



National EMS Network Newsletter

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NEMSN is extremely pleased to announce that Stephen Naylor, Ph.D. has joined our Medical Advisory Panel as NEMSN's Science Advisor. Welcome, Dr. Naylor.

Dr. Stephen Naylor is one of only a handful of distinguished scientists who have devoted years of research in an attempt to achieve a complete explanation of EMS. Known as a chemist, biochemist, toxicologist and business originator, he has co-authored hundreds of scientific research papers and book chapters while delivering uncounted presentations at universities and medical centers worldwide. In the 1990s he and NEMSN advisor Gerald J. Gleich, M.D. partnered at the Mayo Clinic in Rochester, MN to undertake definitive EMS and L-tryptophan research. Naylor and Gleich received NIH and WHO grants and co-authored a number of scholarly papers during that period.



Stephen Naylor received his Ph.D. from the University of Cambridge (UK) in Biochemistry. He completed postdoctoral work at the Massachusetts Institute of Technology where he later became a visiting faculty member in the Division of Biological Engineering and a faculty member of the Computational Systems Biology Initiative. He earned additional scientific degrees from the University of East Anglia (UK), Southampton University (UK) and the University of California. From 1991-2001 he worked at the Mayo Clinic/Foundation, where he was founding director of a laboratory which specialized in determining the structure of chemical and biochemical molecules. He was also a tenured professor at the Mayo Foundation, teaching courses in such varied subjects as biochemistry, molecular biology, pharmacology, clinical pharmacology, and biomedical engineering.

The range of Dr. Naylor's expertise is extraordinary. Among his achievements are contributions to the fields of gene studies, protein studies, metabolism, systems biology, nanofluid studies, computational biology, the miniaturization of mass spectrometry with microchips, and more recently drug discovery, and personalized medicine. Making use of his knowledge of spectroscopy and chromatography, Dr. Naylor has worked with Dr. Gleich to identify and describe the contaminating molecules that are believed to trigger EMS after consumption of tainted L-tryptophan.

Dr. Naylor is currently co-founder and CEO of ReNeuroGen, a spin-out drug discovery company from the Medical College of Wisconsin. He is also founder and CEO of Mai-Health Inc., a personalized medicine/molecular bioprofile diagnostics company in the health and wellness sector.

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NEMSN Welcomes New Board Member

As of a few months ago, NEMSN has a new board member. EMS patient, George E. Bush, of Queens, New York has agreed to join our board of directors. George had been taking L-Tryptophan in 1989, the year he contracted EMS. He recalls seeing a front page article in the *New York Times*, at that moment about the EMS outbreak in New Mexico. He telephoned Dr. Gleich, who was then working at the Mayo Clinic. Dr. Gleich personally took his call and sent George to a local doctor for diagnosis and medical help.

George, we are so happy to have you on the board.

To contact NEMSN about anything in this newsletter

please send an email to us at NemsnTalk@aol.com, phone us at [201-868-5791](tel:201-868-5791), or you may send US mail to...

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In Memoriam

Sally McCullough of
Camp Hill, PA
Our condolences to her family.

From the Editor

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.

Eosinophilia Myalgia Syndrome

by Gerald J. Gleich, M.D.

Earlier this year, Dr. Gleich, advisor to NEMSN and also on the board of directors of the American Partnership for Eosinophilic Disorders (APFED), wrote this informational article on EMS. Portions of the text were contributed by NEMSN. The article in its entirety appears on our website (www.nemsn.org) as well as on APFED's website (www.apfed.org).

Introduction and Background

During the autumn of 1989, an epidemic of a new disease occurred in the United States. The illness was characterized by elevations of blood eosinophils (a type of white blood cell) and myalgia (severe muscle pain) and was termed the eosinophilia-myalgia syndrome (EMS). The disease was first recognized in October 1989 when physicians in New Mexico identified three women with similar clinical findings: All three had consumed manufactured L-tryptophan supplements prior to the onset of their illness [1]. (L-tryptophan is an essential amino acid found naturally in various foods, and L-tryptophan can also be manufactured.) These patients' findings were publicized by the local news media and, soon thereafter, additional cases of the same illness were identified throughout the USA and in several other countries [2].

