



National EMS Network Newsletter

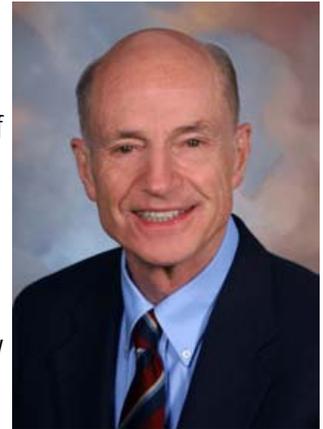
Points of interest

- **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**

Advisory Panel Q & A

(As related to Lois Vierk, NEMSN Public Relations Director)

Gerald J. Gleich, M.D. is recognized internationally as one of the top experts on the eosinophil and eosinophilia. We are honored to have him on our Medical Advisory Panel. Dr. Gleich has authored more than 600 scientific articles and has received numerous professional awards. He spent over 35 years at the Mayo Clinic and currently does research at the University of Utah, where he is Professor of Dermatology and Medicine. Married to Kristin M. Leiferman, M.D., Dr. Gleich has seven children and three grandchildren.



On August 11, I (Lois Vierk, NEMSN Public Relations Director) spoke with Dr. Gleich on the phone and asked him this question from a NEMSN member:

Q: "Early on in the EMS epidemic we patients were advised not to donate blood or most organs because the recipient might be at risk of health problems. What do you think now about EMS patients donating blood and organs?"

A: Dr. Gleich explained that even today there is not much known about EMS. Something in L-tryptophan caused a chemical poisoning, of a type that we still don't understand. For some people, after the initial EMS attack, symptoms have persisted. And for some lucky people, once L-tryptophan use was stopped, they got better and symptoms greatly lessened. Their eosinophilia disappeared, whether treated with drugs or not. In other words, some people were left with a systemic, severe illness, and some seemed to suffer a transient injury that allowed the body to recuperate.

Dr. Gleich's opinion is that if a person is still having symptoms due to EMS, that person should not donate blood or any organs. If a person originally had a mild case of EMS and now is basically recovered and is leading a normal life, it should be OK to donate blood and organs.

We thank Dr. Gleich for his advice. As always, consult your own physician(s) for your own medical condition(s).

We at NEMSN are so happy to have our new Medical Advisory Panel in place to answer questions from EMS patients and their families. We thank the doctors for their time and expertise in giving answers to our questions. The preceding question was e-mailed to NEMSN. If you would like to have your questions submitted to our panel, please e-mail them to: NEMSNnewseditor@gmail.com or mail them to:

*Sandy Kintz
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National EMS Network Newsletter

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Letter to EMS Newsletter from Helga Likens

In response to the EMS Newsletter, Vol. 18, March 2008, and in regard to "Addressing the Cause....". I would like to take the opportunity to bring to attention my article in the National EMS Newsletter, Februar2007.

Now while it is much easier to find the cause of a backache, it is surely much harder to find the cause of EMS. L-Tryptophan in itself is not the cause of EMS, rather the cause of EMS is the contaminants that were created in the production process of L-T.

Since last year I have done more extensive research gathering a lot more information from scientists around the world, and their research into micro and mycobiology, Learning more about the facts of what all is made via bacteria and bacillus is so mindboggling and overwhelming, that I would rather not know the truth.

When it is stated that the genetically engineered bacterial strain that was used to produce the toxic L-T had never been revealed, (Tryptophan Summary, by Dr. John B. Pagan), and from other sources, "that people were, and are, kept in the dark," I find myself in the same position of needing to keep the knowledge to myself, because the truth is so shocking and may cause panic in many people.

On the other hand I cannot agree with doctors when they justify themselves for not getting involved, by stating "there is nothing we can do, as there is no cure". I still stand firm in my conviction that only as we know the cause of an illness, can symptoms be treated properly. Even more important, can we prevent wrong treatment that might cause more harm. (Fern's Story)

There were many important articles in the March EMS Newsletter. Especially the idea to select NEMS as our desig-

nated charity that not only would support NEMS finances, but it would draw attention to the fact, that EMS is not a thing of the past.

