

# Contacts from Epidemic Patients and Possible New EMS Cases

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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, 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.

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 through 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](http://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."