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National Eosinophilia-Myalgia Syndrome Network, Inc.
http:www.nemsn.org

National EMS Network Newsletter

Thirty Years Of EMS -- Where Are We Now?

by Lois Vierk

This year marks the 30th anniversary of the EMS epidemic outbreak in 1989. NEMSN's communication with members reveals just how hard people try to deal with symptoms and to preserve functionality in our bodies. No two of us have had exactly the same experience with EMS or with coping with its many symptoms. We respectfully acknowledge each one's path, each one's efforts. A huge shout out to all of us survivors! A big thank you to our Medical Advisory Panel members for ongoing research, for connecting personally with various EMS patients, for medical advice offered to individuals, and for being available to answer EMS questions. A big thank you also to all who over the years have volunteered to provide support for NEMSN members, by serving on the NEMSN Board or in other ways.

During recent years there have been numerous contacts from new patients as well. These people suspect their EMS-like symptoms are from current L-Tryptophan, 5-HTP or Melatonin supplements. NEMSN has learned that these three substances have chemical similarities. It is proving very difficult for new patients to get a diagnosis because doctors in general know little about EMS.

Articles in this newsletter summarize the ongoing work of NEMSN. Our Medical Advisory Panel members have written articles or weighed in with information and advice in this issue. Gerald J. Gleich M.D. reports "a striking advance in our understanding of the eosinophil". His article entitled "New Understanding of Eosinophils" tells of a recently developed medicine which may help some EMS patients. The medicine, named Benralizumab (known as Fasenra), has potential to help new patients who are experiencing eosinophilia for the first time, as well as epidemic EMS patients if they experience renewed eosinophilia during a flare-up.

Stephen Naylor Ph.D. has written two articles for this newsletter. The first, entitled "What is in a Name? L-Tryptophan, 5-Hydroxytryptophan and Melatonin Explained", describes why these supplements should be considered as similar and the ramifications of such thinking. The second article, titled "Thirty Years of Understanding Eosinophilia-Myalgia Syndrome: Does it Still Exist and Persist?", is an overview of the current scientific thinking about EMS and a progress report on the understanding about what caused EMS and what this means for all of us.

"Contacts from Epidemic Patients and Possible New EMS Cases", co-authored by Nancy Grant and me, is a report on NEMSN communications over the past several years with these two groups of people. In this article, Kim Sing Lo D.O. offers advice to patients for finding relief for ongoing symptoms. Edward Belongia M.D. sheds light on why it is difficult for post-epidemic patients to obtain a diagnosis.

Three articles addressing key organizational matters have been penned by Michael Bird. "Election 2020" addresses the upcoming election of Board members and need for candidates, and "You Knew We Were Going to Ask" is our recurring request for badly-needed contributions. "The By-Laws That Guide Us" summarizes recent Board review of NEMSN's by-laws and offers recommendations for changes. All of these articles seek your input.

Rhonda Farro has recently joined the NEMSN Board. She had been a Board member before, from 2004-2007, and earlier this year she agreed to serve again. Rhonda has written her EMS story for us, entitled "Thirty Years Living With EMS."

Finally, along with hopeful developments, we also have difficult news to report. This past summer, very sadly, we lost Sandy Keating, NEMSN newsletter editor, to illness other than EMS. Many of you knew Sandy and the tremendous work she did for NEMSN. A tribute to Sandy, by Ann Flaherty, is found at the end of this newsletter. We miss Sandy greatly!

In summary, the past 30 years for all of us has been a time of ups and downs -- a mix of tremendous change, frustration, and also hope. Our lives were thrown into disarray when we were first struck with EMS. Over the years we've had to adjust to living with symptoms and to finding ways of dealing with them. We hope this newsletter contains useful, perhaps valuable, information about the progress in EMS understanding and how that might help all of us. NEMSN is a small organization but with the help and support of all of you, we continue to make a difference.

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You Knew We Were Going to Ask

Dear Reader: you've arrived at that section of the newsletter where an appeal is made to your charitable side. Yes, like any non-profit, volunteer organization, it takes dollars and cents to conduct NEMSN's business. Whether it be fine tuning the NEMSN webpage or producing newsletters like this one, the bill comes due. We use the contributions you make effectively and responsibly. We aren't some multi-million dollar operation. Rather, we head toward the conclusion of 2019 with approximately $4,100 in the bank. Ahead are costs for newsletter production and distribution, webpage domain charges and updates, Board of Directors telephonic meetings, communications with medical advisors, victims and interested parties….and the ever-present incidentals.

You are our only source of funding. We hope you value enough what NEMSN does for you and others that you will make a contribution of whatever amount you can. All you need to do is write a check made out to NEMSN and send it to:

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

Thank You.

Special Thanks

NEMSN gratefully acknowledges contributions of time and legal expertise by Michael Majewski, Esq.

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Last but not least, NEMSN gratefully acknowledges help and advice in the production of this newsletter, by Downtown Direct in Amherst, OH. Thanks to the whole team - Rick, Liz, and Kevin Hobson! http://www.downtown-direct.com/

Newsletter Help Needed

Do you have experience with newsletter production or editing? Do you like to write? The NEMSN Newsletter needs you. Please get in touch by emailing nemsntalk@aol.com or phone 201-868-5791.

Inside this issue:

New Understanding of Eosinophils

by Gerald J. Gleich M.D.

NEMSN offers this introduction, as approved by Dr. Gleich: This article describes the new drug benralizumab (known as Fasenra), manufactured by AstraZeneca and approved for the treatment of eosinophilic asthma. The drug works by removing eosinophils from the patient's circulation. For new patients who may have EMS it is worthwhile to discuss this new drug with your physician as a possible therapeutic intervention agent. In the case of NEMSN epidemic patients, if you are experiencing a flare-up, you should consult with your primary physician and have your blood eosinophil levels checked. If the levels are elevated then it may be worthwhile to also discuss Fasenra with your physician and whether it may be of some value in treating your flare-up.

In the past, the eosinophil was thought to repair tissue damage after allergic events, such as anaphylaxis, and after attacks of asthma. However, observations on patients with asthma showed that eosinophils track with disease severity (the sicker the patient with asthma, the more eosinophils are present). This suggested that eosinophils might be mediating tissue damage during disease.

Analyses of eosinophil granules showed the presence of a protein, called the major basic protein (MBP). MBP is a potent toxin for mammalian cells, it kills bacteria and, perhaps most importantly, it kills helminths (worms). MBP is extensively deposited on damaged tissues, such as the airway of patients dying of asthma. Thus, a protein toxin, MBP, was present in disease in association with damage. This observation suggested that the eosinophil plays an inimical role in human disease by damaging tissues.

This view of what eosinophils do has now been essentially proven as a result of the use of a new medication, termed benralizumab. Benralizumab binds to the eosinophil and causes its destruction. Patients receiving this drug are essentially eosinophil deficient with an absence of blood and tissue eosinophils. Benralizumab depletes the eosinophil in patients with asthma and benefits them by reducing asthma exacerbations. Because the only effect of benralizumab is eradication of eosinophils from the blood and tissues, the beneficial effect in asthma indicates that the eosinophil is a key cell causing asthma worsening (and likely worsening in numerous other diseases).

