



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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NEMSN Visions from your President

As seasons change in nature, we at NEMSN are also thinking ahead for change. Hopefully toward growth. Many positives as well as negatives over the past year have made us vulnerable as an organization. We desire to build further in membership strength and in new visions in order to develop as the future does not stand still. What do we want NEMSN to be in the future? I would like to ask our members for their thoughts and ideas.

Do you want us to continue our efforts for research within the NIH? Do you want information concerning EMS as well as other info pertaining to secondary illnesses that many have? Do you want us to continue in our efforts as an organization or fall by the wayside completely by possibly joining another organization and

giving up? Do you prefer we give up our non-profit status and return to an informational organization only, or continue the fight to be heard and not forgotten?

These are questions we need to discuss and act upon, now. Our board can only do so much. We are only as STRONG as our members' input and our willingness to STAND TOGETHER! So my question to you as our members, what do you wish to see?

We are in desperate need of filling our 9 member quota on the board. We need your help and support in this area as well as new volunteers for various assistance. We cannot continue to bring the much needed or wanted information to our members without your help. We currently have 5 other wonderful board members who are striving to do what 9 members

have done before. Needless to say, this is pushing the limits for EMS survivors.

Members, families and friends are welcome to apply for a volunteer position. Sharing a position is also an option for those not able to attend each meeting as a board member or as a volunteer.

I plan to have these areas discussed at the next few board meetings so PLEASE write in, email or phone us with your suggestions and thoughts. This could be vital to NEMSN.

Appreciatively,

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From the editor...

In an effort to improve our newsletter, we encourage your suggestions. Please let us know what type of articles you would like to see in future issues. If you are interested in writing for the newsletter, please contact the news editor.

I am in the process of updating the database. To help keep costs down please let us know your most recent address, phone numbers and e-mail address.

We are a very small group without a large donor base. After sending out the most recent newsletter, many have been returned as unable to be forwarded, as the people have moved and left no forwarding address. This costs us money as we are charged by the post office to give us new addresses if there is a forward order. If not, we have wasted postage and printing costs.

I have just received a request to send a newsletter by e-mail rather than by U.S. mail. The member making this request thought it would save us some money and it will. It is a great idea. It would not only save the postage, but would save paper and printing costs. If there are any more members that would like to receive your newsletter by e-mail, please write to NEMSNnewseditor@gmail.com and I will add you to the newsletter e-mail list. Every little bit helps to keep our costs down so that we can continue to serve you in the future.

Sandy Kintz

Request for Contact



A gentleman with EMS is in his 70s, has now developed allergies to all and any medications, including Prednisone. He breaks out over his entire body with bumps within 24-48 hours after ingesting any medications, with bumps that itch and then develop a hard center core. His palms and soles also turn a dark beet red. His doctors have no ideas so he is in need of contact with a physician who has seen or will see EMS patients in or around Spartanburg, SC.

If you know of anyone else who has experienced these symptoms/ reactions and has EMS, please contact via the editor.

An EMS survivor that is also a breast cancer survivor for 1 year is very much interested in contact from others who have also had a diagnosis of breast cancer. If you are interested in making contact with Johanne, you may e-mail her at ...

jtermotto2006@yahoo.com

(Continued on page 7)

Mission Statement

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

DISCLAIMER

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

Kat's Story On EMS by Katrina Beard

In 1986, I was shocked to learn that I would need a partial hysterectomy and I was only 32 years of age.

Then in 1988 I was back in the hospital for a complete hysterectomy. His findings at that time was, the pathology showed many eosinophils, plasma and lymphocytes cells that were unusual. Also thickening of epithelial layers, and chronic inflammatory changes present. There were also small miliary blisters, plus acute bronchitis present.

I could not take hormone replacement. I was real upset, I had two young children and lost a baby in 1978. WHY ME?

I was just starting to feel a little better, then in the fall of 1988 I was becoming so tired, by the spring of 1989. I was sooo tired and hurt every where. I was cramping, coughing, had a fever of 101 to 103, chilling, sweats, a rash, and my body was swollen. By October of 1989 I was taken to my bed, unaware of what was going on around me and wishing to die and get it over with.

I was passed from doctor to doctor, test after test, blood work, biopsies, ect., then I was finally sent to a rheumatologist.

My eosinophil count was 2920, elevated liver enzymes. I lost all the hair on my arms and legs, had scleroderma-like skin and so on. I had upper and lower GI tests. A biopsy of my left anterior leg, showed chronic inflammatory changes of skin and muscles, and scleroderma skin.