Epidemiological studies were initiated within days of discovery of the epidemic in early November 1989 by state health departments in New Mexico and Minnesota, and these studies demonstrated a strong association between the consumption of manufactured L-tryptophan and the onset of EMS [3, 4]. A national surveillance program was initiated by the United States Centers for Disease Control (CDC) to investigate the new disease [5]. On November 11, 1989, the United States Food and Drug Administration (FDA) issued a nationwide warning advising consumers to stop consumption of manufactured L-tryptophan food products and requested a nationwide recall of all L-tryptophan supplements sold over-the-counter.

After the removal of L-tryptophan supplements from the consumer markets, the number of new cases of EMS diminished rapidly. Nevertheless, more than 1,500 people were affected by the illness and 37 deaths were attributed

to the disease [6]. In many cases the disease struck patients in the prime of life and caused severe, debilitating neurological damage. It is likely that the toll from the disease would have been considerably greater if not for the alertness of physicians who linked the new disease to manufactured L-tryptophan, and for the epidemiological investigations by the state Departments of Health and the CDC, plus the prompt recall initiated by the FDA of products containing L-tryptophan. However, while the epidemiological and chemical investigations indicate that the epidemic of EMS was caused by contaminated L-tryptophan supplements, the precise contaminant causing the disease is still unknown.

Prevalence and reasons for tryptophan use

In 1989, consumption of L-tryptophan products was widespread in the United States [3]. In Oregon [7] and Minnesota [3], approximately 2% of the household members surveyed had utilized L-tryptophan supplements at some time between 1980 and 1989. The most common reasons for using these products were insomnia, premenstrual syndrome and depression. L-tryptophan products were available for therapeutic use and were often recommended by physicians. The products were widely available in the USA without a prescription. Manufacturers did not claim that their products had therapeutic efficacy, and the substance was neither regulated nor approved by the FDA. L-tryptophan itself is an essential amino acid, however, sufficient quantities are present in the diet of most US citizens without the need for supplements.

Eosinophilia-myalgia syndrome: national surveillance data

Information on the numbers of patients afflicted with EMS and death from the disease was reported as of June 1993. By this time, 1,511 EMS cases had been reported to the CDC including 37 deaths [6]. The case definition utilized by the CDC included a blood eosinophil count greater than 1,000 per microliter, generalized debilitating myalgia and no evidence of infection or neoplasm that would otherwise explain the clinical findings. National surveillance data of July 1991 revealed that 84% of

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patients were female, 97% were non-Hispanic white, and 86% were over 34 years of age (median age, 49 years). The true prevalence of EMS is likely underestimated by the surveillance reports because individuals with mild disease were excluded by the surveillance case definition, and therefore many cases were likely not reported.

Epidemiological studies

After initial case control studies showed an association between consumption of manufactured L-tryptophan as a major risk factor for EMS, investigations were begun in Oregon [7] and Minnesota [3] to examine this association [7, 8]. In these studies, consumers of L-tryptophan supplements were classified as either case patients (those who had EMS) or controls (non-EMS L-tryptophan users), and the L-tryptophan lots consumed by each group were traced to determine the L-tryptophan source. At the time of the epidemic, L-tryptophan was manufactured by six companies, and all were in Japan. Analyses of the L-tryptophan source for case patients and controls showed a strong association between EMS and the consumption of L-tryptophan manufactured by a single company, namely Showa Denko K.K. (Tokyo, Japan), a large petrochemical company.

