



National EMS Network Newsletter

Points of interest

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- **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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New L-Tryptophan Research

NEMSN is excited to announce that Stephen Naylor PhD of our Medical Advisory Panel is extensively investigating a heretofore not identified contaminant in Showa Denko L-Tryptophan. It also appears to be present (not yet confirmed) in some of today's commercially available L-Tryptophan supplements. The specific contaminant that caused EMS in 1989 has never been identified. EMS seems to be still occurring from current supplements though not in epidemic proportions. This is the first substantive research of anything pertaining to EMS in many years! Although Dr. Naylor's current work doesn't point quickly to new medicines or therapies for us, it is in the category of research that must be completed before any new treatments for our disease can be developed.

In November 2017 the first of several scientific papers on this research, co-authored by Stephen Naylor PhD, Gerald J. Gleich MD and others, was published online by the journal *Toxicology Letters*: <https://authors.elsevier.com/a/1V-QM1M2r-o4F8>. The print version will come out in January 2018.

Dr. Naylor has also written the following article for NEMSN readers. It is an overview of the current understanding of EMS from a toxicological point of view. It does contain some very technical terms and information, but the meaning of the article is clear even for those of us without an understanding of the chemistry.

Thank you, Dr. Naylor.

Eosinophilia Myalgia Syndrome Contaminants: Past, Present, Future

by
Stephen Naylor Ph.D.

1. INTRODUCTION

All of you are familiar with the outbreak of Eosinophilia Myalgia Syndrome (EMS) that occurred in 1989. Many of you continue to suffer from health issues after taking contaminated Showa Denko K.K. L-Tryptophan associated with EMS onset. Some of you have experienced EMS-like symptoms after taking other brand-name L-Tryptophan, 5-Hydroxytryptophan (5-HTP) or Melatonin. My first conversations about EMS occurred when meeting Dr. "Jerry" Gleich in Rochester, Minnesota. I had been recruited by Mayo Clinic as a research professor in 1991, and was fortunate enough to encounter Dr. Gleich in 1993. As most of you know, he was one of the first physicians to diagnose the condition and recognize that there was a new disease associated with elevated levels of a specific white blood cell called the eosinophil. This disease ultimately became known as EMS.

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direct to charities and schools! I, my-
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purchases. It is so easy to use and
earns us money while we are shop-
ping.

**EMS Diagnosis Code
Changed**

The diagnosis code for EMS is now
M35.8. (Previously it was 710.5.)
The World Health Organization
keeps an extensive list of all medical
diagnoses and their codes called the
International Classification of Dis-
eases. The classification system was
updated to its current form in Octo-
ber 2015.

Check out the EMS diagnosis code
at [http://www.icd10data.com/
ICD10CM/Codes/M00-M99/M30-
M36/M35-M35.8](http://www.icd10data.com/ICD10CM/Codes/M00-M99/M30-M36/M35-M35.8)

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.

DISCLAIMER

The NEMSN does not engage in the prac-
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persons should seek the advice of their
own lawyers & medical professionals.
Opinions expressed by individual writers
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Directors or its committee or subcommit-
tee heads, nor of the Editor. Information
is intended merely to inform readers.
Drugs & treatments & legal issues should
be discussed with readers' own physi-
cians & attorneys.

NEMSN Welcomes New President

As of January 2017, Lois Vierk accepted the NEMSN Board's request to become the President of the Board. Because of health issues and personal reasons, Jann Heston has stepped down as president. She remained a board member for some months, but resigned this position in July. We are all grateful for Jann's many years of service.

Lois says, "I am honored to lead this group. Our mission remains the same as it has always been, as printed below. We welcome and need contact from our members. Please let us know how you are doing and if you have found helpful strategies for dealing with your symptoms. If you want to speak to another EMS patient about what you are going through, please let us know and we'll put you in contact with someone else who understands.

"We are here for members who got sick in the 1989 EMS epidemic and also for new patients who have been diagnosed with EMS or have an undiagnosed EMS-like disease, after taking current L-Tryptophan, 5-HTP, or Melatonin supplements. We have been very pleased to communicate with Stephen Naylor PhD these past months, about his current research on contaminants in Showa Denko L-Tryptophan and in current supplements."

NEMSN Mission Statement: The National Eosinophilia-Myalgia Syndrome Network, Inc., is a non-profit (501 C-3) 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 and other similar auto-immune disorders.



WANTED: \$\$\$\$\$\$\$\$\$\$\$\$\$\$\$\$\$

Trace back to the mid-70s. An English band named The Flying Lizards sang these words to us: "the best things in life are free, but you can give them to, the birds and bees. I want money, that's what I want.....(and so on).

It's not an elegant message. It might not even seem appropriate for this publication. But, hopefully, it is an attention-getter.....so please continue reading.

NEMSN as you well know is a non-profit organization. We operate on a skimpy budget. We are fiscally frugal. We make a dollar stretch a long way in order to provide you quality services. We end 2017 with approximately \$3,000 in the bank. We had only two contributors in 2017 - that won't do for the upcoming year as we hopefully increase the publication frequency of the newsletter and handle regular recurring expenses.

So, we want (your) money. Put more respectfully, we encourage you to make a tax-deductible contribution to NEMSN either before this tax and calendar year ends or early in 2018. We cannot function successfully without your support. In other words, the best things in life aren't necessarily free. So please donate what you can today and send that donation to:

Michael Bird, Treasurer
315 West Kirkwood Avenue, Apt. 403
Bloomington, Indiana 47404

Thank You,
Michael



May your season be bright and merry.