I cannot put all of this in dates as they happened since it's been a while ago and we all know EMS affects our memory. I had carpal tunnel surgery done on both my wrists, not at same time, my left hand was done first as well as another biopsy of my arm. This showed focal chronic inflammation in my wrist and biopsy. Also at site of left carpal, it showed tenosynovitis with fibrosis.

I was put on prednisone starting at 40 mg. I did not get along very well with that, about drove me crazy; it was reduced over the next several months. The side effect was lots of weight gain. I also had an MRI which showed microischemic changes of dysmyelination white matter.

As for the ones of us who know what EMS is, and that it happens, you are aware it came from taking the over the counter health supplement L-Tryptophan. I started taking it in 1984 for weight loss and to help me sleep, it did work, but soon I realized the harm of it. Though I got sick in 1986, before the big out break in 1989, I still believe my total hysterectomy was due to taking L-tryptophan. Though with the weight gain, I'm tempted to take over the counter supplements again but I think of the reasons not to and they win. One, I know how stiff and hurting I am in the mornings, how cold weather affects me, that I have a heart murmur and asthma, chronic coughing, and the recurrence of autoimmune system symptoms. I suffer with pain and depression and so forth.

Most of all it took so long to accept I had EMS, then I got angry, then

I chose to shut it out, not keep up on the news about it, not to talk about it, to just forget it. But it's hard to forget when you live with it every day, and the people around you don't understand it, or what it is doing to you. The once active life it changed so dramatically. I'm so tired I hurt, I swell, I have horrible head aches, can't sleep, hot all the time, the coughing, the cramping, the scar tissue, the blisters that appear that I thought were allergies that are in fact from returning flares of EMS, it has changed my whole body and my personality.

I also suffer with dry mouth, skin and eyes. Skin discolorations, scarring of the skin that the doctors believed to be a blood disorder, turned out to be blood, tissue, organ, skin and muscle disorders.

I still get angry when I want to work in my flower beds and don't have energy to do so, or to clean the whole house, lots of things I cannot do any more, but I'm alive and I see my children and my first grandchild. It's not easy to get on the floor to play with him, and so forth, but I'm very happy God spared me so I can be with my family and friends.

Katrina Beard
Ohio
(Contact via newsletter editor)

*A true friend is
someone who reaches
for your hand and
touches your heart.*
Anonymous

THE THALIDOMIDE OF GENETIC 'ENGINEERING'

L R B Mann, D. Straton & W. E. Crist

By the end of the 1980s some millions of people, mostly in North America, were supplementing their diet with L-tryptophan, an essential amino-acid present in proteins of any normal diet. Amino-acids such as tryptophan are routinely produced in micro-breweries using suitable microbial cultures. One producer, Showa Denko K.K., artificially inserted genes into a bacterial species to increase its production of tryptophan.

Then in late 1989, some 5,000 - 10,000 in North America fell ill with a highly unusual illness, EMS (eosinophilia-myalgia syndrome), caused by Showa Denko tryptophan. Within months, dozens had been killed by EMS and thousands maimed. Today thousands continue to suffer permanent nasty effects, and a trickle of them continue to die early (totaling at least 80 by now in the USA). The epidemic ceased when over-the-counter tryptophan was severely restricted.

Two cases were reported in Australia, and one in NZ. The tryptophan those patients took was not traced to manufacturer.

The total killed is not exactly known but may be in the region of a few hundred. Showa Denko has paid around US\$2,000,000,000 to avoid damages trials.

We emphasize that if thalidomide had happened to cause a type of birth defect that was already common, *e.g.* cleft palate or severe mental retardation, we would still not know about the harm, and pregnant women would

have kept on taking it for its undoubted benefits. The fractional addition to figures that were already relatively large would not have been *statistically* significant. But as it turned out, the damage noticed was of a kind that most doctors never see in a whole career - drastic malformations of the arms & legs - so although the numbers were not huge these cases were picked up.

Similarly, impurities in Showa Denko's genetically 'engineered' (GE) tryptophan happened to cause an illness - EMS - which was novel. The surge of numbers therefore stood out and got noticed. If SDKK's poison had caused the same numbers of a common illness instead, say asthma, we would still not know about it. Or if it had caused delayed harm, such as cancer 20 - 30 years later, or senile dementia in some whose mothers had taken it early in pregnancy, there would have been no way to attribute the harm to the cause.

This reminds us of the need for extreme caution with GE foods. They must be assumed guilty until thorough tests have suggested they are, if not innocent, at worst guilty of only minor dangers. Such is nowhere near the case today as large companies rush to market their GE foods.

