables for a long time. I make it in a crock pot overnight. Then I just drink the broth or make soup out of it. It really helps soothe aching joints.

Books of interest:
- *The Paleo Approach: Reverse Autoimmune Disease and Heal your Body* by Sarah Ballantyne, Ph.D.
- *Gut and Psychology Syndrome* by Dr. Natasha Campbell-McBride
- *Nourishing Broth* by Sally Fallon Morell
- *Nourishing Traditions* by Sally Fallon Morell
- *Wheat Belly* by William Davis, MD

Videos of interest:
- “The Oiling of America” by Mary G. Enig, viewable on youtube.com
- “Your ECO System on MSG: Katherine L. Reid “, viewable on youtube.com or at: [http://tedxtalks.ted.com/video/Your-Ecosystem-On-MSG-Katheri](http://tedxtalks.ted.com/video/Your-Ecosystem-On-MSG-Katheri)

There are a lot of other foods about which there is little agreement.

Some say you should eat a vegan diet or at least a diet with no red meat. Others say eat a Paleo diet, which is high in red meat and animal fat. Dr. Robert C. Atkins became famous for his no carbohydrates, high fat diet. He claimed that it is the combination of sugar with fat that makes for hardening of the arteries and inflammation. Dr. Natasha Campbell-McBride, who developed the GAPS (Gut and Psychology Syndrome) diet, is convinced that leaky gut syndrome is the cause of inflammation, so to cure it, eat a diet high in fermented foods.

I have implemented most of the above suggestions in my own diet and I am feeling considerably better. When the weather changes in the fall, I usually experience several weeks of extremely heightened pain. This year I have not. I would not call it a cure, just a way to function at a better level.

You need to decide for yourself what works for you. I am including a list of books and videos I find helpful. I am convinced you are what you eat. I think we would be better off by eating healthy than by looking for a drug to cure EMS.
HELP WANTED: POSITIONS OPEN NOW:
NEMSN's Board of Directors has two vacancies. The seven current members of the Board are eager to fill these vacancies — immediately! We hope you are eager to lend your experience and commitment to our mutual cause.

No previous experience necessary.

Monthly phone conference calls and occasional shared tasks make it easy to communicate and carry out NEMSN's mission.

Don't hesitate. Express your interest NOW. Call or email Michael Bird, NEMSN's Treasurer, at 812-822-1189 or wiltshirebird@gmail.com for more information.

Doctor Recommendations Needed
NEMSN is trying to update its list of physicians and other healthcare providers who can diagnose EMS and who are helpful in treating symptoms. Do you have a doctor or physical therapist, massage therapist, etc. to recommend? Please let NEMSN know so we can pass the information on to others who are contacting us. The list we are compiling will not be published but will be available to any EMS patient who asks us for help and information. We're looking for doctors and other healthcare providers in the US and anywhere else in the world, too. Please get in touch by emailing NEMSN using the contact information on page 8.

Thank you.
NEMSN Board of Directors

GoodSearch.com is also a way to help earn money for NEMSN.

As of this date, we have earned a total of $395.96 by using GoodSearch.com to search on the web or using GoodShop.com to shop online.

How does it work?

Simply go to www.goodsearch.com for your web searching and earn a penny for NEMSN each time you search the web, and when shopping, click on the GoodShop link or go to www.goodshop.com.

In the "Who do you GoodSearch for" box type in National Eosinophilia Myalgia Syndrome Network. Next, click through to our partner merchants (clicking on the merchant's link will open a new browser window and redirect you to their site) and start shopping! A percentage of your purchase will go to your favorite charity or school.

How much can I generate for NEMSN by shopping through GoodShop?

The amount donated is different for each retailer but it averages approximately 3% of the total sale and can go up to 20% and beyond (the percentage donated is indicated below the merchants logo). The total amount raised can quickly add up and the sky is the limit. The more people shop through www.GoodSearch.com the more money will be directed towards good causes. There is no cap on how much money they will direct to charities and schools! I, myself, use it for almost all of my online purchases. It is so easy to use and earns us money while we are shopping.

From your Board of Directors
Happy Holidays and New Year to all. NEMSN closes out the year with a positive balance in our accounts totaling $3,542.

We are a small organization, so this amount represents enough to remain effective and maintain our services. It also speaks volumes for your generosity. Even with a decent operating balance, we are asking you to make an end of year or 2015 tax-deductible contribution. Why? We continue to make improvements to our web page. Your board of directors continues to conduct periodic conference calls. We would like to restore more frequent distribution of newsletters, especially as new EMS-like cases surface domestically and internationally. We've teamed up with other organizations that focus on rarer medical disorders. So that we can continue to communicate with you, maintain a solid medical advisory capacity and keep you up to date on any developments - make a contribution before 2015 comes to a close.

Thank you.
The NEMSN Board of Directors
NEMSN Contribution Form

Here is my gift to support the work of NEMSN:

$15 $25 $50 $100 $250 $500 $ Other

Make checks payable to NEMSN or National EMS Network. Gifts are tax-deductible to the extent allowed by law. Thank you for your help.

Name __________________________________________________________
Address __________________________________________________________

City/State __________________________ Zip __________ Phone ________-

☐ Check here if this is a NEW address and enter your previous zip code: ________-

☐ Check here if you desire a card acknowledging your gift to be sent to you or another. Be sure to include the mailing address.

Please mail your contribution to NEMSN, 1034 Sassafras Circle, Bloomington IN 47408