Eosinophilia Myalgia Syndrome Contaminants: Past, Present, Future

Continued from page 1

At the time, Dr. Gleich had an active research program at Mayo Clinic investigating the cause of EMS, and he introduced me to those issues, as well as to many members of NEMSN. Dr. Gleich and I began what has developed into an approximately 25-year collaboration. Our intent has always been to try and understand what actually caused EMS onset in patients who took Showa Denko L-Tryptophan. Any comprehension of what occurred may ultimately help prevent further harm to anybody taking dietary supplements in the future. In this article I will try to provide you with my perspective on EMS in terms of past, present and future. It is written in a way to complement Dr. Gleich's excellent article that provides a medical perspective of EMS, and is available on the NEMSN website [1]. Here I try to provide a contaminant/toxicological perspective for you to consider, as well as our future plans for trying to solve the mystery of what actually caused EMS in patients who took Showa Denko L-Tryptophan.

2. EMS CONTAMINANTS-HISTORY

The beginning of the EMS outbreak was first recognized in October 1989 when three women in New Mexico were identified with similar clinical symptoms after consuming L-Tryptophan supplements. After widespread media publicity additional cases in both the USA and elsewhere were identified. Epidemiological studies were initiated and it was subsequently demonstrated that a strong association existed between the consumption of L-Tryptophan supplements and EMS onset [1].

2.1 Epidemiological Studies: A national surveillance program was initiated by the US Centers for Disease Control (CDC) to investigate and understand the causation of EMS. In addition as a precautionary measure, the US Food and Drug Administration (FDA) issued a nationwide warning (November 11th 1989) to stop consumption of manufactured L-Tryptophan food products and required a nationwide recall of all L-Tryptophan dietary supplements sold over-the-counter. As Dr. Gleich has described previously in detail, "initial case control studies showed an association between consumption of manufactured L-Tryptophan as a major risk factor for EMS." [1]. 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, and to the best of my knowledge, six Japanese companies manufactured all L-Tryptophan supplements. 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).

2.2 Showa Denko L-Tryptophan Manufacturing: The L-Tryptophan manufactured by Showa Denko K.K. was produced by a genetically engineered bacterium using a fermentation process. The bacterium, *Bacillus amyloliquefaciens*, had been progressively modified over a period of several years to increase the production of L-Tryptophan. The fermentation process used by Showa Denko utilized a large vat/container filled with nutrients, which was seeded with the *Bacillus* bacteria. As the bacterial colony grew, it began to produce large quantities of L-Tryptophan along with a number of other components using its own internal molecular processes. The large quantities of L-Tryptophan produced were then subjected to a multistep purification protocol. 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. Retrospective analyses of these changes in the process showed an association between the development of EMS and the "contaminated" L-Tryptophan produced with the lower quantity of charcoal and the use of the new strain of the bacterium. Showa Denko K.K. ultimately used this confusing situation to their "advantage" since the causal nature of EMS onset in patients was thereby obfuscated. However, as Dr. Gleich has noted, "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." [1]

2.3 Showa Denko L-Tryptophan Contaminants: As

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noted above, epidemiological studies had demonstrated a clear correlation between consumption of only Showa Denko K.K. L-Tryptophan and onset of EMS. In addition it is noteworthy that the epidemic was essentially curtailed when the FDA removed the L-Tryptophan from the retail market. Analysis of the Showa Denko K.K. L-Tryptophan by high performance liquid chromatography (HPLC) and HPLC coupled on-line with mass spectrometry (LC-MS) revealed the presence of over **sixty** contaminants! Careful and exhaustive epidemiological studies as well as lot analyses of contaminated L-Tryptophan revealed that "six individual contaminants" were identified as being case-associated with the onset of EMS. In other words, these six contaminants had some higher probability of being responsible for the causation of EMS. These case-associated contaminants were labeled as Peaks UV-5 (also known as PAA), E, 200, C, FF and AAA, as determined by their unique HPLC retention. Scientists at the CDC, namely Hill and Philen, concluded that contaminants Peak E and Peak AAA "should receive a high priority for isolation and identification".

Dr. Gleich has described his initial work on the structure determination of one of these contaminants, namely Peak E. He wrote, "Arthur Mayeno, a skilled analytical chemist working in our laboratory, set about testing L-Tryptophan from the various companies and from various lots produced by Showa Denko K.K. Arthur had the critical samples needed to find the contaminant, and he employed HPLC to dissect the L-Tryptophan. But what was peak E? Mayeno focused his chemical skills and soon had a structure for Peak E, which consisted of two tryptophan molecules linked together by another molecule, acetaldehyde".[2]

Since that original work, another four of the six the case-associated contaminants have been identified by Dr. Gleich, our collaborators and myself. We have used powerful analytical instruments such as Nuclear Magnetic Resonance (NMR), mass spectrometry (MS), combined HPLC-MS and tandem mass spectrometry (MS/MS) in order to carry out such tasks. Peak UV-5 was identified as 3-(phenylamino)alanine (PAA) after isolation of the contaminant from Showa Denko K.K. L-Tryptophan. Peak 200 has been identified as 2-(3-indolylmethyl)-tryptophan using, both NMR, and HPLC-MS with MS/MS. Peak C was characterized as 3a-hydroxy-1,2,3,3a,8,8a-hexahydropyrrolo-[2,3-b]-indole-2-carboxylic acid. Peak

FF was also subjected to the same analytical protocols as Peak C and identified as 2-(2-hydroxy indoline)-Trp [3,4]. In the case of the "high priority" contaminant peak AAA, until very recently no complete structure determination had been reported (see below). The reason for the hiatus was that both Dr. Gleich and I left Mayo Clinic to pursue other opportunities. We presented some of our preliminary findings on the structure of "AAA" at a meeting in Los Angeles in 2000, but we were not confident enough at the time that we had completely solved the structure. Thankfully we did not try to publish this early work in a peer-reviewed journal since we were actually wrong in our initial analysis!