It is very disappointing to find a leading physician writing on behalf of the RSNZ about this disaster thus: "Rare cases of EMS were known before the introduction of the genetically engineered bacterium, which further supports the hypothesis that EMS is not

due to the genetic engineering event." An exact analogue of that argument would run: "Rare cases of seal-limb were known before the introduction of thalidomide, which further supports the hypothesis that seal-limb is not due to thalidomide." But even more important is the fact that the trickle of about 100 early EMS cases, years before the epidemic of late 1989, were due to (early versions of) Showa Denko GE bacterial cultures.

None of the half-dozen other manufacturers' tryptophan caused EMS. No other manufacturer used gene-splicing to produce tryptophan.

The contrast is startling with the elaborate procedure before registration of a new drug. It has taken a decade to get legal approval for supplementing humans with (a modified version of) the human hormone amylin, for treating diabetics. Yet GE foods are urged for legal distribution in great haste and with only extremely scanty testing, and the main discussion so far has been whether they should be labeled.

Labeling would not in itself be wrong, but can of course not substitute for the careful lengthy testing that would be needed before any GE food should be approved for human consumption. Labeling of GE food would imply acceptance by authorities, as does the ingredient list of any labeled food.

The Showa Denko disaster is crucial to understanding GE food.

See Genetic Engineering Page 5

GENETIC 'ENGINEERING' (Continued)

If a purified single chemical - the natural amino-acid L-tryptophan, better than 99% pure and definitely satisfying the notorious 'substantial equivalence' test - can turn out when GE'd to kill a hundred or so and cripple thousands, what will it take to check properly a potato expressing a synthetic 'exact' copy of a gene for a toxin from the African clawed toad?

And most urgently, the attempt to count purified amino-acids, sugars, oils etc. as 'substantially equivalent' is shown by the Showa Denko disaster to be a gamble. The assumption that soy oil from GE soybeans is exactly equivalent to ordinary soy oil requires the most careful scientific measurements to check it. Merely assuming 'substantial equivalence' will not do.

Those who search the Internet on this topic will soon discover the claim by apologists for GE that the problem was only decreased purification of tryptophan. We disagree for several reasons - mainly, the first three GE strains had been causing EMS (about 100 cases) for years before this slackening of purification procedure in Jan 1989 when also the "superproducer" strain went into production and caused the epidemic. But this question cannot be settled with finality unless Showa Denko releases the GE microbes for detailed examination.

Whether you believe the impurities were due to incompetent purification & monitoring, or to deviant metabolism in the GE-bugs, or both, you had better believe that the fabled

'substantially equivalent' assumption flopped in that epidemic of crippling & lethal illness.

Although GE proponents claim that the EMS epidemic was caused solely by faulty filtering, it is possible to question their seriousness. None of them has publicly argued that the Health Food supplement industry should be subject to legal controls for purity & efficacy comparable to those applied to the pharmaceutical industry; yet this would be logical if indeed such a deadly epidemic occurred solely as a result of inadequate purification in manufacturing.

Either way, biotechnology - which includes GE but also includes other processes such as purifying the mixture "lyprinol" from mussels - requires much-enhanced scrutiny.

Main sources

1. L-Tryptophan Puzzle Takes New Twist, *Science* 249 988, 31 August 1990
2. Does Medical Mystery Threaten Biotech? *Science* 250 619, 2 November 1990
3. EMS and Tryptophan Production: A Cautionary Tale, *Trends in Biotech* 12 346-352, Sept 1994
4. Eosinophilia-myalgia syndrome. Results of national surveillance, *J Am Med Assoc* 264 1698-703 1990

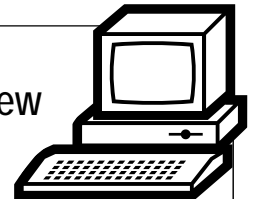
Dr Mann <robtm@maxnet.co.nz>, a biochemist, served for its first dozen years on the Toxic Substances Board advising successive New Zealand Ministers of Health on poisons.

Dr. Straton is a psychiatrist who has taken a special interest in therapeutic uses of tryptophan. Mr. Crist is a publicist who has interviewed researchers, victims, and lawyers involved with EMS.

This article is available at <http://www.gmfoodnews.com/trypto.html>. It is updated from *Soil & Health* Aug 1999.

This article is available at... <http://www.connectotel.com/gmfood/trypto.html>. It is updated from *Soil & Health* Aug 1999.