In New York state, a study showed that 98% of case patients had consumed L-tryptophan manufactured by Showa Denko K.K. compared with 44% of controls [8]. In the Minnesota study, 97% of case patients had consumed L-tryptophan manufactured by Showa Denko K.K., compared with 60% of the controls [3]. The ratio of the odds of the disease occurring in exposed individuals compared to unexposed individuals was 9.3 (95% confidence). One EMS case in Minnesota was not initially traced to Showa Denko, but further chemical analysis showed characteristics of that company's products, revealing that the L-tryptophan was indeed produced by Showa Denko.

Particularly revealing information was obtained from epidemiological studies of L-tryptophan users in a South Carolina psychiatric practice [9]. These findings provide an estimate of the rate of occurrence of EMS in persons exposed to the product. Among patients taking greater than 4 g of the particular brand of L-tryptophan supplement in this study, the definite EMS attack rate was 59% and the pooled attack rate (definite and possible EMS) was 84%. This study suggest that most, if not all, individuals are susceptible to EMS if exposed to sufficient quantities of the agent.

Manufacturer of L-tryptophan

L-tryptophan produced by Showa Denko K.K. was manufactured by fermentation using a bacterium which had been genetically modified over several years [10]. In December 1988, a new strain of the bacterium was introduced which had been further genetically modified to increase L-tryptophan production. The organism was grown in a large fermentation vat, and L-tryptophan was purified utilizing filtration, crystallization and separation processes. During manufacture from October 1988 to June 1989, some of the fermentation batches bypassed a filtration step and, in some cases, quantities of powdered activated carbon used to purify L-tryptophan were reduced. Analyses of the importance of these processes showed an association between the development EMS and less-pure L-tryptophan processed with the lower quantity of charcoal and the use of the new strain of the bacterium.

Contaminants associated with EMS

As soon as the link between EMS and manufactured L-tryptophan was established, chemical analyses were conducted at the Mayo Clinic (Rochester, MN), the FDA, the CDC, and the Japanese National Institute of Hygienic Sciences to determine if any contaminants were associated with EMS. These studies showed a distinctive chromatographic pattern for the product from each of the companies, such that inspection of the chromatogram permitted identification of the producer. In all cases, the L-tryptophan, though sufficiently pure by chemical standards, nonetheless contained a series of contaminants. The product from Showa Denko K.K. demonstrated a single peak that was associated with EMS [11]. Later, the structures of the most of these contaminants were determined [12-14].

Taken together, epidemiological and clinical findings in the EMS patients could be explained by changes in the manufacturing process of L-tryptophan from 1985 until 1988, which resulted in sporadic contamination of the product with increased quantities of contaminants in 1989.

Risk factors

Aside from consumption of implicated L-tryptophan lots, two risk factors for EMS have been identified: the amount of L-tryptophan consumed and the age of the individual [9]. The risk of developing EMS increased with larger doses of

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L-tryptophan and with increasing age. The reason for the increasing incidence with age is not entirely understood, although it may be due to aging organs or liver function.

Clinical features

EMS is a syndrome with multiple clinical presentations and variable severity. The first clinical reports showed that most patients developed profound eosinophilia and severe myalgias. Further, other symptoms included joint pains, weakness or fatigue, difficulty breathing or cough, rash, headache, peripheral edema (swelling), fever and abnormal tingling sensations [1, 2, 15]. Most patients also showed an elevation of an enzyme called serum aldolase, which is an indicator of muscle damage. About one-half of the patients had abnormal liver function tests.

Clinical and histopathological findings of EMS overlap those of [eosinophilic fasciitis](#) [16, 17], a fibrotic syndrome characterized by tender swelling and hardening of subcutaneous tissues especially in arms and legs.

There are no medical tests to definitively diagnose EMS. Many physicians lack knowledge of EMS, and therefore, patients may be diagnosed with diseases that have overlapping symptoms, such as fibromyalgia, chronic fatigue syndrome, lupus, arthritis, fasciitis, and other autoimmune or neuromuscular disorders with similar symptoms. Criteria for the diagnosis have been described that are useful [18].

