



National EMS Network Newsletter

Points of interest

- **Your continued donations have kept this Newsletter and NEMSN alive. Please keep those donations coming no matter how large or small. Our thanks.**
- **We do appreciate all the letters to the Editor and hope that you keep writing. We look forward to your letters and comments.**
- **We are interested in your story. Please take the time to write it and send to us for our newsletter.**
- **If you have not seen our web site yet, it's improved and holds a lot of information.**
- **CHECK OUT WWW.NEMSN.ORG**

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Chronic Pain

From the National Institute of Neurological Disorders and Stroke web site. <http://www.ninds.nih.gov>

What is Chronic Pain?

While acute pain is a normal sensation triggered in the nervous system to alert you to possible injury and the need to take care of yourself, chronic pain is different. Chronic pain persists. Pain signals keep firing in the nervous system for weeks, months, even years. There may have been an initial mishap -- sprained back, serious infection, or there may be an ongoing cause of pain -- arthritis, cancer, ear infection, but some people suffer chronic pain in the absence of any past injury or evidence of body damage. Many chronic pain conditions affect older adults. Common chronic pain complaints include headache, low back pain, cancer pain, arthritis pain, neurogenic pain (pain resulting from damage to the peripheral nerves or to the central nervous system itself), psychogenic pain (pain not due to past disease or injury or any visible sign of damage inside or outside the nervous system).

Is there any treatment?

Medications, acupuncture, local electrical stimulation, and brain stimulation, as well as surgery, are some treatments for chronic pain. Some physicians use placebos, which in some cases has resulted in a lessening or elimination of pain. Psychotherapy, relaxation and medication therapies, biofeedback, and behavior modification may also be employed to treat chronic pain.

What is the prognosis?

Many people with chronic pain can be helped if they understand all the causes of pain and the many and varied steps that can be taken to undo what chronic pain has done. Scientists believe that advances in neuroscience will lead to more and better treatments for chronic pain in the years to come.

What research is being done?

Clinical investigators have tested chronic pain patients and found that they often have lower-than-normal levels of endorphins in their spinal fluid. Investigations of acupuncture include wiring the needles to stimulate nerve endings electrically (electroacupuncture), which some researchers believe activates endorphin systems. Other experiments with acupuncture have shown that there are higher levels of endorphins in cerebrospinal fluid following acupuncture. Investigators are studying the effect of stress on the experience of chronic pain. Chemists are synthesizing new analgesics and discovering painkilling virtues in drugs not normally prescribed for pain.

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Newsletter**

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 *From the Editor...*

To all members,

Please help NEMSIN to keep its costs down. Every time we send out an issue of our newsletter, it costs us 75 cents for each newsletter that is returned or for each address change that is sent to us by the post office.

If we receive an address change but they do not forward the newsletter, then it also costs us for a stamp, or two, (depending on the weight of the newsletter) to mail it on to the new address.

These charges add up. Some days the bill from the post office is over \$25.00. This can be avoided if you write, e-mail or call me with your address changes. We want you to keep receiving your newsletter in a timely manner, so please keep our database updated with your current addresses, phone numbers and email addresses.

Sincerely,



NEMSIN Newsletter Editor



**Join our
email list**

NEMSIN Connections

An email list to help NEMSIN members stay in touch, receive announcements and news from the NEMSIN Board of Directors, and possibly serve as a method to connect members in other ways (surveys, etc.) has begun anew. Faith Rumph, a former newsletter editor of NEMSIN, will coordinate the list. She plans to send out membership updates and NEMSIN news or announcements monthly.

If you are a member who has been diagnosed with EMS or who has used Tryptophan and become sick, please consider contacting Faith to join ***NEMSIN Connections***. At that time she can answer your questions and explain in more detail the purposes of the email list. To join, email Faith at this address: **faith_rumph@yahoo.com**

Mission Statement

The National Eosinophilia-Myalgia Syndrome Network, Inc., is a non-profit organization dedicated to helping EMS survivors and their families by offering educational information and peer support. NEMSIN is also committed to encouraging research to improve treatment for L-tryptophan-induced EMS and to increasing awareness of the cause and effects of the disease.

DISCLAIMER

The NEMSIN does not engage in the practice of medicine or law & does not claim to have legal or medical knowledge. All persons should seek the advice of their own lawyers & medical professionals. Opinions expressed by individual writers herein are those of the writers & not necessarily those of the NEMSIN Board of Directors or its committee or subcommittee heads, nor of the Editor. Information is intended merely to inform readers. Drugs & treatments & legal issues should be discussed with readers' own physicians & attorneys.