However, a startling new observation has emerged from the utilization of benralizumab for the treatment of asthma. Presently, approximately 40,000 patients are receiving this drug, and, remarkably, the absence of the eosinophil does not seem to be associated with any abnormality. Whereas some studies suggested that the eosinophil has a variety of functions, including bone marrow maturation, breast development and even a role in reproduction, the findings in patients receiving benralizumab argue that we do not need eosinophils for our normal health in 2019.

Therefore, one wonders why we have eosinophils. Observations dating back over 100 years have shown that eosinophilia is strikingly present in helminth (worm) associated diseases, and paleontologists (scientists concerned with studies of the past) have evidence that humans have been afflicted with helminthic diseases essentially since our presence on the planet. Whereas now helminth infections are uncommon (in modern societies with proper hygiene), in the past, these diseases may have been a significant threat to overall health.

Knowledge that benralizumab eradicates eosinophils and benefits eosinophil-related diseases without significant adverse effects should be encouraging to sufferers of Eosinophilia-Myalgia Syndrome (EMS). Any recurrence of EMS would be treated with this drug (and others, such as mepolizumab and reslizumab which also reduce eosinophils) and the eosinophils would be markedly reduced in blood and tissues. An advantage of these new treatments is that they are very well tolerated; in contrast, prednisone that was our main treatment in the past has many adverse side effects.

Update Your Email and Contact Information

We need your email address! We'd like to be able to keep in touch better with our members and there's also the option to receive our newsletters by email, if you prefer. We need any updates to your US mail address, too. Please email NEMSN at nemsntalk@aol.com or phone 201-868-5719. You can send us a letter - NEMSN, P.O. Box 4171, Monitor Stn., West New York, New Jersey 07093.

Thirty Years of Understanding Eosinophilia-Myalgia Syndrome: Does it Still Exist and Persist?

by Stephen Naylor Ph.D.

1. INTRODUCTION

A fateful series of events unfurled thirty years ago. The subsequent outcome dramatically affected all of your lives. During October of 1989, three different women in the state of New Mexico manifested unique symptoms characterized by myalgia (pain), elevated white blood cell (eosinophils) levels and assorted other symptoms. One of those individuals was Ms. Bonnie Bishop, a current member of NEMSN. Dr. Edward Belongia (a member of the NEMSN Medical Advisory Board) recounts her story in his detailed book chapter entitled "Toxic Tryptophan? Investigating the Eosinophilia-Myalgia Syndrome in Minnesota" (1). I appreciate that all of you have your own individual experiences and stories to tell about that period. But at the time the situation was fraught with lack of any understanding, fear, anxiety and uncertainty. Another member of the NEMSN Medical Advisory Board, Dr. Gerald "Jerry" Gleich was also a central figure in helping to unravel the complex, unfolding events. He was a renowned expert in eosinophil biology and related disease states, and helped treat identified patients such as Bonnie Bishop with prednisone. Ultimately, as you all know, it was determined that contaminated L-Tryptophan, manufactured by the Japanese company was the cause of this condition and Eosinophilia-Myalgia Syndrome (EMS) was alas "born".

2. CAUSE OF EMS

A number of epidemiological studies have demonstrated a clear correlation between consumption of Showa Denko 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. Analyses of the Showa Denko L-Tryptophan by high performance liquid chromatography (HPLC) and HPLC coupled on-line with mass spectrometry (LC-MS) revealed, at the time over **sixty** contaminants. I should note that in recent studies done with my colleagues Dr. Klaus Klarskov (University of Sherbrook) and Dr. Gerald Gleich (University of Utah) we have found over **six hundred** contaminants present in the same Showa Denko L-Tryptophan! Careful and exhaustive epidemiological studies as well as sample 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 significant probability of being responsible for the onset of EMS. These case-associated contaminants were labeled as Peaks UV-5, E, 200, C, FF and AAA, as determined by their unique analytical properties. Dr. Gleich and I, along with others have now identified all the case associated contaminants of Showa Denko L-Tryptophan. We recently determined the structure of the last case-associated contaminant Peak AAA with our colleague Dr. Klarskov. This contaminant turned out to be two closely related compounds re-labeled as AAA-1 and AAA-2, taking the total number of case-associated contaminants up to seven (2).

The determination of EMS causal onset has focused primarily on the structure determination and biology of the actual case-associated contaminants of Showa Denko L-Tryptophan. However there have been alternate suggestions as to the cause of EMS. Quinolinic acid (QA) is a metabolic product of L-Tryptophan. This compound has been shown to be a potent neurotoxin and implicated in a number of psychiatric disorders. 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. Whilst the experiments were unique the theory has found little credence as a cause of EMS. Another drumbeat suggesting that high doses of uncontaminated L-Tryptophan alone were solely responsible for the onset of the EMS epidemic has been proposed. Smith and Garrett suggested that the "reliance on a finite impurity from one manufacturer is both unnecessary and insufficient to explain the etiology of EMS" (3). They artfully suggested that excessive histamine activity induced blood eosinophilia and myalgia. However, it is difficult to reconcile their findings with the original epidemiological work carried out by Belongia and others. Indeed, numerous clinical studies utilizing mega-doses (up to 18 grams per day!) of L-Tryptophan have never resulted in any manifestation of EMS-like symptoms in those closely supervised trials.

One additional factor to consider for EMS patients is their genetic profile. In previous studies it has been shown that approximately 2-5% of all people taking Showa Denko L-Tryptophan ultimately manifested EMS symptoms. This suggested a genetic predisposition due to the presence/absence of one or more deleterious or protective genes. This has been further explored by other researchers, who have reported a number of genes present in EMS patients that likely led to a predisposition of disease onset (4,5). This field of enquiry is still nascent, but it is generally agreed that your genetics play a critical role in whether you may suffer EMS onset. However, in the case of the original outbreak, this was clearly brought about by the consumption of contaminated Showa Denko L-Tryptophan. Numerous studies demonstrated that the severity of EMS onset was also related to the amount of L-Tryptophan you consumed on a daily basis. Varga and colleagues have argued that "The pathogenesis of EMS is thought to involve exposure to certain preparations of L-Tryptophan in a genetically-susceptible host that trigger acute inflammation and eosinophil activation and degranulation

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with resulting chronic tissue fibrosis. However, because EMS has been reported in individuals who have never consumed L-Tryptophan, it is likely that xenobiotics other than L-Tryptophan preparations can also trigger a similar immune response" (5). I tend to agree with much of what Varga and his colleagues wrote back in 2011, but I would put it somewhat differently. The specific cause(s) of EMS is still uncertain. However I would suggest that it may be a combination of the following; i) genetic predisposition, ii) repeated consumption of L-Tryptophan (or structurally related compounds such as Melatonin or 5-Hydroxytryptophan (5-HTP)), iii) presence and amount of one (or more) contaminant(s) reported to be present in Showa Denko L-Tryptophan.