2.4 Other Contaminants- Toxic Oil Syndrome: In 1981 the ingestion of cooking oil fraudulently sold by Spanish street-vendors as olive oil, caused an outbreak of what became known as Toxic Oil Syndrome (TOS). Causation was attributed to the ingestion of adulterated rapeseed oil (also known as canola oil) used widely in Spanish cooking at the time. In this case the oil had been deliberately contaminated with a mixture of industrial aniline derivatives [5]. The clinical symptoms manifested by TOS patients closely resembled those of EMS patients and were characterized by incapacitating myalgias and elevated peripheral eosinophils. The human impact was traumatic since in excess of 20,000 individuals were affected and over 300 people died in the first twenty months of the TOS epidemic. It was further estimated that it also led to the premature death of approximately another 1690 people during the time period 1983-1997.

Dr. Gleich and I were, and still are, of the opinion that contaminants in the L-Tryptophan and in the rapeseed oil were involved in the onset of eosinophilia and other related symptoms, in both EMS and TOS, respectively. Therefore we looked for evidence that EMS and TOS causation may have a common etiological contaminant trigger. In an effort led by Arthur Mayeno we demonstrated that a known TOS contaminant, 3-phenylamino-1,2-propanediol (PAP), was metabolized in both rat and human liver tissue to produce PAA, a known case-associated contaminant of Showa Denko K.K. L-Tryptophan implicated in EMS onset [6]. In addition a number of other case-associated TOS contaminants have been identified, and they include the fatty acid esters of PAP, namely the 1-oleyl-ester (O-PAP) and the 1,2-di-

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oleyl ester (OO-PAP) [5].

2.5 Other Sources of Contaminants- 5-HTP & Melatonin: For over 25 years now there have been numerous, albeit sporadic reports of EMS-like symptoms apparently caused by taking either 5-HTP supplements or Melatonin supplements. These two other supplements have been used to facilitate sleep and control weight gain. In addition the chemical structures of both supplements are very similar to L-Tryptophan in that all three compounds contain an indole ring. All these compounds are also found naturally in your brain and are part of the serotonin pathway that controls many aspects of mood and other important functions.

After the temporary withdrawal of L-Tryptophan as an over-the-counter supplement, 5-HTP was marketed and promoted as a safer, superior replacement. The increased usage of 5-HTP and vigilance over the possible role of contaminants in EMS onset prompted a report in 1994 that three members of a Canadian family using 5-HTP manifested EMS-like symptoms. The mother was exposed to 5-HTP in 1991 by inhalation and/or by contact with the skin as she made a fine powder preparation of 5-HTP for her young children. The two infants ingested the 5-HTP as part of a medical treatment that included tetrahydrobiopterin and L-dopa/carbidopa, for tetrahydrobiopterin deficiency. The children developed asymptomatic eosinophilia. Their mother was diagnosed with 5-HTP related EMS. The children's symptoms ceased when they stopped consuming the contaminated 5-HTP. The mother required treatment with prednisone to alleviate her symptoms. Analysis of the case-implicated product by HPLC with ultraviolet (UV) detection in 1994 revealed the presence of a unique contaminant, designated as Peak X. Dr. Gleich and I ultimately identified case-associated Peak X as 4,5-tryptophan-dione (4,5-TD) and detected its presence in a number of commercially available 5-HTP supplement brands [7,8]. Our findings were subsequently confirmed by independent analyses carried out by the USA Food and Drug Administration.

There have been numerous reports from a variety of sources, including NEMSN, that taking Melatonin can cause EMS-like symptoms. Such reports from NEMSN began around 1996. In a clinical study in 1993 where Melatonin was being evaluated as an anti-cancer agent, several patients developed eosinophilia. Based on these reports Dr. Gleich and I analyzed three commercially avail-

able Melatonin supplements bought from a local pharmacy in Rochester, Minnesota. Analysis of these Melatonin tablets by LC-MS/MS enabled the structure determination of seven contaminants. The reason that these data were so interesting was because of the structural similarity to the L-Tryptophan case-associated contaminants [9]. Two of these contaminants were identified as hydroxymelatonin isomers, which closely resemble the structure of Peak C in Showa Denko L-Tryptophan. The other Melatonin contaminants were identified as formaldehyde adducts. This was an even more significant observation, as these Melatonin-formaldehyde condensation products were structural analogues of peak E. As you will recall this is one of the more important case-associated contaminants in Showa Denko L-Tryptophan [9]

In 2016 working with Dr. Gleich and Dr. Klarskov (Sherbrooke University), we identified the contaminant Peak X in samples of both Showa Denko L-Tryptophan as well as commercially available L-Tryptophan. Recall that Peak X (see above) was the case-associated contaminant identified from the 5-HTP sample associated with EMS-like symptoms in the Canadian family. Hence Peak X has now been found in Showa Denko L-Tryptophan, in the 1991 5-HTP which made the Canadian family sick, and in currently available commercial L-Tryptophan. Our work on this is in the process of being submitted to a journal for publication. However the relevance is that many of the original case-associated contaminants of both L-Tryptophan and 5-HTP seem to be present in all three indole ring supplements, namely L-Tryptophan, 5-HTP, and Melatonin. Is this a coincidence or has it some relevance to causal onset of EMS in patients taking these supplements?