Symptoms associated with EMS vary widely and may include:

Initial Symptoms

- Acute pain
- Elevated eosinophil count in the blood
- Severe muscle cramping and/or pain
- Pain in muscle tissues
- Neuropathy (nerve malfunction resulting in numbness, weakness, burning pain and loss of reflexes)
- Joint pain
- Tremors
- Swelling of soft tissues
- Numbness, tingling, or burning sensations
- Tenderness and swelling of extremities
- Patches of yellow or ivory colored rigid dry skin which become hard and slightly depressed

- Low grade fever
- Pulmonary disorders
- Rashes
- Weakness and severe fatigue
- Gastrointestinal disorders
- Cardiac arrhythmias
- Hair loss
- Cough
- Headache

Symptoms and complications developing later

- Short term memory loss, diminished concentration, communication problems
- Muscle and joint pain
- Severe nerve pain
- Cardiomyopathy (disease of the heart muscle)
- Irreversible scarring of the liver
- Internal fibrosis (excessive growth of hard, fibrous tissue that replaces normal bone tissue in a single bone. Symptoms include pain and bone fracturing)
- High blood pressure
- Desmoid tumor (benign soft tissue tumors which intertwine extensively with the surrounding tissues)
- Malignant fibrous histiocytoma (a rare disorder in which histiocytes start to multiply and attack the person's own tissue or organs resulting in tissue damage, fatigue and other symptoms)
- Scleroderma-like syndrome (a fibrosing disease of connective tissue in the skin and sometimes also in other organs of the body)
- Fibromyalgia syndrome (chronically causes pain, stiffness, and tenderness of muscles, tendons, and joints without detectable inflammation)
- Chronic fatigue syndrome
- Post-traumatic stress disorder (a psychological disorder that develops in individuals who have had major traumatic experiences)
- Depression
- Vision and dental problems
- Sleeping disorders

Treatment

There are no peer-reviewed guidelines for the standard of care of EMS patients. Because of the variety and diversity of how EMS manifests, patients are treated based on their

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individual symptoms and may be prescribed muscle relaxants, analgesics, and diuretics.

High doses of corticosteroids may help reduce inflammation. However, most researchers have concluded that this course of treatment does not reduce the severity or duration of EMS symptoms [19].

In the acute phase, patients who have intense muscle pain and cramps may need to limit or avoid strenuous physical activity. Some patients have required hospitalization. In the chronic phase, patients who keep as physically active as possible seem to do better than others.

Connection with the toxic oil syndrome

The clinical and pathological findings of EMS strikingly resemble those of the toxic-oil syndrome (TOS), an epidemic that occurred in Spain in 1981 [20]. Over 20,000 people were affected, and 839 died. In contrast to EMS, respiratory symptoms including cough and difficulty breathing were prominent in the TOS epidemic [21]. Other symptoms were similar to those listed above for EMS. In many TOS patients, the disease progressed to a chronic phase that resembled EMS quite closely. Epidemiological investigations implicated ingestion of aniline-denatured rapeseed oil sold by traveling salesmen after being processed illegally. A finding of considerable interest is the chemical structure of one contaminant, 3-phenyl amino-1,2-propanediol [22], to a L-tryptophan contaminant, phenylamino alanine [23]. The strong similarities between the clinical syndromes, EMS and TOS, suggest that they might share a final pathway leading to neuromuscular damage.

Animal and in vitro models

A critical step in further investigation of EMS is the development of an animal model. However, feeding L-tryptophan implicated in causation of EMS to rats, mice, and monkeys failed to reproduce the syndrome [24]. These negative results are similar to negative results in TOS where, despite many years of investigations, an animal model was not produced [25, 26].

An in vitro model would also be useful, but numerous studies of L-tryptophan and its products including the contaminants failed to cause stimulation of blood cells including purified lymphocytes in vitro [27].

The failure to have an animal model and the failure to

develop an in vitro test for the contaminants involved in EMS and TOS is crucial. The implication from this failure is that these diseases will likely occur again because we have no way of identifying the critical contaminants.