3. PERSISTENCE OF EMS

Few clinicians are aware of the existence of EMS and how to diagnose and treat the disease. In part this is because EMS is a relatively rare disease that occurs sporadically, and our understanding of causation and onset is still very limited. Nevertheless, based on information from NEMSN, as well as on occasional reports in the 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 that provides 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. Since 2011, when a systematic reporting protocol was adopted, approximately ninety new individuals have self-reported EMS-like symptoms to NEMSN. Nancy Grant and Lois Vierk have discussed this issue in their article entitled "Contacts from Epidemic Patients and Possible New EMS Cases" published in this same newsletter. Patients indicated in the completed questionnaires that consumption of L-Tryptophan (~30%), 5-HTP (~35%), Melatonin (~1%), some combination of L-Tryptophan/5-HTP/Melatonin (~8%) or Other/Unknown (~22%) had occurred prior to onset of symptoms. However, I should make clear that the vast majority of these individuals have not officially been diagnosed with EMS. Indeed in at least two cases, individuals were more likely to be suffering from Post-Finasteride Syndrome (PFS) since they had been taking Finasteride (Propecia) for years to treat hair-loss (6). A number of PFS symptoms are similar to those encountered by EMS patients, although there are notable symptomological differences. These examples highlight the difficulties of diagnosing EMS. In order to provide more inclusive and accurate diagnostic criteria, Hertzman and colleagues redefined EMS diagnostic criteria such that elevated eosinophils did not have to necessarily present to be diagnosed with this syndrome (7).

The NEMSN website (www.nemsn.org : see Updates and New Cases page) also contains details of more recent literature reported occurrences of EMS. Briefly they include: 1) The journal Arthritis & Rheumatism published an article by Varga and colleagues in 2011 that detailed a "new" diagnosed case of EMS from a Chicago woman who took Uber Rest L-Tryptophan (5). 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 in 2015 of a case involving 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 (8).

In a 2015 follow up investigation 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 (eleven out of seventeen) incorrectly listed the amount of Melatonin by 1.0–15% less than declared on the label. In addition the majority of Melatonin tablets tested 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 (9). However, it should be noted that Melatonin itself contains contaminants that are very similar to those case-associated contaminants found in Showa Denko L-Tryptophan (10). This is discussed in a separate article entitled "What is in a Name? L-Tryptophan, 5-Hydroxytryptophan and Melatonin Explained", published in this same anniversary newsletter.

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What is in a Name? L-Tryptophan, 5-Hydroxytryptophan and Melatonin Explained

by Stephen Naylor Ph.D.

The EMS epidemic of 1998-90 was caused by the consumption of contaminated Showa Denko L-Tryptophan. However, over the past twenty-five years there have been a number of sporadic reports of EMS-like symptoms from individuals taking either 5-Hydroxytryptophan (5-HTP) or Melatonin supplements. These include a number of patients who have self-reported through NEMSN, and this is detailed more in the article by Nancy Grant and Lois Vierk entitled "Contacts from Epidemic Patients and Possible New EMS Cases" published in the current NEMSN newsletter.

5-HTP & Melatonin: After the temporary withdrawal of L-Tryptophan due to the EMS epidemic, 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. Analysis of the case-implicated product 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. 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 also cause EMS-like symptoms. 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 available Melatonin supplements bought from a local pharmacy in Rochester, Minnesota. Analysis of these Melatonin tablets enabled us to determine the chemical structures of seven contaminants. The structural similarity to the case-associated contaminates found in Showa Denko L-Tryptophan was striking. Two of these contaminants were identified as Peak C (L-Tryptophan case-associated contaminant) analogs. The other Melatonin contaminants were identified as Peak E (L-Tryptophan case-associated contaminant) analogs.

Chemical Structure of Contaminants: The contaminants found in L-Tryptophan, 5-HTP and Melatonin all have complex names and chemical structures. The determination of these structures 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. 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).

L-Tryptophan, 5-HTP and Melatonin Same or Different?: All three supplements have been used to facilitate sleep, control weight gain, aid in the relief of depression and other assorted maladies. Many people who take L-Tryptophan, 5-HTP and/or Melatonin believe that they are unrelated, and very different supplements. So why has each one of these supplements been associated with EMS-like symptoms after consumption by individuals? Organic Chemists and Toxicologists would inform you that all three supplements are closely related based on their chemical structures. As an example think about three different houses you are evaluating to purchase for you and your family. All three houses have an identical foundation and structural framework. However, they differ in color and type of siding, window frames and door entranceways. Casual observation suggests three distinct houses, but to the building constructor they are essentially the same type of house with cosmetic changes. Those minor changes can elicit very different responses form potential buyers.

In the case of L-Tryptophan, 5-HTP and Melatonin the structural framework is identical, and consists of what organic chemists call an indole ring system. However, just like the house analogy, some of the appendages (called functional groups) are different. These minor structural changes determines that each of these compounds can react differently in the human body. But L-Tryptophan, 5-HTP and Melatonin also react with other molecules in such a way that produces structurally similar contaminants that may induce identical symptoms of a disease like EMS. ***All individuals should remember that L-Tryptophan, 5-HTP and Melatonin are very similar from a chemical structure perspective and this must be considered the next time you think about purchasing a supplement for personal consumption.***

(Please note the opinions expressed in this article are solely those of the author and do not necessarily reflect the views of NEMSN.)

Contacts from Epidemic Patients and Possible New EMS Cases

by Nancy Grant and Lois Vierk

NEMSN has a steady correspondence from our membership and from new individuals who have questions regarding symptoms they are experiencing after the ingestion of over-the-counter supplements of L-Tryptophan, 5-Hydroxytryptophan (5-HTP) and/or Melatonin. Lois Vierk, NEMSN president and second author of this report, is usually the first to respond to all of these individuals. Any online communication is answered by email, which sometimes leads to follow-up communication by phone. Over the years, NEMSN board member, George E. Bush, has joined Lois in communicating with our membership and new individuals by phone. If a contact from a new individual who is reporting symptoms which seem like a new case of eosinophilia-myalgia syndrome (EMS), our Medical Advisory Panel is consulted if the individual gives permission. Individuals from our membership also submit questions to our advisors, who will answer as appropriate for the situation and subject.