2.6 Importance of Contaminants: All of the contaminants described above have complex names and equally complex chemical structures. The determination of the chemical structures of such compounds is both expensive and complicated. These efforts require access to analytical instrumentation that can cost millions of dollars and requires many years of specialized training. So why go to such efforts to determine the structures of these contaminants? The structure of a molecule, particularly a contaminant, can provide valuable insight into how disease symptoms such as those in EMS occur. In other instances the structure and shape of a molecule determines how it interacts with the body. For example, everybody is familiar with the analgesic Aspirin, as well as the cholesterol reducing drug Statin.

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These widely used drugs have very different chemical structures and thus react with different parts of your body in order to bring about the effects we are all familiar with after taking them. The same principle applies to contaminants; by determining their structures it may be possible to unravel the mechanism by which they harm your body. Once we have such an understanding then it is both possible to prevent further damage as well as possibly treat the effects of the contaminant(s).

2.7 Animal Models: Once a contaminant structure is determined, then typically it is evaluated in an appropriate animal model such as a rat or mouse. The intent is to try and mimic some of the same symptoms manifested by EMS patients upon administering the contaminant to the animal. Unfortunately simple administration of the Showa Denko L-Tryptophan into mice, rats, monkeys and other animals for the most part has failed to reveal anything of significant value [1]. These same negative findings have been mirrored in the toxic oil animal studies associated with TOS [3]. Finally Dr. Gleich and I were awarded a grant (funding research from 1998-2000) from the World Health Organization while we were both still at Mayo. We evaluated a number of animal models and administered separately, both Showa Denko L-Tryptophan and toxic oil. In all cases we did not observe any detectable adverse effects from either the L-Tryptophan or the toxic oil. All these disappointing efforts have led to a general abandonment of efforts to try and find a cause for EMS or TOS onset. Not least because as Dr. Gleich has noted "... 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". [1] However, we now believe that declaring there is no way of identifying the critical contaminants may be somewhat premature, and this issue is discussed more below.

3. CONTAMINANTS- CURRENT PERSPECTIVES

EMS is a neglected and forgotten disease state. Few clinicians are aware of its existence and how to diagnose and treat the disease. In part this is because EMS is a relatively rare disease that does not occur widely in the general public, but it is also because our understanding of onset and causation is still very limited. Nevertheless, based on

anecdotal information from NEMSN, as well as on occasional reports in medical literature, EMS-like symptoms continue to be reported by patients worldwide.

3.1 Continued Occurrence of EMS: The efforts of NEMSN in publicizing EMS as well as providing a website of information content and a focused contact source has continued to facilitate individual reports from patients exhibiting EMS-like symptoms. These reports typically involve the use of L-Tryptophan (now available again in the USA), 5-HTP and Melatonin. In addition on the NEMSN website there is a page that lists more recent literature reported occurrences of EMS [10]. Briefly they include: 1). The journal *Arthritis & Rheumatism* published an article in 2011 that detailed a "new" 2009 case of EMS after taking L-Tryptophan. The article is entitled "Post-epidemic eosinophilia-myalgia syndrome associated with L-tryptophan". 2). The medical journal *Case Reports in Rheumatology* published an article in 2012 entitled "Severe Eosinophilic Syndrome Associated with the Use of Probiotic Supplements: A New Entity?" The abstract of the article details two current cases of an EMS-like illness from taking probiotic supplements. 3). The medical journal *Reactions Weekly* published an article in 2013, describing new EMS cases in France from 2001-2012, attributed to taking 5-HTP supplements.

In addition there have been several other reports and developments that include the following cases. There was a recent report (2016) of a case of a 59-year old female who started a special weight-reducing diet regimen that included excessive cashew nut ingestion. She presented several months after consumption of the cashew nuts with peripheral blood eosinophilia and constitutional symptoms. She was diagnosed with EMS due to extreme L-Tryptophan intake, a compound found in the cashew nut oil. She responded well to cashew nut withdrawal and steroid therapy. In the follow-up period she remained stable with a normal eosinophil count and there was no need for any specific therapy [11].

In a follow up investigation in 2015 of Melatonin, eight L-Tryptophan related contaminants were detected and their structures determined. This was actually due to the PRESENCE of L-Tryptophan in the Melatonin. Most of the commercially bought samples (11/17) incorrectly listed the amount of Melatonin by 1.0–15% less than declared on the label. In addition the majority of Melatonin tablets tested

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actually contained L-Tryptophan. The researchers had been interested in evaluating the purity of the Melatonin supplements, yet they made the surprising discovery that L-Tryptophan, along with L-Tryptophan contaminants, were actually found in the Melatonin supplements. One Melatonin supplement tested listed L-Tryptophan on the label as an ingredient, but the rest of the samples tested did not! [12].

3.2 Alternative Theories of "Contaminants": Causal onset of EMS efforts has focused primarily on the actual case-associated contaminants of Showa Denko L-Tryptophan. However there have been alternate suggestions as to the cause of EMS, as follows.

