



National EMS Network Newsletter

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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NEMSN and the American Partnership For Eosinophilic Disorders

NEMSN and the American Partnership For Eosinophilic Disorders (APFED) are cooperating to produce an informational webpage on EMS, which will soon appear on APFED's website:

<http://apfed.org/>

Quoting APFED, "The American Partnership For Eosinophilic Disorders is a non-profit advocacy organization for those living with eosinophilic esophagitis, eosinophilic gastroenteritis, eosinophilic colitis, hypereosinophilic syndrome, and other eosinophilic disorders. We are a resource for patients, their families, physicians and the medical community.

"APFED provides accurate, up-to-date information on eosinophil-associated diseases. Our goals are to increase awareness, educate patients and physicians, increase funding for research and provide support for the eosinophilic community.

"Our mission: To passionately embrace, support, and improve the lives of patients and families affected by eosinophil-associated diseases through education and awareness, research, support, and advocacy."

Gerald J. Gleich MD, a member of NEMSN's Medical Advisory Panel and of APFED's board of directors, and who is perhaps the world's foremost authority on the eosinophil, recently suggested this online cooperation between APFED and NEMSN. Mary Jo Strobel, APFED's Executive Director, comments, "APFED has long admired the work of NEMSN, and it is an honor to partner with them to offer credible information about Eosinophilia Myalgia Syndrome and to increase awareness of this disease."

NEMSN's board of directors welcomes this cooperation. The coming page about EMS on APFED's site will be another place online, besides our own site, to find correct information on Eosinophilia Myalgia Syndrome. Besides this, if you check out APFED's home page, you'll see there is a "Doc Finder" function, which hopefully will locate physicians who know something about treating EMS. There are other resources as well for eosinophilia patients at apfed.org.

National EMS Network Newsletter

Published by

The National EMS Network, Inc.
767 Tower Boulevard
Lorain, OH 44052-5213

Board of Directors

*

Jann Heston.....President
155 Delaware Avenue
Lexington, OH 44904
Email only: NEMSN2005@yahoo.com

*

Jinx Engstrom.....VP/Web Administrator
4036 Aldrich Avenue South
Minneapolis, MN 55409
612-825-9135
Email: grandmajinx1@usiwireless.com

*

Ann Flaherty.....Secretary
2727 Shakespeare Lane
Avon, OH 44011
440-937-1537
Email: annflaherty2727@yahoo.com

*

Michael Bird.....Treasurer
1034 Sassafra Circle
Bloomington IN 47408
812-822-1189
Email: wiltshirebird@gmail.com

*

Sandy Kintz Keating.....Newsletter Editor
767 Tower Boulevard
Lorain, OH 44052-5213
440-960-5910
Email: NEMSNnewseditor@gmail.com

*

Nancy Grant.....Med/Research Director
4308 Alcove Avenue Unit 104
Studio City, CA 91604
818-623-9199
Email: nancy.grant@juno.com

*

Lois Vierk.....Public Relations Director
P.O. Box 4171, Monitor Station
West New York, NJ 07093
201-868-9572
Email: elveevee@aol.com

*

Website: www.nemsn.org

*The National EMS Network Newsletter is published
by The National EMS Network, Inc.,
a nonprofit charitable organization
under section 501 (C) (3)
of the Internal Revenue Service.*

Five Steps to Avoiding the Flu Naturally

It's a fact that disease-causing viruses and bacteria are all around us. Whether you come into contact with the flu or another variety, you need to focus on maintaining a robust and well-functioning immune system to avoid getting sick. Optimizing your vitamin D levels is one of the most potent preventive strategies available, followed by diet (including fermented foods to optimize your gut flora), stress relief, exercise and sleep.

There are other factors that can come into play too, of course. The following guidelines will also act in concert to support your immune system and help you avoid getting sick:

Take a High-Quality Source of Animal-Based Omega-3

Fats. Increase your intake of healthy and essential fats like the omega-3 found in krill oil, which is crucial for maintaining health. It is also vitally important to avoid damaged omega-6 oils (think vegetable oils) as it will seriously damage your immune response.

Wash Your Hands. Washing your hands will decrease your likelihood of spreading a virus to your nose, mouth or other people. Be sure you don't use antibacterial soap using synthetic chemicals for this – conventional antibacterial soaps are completely unnecessary, and they cause far more harm than good. Instead, identify a simple chemical-free soap that you can switch your family to.

Tried and True Hygiene Measures. In addition to washing your hands regularly, cover your mouth and nose when you cough or sneeze,

ideally with the crook of your elbow (to avoid contaminating your hands). If possible, avoid close contact with those who are sick and, if you are sick, avoid close contact with those who are well.