In 2011 NEMSN began collecting and saving responses from our online questionnaire, as well as from emails and phone communications from individuals who have chosen to contact us. This is a rich source of information which we thought would be useful to summarize and describe to our membership. For the purposes of this report, we will break the respondents into two groups: The epidemic group which will consist of those individuals who became ill during the 1989 epidemic from having taken L-Tryptophan, along with a few individuals who became ill prior to the epidemic, and the post epidemic group which will consist of those individuals who became ill and reported EMS-like symptoms after having taken what was their present-day over-the-counter supplement of L-Tryptophan, 5-HTP and/or Melatonin. This is a report on those communications. It's not a formal survey, just a summary of what individuals have chosen to tell us

Number of Contacts and Geographic Distribution

NEMSN has had a total of 128 individual contacts from 2011 to the end of August 2019, Of the 128 contacts, we have had 40 contacts from the epidemic group all of which came from the United States and Canada, 70 contacts from the post-epidemic group which came from the United States, United Kingdom, Canada, Australia, India, South Africa, Denmark, Finland, Israel, Saudi Arabia, Italy and New Zealand, and 18 contacts from individuals who used other or unknown products and whom we will not be summarizing for this report. Of the post-epidemic group, those individuals who became ill and reported EMS-like symptoms after having taken L-Tryptophan, 5-HTP and/or Melatonin, we cannot say that all of these people do indeed have EMS, just that they are concerned about having EMS-like symptoms after taking the supplements. We know from this group that it is almost impossible to get a diagnosis of EMS now. Many doctors today know little or nothing about our disease and will not even consider making an EMS diagnosis even when many other medical conditions have been ruled out

Diagnoses

Among the epidemic group of 40 contacts, 31 individuals had taken L-Tryptophan and were diagnosed with EMS during the epidemic (like typical NEMSN members), one pre-epidemic individual took L-Tryptophan, became ill with EMS-like symptoms in 1984 and was retroactively diagnosed with EMS (after identification and naming of syndrome during epidemic), and eight individuals had taken L-Tryptophan in 1989 and became ill with EMS-like symptoms but were never given an EMS diagnosis. This last group of individuals is wondering even today if the L-Tryptophan they took thirty years ago could have caused their ongoing EMS-like symptoms. Two of these eight have never received a diagnosis of anything at all to explain their symptoms but still remain physically impaired. Two were diagnosed with chronic fatigue syndrome. One was diagnosed with eosinophilic fasciitis, one with fibromyalgia as well as gastroesophageal reflux disease and gastritis, one with myositis (inflammation of the muscles), and one with glandular fever. They all still wonder, however, if L-Tryptophan could be at the bottom of their life-long health issues.

Relative Health

Of the 31 epidemic individuals and one 1984 individual with an EMS diagnosis (32 total), two report that they are doing well today. The rest report that after surviving the initial attack and having symptoms abate, they are still having a lot of trouble. Some report that various symptoms have gone away but new ones have come along over the years. Several say that they went for up to 20 years with reduced symptoms and that suddenly symptoms came on again with the intensity of the original attack. A few ask if EMS can "come back".

Symptoms and Other Diagnoses

This group of 32 individuals reports currently having the symptoms that follow. Pain, of course, is the most universal complaint. Specifically, there is muscle pain, joint pain, inflamed joints, burning sensation or tingling and other neuropathy in the limbs, spasms in various parts of the body. There is loss of function, especially in the legs, difficulty walking and driving. People report food and chemical allergies and sensitivities, as well as intolerance to heat and cold. Psoriasis, hard areas on the skin, and development of fibrous tissue in the body are other conditions. Some of these individuals are suffering various gastrointestinal and digestive system problems, also frequent choking. Cognitive dysfunction problems were cited by a number of people. Extreme shortness of breath was mentioned,

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also difficulty sleeping, fatigue and exhaustion. People report hair loss and teeth falling out. Recovery time after surgeries and invasive medical procedures can be much longer than expected by patients or doctors. Depression, anger and frustration are common.

Other diagnoses and conditions that this group reports are an atypical form of Crohn's disease, eosinophilic fasciitis, thyroid problems including Hashimoto's disease, unnamed central nervous system disorders, nerve damage, scleroderma, arthritis, psoriatic arthritis, and heart problems. One person is told her "veins are leaking". People also report joint and tendon damage, and compromised fascia. Other diagnoses are pulmonary fibrosis (scarring in the lungs), fibromyalgia, and small intestine bacterial overgrowth. Some individuals tell us of dry mouth and dry eye, and frequent bronchitis.

Concerns

What are the main concerns of these 32 patients? They want to find better ways of dealing with their pain. They have found very few doctors who know about EMS. They want to find doctors who can help them.

What Helps

What do these individuals do for their symptoms? One individual has found relief from taking the medicine gabapentin. Others take over-the-counter pain medicine as well as Lyrica, Ambien and various pain killers including opioids, and muscle relaxants. Some emphasize that they need to consistently exercise, and in particular one individual uses a small home trampoline. One other individual says that she must not exert her muscles. One individual cites relief from Osteopathic Manipulation Treatment (OMT) administered by a physician. Others get help from acupuncture, electric acupuncture, hydrotherapy, and chiropractic treatment. One individual has had epidural injections and another has tried neurotransmitter implants. Other individuals take various supplements, use heating pads, and rely on various types of massage as well as hot baths, including Epsom salt baths.

Medical Advisory Panel

Over the years, our Medical Advisory Panel has weighed in on various concerns these epidemic and post-epidemic individuals have brought to us.

Gerald J. Gleich, M.D. expert on many types of eosinophilia, can evaluate, for example, if new patients possibly do have EMS from the current supplements they've been taking, even when the patient's local doctor has dismissed or not considered the possibility. Dr. Gleich has recommended specific medicines to epidemic and post-epidemic patients, as determined by symptoms.

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Edward Belongia, M.D. epidemiologist on our panel, has offered an informative explanation about diagnosing EMS in epidemic times and diagnosing EMS today. He writes, "Any unusual disease (such as EMS) will be diagnosed more often in an outbreak situation because publicity raises awareness among both doctors and patients. The majority of doctors in practice today did not experience the EMS outbreak, and it's not something they would learn about in medical school. I'm sure rheumatologists have heard of it, but most have not had any direct experience. In addition, EMS has characteristics that overlap with other conditions, such as eosinophilic fasciitis. When we are only seeing sporadic cases, it is very difficult to attribute the disease to a specific exposure which might be coincidental. I suspect EMS is largely viewed as a historical disease related to a product that is no longer on the market (Showa Denko L-Tryptophan), but the reality is that we don't know if contemporary L-Tryptophan or 5-HTP might be triggering cases at a low level in the absence of an identified outbreak."

Stephen Naylor, Ph.D. biochemist and toxicologist, has been able to share much information with patients about symptoms and sometimes about diagnosis. His knowledge is based on Dr. Gleich's and his current research into EMS toxins and also his recent interviews with quite a number of patients, both epidemic and post-epidemic, about EMS symptoms and flare-ups. He has spent a lot of time talking to patients on the phone.

Kim Sing Lo, D.O. osteopathic physician on our panel, has advised quite a few EMS patients to seek help for their medical condition and relief from pain through Osteopathic Manipulation Treatment (OMT) as administered by a doctor. We note that both Lois and George have found considerable relief of EMS symptoms over the years though the gentle hands-on treatment OMT. Several new patients have tried OMT and have subsequently reported improvement in symptoms. The website Dr. Lo recommends for finding OMT physicians, hopefully close-by the patient, is www.cranialacademy.org.