Editor's Note: NEMSN does not endorse or necessarily agree with the opinions stated in this unsolicited member editorial. Everyone is advised that the editorial has been published to give members a chance to hear another's opinions and to stimulate thought. The claims made have not been evaluated by scientists or medical doctors, but are the opinions of the writer.

Member Editorial *by Helga Likens*

First of all I want to thank all the people who worked for the EMS News Letter over the past years, providing us with valuable information. But also I want to thank all EMS afflicted persons for taking the time and effort to write and share their stories.

I have never taken that step because with the daily aches and pains it is not only extremely hard to concentrate but more so it is too overwhelming to think about it and find the energy. Besides living with the constant frustration and uncertainty, as for most of us there is not enough support coming from doctors we depend on. It is one thing that we are chronically ill because of the contaminated L-Tryptophan but adding on to it that we are getting less and less attention. That is really hard to take.

Lucky for those who found help and support from their doctors and are doing better now, but for the others, who are still very much [afflicted] with pain and suffering and are still looking for answers, I am going to say keep on looking and searching.

While doctors no longer have interest for research, lacking the time or simply are accepting the fact that there is no cure, and as grant money ran out and lawsuits are settled, everything seems to have come to a standstill. Even the EMS newsletter seems to get low on ideas and new information. So finally I realized that whoever is still looking for answers it will never come from physicians. So let's face it, research and looking for answers is left to us who suffer but still have not lost entirely our intelligence.

Again I will point out, while everything seems to have come to a dead end with doctors, research has not ended for the simple fact that science does not stop. So our best bet is to look to the scientists and their latest findings. Forget about the generalized articles on EMS. The old are stale and the new are toned down.

From scientists on the other hand, even if they are not doing research in our interest, but for their own curiosity in microbiology, (mycology¹) and genetic engineering, we can pick up a lot of information, including how this contaminated L-Tryptophan was made.

Most of us, after being diagnosed with EMS, and who were registered at the Centers for Disease Control, had received a lot of medical literature and articles written by physicians on EMS. Looking back on it now, I am surprised that while so many theories were discussed, there is nowhere the possibility of bacterial contamination mentioned. The different peaks and merely the stating of amyloliquefaciens² that were gene altered does not really explain anything.

For me, it had always been of interest to go to the bottom of things. Therefore, it seems logical to try to find out not only what bacteria's [sic] were used but also what chemicals were involved in the production of this gene altered L-Tryptophan. Truly not having any medical education, and not even an internet connection, it was not easy. But for a start I picked up on the findings that there was a bacitracin-like³ contaminant. (From the article 3-(Phenylamino⁴) Alanine⁵, a Novel Aniline⁶ Derived Amino Acid, associated with the Eosinophilic Myalgia Syndrome.)

Next step I looked up bacitracin in the Webster Dictionary, and found that it is made from B-subtilis⁷. I also looked up Aniline and a lot of other things, but concentrated on everything I could find out about bacillus B-subtilis. In short, next to coping with my physical problems, and getting worse, it took me years to finally get a complete picture.

With the help from the medical library I found out that practically the whole world is intensively interested in this B-subtilis

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Helga Likens Editorial *continued from page 3*

bacillus. It also became clear that there are many strains of this gram positive bacillus, including subtilis 168, that produces heat resistant spores, and are almost impossible to kill. So of course it comes to my mind that charcoal filters that were reduced, could not secure an infectious free product.

Remembering also from a video that the lady died having taken only a few tablets, and I myself also only about 12 or so, it could not possibly be from having taken too much L-Tryptophan. On the other hand, for infection it takes only one bacillus to enter our system.

Thinking further along, and realizing that there are many strains of this bacillus (including any other strains and bacteria's [sic] that have been used and altered), I looked for articles that in any way mention anything about L-Tryptophan, like "Activation of the tip RNA⁸ Binding Attenuation Protein" or "Effects of Mutations in the Tryptophan Binding", or "Accumulation of Anthranilic⁹ acid in the pathway of Tryptophan". Also, next to the article "Novel Aniline derived Amino Acid, associated with EMS", one may look for "Basilysocin, a Novel Phospholipid¹⁰ Antibiotic produced by bacillus subtilis 168".

Most interesting is the article "Accumulation of Anthranilic acid by *Claviceps*¹¹ *purpurea* recombinant strains" and after this, investigating "Ergot *Claviceps*" spores, and the "Mystery of Morgellons¹² Disease". (Mystery Illness Baffles Doctors, Frustrates Patients). All important for comparing symptoms. But remember not to look for clues in papers on EMS.

It had been believed that B-subtilis was relatively harmless, and since it yields its DNA so freely, it is used to pump out enzymes for industry. The true nature of this bacillus was not known yet at the time the contaminated L-Tryptophan was produced.