Also the information that more and more EMS'ers realize that certain foods can make our EMS symptoms worse, and that EMS is a strange, frustrating and complex illness. As well as the news that Faith Rumph joined the Board again. (Editor's Note: She has since resigned)

In reference to my research I will mention that indeed L-T was already contaminated long before 1989, and unsafe as reported by ABC NEWS in 1986, yet the amino acid was not only sold as L-T but went also, as additives into health food products, and animal feed.

Not only were there endotoxins, and phage problems already, but the DNA recombinants that were used in a new production procedure, that created an extra novel amino acid, had been first found in Germany in 1988. It was rejected by Germany because the cause of the contaminant was not explained

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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. NEMS 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 NEMS 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 and not necessarily those of the NEMS 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.

Jeanine's Story

I was always healthy and very athletic. I danced as a ballerina when I was younger and participated in many sports. In 1989, I was very thin; so I joined a gym to put on weight and build up a few muscles. The trainer suggested I take L-Tryptophan because it is known to help build muscles. After a little research, I decided to try it. I started taking it July 4th weekend, 1989. Within 2 weeks, I started having symptoms of EMS. My joints started to hurt badly, and there was something wrong with my memory. I attributed the joint pain to my workouts; and I had no idea what was going on with my memory. At work, if I got a phone call, by the time I walked into my boss's office to let her know someone was on the line, I could no longer remember who it was that was calling. I needed a notebook to write everything down because it seemed I could not remember a single thing. At the gym, swimming started to become difficult. My shoulder muscles started to spasm and I could not swim as much. I began to gradually cut down my laps until they went from 20 to 2. I started to realize that something was wrong.

I went to the doctor. She thought, at first, that the joint pain was arthritis. I was only 32 at the time. She did blood work and called me the next day, in a panic. My eosinophil level, which she said should have been between 1% - 3%, was 38%. She repeated the test and got the same results. This began months of tests. During this time, I became sicker. I was in so much pain that I could not even be touched. My cat brushing against my leg caused me pain. Everything became so tight that I could barely get dressed. By September, I was bedridden with what seemed like a very bad flu. I never got sick, not even colds. By October, I was on crutches. My skin started to get very thick and look very strange, almost lizard-like. In January, 1990, my breathing started to become a problem. I sat up in bed many nights, just trying to get air in me. I was terrified by now. There were no answers from the doctors yet. I was in agonizing pain. It seemed as if I could not stretch any part of me. Considering the fact that I danced and was so athletic, this was very strange, indeed. I was no longer taking the L-T, since I had heard people had died from taking contaminated L-T in November. I did not attribute this to my illness.

In March, 1990, I could no longer work. Everyday life was one of pain and suffering. My hair was falling out; I was losing weight rapidly; I looked like a lizard; and I could not

walk. There were many other symptoms that I can no longer remember well. The worst was the pain; and I was not getting any medication for it. I could not find any position that would make me comfortable. I fought it. Every morning I got out of the house by 6am to go eat breakfast. I'd come home and rest on the couch, almost crying from the pain. In the evening, I'd go out for dinner. I ate a lot, yet my weight dropped 20 lbs to 98 (I am 5'7"). I went to a nutritionist who could not understand why I was losing the weight. She put me on a 4,000 calorie a day diet. I did not gain an ounce.