Rewards

Finally, connecting with EMS patients has been a rewarding experience for those of us on the NEMSN board. We've met some inspiring people who are determined to live life as fully as possible. George E. Bush, after speaking with a number of epidemic EMS patients, says, "As a board member I have had the privilege of speaking to a variety of people. Naturally there are samenesses and differences among them, however there are some common points. All were very sick in 1989 when the epidemic broke and they sought explanations. When EMS was discovered they all showed a tremendous faith and hope which got them through and they continue to demonstrate great courage in living with the obstacles that EMS presents."

The By-Laws That Guide Us

by Michael Bird

Like other non-profit organizations, NEMSN is governed by its membership and By-Laws. NEMSN's By-Laws were last amended in 2000. Much has changed since then. Furthermore, it is advisable and healthy to periodically review the provisions and activities that guide us. And any review should seek to make us a stronger and more effective organization for you.

Over the last few months, your Board of Directors has examined and discussed our By-Laws. That examination and discussion has raised the question as to whether the By-Laws should be fine tuned, edited, changed and/or amended. The Board of Directors has concluded that some changes are needed. We have developed some preliminary recommendations which follow. WE NOW SEEK YOUR COMMENTS AND SUGGESTIONS. Ultimately, any change, even if it is only a punctuation change, must be approved by NEMSN's membership in March, 2020 (according to the By-Laws as now written). So, we want to ensure you have sufficient time to read our recommendations, respond with your own suggestions and comments and edits, and ultimately cast a vote for or against recommended changes.

What changes are we recommending? The recommendations address the organization's purpose, the organization's membership criteria, terms of office and election of members of the Board of Directors, meeting frequency, dissolution of the organization and incidental changes. More specifically, here are our recommendations which are highlighted in **BOLD**;

1. ORGANIZATIONAL PURPOSE. Current provisions generally state that NEMSN exists to promote the health and well-being of persons with EMS, to educate the public and victims about EMS, and to promote educational programs via a newsletter, conferences, committees, projects and programs. Your Board of Directors recommends adding **THE MAINTENANCE AND UPDATING OF AN ORGANIZATIONAL WEBSITE** to NEMSN's general purposes.

Additionally, current provisions clearly state that NEMSN serves those persons diagnosed with EMS caused by having taken L-Tryptophan and associated illnesses. Given current medical findings and diagnoses, your Board of Directors recommends that this be expanded to include **PERSONS WITH OR WITHOUT AN EMS DIAGNOSIS AND HAVING EMS-LIKE SYMPTOMS AND MEDICAL ISSUES FROM HAVING TAKEN L-TRYPTOPHAN, 5-HTP AND/OR MELATONIN**.

2. NEMSN MEMBERSHIP. Under the By-Laws adopted in 2000, membership in NEMSN includes individuals with an EMS diagnosis, family members, caregivers and significant others of victims and professional persons engaged in treatment, research and legal issues connected with EMS. Additionally anyone receiving the newsletter as of **January 1, 2000** (which should include all the individuals mentioned above) is grandfathered into the organization. Your Board of Directors recommends changing the grandfather date to JANUARY 2, 2020. It also recommends expanding membership to include **PERSONS WITH OR WITHOUT AN EMS DIAGNOSIS BUT HAVING EMS-LIKE SYMPTOMS AND MEDICAL ISSUES FROM HAVING TAKEN L-TRYPTOPHAN, 5-HTP AND/OR MELATONIN**.

3. TERMS OF OFFICE. Current provisions state that a member of the Board of Directors serves a two year term and can be elected an unlimited number of times. Your Board of Directors recommends changing this to **FOUR-YEAR TERMS, A MAXIMUM OF THREE CONSECUTIVE TERMS FOR ANY INDIVIDUAL, AND AN EXCEPTION TO SERVE MORE THAN THREE TERMS ONLY IF THERE ARE INSUFFICIENT CANDIDATES FOR VACANT BOARD POSITIONS.**

4. MEETING FREQUENCY. Current provisions state that the Board of Directors must meet 10 out of every 12 months, not meet in July and December, and conduct as one of its 10 meetings an annual meeting of the membership in March. There are provisions that allow the Board to meet at other times if deemed necessary. Your Board of Directors recommends changing this to **A MANDATORY MEETING EACH QUARTER OF EACH YEAR, MAINTAINING THE MARCH MEETING AS NEMSN'S ANNUAL MEMBERSHIP MEETING, AND PERMITTING THE BOARD TO MEET MORE FREQUENTLY AS DEEMED NECESSARY.**

5. DISSOLUTION. Current provisions state that should NEMSN cease to exist, then its assets shall be distributed among the National Arthritis Foundation, the Scleroderma Foundation and the Chronic Fatigue Syndrome Association. NEMSN does not interact with any of these organizations today. It does interact with two others. Therefore, your Board of Directors recommends that the By-Laws be amended to list the **NATIONAL ORGANIZATION FOR RARE DISORDERS (NORD) and the AMERICAN PARTNERSHIP FOR EOSINOPHILIC DISORDERS (APED) AS THE TWO BENEFICIARIES OF NEMSN'S DISSOLUTION SHOULD IT OCCUR.**

By-Laws Continued on page 10

By-Laws Continued from page 9

6. INCIDENTALS. The current By-Laws are comprised of 12 articles. Oddly enough, there are two Article IIIs and two Article VIIIs. In other words, there are really 14 articles. Your Board of Directors recommends cleaning up these duplications and NUMBERING THE BY-LAW ARTICLES FROM I – XIV (one to fourteen).

The Board stands ready to converse with you about any and all of these recommendations. Michael Bird has taken the lead on this effort and you are welcome to contact him at either 812-822-1189 (talk) or at 812-318-4345 (talk or text) or at his email address wiltshirebird@gmail.com. All of the other Board members are also available.

We want to hear from you. Your comments, ideas, edits and suggestions are most welcome. The goal is to cooperatively reach agreement on what should be done with our organization's By-Laws.
NEMSN's membership in March, 2020 (according to the By-Laws as now written). So, we want to ensure you have sufficient time to read our recommendations, respond with your own suggestions and comments and edits, and ultimately cast a vote for or against recommended changes.

Elections 2020

by Michael Bird

As the country prepares for a bevy of national and state elections next year, NEMSN also has an election to conduct. NEMSN's Board of Directors is made up of a maximum of nine volunteers. We currently have 7 serving members and two vacancies. To serve on the Board and to vote in NEMSN elections, one must be an individual with an EMS diagnosis or a family member, caregiver or significant other of an individual diagnosed with EMS.

Five Board of Directors seats are up for election in March, 2020. That includes the seats of three currently-serving members (Michael Bird, Nancy Grant, Lois Vierk) and two vacancies. Those who are currently serving must determine if they prefer to seek another term of office. There is no limit on how many candidates there can be in any one election. However, only five can be elected. Terms of office are two years (proposed to be changed to four years...see article on by-laws).