Also one must realize that Showa Denko experimented with many strains and combinations, so not all of us are affected in the same way. Some may indeed have gotten ill from taking too much L-Tryptophan, while others might have been more resistant and therefore were able to get better in time. On the other hand, most might have taken from more than one bottle, so one would have to be very objective. Especially sort out side effects from other medications, including medication for EMS symptoms.

It is very important to observe symptoms and look for similarity in other patients. What are the most prominent, from the acute onset and the chronic condition, apart from the fact that the nervous system is involved. How about the feet and legs? (discoloration, neuropathy¹³ and difficulty with walking?). The severe headaches, terrible spasms with any kind of stress (physical, emotional or mentally) next to the vision and skin problems, such as have not gotten better but rather gotten worse. Also is your immune system still overactive? Against what?

To know the truth should not scare us, rather it lifts the frustration of uncertainty, and many of our symptoms being perceived as imaginary. Even as there really might not be a cure, many already are convinced that there is some allergy to certain foods, so we then can more closely choose the right things of what is good for us and what not (including medication).

In the end I will point out that indeed our amino acid metabolism and protein syntheses is somewhat permanently altered, as well as the hypothalamic, pituitary adrenaline axis is out of balance. So all the extensive study on EMS in regard to pathways and analyzing of the impurity peaks etc. and comparing EMS with the Toxic Oil Disaster, is well justified and important. Yet knowing more about bacillus and their metabolic changes within themselves concludes that the offset of our systems is first of all bacillus related. The recombinant bacillus itself, that made so much L-Tryptophan, created its own metabolic pathway including endotoxins via enzymes and Anthranilic acid, and incorporated itself into our system.

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Helga Likens Editorial *continued from page 4*

Dr. H.A. Matthews with his Hypotheses was not too much off when he talks about a continuous cycle of events, due to a latent actinomycete¹³ infection, that can become reactivated under certain conditions, medications, or foods. The only thing he did not know was that instead of Actinomycetes it was B-subtilis bacillus strains and recombinant strains, with DNA alterations, and interchanges with bacteria's [sic], that caused EMS.

The big question remains, what was (is) so neurotoxic? The Eosinophils, Granules, or the quinonilic acid? The aniline (Anthranilic acid) or some kind of other chemical or acids? Or is the toxin in question directly Bacillus related? The missing clue cannot be found by analyzing the L-Tryptophan, and not by trying to fit symptoms into known diseases (like Lupus or fibromyalgia etc.) and neither by muscle biopsies, but the missing clues should be looked for in the bacillus and bacteria's {sic} itself that were used to create this "Novel Amino Acid".

If anyone wants to learn more, keep on searching and ask questions.

Sincerely,



Helga Likens
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Money Talk

The federal government's debt is soaring toward \$10 trillion. Our nation's trade deficit eclipsed \$700 billion last year. And then there's personal credit card debt. Oh my, pretty bleak! However, the debtor nation plague has not tainted NEMSN's operations.

We commence 2007 with \$6,440 in the bank. One-third of that is reserved for protection of the MDL documents. A part of our balance is the result of exceptional economies your Board of Directors initiated last year. We found a new communications source for our Board meeting conference calls, cutting costs by nearly 65 percent. We published four newsletters, all for less than three newsletters cost us in 2005.

In 2006, NEMSN's expenses totaled \$4,882. Your contributions totaled \$4,681. In other words, our spending and revenue were virtually the same, meaning we did not have to tap into our "rainy day" reserves. The Board thanks you for your generosity. We anticipate the usual expenses in the coming year: newsletters, web page management and equipment changes as necessary. Board meetings and just the nuts and bolts of keeping our small organization humming.

Your contributions remain essential. There have been years when extraordinary but essential expenses were unavoidable. They might recur in 2007. We continue to pursue avenues to communicate with you as regularly as possible - and respond to your requests for assistance. So, please continue to contribute what you can, when you can - and we will continue to spend wisely and prudently.

Michael Bird, Treasurer

Election 2007

NEMSN's by-laws call for annual election of a Board of Directors, with those concluding their second year of service to stand for re-election should they wish to continue. It is also the time for you to decide from among a slate of candidates who, in addition to any incumbents, merits your vote for the Board.