3.2.1 Quinolinic Acid: Quinolinic acid (QA) is a downstream product of L-Tryptophan metabolism that occurs by the well-described kynurenic pathway. QA has been shown to be a potent neurotoxin and has been suggested as a key compound involved in a number of psychiatric disorders as well as neurodegenerative diseases. In 2006 an Australian research scientist performed an unusual experiment. He injected himself with QA in order to show that it was a causative agent in eosinophilia. Here he describes in his own words what he did in the name of science! "The principal author (Noakes) received a series of subcutaneous injections of Quinolinic Acid. A total of 1200 mg was administered over a 1-month period. Peripheral blood eosinophil counts were monitored and biopsies taken for H&E and immunohistochemical stains. Over the 1-month period the eosinophil count rose from $0.3 \times 10^9/l$ to $0.8 \times 10^9/l$ before falling to $0.4 \times 10^9/l$ approximately 5 weeks later. H&E sections showed a mixed infiltrate of eosinophils and neutrophils extending through the reticular dermis and septa of the panniculus. No deep fascia was obtained on biopsy. The immunohistochemical stain for transforming growth factor beta 1 showed staining of endothelial cells and dendritic cells. The interleukin-5 stain was negative. Our results suggest that Quinolinic Acid may play a role in cutaneous eosinophilic disorders" [13].

3.2.2 Uncontaminated L-Tryptophan: In 1999 Gross and colleagues [14] evaluated if uncontaminated L-Tryptophan alone could cause EMS-like symptoms in a rat model. They took three-month-old female rats and fed them at 3,6,12 weeks on a diet containing 20% protein diet derived from casein and supplemented with 1%, 2% or 5% L-

Tryptophan. On the last week of feeding, half of the animals fed on a control diet and half of the animals fed on the L-Tryptophan diet were injected with para-chlorophenyl alanine (p-CPA), an L-Tryptophan hydroxylase inhibitor. This causes L-Tryptophan metabolism to occur primarily via the kynurenic pathway described above. The authors concluded "that a cumulative dose of L-Tryptophan and the duration of exposure appears to be important in induction of pathological changes in some tissues. Induction of the kynurenic pathway by injection of p-CPA augments some of the pathological changes and might increase mortality rate. The present observation also confirms previous literature postulating a role of L-Tryptophan and its metabolites in induction of fibrosis and inflammatory reaction." [14]. This was far from a compelling result but appeared to suggest that the kynurenic metabolic pathway may play a role in the manifestation of some of the symptoms of EMS.

These data led to what is an ongoing drumbeat suggesting that high doses of uncontaminated L-Tryptophan were solely responsible for the onset of the EMS epidemic. Dr. Gleich organized a one-day symposium, sponsored by NIH and held on October 21st 2004, to discuss the "current" status of our understanding of EMS. Both Dr. Gleich and I attended and presented, as well as a number of then NEMSN board members [15]. One presentation in particular was intriguing in that Dr. Lori Love (FDA) appeared to argue and suggest that high doses of L-Tryptophan alone were the possible likely cause of EMS onset. This idea was reinforced and presented in a paper by Smith (FDA) and Garrett (University of Virginia) in 2011. They argued "reliance on a finite impurity from one manufacturer is both unnecessary and insufficient to explain the etiology of EMS" [16]. They artfully suggested that excessive histamine activity induced blood eosinophilia and myalgia. They went on to suggest, "overloads of tryptophan supplements cause – among other relevant side-effects – an increased formation of formate and indolyl metabolites, several of which inhibit the degradation of histamine". Finally they suggested, "a final common pathway for syndromes characterized by eosinophilia with myalgia is now evident" [16]. However, it is difficult to reconcile their findings with the original epidemiological work carried out and the subsequent conclusions of Hill and Philen, on Showa Denko-L-Tryptophan. This is discussed in more detail below.

3.3 L-Tryptophan Contaminants-AAA: As we noted above, six compounds present in the Showa Denko L-

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Tryptophan were reported to be case-associated contaminants. However, "one" of these compounds, Peak AAA has remained structurally uncharacterized, despite the fact that it was described by the CDC as "the only statistically significant ($p=0.0014$) contaminant". Recently, we used LC-MS and MS/MS technologies to determine that Peak AAA is in fact two structurally related isomers. Peak AAA₁ and Peak AAA₂ differed in their HPLC retention times. By comparing the LC-MS and LC-MS-MS retention times and spectra with authentic synthetic standards that my Canadian colleagues at the University of Sherbrooke made for us, Peak AAA₁ was identified as the intermolecular condensation product of L-Tryptophan with anteiso 7-methylnonanoic acid, to afford (S)-2-amino-3-(2-((S,E)-7-methylnon-1-en-1-yl)-1H-indol-3-yl)propanoic acid. Peak AAA₂ was determined to be a condensation product of L-Tryptophan with decanoic acid, which produced (S)-2-amino-3-(2-((E)-dec-1-en-1-yl)-1H-indol-3-yl)propanoic acid.

The structure determination of the two isomers, AAA₁ and AAA₂, finally completed the identification of the "six" original case-associated contaminants identified by Hill and Philen. One of our colleagues who is a food chemist in Germany, Dr. Simat, has argued that the fermentation process used to manufacture L-Tryptophan produced six different types of contaminants that include i. metabolites; ii. oxidation products; iii. carbonyl condensation compounds; iv. 2-substituent-Tryptophan derivatives; v. 1-substituent-Trp derivatives and vi. PAA and related compounds. AAA₁ and AAA₂ are actually type iv) 2-substituent-Tryptophan derivatives. However the presence of the fatty acid derived aliphatic chains in AAA₁ and AAA₂ will result in very different metabolic and distribution pathways through the body of a person consuming SD L-Tryptophan. Whether this is of relevance in ascertaining the causal onset of EMS is still to be determined.