The bottom line is: WE NEED A FEW GOOD MEN AND WOMEN TO RUN FOR THE BOARD OF DIRECTORS!! To do so is QUITE SIMPLE. Just submit your name and a statement of your qualifications (no more than 100 words) to the address below by January 1, 2020. You can nominate another NEMSN member…..but they must verify they are willing to serve if elected.

In January of 2020, ballots with all candidates will be sent to you. You will return those ballots with your choices by February 20, 2020. But for now, DON'T BE SHY OR RESERVED. THE NEMSN BOARD HAS THRIVED ON THE WORK OF MANY BOARD OF DIRECTOR VOLUNTEERS THROUGHOUT ITS HISTORY. It does require attending (by telephone) several meetings per year, communicating with NEMSN members and others, perhaps assuming duties as an officer or committee member, and infrequently drafting a newsletter article. NEMSN AND ITS MEMBERSHIP WOULD BENEFIT FROM YOUR PARTICIPATION. SO, PLEASE COMPLETE THE FORM BELOW AND SEND IT TO:

Michael Bird
315 West Kirkwood Avenue, Apartment 403
Bloomington, Indiana 47404

NEMSN BOARD OF DIRECTORS CANDIDATE

NAME

ADDRESS

CITY, STATE, ZIP

PHONE NUMBER

EMAIL ADDRESS

(On a separate sheet, please complete a maximum 100-word statement on your qualifications and send it in with this form. Thank you.)

Thirty Years Living With EMS

by Rhonda Farro

In 1989 I was 34 years old and taking a rather high dose of L-Tryptophan on the advice of my doctor for difficulty sleeping and depression. I was feeling good, working full time, and had an active lifestyle, which included dancing, hiking and skiing. My boyfriend and I married in September of 1989 and took a long honeymoon to Glacier National Park where I had previously worked and then on to Banff and Jasper to do more hiking and camping. My body felt very achy and tired on the trip and I kept wondering if something was wrong.

Our first night home I was looking forward to sleeping in a real bed but woke up with sharp shooting pains going down my legs all night long. My skin started burning and I really didn't want the sheets or covers to touch me even though it was a cold night. I had this strange feeling that I had been poisoned somehow or had a bad allergic reaction to something. I wondered if it could be L-Tryptophan but I had taken it for about 10 months with no problems. The next day the inside of my mouth started burning and swallowing was a little difficult so I quit taking L-T just in case.

I went to my doctor and he said I had the flu. At home, I felt very discouraged because I knew it wasn't the flu. I decided to call him and insist he run some blood tests. The tests revealed that I had 78% eosinophils and elevated liver enzymes so he prescribed different prescription pain pills that did nothing. We discussed me taking prednisone but he was reluctant to prescribe it.

As the days progressed, I developed burning pain over most of my body. My scalp was burning and itching like crazy and eventually half my hair fell out. I had sharp pains and weird sensations going off in my ears. I developed a terrible pain in my chest, hard tight skin on my back and my muscles felt like they had lost their elasticity. I couldn't completely straighten my arms.

After two months my in-laws convinced me to see a doctor in Sacramento, about three hundred miles from my home. The morning of my appointment there was an article on the front page of the Sacramento Bee titled "L-Tryptophan Linked to Fatal Disease". It was a relief to know what had caused my condition but frightening to realize there was no medical cure.

I returned home and my local doctor reported my case to the CDC. He thought I would gradually get better. I complained of severe muscle spasms and my heart racing at night. He listened to my heart and lungs and said they were fine and I was probably having panic attacks. I wished I could agree!

Over the course of two years I slowly improved but was still living with pain throughout my body and fatigue. The more severe symptoms would come and go. My husband and I really wanted kids and it felt like L-Tryptophan had taken that away from us. Still we tried and in 1992 I became pregnant and immediately noticed that I was mostly pain free! My doctor said that people with auto-immune disorders often feel better while they are pregnant. We had our daughter in December of 1992 and our son in August of 1994 when I was 39 years old. We were so relieved that they were both healthy. I felt pretty good until I stopped nursing my kids. Perhaps my hormones changed. I really don't know the reason but I had a huge EMS flare-up in 1996. Until that time, I had no idea that I could have a flare-up. It was devastating but I had these two adorable children to raise and they motivated me to get up every day and keep going.

In 1998 I heard about a local doctor who was treating people with auto immune disorders by testing for allergies. This doctor sent my blood sample to a lab that tested my blood for reactions to over 500 foods and chemicals. The test results showed major reactions to carrots, spinach, raspberries, perfume and the chemical BHT (butylhydroxytoluene). I had mild reactions to dairy and safflower oil. I stayed away from these items as much as I could, and had a reduction in pain from ~7 down to ~5 on a ten-point scale. This doctor also prescribed a very low dose of amitriptyline (Elavil) at night for sleep and pain. I don't like taking pills of any kind but I trusted his advice. Amitriptyline brought my pain level down more and I was thrilled just to be making progress.

With the internet I found NEMSN and other people with EMS. What a relief to not feel alone! One person told me she had been skiing so I was curious how she was coping with the pain of EMS. She said that gabapentin (Editor: also known as Neurontin, Gralise, Gabarone, Fanatrex or FusePaq - typically used as an anticonvulsant in epilepsy, as well as treating pain caused by shingles. This drug can be prescribed off-label by your physician.) had really helped her with nerve pain even though she wasn't completely pain free. I went straight to my doctor and asked for a prescription for gabapentin. It took a while to work up to the right dose because it made me very sleepy but eventually my body adjusted and I really felt good. My pain level decreased more and for almost 20 years now I have been living with only mild amounts of pain that comes and goes.

Several years back I ate a large spinach salad for dinner with the thought that I was probably not allergic to spinach anymore. After I went to bed, my arms started aching and burning and my hands were going numb. The next morning my husband reminded me that I had eaten a lot of spinach. Lesson learned!

A combination therapy of avoiding my allergy triggers and taking gabapentin and low dose amitriptyline has worked very well for me. Currently I hike, paddle board and garden. My memory and word retrieval are often pretty bad but I feel good most of the time. Occasionally I walk into a room and get chest pain and I usually think perfume has triggered it but I'm never sure. Smoke usually triggers it also. It is mild and short lived. About five years ago I started having a chronic cough and last year my doctor ordered a CT scan of my chest which diagnosed scarring on my left lung with fluid accumulation. The Merck Manual refers to this as eosinophilic pulmonary fibrosis and lists L-Tryptophan as one of the causes. So far, it's not a big problem and I'm hoping I'll get lucky and have more years of being active and mostly pain free.