I spent a year going from doctor to doctor. I was even hospitalized at one point. Nobody knew what was wrong, even though all the tests were abnormal. They started telling me that it was all in my head. I knew this to be false, especially since the tests came back abnormal, even the ones done while I was asleep. After a year, I was at the end of my rope. I prayed hard for answers, not even for a cure — just for an answer. I finally got that answer. I went to a new doctor who listened carefully to what I had to say. She examined me & scheduled another appointment in a week, giving her time to think about it. When I returned, the first thing she asked me was, "have you ever taken L-Tryptophan?" I was shocked because the answer was yes. She put her head down on the desk and said, "oh, no." She told me I had EMS. She said I had to be seen by a rheumatologist, and she called one. I went to the other doctor who examined me. Then she sat there with a clipboard and told me to tell her every single symptom I had been having, no matter how strange it sounded. I did that. She said I had a textbook case of EMS. She told me she would have to call the CDC to let them know.

My first reaction was happiness. That was because my problems now had a name and a reason. This lasted for 2 months until I realized that it was not going away. The concept of staying this way was mind-boggling. At least I was given a mild pain-killer, which barely touched the pain, but was better than nothing. At this point, I had no more life. I wanted to get that back. I could no longer learn anything because it seemed I no longer had a short-term memory.

As the years went by, I finally found a wonderful team of doctors to treat me. They included a rheumatologist, a neurologist, an endocrinologist,

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Jeannie's Story *continued from page 3*

a dermatologist, an osteopath, an acupuncturist, a pain management specialist, and others. I was given appropriate medications to help with the pain. I was put on methadone, morphine immediate release, Fentanyl patches, Valium for muscle spasms, NSAIDS, Prednisone, and many others on and off. I needed a full-length leg brace for my right leg, along with the crutches. However, I could not walk more than 4 blocks without needing to sit down. I was so weak, and the pain was too great. In 1995, I was told I needed to be in a wheelchair because the bones in my shoulders were being crushed together. I had no upper body strength to use with the crutches. I fought this for about 2 years, thinking that using the wheelchair was a sign of quitting. However, in 1997, part of my left arm became paralyzed (along with other areas of my body). This forced me into the wheelchair. I also started to need nursing care. At this point, I have been bedridden for over 3 years.

EMS has caused several secondary diseases. I have ALS (Lou Gehrig's Disease). The doctors told me that I had about 3 to 5 years left to live. That was almost 8 years ago! I also have Lymphoma; but I cannot have chemotherapy or radiation because my immune system is far too weak. When my husband asked the doctor why I couldn't have chemo, the doctor calmly answered, "because she'd be dead in a week." I have COPD, GERD, Polyglandular Disease, which caused Premature Ovarian Failure; Hypothyroidism; Diabetes Type 1; and Cushing's Syndrome. I have Sjögren's Syndrome, Reynaud's Phenomenon, and various other illnesses. I can not have major surgery because only one half of one lung is left working. I have been using oxygen for about 8 years; and for the last 6 months or so, I have been using a respirator - a CPAP machine attached to my oxygen machine - I use it 24 hours a day. I am no longer strong enough to inhale on my own. My body has blown up terribly with severe edema. My right arm and leg have Lymphedema, making them extremely enlarged. The rest of me is very edemic, making it difficult to move.

Even though EMS has been progressively destroying my body all these years, it has not been able to destroy my spirit. I have always been a positive, optimistic person who strongly believes that when one door is closed, another one is opened. I wake up each day feeling happy, looking forward to what the day has to offer. It took me a

few years to accept that my memory was not going to return. When I finally accepted that reality, I looked for right-brain activities, such as art. I couldn't draw because it was too painful. I couldn't paint in oils because I couldn't lift my arms up to an easel. So, I chose watercolors. I could paint in short bursts and then take breaks to rest. I learned that I had a hidden talent and became quite good at painting. I had a group of paintings shown at 2 different exhibits. A representative from a bedding company wanted to buy a floral abstract painting to use as a design for bed sheets. I had just finished the painting, so I was not ready to part with it; therefore I did not sell it. Silly me. Eventually, I could no longer hold a paintbrush. That ended my painting "career." I moved on to the next door. Photography.