The presence of the anteiso aliphatic chain in AAA₁ indicates that *Bacillus amyloliquefaciens* was under cellular stress during the fermentation process. In order to control bacterial cell viability, *Bacillus* species change membrane fluidity and permeability by altering fatty acid composition, chain length, and the ratio of branched-to-linear chain structural isomers. An increase in the anteiso-to-linear or iso-to-linear ratio results in an enhanced fluidity and permeability of the cell membrane. Such a change would facilitate an increased transportation of excess L-Tryptophan

from within *Bacillus amyloliquefaciens* out into the fermentation broth, through the more permeable cell membrane. Finally the presence of AAA₁ and AAA₂ indicate that the production of at least these contaminants was due to the fermentation conditions themselves, not as previously stated an inefficient purification process.

4. FUTURE AND CONCLUSIONS

In the past two years Dr. Gleich and I, along with Dr. Klarskov and Dr. Marsault (both at the University of Sherbrooke, Canada), have devoted considerable time and effort to the structure determination of "Peak AAA". In addition we have been analyzing current commercially available L-Tryptophan and 5-HTP that has been taken by patients who subsequently manifested EMS-like symptoms. This latter effort has been undertaken with NEMSN board members who have identified individual patients who were then kind enough to provide original tablet samples. These new efforts have proved fruitful and interesting and offer some ways forward in terms of our possible understanding of causation of EMS.

4.1 Future Studies: As discussed above, the structures of AAA₁ and AAA₂ are completely different from any other L-Tryptophan contaminant reported. These structures resemble known metabolites in the body that cause eosinophils to migrate towards them wherever they are in the body. Therefore, we are now in the process of arranging to evaluate AAA₁ and AAA₂ in a variety of biological tests to determine if they played any role in causation of EMS patients who took Showa Denko L-Tryptophan. In addition we are testing current commercially available L-Tryptophan and 5-HTP to see if they contain AAA₁ and AAA₂. If these further studies prove successful, then the goal is to submit an NIH grant application for additional funds to more fully evaluate AAA₁ and AAA₂ in appropriate animal models.

4.2 Conclusions: The causal factors associated with EMS onset are still poorly understood. Indeed there continues to be an ongoing discussion as to whether contaminants of Showa Denko L-Tryptophan or high doses of L-Tryptophan caused the EMS epidemic. However, one compelling piece of evidence that suggests the Showa Denko L-Tryptophan contaminants caused the outbreak is as follows. In the late 1980's there were six Japanese companies manufacturing and providing L-Tryptophan to the US market. Hill and

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Philen at the CDC in their methodical and meticulous studies clearly demonstrated that it was only Showa Denko L-Tryptophan that caused EMS [17]. Patients had been taking high doses of L-Tryptophan manufactured by both Showa Denko as well as by the other five manufacturers. If high dose L-Tryptophan alone was responsible for EMS onset [16], then patients across the spectrum should have manifested symptoms. This was clearly not the case, and thus one concludes based on the epidemiological studies that something unique to Showa Denko L-Tryptophan caused the EMS epidemic.

It is however also clear that a simple relationship between ingestion of Showa Denko L-Tryptophan and onset of EMS does not exist. There have been a limited number of studies and suggestions that the genetics and immunological profiles of individual patients made some individuals more susceptible to EMS onset than others. Our understanding of this susceptibility is extremely limited. Part of our future studies would involve trying to unravel this added complexity. Finally, our ability to understand what caused EMS in patients will not, alas, alleviate the symptoms that you have lived with for many years. It will allow us to hopefully prevent any future outbreaks, as well as to possibly develop a therapeutic drug that could be used to treat patients in the early stages of eosinophilia, but that is for the future.

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BIO



Stephen Naylor PhD is a renowned biochemist/toxicologist and entrepreneurial founder of several biomedical specialty companies. He is the Founder and CEO of ReNeuroGen LLC, a virtual pharmaceutical company developing precision medicine drug therapies for the treatment of stroke, multiple sclerosis, sickle cell disease and cardiovascular protection. He is also a Founder and Chairman of the Board of iMBP, a biopharmaceutical company developing therapies for the treatment of hyperlipidemia related disorders. In addition he is the Founder, Chairman and CEO of MaiHealth Inc, a systems/network biology level diagnostics company in the health/wellness and precision medicine sector. He was also the Founder, CEO and Chairman of Predictive Physiology & Medicine (PPM) Inc, one of the world's first personalized medicine companies. He currently serves as an Advisory Board Member of CureHunter Inc., a computational biology drug discovery company, and as a business adviser to the not-for-profit Cures Within Reach. He previously held professorial chairs in Biochemistry & Molecular Biology; Pharmacology; Clinical Pharmacology and Biomedical Engineering, all at Mayo Clinic in Rochester, MN, USA. He holds a PhD from the University of Cambridge (UK), and undertook a NIH funded fellowship at MIT located in the "other" Cambridge, USA.

Dr. Naylor welcomes questions and comments on his article. Please contact NEMSN, and we will forward your concerns to him. Our email address is NemsnTalk@aol.com and our phone is 201-868-5791. You can send letters to...