Thirty Years of Understanding Continued from page 5

Finally, it is noteworthy that two of the "new" patients that contacted NEMSN have continued to discuss their cases with the Medical Advisory Board. In addition both patients have kindly provided samples of the supplement they consumed prior to onset of their EMS symptoms. This is the first time since the epidemic that samples consumed by the patient can now be directly analyzed for the structure determination and amounts of contaminants present. In one case the patient is from Europe and was taking L-Tryptophan prior to manifestation of elevated eosinophils and myalgia. In the other case the patient is from the USA and was taking 5-HTP prior to onset of EMS -like symptoms. These samples were recently analyzed and both the L-Tryptophan and 5-HTP tablets/ capsules contained numerous contaminants. Currently we are working through the data to determine the structures of all these contaminants to see whether there are case-associated compounds present in both samples. These current scenarios serve to remind us of two things: i) EMS continues to persist in the general population associated with individuals taking the supplements L-Tryptophan and 5-HTP (and possibly Melatonin); ii) exemplifies the value of NEMSN as an organization. This patient support and advocacy group continues to serve as a focal point for information, contacts and facilitates important interactions in furthering our understanding of EMS.

4. EMS - CURRENT UNDERSTANDING

Our understanding of the causal onset and progression of EMS is still poorly understood. In part this is due to the relatively small number of patients, and the very limited scientific and clinical literature on the subject. I have suggested above (Section 2) that onset of EMS is caused by consumption of contaminated L-Tryptophan (or other related compounds such as 5-HTP or Melatonin) that triggers an acute inflammatory response in genetically susceptible patients. This is indicative of an auto-immune response, and most clinicians with EMS expertise agree that EMS is an example of such a disease type. There are other examples where consumption of either food or therapeutic drugs have caused EMS-like symptoms. They include Toxic Oil Syndrome (TOS), drug reaction with eosinophilia and systemic symptoms (DRESS) and drug- induced lupus erythematosus (DILE). Whilst these conditions are not identical to EMS they all are auto-immune disorders, and patients have eosinophilia and associated pain symptoms. The evaluation of these closely associated disease states allow the expansion of the patient, scientific and clinical literature base in order to more fully understand what is occurring in EMS. For example if you do a scientific and clinical literature search on Google Scholar for EMS (in the title) since its occurrence in 1989 there have been 329 published papers, and since 2010, only 10 manuscripts on the subject have been published. This is in stark comparison to DRESS, where since 1989 there have been 11,100 papers published and an impressive 5,150 manuscripts since 2010 alone!

4.1 Persistence of EMS: The insights provided by consideration of the TOS, DRESS and DILE literature in conjunction with our limited EMS understanding prompted further questions. It is useful to consider all these disease states as part of a related spectrum, such that they have common symptoms and possible etiologies, but also have some distinct differences at a clinical level. A comparison with Type I, Type II and gestational diabetes is useful to consider as a model to understand the relationships of EMS, TOS, DILE and DRESS. For a variety of reasons these new analyses prompted me to revisit the concept of flare-ups. I had originally been of the opinion in the 1995-2010 period that the initial EMS event in individual patients did systemic damage due to the presence of excessive eosinophil cells releasing their toxic molecular cargo, but there was no reoccurrence. But on reconsideration, I began thinking about a "Destructive Cycle" possibly occurring in each EMS patient. Oxidative stress (molecular imbalance in your body) is something we all experience. This is different from the common everyday stress we are all familiar with in our daily lives. In the case of oxidative stress in EMS patients, this can lead to systemic inflammation, and as a result a chronic immune response. For EMS patients, whose immune system is already compromised, the aforementioned "Destructive Cycle" of oxidative stress coupled with systemic inflammation and systemic immune response leads to flare-ups. I must caution all of you that at the moment this is still an unproven theory. However in the past three years with help from Lois Vierk and the NEMSN Board I have spoken with a number of you about your continued health experiences post the epidemic. Many of you experience flare-ups on an episodic basis. But, not all of you report being subjected to flare-ups. This can be explained by the working hypothesis of the "Destructive Cycle".

4.2 EMS and Flare-Ups - Treatments: In the case of flare-ups it is possible that careful attention to diet as well as therapeutic agents to alleviate inflammation and systemic auto-immune responses may be useful for treatment. *Unfortunately, this is still a working hypothesis, and we still need to understand more fully about flare-ups in terms of occurrence, and factors that cause them. Therefore if you have the time and inclination please contact me to take the simple questionnaire developed for EMS patients concerning flare-ups. In addition any actions you take to alleviate flare-ups should be done in conjunction with your primary physician.*

Patients that are experiencing EMS-like symptoms for the first time are typically administered corticosteroids such as prednisone. Whilst such treatments are effective in reducing

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Thirty Years of Understanding Continued from page 12

eosinophil levels back to normal range, as well as reducing inflammation, the significant side effects are not conducive to long-term use. In this current newsletter Dr. Gleich in his article entitled "New Understanding of Eosinophils" describes a promising new drug Fasenra (benralizumab) for EMS treatment. In addition Rhonda Farro in her article entitled "Thirty Years Living with EMS" describes a combination therapy that has helped her personally to overcome the issue of elevated eosinophils as well as flare-up occurrences, namely gabapentin plus amitriptyline.

5. CONCLUSIONS - THE FUTURE

In the past three years Dr. Gleich, Dr. Klarskov, and I have devoted considerable time and effort to the structure determination of "Peak AAA". We are currently in the process of evaluating if the AAA-1/AAA-2 case-associated contaminants cause eosinophils to migrate towards these compounds when present in the body. This process of a compound causing a cell, such as the eosinophil, to move towards it is known as chemotaxis. These findings may provide considerable insight into a possible mechanism of how contaminants in Showa Denko L-Tryptophan caused EMS onset in patients. 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 considerable help from NEMSN board members who have identified individual patients who were then kind enough to provide original tablet/capsule samples. These new efforts have proved fruitful information and offer some ways forward in terms of our understanding of EMS auto-immune causation. If all these studies prove successful, then the goal is to submit an NIH grant application for additional funds to more fully evaluate AAA-1 and AAA-2 in appropriate animal models and better understand the cause of EMS.

Our understanding of flare-ups in epidemic patients is still in its infancy, but through conversations with NEMSN members we at least now recognize the existence of this phenomenon. In addition our working hypothesis suggests that flare-ups may be much more controllable and therefore less debilitating in the future. Finally, new therapeutic drugs are becoming available for treatment of EMS onset, and this includes Fasenra (benralizumab). Whilst there has been very slow progress in the past thirty years, a possible light on the horizon of our understanding of this disease as well as more effective and safe treatments is emerging. This provides us all with a sense of hope for the future in conquering this complex and debilitating syndrome!

(Please note the opinions expressed in this article are solely those of the author and do not necessarily reflect the viewpoint of NEMSN.)

ACKNOWLEDGMENT

I would like to thank all the people of NEMSN who have been so kind to me with their time, thoughts and ideas. My many questions about all the problems that you encounter in your daily lives have always been described with detail, dignity and humor. I would also like to thank Lois Vierk and the Board Members of NEMSN for the many hours of perseverance and willingness to share their thoughts and ideas, as well as facilitate all my NEMSN contacts over the past several years. Finally I would like to acknowledge my colleagues Dr. Jerry Gleich and Dr. Klaus Klarskov for their continued willingness to work on our unpaid research efforts into understanding causation and long-term effects of EMS on past, present and future patients.