Lessons from the EMS outbreak

We may have been lucky in the case of EMS in that the disease was quickly recognized, and the FDA quickly banned the sale of manufactured L-tryptophan. The L-tryptophan was carefully manufactured, and it was quite pure. Nonetheless by high-performance liquid chromatography, L-tryptophan, implicated as the cause of EMS, contained greater than 60 trace contaminants, some at concentrations of several hundred parts per million. Going forward from this time, if a manufacturer wished to guard against the possibility that a product might cause EMS, chemical purity is critical. Next, the manufacturer would need to test the product to ensure that it could not cause harm. However here, the lack of an animal model is critical; in the absence of an animal model a manufacturer cannot do the needed toxicological tests.

The similarity of EMS and TOS highlights the potential for environmental agents to induce disease, exemplified by these disorders. Although disease activity in a large proportion of affected individuals continues to lessen, the ultimate consequences of their disease are not well-defined and need further study.

Subsequent developments

In 1994 Congress passed the Dietary Health Supplement Education Act (DHSEA), which President Clinton signed into law. This law greatly weakened FDA's ability to regulate dietary supplements. As a result, manufactured L-tryptophan is legally sold again.

There had been isolated cases of EMS diagnosed before the epidemic of 1989 and there have been after, as well. The isolated cases of EMS diagnosed before the epidemic of 1989 were attributed to L-tryptophan dietary supplements [28]. The isolated cases of EMS that are currently being diagnosed are attributed to L-tryptophan or 5-HTP dietary supplements. During the time that L-tryptophan was taken off the market, the closely related dietary supplement 5-hydroxytryptophan (5-HTP) was used as a substitute, and it continues to be so used. The amino acid 5-HTP is found on the metabolic pathway that converts the essential amino acid L-tryptophan

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to the neurotransmitter serotonin. Because serotonin helps to regulate sleep and mood (among other things), it is thought that ingesting L-tryptophan or 5-HTP, thus purportedly improving sleep and mood, will increase this neurotransmitter.

[The National Eosinophilia Myalgia Syndrome Network \(NEMSN\)](#), for the past several years, has also been receiving reports from people who have developed EMS-like symptoms soon after ingesting manufactured L-tryptophan, 5-HTP, or other products containing L-tryptophan or 5-HTP, such as certain body building products, weight loss supplements, and sleep aids.

Furthermore, as described below, the lack of regulation of dietary supplements has resulted in the occurrence of an epidemic (unrelated to EMS) of acute hepatic damage. Acute hepatitis has been linked to a muscle-building product, OxyElite. The CDC investigation of this matter revealed that acute hepatitis and liver failure followed the use of this dietary supplement intended for weight loss or muscle building (<http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6240a1.htm>). According to CDC, 97 persons with acute non-viral hepatitis were identified in an outbreak, 72 of whom had reported exposure to an OxyElite Pro branded product. Of these cases, at least 47 were hospitalized, at least three received liver transplants, and one death was reported. The estimated illness onset dates ranged from April 10, 2013 to October 24, 2013. On October 11, 2013, the FDA issued a warning letter to US-Plabs LLC of Dallas, Texas, informing the company that the dietary supplements OxyElite Pro and VERSA-1 were adulterated, and that failure to immediately cease distribution of these products could result in enforcement action. The warning letter stated that the products were deemed to be adulterated because they contained aegeline, a new dietary ingredient (i.e., a dietary ingredient not marketed in the United States before October 15, 1994) that was not the subject of a required notification to FDA (<http://www.fda.gov/Food/RecallsOutbreaksEmergencies/Outbreaks/ucm370849.htm>). On November 17, 2015 the United States Department of Justice pursued civil and criminal cases against more than 100 makers and marketers of dietary supplements including USPLabs LLC and several of its corporate officers (<http://www.justice.gov/opa/pr/justice-department-and-federal-partners-announce-enforcement-actions-dietary-supplement-cases>).