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best
 wishes
 FOR THE
 holidays



Editor's Note: Special thanks to Julie Ann Allender and to Sophia DeFelice who have taken the time and effort to write articles for us about living with EMS and dealing with symptoms. Thanks also to Dreama Poe for her question to EMS patients. See below.

Update from Julie Ann Allender EdD, Licensed Psychologist

February 4, 2017

I was reading through the NEMSN website and was surprised to find my article from years ago. Not that I didn't write it, but so much time has gone by I had totally forgotten about it. Anyone with EMS can understand that. I talked with Lois and offered to update it and she was thrilled. So that is what I am going to share...

Struggling with EMS for 30 years has a lot of downs, not too many ups. However, as I say to my patients, one must learn to live with what one has and make the best of it. Two of my closest mentors with EMS both succumbed to the disease not so few years ago. I am now the same age they were when they died and can't tell you why I am still alive, but I am.

I have simplified my life at this point as much as I can. I live alone on a 3+-acre piece of property in a double rancher, divorced for almost 20 years from my husband who also is an EMS survivor. He chose different methods to cope than I have. I chose alternative medicine.

The place I bought in Sellersville, PA is much too big for me and if I could do it over again I would have bought much less space. Somehow I manage to keep it afloat, but I also know that the very small amount of money I got from the lawsuit against Showa Denko helps as a backup. I have a person to clean the house. I have a wonderful man who helps me four hours on Saturday and a wonderful man who cuts two of the acres that need to be cut.

My professional practice has dwindled. I am no longer able to work for so little that patients' insurance companies pay. The stress this created only made the

EMS symptoms worse. When I did work it had meant seeing 30 hours of patients and working 80 hours a week. I now accept only two insurance companies, see 15 hours of patients, make less money, but have more time to care for myself. This also means I have more time to keep up with my work load which gets harder as I get older and my memory fades. I was just checked for dementia and the psychologist laughed when he reported the results. He said it was just aging EMS and ADHD.

What I do today to keep the EMS symptoms bearable is to walk five 15-minute walks per day, which equals over an hour of walking. I cannot walk an hour straight, but I can walk short walks often. I swim a half-mile twice a week and work out 20 minutes at La Fitness on the equipment and weights, after my swim. The swim, which is non weight bearing and easy on the legs, is no problem. As for the workouts, sadly, I haven't been able to increase weights or the amount of time. I have been using 5-pound weights for 10 years. I tried to up it to 7.5 lbs., but it wasn't worth the pain. I have accepted knowing I don't produce lactic acid and that less is best. Thank you EMS.

I have learned to accept my word recall problems, laugh at them and ask even my patients for help with the smallest of words. I have difficulty reading, hearing, seeing and even tasting. I had minor surgery on my tongue in 2012 and it still doesn't heal. My hypoglycemia has turned to diabetes and has been out of control for a few years. I gained another 40 pounds and have only this last month found a supplement, GABA, to help me lose weight. The insulin makes it tough. I eat organic, grow my own food, dehydrate, can, freeze and stay away from processed foods, yet I can still gain. I was sick this past summer with a strep B infection didn't eat for three weeks and didn't lose weight. Thank you EMS. I was 110 pounds before being poisoned by L-T.

I still, as many of you know, find most of my answers in alternative medicine. I take Milk Thistle for my liver, B-complex 100 for overall body health, magnesium for muscle spasms, Vitamin D3 and C, Curcuma, turmeric for my hypertension, along with prescription Rx, Standard Process Ligaplex II for damage due to all my falls and much more. It is hard not to fall since I drag my feet.

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Update from Julie Ann Allender EdD

Continued from previous page

With EMS I have become so chemically sensitive I never know what I am going to react badly to next. I spend months trying to figure it out and am usually covered head to foot in horrible rashes as I am right now. Once I figure it out the trick will be to get rid of it and get my skin back to normal. Right now I have the allergens under control, however my chemical sensitivity doesn't allow me to use even basic Aloe Vera, coconut oil or similar to hydrate my skin. I can use Aveeno.

The one thing I don't get much of which I know is so critical is more sleep. It becomes harder and harder to get enough sleep when my body itches and the level of pain is often unreasonable. I do have a godsend, a hydro massage table which I use every night I can before I go to bed. It breaks up the muscle spasms and allows me to sleep a few peaceful hours. I also do Yoga, which stretches the muscles.

The other thing that helps a lot is chiropractic and acupuncture. I go religiously once a month to each one. I find the Korean acupuncture to be the best.

My son, now 31, was born with EMS, as I was pregnant when poisoned. He no longer wants to talk about EMS, but via the grapevine I hear how he describes his painful legs, feet, memory problems, neuropathy, etc. He gets some relief from a chiropractor. He is not open to most medical options. Because he was born before EMS was officially recognized, we couldn't prove to the legal system he had EMS, so he suffers without the luxury of any settlement. It wasn't because professionals didn't try. Dr. Gleich and members of NEMSN were major players in trying to help with his lawsuit.

That is my updated story. Anyone with questions is free to contact me at drjaallender@gmail.com. I'm a past board member of NEMSN.org, an organization that gave me the support and friendships I needed to learn how to work with the EMS.

Editor's note: For people who take supplements, Edward Belongia MD, epidemiologist on our Medical Advisory

Panel, cautions that there is very little oversight or regulation of the supplement industry. Dr. Belongia recommends consulting ConsumerLab.com, a private laboratory that analyzes various kinds and brands of supplements and issues reports on quality and purity. You must become a member of the organization and pay a fee to get their reports. ConsumerLab.com has refrained from analyzing L-Tryptophan or 5-HTP.