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Notes on NEMSN History

by Rhonda Farro and Jinx Engstrom

The National Eosinophilia Myalgia Syndrome Network was formed by a group of people with EMS who were concerned about the lack of information available about the disease. The national group was incorporated in 1993. Previous to this, there had been local EMS support groups in various places across the US. The purpose of NEMSN, according to the bylaws, was to promote the health and well-being of persons with Eosinophilia Myalgia Syndrome caused by having taken L-Tryptophan and to educate those people and the public about EMS.

To further these goals we have elected a board who meets regularly to manage a website and to produce a newsletter to educate and inform our members. In 1994 our members put on a conference in Washington, D.C. which brought together EMS survivors to share their experiences and to attend presentations by five doctors familiar with EMS. In 1996 there was a second conference for members in San Diego and on the agenda were sessions on EMS research, health foods & product safety, discussions on living and coping with EMS symptoms, and even help understanding disability determination. In Oct of 2004 some of us attended a conference organized by Dr. Jerry Gleich (NEMSN Medical Advisory Board member) and funded by the NIH. We were able to speak with the agency heads of NIAID, NAIMS as well as CDC and FDA to have the opportunity to review what has been learned about EMS and to discuss steps to prevent new cases of eosinophilic diseases. The conference led to spirited discussion about the cause of EMS, and was an attempt to rekindle interest in EMS as an underfunded disease condition.

Due to a sizeable number of epidemic patients and also new people contacting us through our website questionnaire, in 2007 we sought out a group of doctors/ researchers to advise us. Our current Medical Advisory Panel, namely Edward Belongia M.D., Gerald J. Gleich M.D., Kim Sing Lo D.O. and Stephen Naylor Ph.D., continues to be available to answer questions that patients pose to them.

Letter To the Editor

I'm hoping for a more recent update on the health and symptoms of those of us affected by the contaminated L-Tryptophan in 1989-1990 who were diagnosed with EMS as a result.

I believe I am experiencing a resurgence of the primary symptoms of my initial reaction to the contaminated product. I'm experiencing muscle pain again, primarily in my calf muscles, as though I had been doing a lot of heavy-duty bending and stopping while weeding and planting in my garden. I also work three days a week which involves a lot of walking on concrete, bending and stooping while handling plants, trees and shrubs as I work in a garden center. I am also experiencing increased shortness of breath while climbing stairs and/or walking on moderately hilly terrain.

Have other survivors of the original outbreak in 1989 been experiencing a return of their original symptoms? What exercises have EMS survivors/patients been using to cope with muscle tenderness, etc., etc.? Have their been any ongoing studies about the long-term effects of EMS? I am now 73 and still fairly active, especially as a passionate gardener and I would like to continue being so without the increased levels of muscle pain and shortness of breath.

Hoping to hear from someone in NEMSN in the near future.

Connie O. Byrne
Replies to Connie Byrne can be emailed directly to NEMSN: nemsntalk@aol.com. Phone us at 201-868-5791 or send a letter to:
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P.O. Box Monitor 4171
West New York, New Jersey 07093

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NEMSN does not engage in the practice of medicine or law and does not claim to have legal or medical knowledge. All persons should seek the advice of their own lawyer and 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 and treatments and legal issues should be discussed with reader's own physicians and attorneys.

Tribute to Sandy Keating
1938-2019

I knew Sandy Keating as a friend for many years. When I first met Sandy, she was singing in a club. She performed professionally as well as at her church and other events. Sandy had a big family, including three grandchildren.

Sandy had been a registered x-ray technologist, golfer, bowling instructor, newspaper sports columnist and vocalist for local bands. She also had experience doing newsletters for non-profits, such as nursing homes and women's groups. She was involved with the American Cancer Society and her local YMCA.

Sandy became sick with EMS in the fall of 1989. She had been prescribed L-Tryptophan by the Cleveland Clinic, which supplement turned out to be the Showa Denko contaminated drug. Sandy became the NEMSN Newsletter Editor in February of 2006. She was very skilled with the computer and worked tirelessly on the newsletter. She was very dedicated to encouraging her fellow EMS survivors and keeping them informed.

After my husband passed away in 2006, Sandy told me that the NEMSN Board was in need of a secretary and thought that I could be of help. At her urging, I joined the NEMSN Board.

Sandy had a great deal of compassion for people, especially those who were sick or less fortunate. She fought EMS valiantly and also the cancer that came later. Sandy was a beautiful person in every way. She will be missed by her family, friends and the NEMSN Board.

Ann Flaherty

Another Tribute to Sandy

I have been thinking about Sandy, and I am sorry that her long fight against all of her adversities is now over, particularly since she approached them with such determination and vigor.

For me she came to typify the attitude of almost all EMS patients who try to get on with their lives against in many cases tremendous health hurdles, which often were/are compounded by other complicating and in some cases life threatening illnesses.

Stephen Naylor

Tribute to EMS Patient
Wendy Beth Rosenblatt, 1955-2019

Wendy was born in Brooklyn, New York. She was a gifted student and possessed a vibrant spirit with a zest for life, and enjoyed traveling to exotic locales. She was an expert scuba diver who loved the ocean, where she found peace later in her pain-laden life. Music was also a passion, which she enjoyed to the fullest extent, spending time with Carlos Santana, and other radio, television and Broadway celebrities. She celebrated life and lived it each day, always staying in excellent physical condition and health before EMS. In 1989 she took the supplement L-Tryptophan that changed her life thereafter. All the activities she loved to do were replaced by constant visits to physicians and hospital stays for the remainder of her life. She decided to take an early legal settlement with the L-Tryptophan manufacturer, and focused on raising her beautiful daughter Rebecca. She channeled all her remaining energies into being the best mother she could, taking her daughter to all kinds of wonderful places, spending time with Rebecca, no matter how much the EMS attempted to intervene. Wendy had her own software company, constructed websites and had her own line of self-made jewelry, and was an astute businessperson. In spite of constantly fighting off the ravages of EMS, she remained an engaged, intelligent, charming person but was also tough and courageous. She suffered in silence and never complained and would never let anyone know she was sick. Wendy was beautiful both inside and out with a indomitable spirit. People still remark as to how shocked they are at her passing.

I met and fell in love with Wendy a number of years ago and she told me of her battle with EMS. We researched EMS together and tried to learn more about this perplexing and complex condition. This entailed going to more doctors, meeting specialists and visiting hospitals. We reached out to people at NEMSN for more help, advice and information. Wendy was always grateful for all the positive encouragement and advice received as she sought once again to fight EMS. Sadly for Wendy it wasn't to be. EMS is an insidious disease but Wendy never backed down. I was blessed to be loved by such an astounding woman who gave me everything when she had nothing but love to give. She is in my heart forever, and I miss her laugh, her smile and her spirit, the latter of which is now free from pain.

Paul Becker, Manalapan, NJ

In Memoriam

We've been informed that these members have passed away:
Leslye Philips
Joan Merrill Sherman
NEMSN extends heartfelt sympathy to their family and friends.

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