Medical research articles document current isolated cases of EMS from L-tryptophan and from 5-HTP

In November 2011 the medical journal *Arthritis & Rheumatism* published an article reporting a new 2009 case of EMS from current L-tryptophan supplements. 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 [29]

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. The article, entitled "Eosinophilia-myalgia syndrome induced by L-5 hydroxytryptophane: about 3 cases".

In addition to new cases of EMS being identified in association with the consumption of manufactured L-tryptophan and 5-HTP, the NIH warns of the possible danger in taking 5-HTP, stating in 2015 that "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)"

Furthermore, the National Eosinophilia Myalgia Syndrome Network (NEMSN) reports recent and ongoing contact from people who attribute their EMS-like symptoms to L-tryptophan supplements, 5-HTP supplements, and other products containing L-tryptophan or 5-HTP.

No more EMS epidemic outbreaks have been recognized since 1989. The risk of developing EMS after L-tryptophan or 5-HTP consumption is uncertain.

If you or someone you know has become sick from taking a product containing L-tryptophan or 5-HTP, tell them to save the product and contact NEMSN via their website www.nemsn.org, and to make sure to report the adverse reaction to the FDA via this online form:

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

Can This Happen Again?

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)

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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.

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.

Summary

EMS is an inflammatory disease resulting from ingestion of L-tryptophan manufactured by one company. EMS is clinically similar to eosinophilic fasciitis and the Spanish toxic oil syndrome (TOS). A series of contaminants contained in implicated L-tryptophan were discovered, but in the absence of an animal model and an in vitro test, none of the contaminants can be indicted as the cause of EMS. Therefore, at the moment we are at the mercy of fate because at some point a 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.

The FDA ban on manufactured L-tryptophan was removed during the 1990s, after Congress passed the Dietary Health Supplement Education Act, weakening the FDA's ability to regulate dietary supplements. Presently, cases fulfilling the clinical criteria for the diagnosis of EMS are occurring in patients consuming manufactured L-tryptophan or 5-HTP. However, these sporadic cases pose a serious problem in their investigation because often the L-tryptophan or 5-HTP product itself has been disposed of and the diagnosis of EMS may be in doubt.

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Editor's Note: A person's name will be listed every time they donate to NEMSN.

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BALANCING THE NEMSN BUDGET

Wise words from an anonymous source: "It's easy to meet expenses - everywhere we go, there they are." Since 2000 and perhaps from its inception, NEMSN has balanced its annual budget and left ample surplus funds to keep comfortably operating into the following year. Oh if we could only get the federal government to do the same.

"It's easy to meet expenses" states the opening quote. At NEMSN, that is definitely true. Efficient fiscal management coupled with your generosity through contributions has been our enduring recipe for success. That is the case for 2016 just as it has been in prior years. But, when 2016 ends, NEMSN will have a small surplus of approximately \$1,000. Yes, we are a small organization. Expenses for most recent years have added up to \$1,500 or so per year. NEMSN spends most of its contribution dollars on newsletter production and distribution and webpage maintenance and modernization. Smaller amounts are spent on Board of Director conference calls, postage and participation with other non-profit organizations serving individuals with rare and little known diseases.

Contributions are critical for NEMSN to accomplish just the basics. Reality, however, shows that we will end up with under \$1,000 in total contributions for the year. These come from a dwindling group of regular contributors. Short-term, this is okay. Long-term, our visibility and capacity to assist and inform you will fade. And that would be a tragedy since we are the only organizational voice out there for those afflicted with EMS.

So, can you help with a small, modest or handsome contribution? Do so before the year is out and you can deduct it on your federal or state tax forms. Or, taxes aside, simply show your generosity. Remember, "it's easy to meet expenses - everywhere we go, even in NEMSN, there they are."

Michael Bird, Treasurer

(Editor's Note: To make a donation, Michael's address is on page 9 under the Donor Honor Roll)

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