We have some peculiar circumstances this year. First, no candidates have surfaced for the (number) vacancies on the Board. No candidates have surfaced to compete with current Board members seeking re-election. With this in mind, the current Board of Directors has asked your approval or disapproval of the following:

Below is a ballot and volunteer application. Please fill the ballot out right away and if you are able to share of your time with NEMSN, please fill out the volunteer application. When finished, please mail the ballots/application as soon as possible to NEMSN in the donation envelope enclosed in the newsletter, along with any donation you may/may not make. You may also e-mail a ballot to popsies@aol.com



Ballot

*** I choose to continue the term of NEMSN Board members for the remainder of 2007.**

Y___ / N___ Jann Heston, President

Y___ / N___ Nancy Grant, Med/Research Director

Y___ / N___ Jinx Engstrom, Vice President

Y___ / N___ Lois Vierk, Public Relations Director

Y___ / N___ Michael Bird, Treasurer

Y___ / N___ Sandy Kintz, Newsletter Editor

Y___ / N___ Ann Flaherty, Secretary

* Note: there is one current vacancy on the Board of Directors. Needed positions are possible Med/Res/Dir and Volunteer Coordinator. Other volunteers needed for med/res/assistance, contact persons for various regions of the U.S., and writers for articles or short columns in newsletter on various topics.

We have chosen to take this course of action because each of the current Board members has expressed a desire to remain on the Board for one additional year. However, more than one Board member has experienced medical challenges beyond EMS during 2006 that has compromised and might continue to compromise their consistent participation in Board management and activities. Therefore, if you know of anyone, or are willing yourself, to volunteer to fill one of the vacancies, NEMSN would welcome you.

NEMSN Volunteer Application

_____ A) Serving as one of nine members on the NEMN Board. The board meets ten times/year via teleconference. Positions on the board include its officers, newsletter, web site, medical research, public relations and special projects. (OR)

_____ B) Serving as a support person by participating in e-mail groups or listing as a contact person on our web site NEMSN.org.

Experience: _____

Thank you so much for your willingness to share your time with NEMSN. You will be contacted by one of our officers within the next month.

Name: _____

Address: _____

City: _____ State: _____ Zip: _____ - _____

E-mail address: _____

Donor Honor Roll

November 18, 2006 through February 5, 2007

Contributors (Regular) \$5 - \$49

Doris Cortopassi	Jerry Kozitza	Faith Rumph in memory	Michael Vitolo
Shirley Haislip	Ruth Malis	of Arlene Jolley	James Longino
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Contributors (Sustaining) \$50 - \$99

Barbara Gartner	James Haire	A. Joy Hunter	Joseph J. Pitonak
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Contributors (Friends) \$100 - \$249

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of Gayle A. Sager	Kathleen Sobolik	

Contributors () \$250 - \$499

Kathleen Quinn	The Cast & Crew of "Hairspray" on Broadway through Lisa Jolley in memory of Arlene Jolley
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Contributors (Sponsors) \$500 - \$999

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Please mail your check in the courtesy reply envelope to the Treasurer, Michael Bird. If you lose the envelope, mail in your own envelope to this address: Michael Bird, Treasurer, 219 Twinlakes Drive, Fredericksburg, VA 22401

NEMSN Contribution Form

Here is my gift to support the work of NEMSN:

_____ \$15 _____ \$25 _____ \$50 _____ \$100 _____ \$250 _____ \$500

\$ _____ Other

Make checks payable to NEMSN or National EMS Network. Gifts are tax-deductible to the extent allowed by law. Thank you for your help.

Name _____ Address _____

City/State _____ Zip _____ - _____ Phone _____ - _____ - _____

- Check here if this is a NEW address and enter your previous zip code: _____ - _____
- Check here if you desire a card acknowledging your gift to be sent to you or another. Be sure to include the mailing address.

Helga Likens Editorial Footnotes: *continued from page 5*

1. *Mycology - science of fungi.*
2. *Bacillus amyloliquefacies is a species of bacteria*
3. *Bacitracin - an antibiotic substance obtained from a strain of Bacillus subtilis.*
4. *Phenylamine - The simplest aromatic amine, an oily liquid derived from benzene. Used in manufacture of dyes for medical and industrial use.*
5. *Alanine - also 2-aminopropanoic acid is a non-essential α -amino acid.*
6. *Aniline - an organic compound used mainly in the manufacture of polyurethane.*
7. *B-subtilis - gram positive bacterium commonly found in soil.*
8. *RNA - serves as the template for translation of genes into proteins.*
9. *Anthranilic acid - is an odorless white to yellow crystalline acid, which is freely soluble in water.*
10. *Phospholipids - a class of lipids formed from four components: fatty acids, a negatively-charged phosphate group, nitrogen containing alcohol and a backbone.*
11. *Claviceps purpurea - fungus, (parasitic) on grasses and cereals.*
12. *"Morgellons" or "Morgellons disease" is a controversial name that has been given to a speculated and equally controversial medical condition with no know cause or treatment.*
13. *Neuropathy - strictly speaking, is any disease that affects the nervous system. In common usage, however, neuropathy is short for peripheral neuropathy, meaning a disease of the peripheral nervous system.*
14. *Actinomycetes - are a group of Gram-positive bacteria.*

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