Question from EMS Patient Dreama Poe

Dreama Poe emailed us this question. Has anyone tried a product called Surforce? It is described as a "cryopreserved amniotic membrane allograft" which is injected into the body. The company claims it can "reduce pain and inflammation" and treat conditions including "soft tissue damage, rheumatoid arthritis, plantar fasciitis", etc. If you have any experience with this, please contact NEMSN and we will forward your comments to Dreama. (NEMSN itself has no knowledge of this product.)

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 2.

Thank you.
NEMSN Board of Directors

Using Home Trampoline Helps My EMS Symptoms

by Sophia DeFelice

April 11, 2017

Children bouncing and jumping always remind me of laughter and fun. At my lowest point with EMS, I could barely walk half a city street! I became out of breath and felt an enormous weight in the chest area. I avoided taking public transportation as I feared collapsing suddenly from exhaustion. I feared having no control over this type of extreme weakness. I certainly could not imagine jumping, bouncing and feeling good! I was diagnosed with EMS in the Spring of 1991 by Dr. Elaine Lambert. After a year and a half of endless searching and many meetings with various physicians, she was recommended to me. Dr. Lambert confirmed I was not imagining my symptoms. I felt a sense of relief that there was a reason for my dilemma and I hoped one day there would be a cure. Dr. Lambert stressed the importance of managing to stay active and of the benefits of exercise. I had little energy and couldn't muster up the strength for exercise. This was a very strange situation for me because I was a classical dancer at an earlier point in my life. Having a family kept me active and I was health conscious. I did attempt mild yoga exercises but paid for it dearly the following day with even more fatigue and even more brain fog.

I did research on the possible health benefits of bouncing on a trampoline, and then I purchased ReboundAir Rebounder, a very well made mini trampoline. Besides the fact that it is well constructed, the unit is in my home, available for use at any time of day. Some of the benefits company promises impressed me and are listed below, as quoted from the website:

- A. Rebounding provides an increased G-force (gravitational load), which benefits the body by strengthening the musculoskeletal systems.
- B. Rebounding protects the joints from the chronic fatigue and impact delivered by exercising on hard surfaces.
- C. Rebounding benefits lymphatic circulation by stimulating the millions of one-way valves in the lymphatic

system. This benefits the body's immune capacity for fighting current disease, destroying cancer cells, eliminating antigens and preventing future illness.

D. Rebounding circulates more oxygen to the tissues.

E. Rebounding establishes a better equilibrium between the oxygen required by the tissues and the oxygen made available.

F. Rebounding increases capacity for respiration & Rebounding is enjoyable.

Quoting from the *Journal of Cardiopulmonary Rehabilitation*, 1990: 10; 401-408, "The mini trampoline provides a convenient form of exercise with a major advantage being its apparent low level of trauma to the musculoskeletal system."

Another plus is that if one cannot get on the unit to bounce, simply sit on the edge of it while another person does the bouncing and both parties receive the benefits! I couldn't resist!

I imagined I would bounce for 5, maybe 10 minutes, on my first try. The reality was that 2 minutes of a gentle steady bounce seemed like forever. This upset me. The salesperson reminded me that I would be better served by a 1-minute bouncing session a few times a day (moving the lymphatic system) than doing a 10-15 minute work out at one go. Fact is, as much as I trusted what he said to be true, I still was sad I couldn't do more time. And while I found Rebounding to be fun and exhilarating, I would feel the effects the next day if I overdid it. I learned to accept my 1-, 2- or 3-minute regime and slowly built up to 8-10 minutes on my best day after a LONG while. The fact is you are using less of your own body force and instead making use of the benefits of gravity to get the best workout. Today, I don't fear walking around the neighborhood nor taking public transportation when necessary. I am able to gauge my own condition at the moment quite well. I still don't use the Rebounder for more than 10 minutes, 2 times a week. Yet, I go up and down three flights of stairs in my housing complex, which has no elevator...some days 2 or 3 times up and down. This beats what I could do at my lowest point with EMS. Ergo, I am content.

www.rebound-air.com



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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In Memoriam - Sharron Lobaugh

by Michael Bird

How many nouns can a person be during a lifetime? "Many" is the answer if you're talking about Sharron Lobaugh, past President of the NEMSN Board of Directors who died earlier this year at her long-time residence overlooking Juneau, Alaska.

For NEMSN members and friends, she was our leader, an empathetic soul, a doer, a tireless and zealous advocate, a telephone companion, and an EMS survivor. During her tenure, she helped organize the last NIH-sponsored conference on EMS and ensured that newsletters went out periodically to members. She walked the halls of Congress, securing language in appropriations bills encouraging more research on EMS. She helped keep us current on the latest medical and health developments. And, she inspired some of NEMSN's most successful fundraising efforts. When asked "why," Sharron's typical response was "why not?"

For many others, Sharron was a wife, mother, gardener, outdoorswoman, teacher, activist, traveler and advocate. She was a member of the Juneau School Board, a teacher trainer, a Sierra Club member and wilderness supporter, a Co-founder of the Alaska Alliance for the Mentally Ill and a holder of multiple university degrees in education and psychiatric rehabilitation. Perhaps most of all, she was an artist. Her watercolors and oils are known to many - in Alaska, and beyond. In many ways she was NEMSN's artist, painting a panorama of caring, hope and personal relationships.

We tip our easels to you Sharron and thank you for being a part of us for so many years.

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