Editor's Note: The opinions stated in the above story are those of the authors and not necessarily those of NEMSN. We know that there are many different thoughts on this subject and even the experts don't agree.



Join our new e-mail list "The NEMSN Connection"

This is a private email service provided by NEMSN to communicate personally with other members via email. To be placed on our Connections list, please write to NEMSN2005@aol.com typing NEMSN Connection on the subject line. You may use your first name, first and last name both, or you may use a pseudonym for your ID. It doesn't matter which name you use. List up to four personal interests and include your valid e-mail address.

Please JOIN and get connected.

NEMSN2005@aol.com

EMS Story By Florence Mudrick

I'm a 78-year-old Canadian woman, with three children and seven grandchildren, divorced in 1983 and diagnosed with Eosinophilia Myalgia Syndrome (EMS) in 1989 and hospitalized from January 12 to January 31, 1990.

I had been using Canadian-manufactured L-Tryptophan (LT) as a sleep aid for many years without any problems. During a trip to Florida I purchased a supply of this drug and soon after began the downhill struggle I have since been on.

I'll keep this as brief as possible but I want to share with you what has been happening with me, so that you will be aware of what my experience has been and of what could happen to you now or in the future.

My Fibromyalgia Syndrome (FMS) and Chronic Fatigue Syndrome (CFS), resulting from the EMS, are getting progressively worse; so much so that walking even very short distances has become extremely painful and, even when resting, I am in almost constant pain. Strangely, the pain begins in one area, stays for some time (it varies in length) then disappears from that area and moves into another. The most painful areas are my feet and legs, which are becoming increasingly weak and more painful.

The CFS has not only become worse but, during the short intervals that I am able to sleep, I am having awful nightmares from which I often awake with full-blown anxiety attacks. I feel like I am in a constant

battle, trying to prevent anxiety attacks all day as well.

I was recently at a family celebration and am just now beginning to feel a little calmer and able to function reasonably well again. I seem to go into a sensory overload type of state, which makes it extremely difficult for me to go into any crowded, noisy, brightly-lit, etc. situations. Even being in a setting where there are several conversations going on at once is exhausting for me.

During the past year or so, I have developed high blood pressure as well as high cholesterol and triglycerides, diabetes, a partial blockage of an artery in my right calf and unexplained polyps inside my lower lip, which were removed and proved to be benign. After a routine blood workup a few months ago, I was advised that my eosinophil count has gone up again. As you can imagine, this was more than a little frightening. I was seen by a hematologist, who suggested I wait for a while to see if it would level itself within a reasonable time, which fortunately it did.

Also, I had cataracts removed from my eyes last year and they found that I have dry macular degeneration and that the retina in my left eye has been damaged. It's supposed to be flat but mine has somehow become wavy. They can perform surgery on it but can give no guarantee as to how much, if any, improvement there would be and there is a strong possibility that I could lose the eye. I'm sure you can guess what choice I have made.

I don't mean this to sound like an

invitation to a pity-party for me. I know I'm better off than a lot of other EMS "survivors." I am grateful that I am well enough to live on my own (with the help of a cleaning woman every two weeks, since my muscles are not strong enough to handle things like vacuuming, washing floors, etc.); can still drive my car, so that I'm not housebound; shop for my groceries (extremely painful but it's about the only exercise I get); and, most importantly, that I have a wonderful sister, with whom I spend a fair amount of time. I am also grateful for many other things - particularly my children and grandchildren.

I think that what I regret most was having to move from a very active role in the lives of my children and grandchildren to a very passive one where, for the most part, I have to accept that I must now be content to just sit and watch.

Editor's note: You may contact Florence via the newsletter editor.

Coping with chronic illness

I put the words chronic illness in a search engine and it came up with many web sites. I have listed just a few below.

- <http://mindpub.com/topic16.htm>
- <http://showcase.netins.net/web/fmd/chronic/>
- <http://www.mychronicillness.com/invisibleillness/home.htm>
- <http://www.chronicillness.com/>
- <http://www.myida.org/index.html>

This following book was also listed under chronic illness and the excerpt was very informative. *After The Diagnosis* by Dr. JoAnn LeMaistre. Dr. LeMaistre is a Ph.D. and has multiple sclerosis.

Request for Contact

(continued from page 2)

Another EMS survivor was treated in 1989 at Mayo Clinic in Minnesota and is wondering if anyone who had problems with their legs back in the beginning is now having problems again. She is starting to have problems again and is wondering if it is EMS or something entirely different. Please respond via the newsletter editor.