Use Natural Immune-Boosters. Examples include oil of oregano and garlic, both of which offer effective protection against a broad spectrum of bacteria, viruses, and protozoa in your body. And unlike pharmaceutical antibiotics, they do not appear to lead to resistance and the development of 'super germs.'

Avoid Hospitals. It is recommended you stay away from hospitals unless you're having an emergency and need expert medical care, as hospitals are prime breeding grounds for infections of all kinds. The best place to recover from illness that is not life threatening is usually in the comfort of your own home.

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.

EMS and EMS-like Sickness from Today's L-T and 5-HTP

Since 2011 NEMSN has been getting regular contacts from people who have taken current L-tryptophan or 5-HTP (which is chemically similar to L-tryptophan) and who have gotten sick with EMS-like symptoms. The patients attribute their illness to today's L-tryptophan supplements, 5-HTP supplements, or their products containing these ingredients, such as various body-building, weight-loss and sleep-aid supplements. Some of these contacts also report eosinophilia. In general, their local doctors don't know much of anything about EMS and so won't consider EMS as a diagnosis. As a result, some very sick people are getting diagnosed with nothing at all. There is no observed epidemic at this time, but there are isolated cases of EMS and EMS-like illness.

Our Medical Advisory Panel is aware of the situation. However, without a number of EMS diagnoses, there is little if anything that our advisors can do to help get harmful products off the market.

In contrast to the general lack of diagnoses that our contacts report, there are medical articles that do, in fact, document cases of EMS caused by today's supplements. For example, in June 2013 the medical journal *Reactions Weekly* published an article describing new EMS cases in France from 2001-2012, attributed to contemporary 5-HTP supplements. (5-HTP is also known as L-5-hydroxytryptophane, as this article identifies it.) The article, entitled "Eosinophilia-myalgia syndrome induced by L-5 hydroxytryptophane: about 3 cases", is a report from the 8th Congrès de Physiologie de Pharmacologie et de Thérapeutique in Angers, France, April 2013. It appears at this web address:

http://www.atout-org.com/p2t2013/abstract_display!fr!!!!487a1a72-7fab-1030-b866-9251dd645b9d!bc9884ec-d673-1030-b866-9251dd645b9d

Besides this, in November 2011 the medical journal *Arthritis & Rheumatism* published an article that details a new 2009 case of EMS from contemporary L-tryptophan. The article, "Post-epidemic eosinophilia-myalgia syndrome associated with L-tryptophan", is found in *Arthritis & Rheumatism*, Volume 63, Issue 11, pages 3633-3639, November 2011. The abstract can be found online at:

<http://onlinelibrary.wiley.com/doi/10.1002/art.30514/abstract>

Also the NIH itself warns against taking 5-HTP. The National Institutes of Health states that 5-HTP supplements may cause EMS. Their webpage, reviewed in July 2014, is at this address:

<http://www.nlm.nih.gov/medlineplus/druginfo/natural/794.html>

Here's an excerpt.

"Don't use 5-HTP until more is known. 5-HTP might be UNSAFE. Some people who have taken it have come down with eosinophilia-myalgia syndrome (EMS), a serious condition involving extreme muscle tenderness (myalgia) and blood abnormalities (eosinophilia). Some people think the EMS might be caused by an accidental ingredient (contaminant) in some 5-HTP products. But there is not enough scientific evidence to know if EMS is caused by 5-HTP, a contaminant, or some other factor. Until more is known, avoid taking 5-HTP."

NEMSN is here to help both epidemic patients and new patients, and we are also looking for information about the safety of today's supplements. If you know of anyone who has gotten sick with EMS-like symptoms after taking L-tryptophan or 5-HTP, please ask them to contact NEMSN. Ask them to tell the FDA, also, by filling out and submitting the MedWatch Online Voluntary Reporting Form online:

<https://www.accessdata.fda.gov/scripts/medwatch/>

Please remember to use GoodSearch.com, GoodShop.com and iGive.com when surfing the web. It is so easy. Instead of using Google, Bing or Yahoo, type in GoodSearch and chose NEMSN as your charity. We get 1 cent for every search, so that can build up quickly if you all use it as your search engine.

Use GoodSearch when searching the web and GoodShop and iGive when making purchases online. Type in NEMSN as your charity. This money adds up, so please use these sites when possible. We need more supporters to help us earn much needed money. Thanks to all who have used these sites in our name.

EMS Again?