I taught myself how to do photography. I was now in a wheelchair, which actually gave me much more freedom than the crutches did. I zoomed around in a motorized chair, able to go as far as I wished. Camera equipment was on my lap, and my nurse became my "assistant" too. I specialized in bird photography. Central Park in New York, was where I took pictures of many types of birds. I even had a photograph, along with an article, published in *Birder's World*, in the December, 1999 issue. That was so very exciting. Since 1997, I had been following a now-famous red-tailed hawk named Pale Male. He arrived in Central Park and, along with his mate, made a nest on a swanky Fifth Avenue building. I was part of a group called the "regulars," who stayed all day to watch Pale Male raise his babies, all the while taking many pictures of them. One of my friends, Frederic Lilien, made a movie named, what else, Pale Male. It took him 7 years to do this; and I was in the movie. I felt like a movie star. The film won many awards the first year. I was brought to one of the movie's showings. After it was over, Frederic, on stage, thanked the many people who took part in the making of the film. He came down from the stage and walked all the way to the back, where I was, and presented me with a bouquet of flowers. I was embarrassed but very happy. The applause made me feel like a star.

Eventually, I could no longer hold up a camera. That ended my "career" as a photographer. I thoroughly enjoyed each activity I took part in. Now I became bedridden. What was I supposed to do there? How could I be of any use to society or be productive? What door could

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Save Your Breaths: Easier Form of CPR Approved Hands-only CPR suggested

When someone suddenly collapses and goes into cardiac arrest, performing CPR (cardiopulmonary resuscitation) can double or triple their chances of survival.

A new survey by the American Heart Association (AHA) reveals that most Americans are willing to help in such an emergency – but do not feel confident about performing CPR effectively.

For that reason, the AHA now recommends chest compressions only for bystanders. Hands-only CPR has been found to be more effective than taking no action at all.

Bystanders often hesitant

“A lot of people believe they aren’t qualified to perform CPR, or they are concerned about infection when giving breaths,” explains Jonathan Glauser, MD, Chair of Cleveland Clinic’s Emergency Services Institute. “But somebody’s life is at stake, and trying CPR may be their only shot.”

During cardiac arrest, the heart’s electrical system is malfunctioning. The heart beats ineffectively - without appropriate contractions - eventually causing loss of consciousness. Without CPR, the heart attack victim’s chances of survival diminish with each passing minute.

What to do in an emergency

If you encounter an adult who suddenly collapses, follow two simple steps:

1. Call 9-1-1 immediately for help.

2. Start chest compressions. Push hard and fast in the center of the chest – 100 times per minute. Press down one-third to one-half the depth of the person’s chest (about 1-1/2 to 2 inches in adults).

Goal: saving more lives

“I think the hands-only method of CPR will make more people feel comfortable helping out in emergencies, because they’ll think, ‘I can do this,’” says Dr. Glauser.

“You’ve got about 330,000 cardiac arrest victims who die outside of hospitals each year, so we’re talking about the potential for saving a lot of lives.”

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Jeanine’s Story

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open to me now? I am a very spiritual and religious person. That has always been an important part of my life, and is probably the reason I handled my illnesses as well as I have. Almost 2 years ago, my husband bought me a laptop computer. I learned how to use it, little by little. I joined a website for EMS patients. I found that to be very helpful. From there, I joined another website for people who suffered various diseases. I ended up being able to share my encouragement, my support to others. I shared my spirituality, my love for life. This became my new endeavor - helping others. Before I became sick, I always helped people by doing volunteer work, teaching Sunday School, and other things. Now that I was sick and bedridden, I was still helping people by sharing myself, by giving them what I had to offer. I have learned that there is always a means to being a useful, productive person, no matter what your situation is.

I did miss being able to go to the park to watch Pale Male and his family. He had 23 offspring, who were making nests throughout the city. Several of the "regulars" visit me once a week, telling me all the adventures of the week. I recently learned that I am "famous" again. One of the bird watchers wrote a book for children. All of the characters are cartoon style. On one page is the group of "regulars." To my surprise, I am also included! There is a picture of me, in my wheelchair, sitting with all my friends watching Pale Male. How excited I was to first see

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Letter to EMS Newsletter from Helga Likens *...continued from page 2*

to them.