Anyone who has experienced "heat generation" in specific areas of the body please call the number below. If no answer, leave a message and she will return your call. Her numerous doctors cannot define the cause and have ruled out any normal causes, i.e. arthritis, etc.

Mrs. Neva Spinks
MA 02459
617-244-9548

Editor's Note: Written responses may be sent to ...
NEMSNnewseditor@gmail.com.
Please write Neva Spinks in the subject line.

Happy Mother's Day

"We only have One Mom,
One Mommy,
One Mother in this
World, One life.
Don't wait for the
Tomorrows
to tell Mom,
you love her"

~Author Unknown~

EMS Questions & Answers: Dr. Peter E. Callegari

By Peter E. Callegari, M.D.
Formerly Assistant Professor of
Medicine & Chief of Clinical Ser-
vices, Division of Rheumatology,
The Hospital of the University of
Pennsylvania

Q: How does EMS differ from Fibromyalgia?

A: Eosinophilia myalgia syndrome is a condition which has resulted from the ingestion of contaminated L-tryptophan. As a result of this ingestion, a large number of clinical problems have developed. These range broadly from problems directly related to muscle, such as muscle weakness, severe muscle spasm and inflammation in muscle, to problems related to skin, such as scarring and skin rashes, to problems involving the central nervous system and the nervous system including nerve-related injuries called neuropathies, to cardiac symptoms or irregular heartbeats. There are a number of other medical problems associated with eosinophilia myalgia syndrome. There are also a number of common complaints associated with this, ranging from fatigue, confusion, inability to concentrate, to severe pain to severe muscle spasms.

Fibromyalgia is a condition which is characterized by non-restful or non-restorative sleep, the presence of multiple tender points in reproducible areas in muscle and a generalized pain and fatigue. Fibromyalgia, although it can be disabling, does not lead to direct organ injury or permanent organ damage. It, too, is characterized by general complaints of fatigue, muscle pain, inability to con-

centrate, short-term memory loss and neurologic symptoms. The difference is that people with fibromyalgia syndrome do not have any permanent organ injury that can be detected. People with eosinophilia myalgia syndrome can be left with severe permanent disabilities, ranging from permanent muscle injury, permanent skin changes, to permanent neurologic injury. People can develop fibromyalgia secondary to another illness. It is possible to have fibromyalgia as a result of eosinophilia myalgia syndrome. It is possible to have fibromyalgia as a secondary result of rheumatoid arthritis or other underlying rheumatic conditions.

In summary, eosinophilia myalgia syndrome and fibromyalgia are different entities although they share many common complaints. It is possible to develop fibromyalgia as a result of eosinophilia myalgia syndrome. It is not, however, possible to develop eosinophilia myalgia syndrome from fibromyalgia. As we said, EMS can only result from contaminated L-tryptophan ingestion.

Q: Does anyone ever recover from EMS?

A: People with EMS have presented with a wide range of physical complaints and physical findings. As you know, the initial characteristics of the disease are an abnormally elevated eosinophils, a certain type of white blood cell in the blood, as well as severe muscle aches and often muscle swelling. We presume that some people with L-tryptophan exposure

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EMS Questions & Answers: Dr. Peter E. Callegari *(Continued from page 7)*

develop very mild forms of this disease and have subsequently recovered with little persistent problems or complaints. There is, however, a large group of people who have developed eosinophilia myalgia syndrome whose symptoms and problems continue to persist long after their exposure to the contaminated L-tryptophan. The illness in each of these people varies as well, some with more profound and severe disease and others with generally mild disease and less obvious long-term damage.

People who suffer permanent damage or scarring from EMS are unlikely to ever repair that damage or scar. If you define recovery as return to functioning or improving to allow to

return to functioning and to their daily activities, then some people with EMS do recover or do improve. If by recovery you mean a complete reversal of any injury that has taken place to date, that has not happened. This is not only true of EMS but any condition that leads to permanent injury or scarring that does not improve over time. We presume that some people who had mild EMS went unreported and recovered without any obvious long-term problems, but most people with EMS have suffered more long-term lasting injury. These people can recover to resume their normal lives but in many instances, like in other diseases, must modify their activities and expectations in relation to the extent of injury which they have suffered.

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DISCLAIMER: Each person should seek the advice of their own medical professional for their own situation. The information contained in this feature is of a general nature.

Editor's Note: These questions were in a previous 1996 newsletter, but are still of interest to our many EMS readers. From time to time we will publish other pertinent questions as a reminder to some of us, and as new information to our new members.