Words of Wisdom from Dr. Gleich and Dr. Belongia

In light of documented EMS and other reports of EMS-like illness from today's L-tryptophan and 5-HTP, it seems a good time to revisit what two of our Medical Advisory Panel doctors wrote for NEMSN in 2009, the 20th anniversary of the 1989 EMS outbreak, about the possibility of the occurrence of new cases of EMS. Here are excerpts of articles by Edward Belongia MD and Gerald J. Gleich MD that appear on our website in complete form.

**Excerpted from "Could EMS have been Prevented? Will Future Outbreaks be Prevented?"
by Edward Belongia, M.D.**

The specific contaminant that triggered EMS has never 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. We have some good candidates, but it's hard to prove that any of them caused EMS because the syndrome cannot be reproduced in animals. 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.

**Excerpted from "EMS Disappointments"
by Gerald J. Gleich, M.D.**

Though chemical analyses provided a link between the contaminants in L-tryptophan to contaminants in the toxic oil responsible for a massive Toxic Oil Syndrome (TOS) epidemic in Spain in 1981, investigations of TOS had failed to generate an animal model or a bioassay, even though many animal species were exposed to contaminated oil. Thus, the same frustrations experienced by the TOS investigators were shared by those researching EMS. Both TOS and EMS scientists failed to identify any useful tools (such as a bioassay or an animal model) to determine which contaminants in the L-tryptophan and the toxic oil were the critical ones.

In retrospect, the epidemiologists obtained the most significant information about EMS. They showed the critical

relationship to L-tryptophan ingestion and the link to L-tryptophan produced by Showa Denko. We were able to identify a series of contaminants in Showa Denko L-tryptophan, but without a bioassay or animal model we were not able to understand how the contaminants caused the disease or which contaminant(s) were the critical ones.

Sometime in the future, another epidemic related to TOS and EMS will likely occur. Hopefully, the experiences from these epidemics will allow future investigators to start where we ended. However, the failure to provoke either the Spanish toxic oil syndrome or EMS in experimental animals or stimulate reactions in patients' cells in test tubes may indicate that these diseases are uniquely human and related to a peculiar human biochemical or immunological characteristic.

Given these words of wisdom from our Medical Advisors, we understand that EMS has to date been incompletely researched. Conclusions of various sorts, including many made by supplement manufacturers and doctors alike, have been prematurely drawn. Caution is called for, not unverifiable statements to the effect that EMS happened once and can never occur again, which is the sort of misinformation which we run across all too often.

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.

Getting the Word Out with NORD

For about three years NEMSN has been a member of NORD, the National Organization for Rare Disorders. This non-profit group describes itself as "a unique federation of voluntary health organizations dedicated to helping people with rare 'orphan' diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service." There are about 150 member organizations. You can read about NORD on their website: <http://rarediseases.org/>.

This past fall NORD contacted NEMSN to offer a couple opportunities for us to get the word out on EMS. In September NORD solicited its member organizations for information on rare diseases that have been caused by pharmaceutical products. Although our rare disease EMS was caused by a supplement and not prescription medicine, NORD gladly took our write-up for use in a conference they were participating in, which was held in Philadelphia on September 10-11. The title of the conference was "Pharmacovigilance 2014 - Ensure Benefit-Risk Communication and Patient/Physician Understanding in the Midst of Global Regulatory Uncertainty."

NORD gave a presentation at the conference and relayed its member organizations' reports of illness caused by medicines and other products. NORD's Vice President for Communications, Mary Dunkel, and Director of Membership, Lisa Phelps, spoke about how to "connect the patient community with NIH, FDA, medical researchers, clinicians, social services and pharma/biotech industries to better understand patient and physician gaps in comprehensive risk understanding" among other matters. They included a power point slide about NEMSN, which demonstrated our concerns about EMS and EMS-like disease from L-tryptophan and 5-HTP supplements.

The next contact from NORD came in October, when they asked members for brief descriptions of our rare diseases and what we want the world to know about them, for inclusion in a Member Guide. NORD is developing this document for use at upcoming conferences and other events. The guide will be shared with the press, research institutions, the FDA, NIH, and other government agencies. NEMSN sent NORD the requested information on EMS so that our story will be included and read by others.

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 \$3,300. 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 2014 comes to a close. Thank you. The NEMSN Board of Directors

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.

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To contact NEMSN about anything in this newsletter please send an email to us at NemsnTalk@aol.com, or phone us at [201-868-5791](tel:201-868-5791), or you may send US mail to NEMSN, 767 Tower Blvd.,

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

“Friends Supporting Friends”