So there we are again with searching for the cause. It seems that physicians really have no clue about the true cause of EMS, and I find it rather amusing with what quick new diagnoses of EMS symptoms doctors have come up with over the past years. Treating each symptom as a separate condition and health problem while ignoring EMS as the underlying cause.

In conclusion I will list some of the symptoms I had from the beginning of EMS, but that have gotten worse by now. Namely the severe headaches and nerve pains involving the teeth (even without cavities), and at the base of my head and circling, more on the right side behind the ear and at the temple, plus stabbing pain in my eyes and blurry vision. In acute attacks this is the most disabling, since it involves balance and the inability to concentrate.

Everything seems to originate in the brain affecting the whole nervous system, hormone balance and neurotransmitters, responsible for the vasoconstriction and muscle spasm. I still have muscle contractions at the midriff, but they no longer are painful while in the beginning it felt like it is tearing my whole body apart.

Clenching of teeth from tension and spasms in the jaw, at one time changing drastically my bite for 2 weeks. Also I suffer from chronic gum and mouth inflammation, and gastrointestinal problems.

The most strange symptoms involve the feet and the legs. From early on the discoloration is still there and extends by now, almost up to the knees. (My upper extremities are affected also) At one time they feel hot and burning, while at other times they are cold. (Periods of hot or cold have a bad effect on my body.)

The odd thing is that my feet feel like having a tight cast on my legs, and the skin feels stiff and dry like it is going to break under my toes, yet at the same time my legs are very sensitive to touch. I am not able to pull up elastic support stockings, plus they make my circulation worse.

So far, it still only affects the alertness, concentration and short time memory, and the ability to cope with stress and too many impulses at the same time, but not the deeper intelligence.

I am hypersensitive to most antibiotics and medications, and avoid invasive procedures, but I knew from the very beginning that a strong will to live is a must with this strange unpredictable illness, and that in spite that, my immune system

is overactive, it must not be repressed. I am still on prednisone to keep inflammation down, but also for adrenal balance, because it is a fact that this illness causes a chronic Hypothalamic, Pituitary, Adrenalin imbalance.

The unpredictable sudden drop of energy, and the sudden vascular spasms, that spontaneously subsided in the past, are now a permanent condition to struggle with, and yet surprisingly there can still be moments of well feeling, especially in the late evening, in spite of the vision and walking disability.

So I ask myself, what toxins can cause all those unpredictable, contradictive and wired sensations, next to the obvious disability like the bad vision, walking difficulty and skin problem diagnosed as exocytosis, but literally expels from deep within hundreds of tiny substances so my skin is not only paper thin, but now depletes the underlying tissue.

EMS victims experiencing similar symptoms should speak up, and press for explanation and research. Especially in regard for more investigating towards finding the contaminant that causes all our suffering, so that right treatment could be found, and wrong treatment prevented.

Going over some of the old EMS News Letters, I find of interest - Dr. Noel Rose "In my opinion, the only way we're going to develop really effective treatments will be to treat the cause of the disease, not the symptoms".

In the interview with Dr. Clauw (EMS News Letter Volume 111) "The only way that you could stop that from happening again is, if we identified that incredibly toxic compound. We can't do that because we don't know what it is."

In the interview with Dr. Naylor, "some of the fundamental questions really revolve around what are the structures of the contaminants that were present in the tryptophan which caused this terrible illness".

I wonder after all these years, do they still really not know the exact organism that caused EMS? Has Dr. Gleich still not found the missing link in spite of having had access to the MDL papers, and knowing the molecular weight of the major contaminant? Will the final clue turn up as more and more of us become the living proof of the unforeseen consequences as a result of this DNA manipulation and interchanging of bacillus and bacteria and the terrible crime against humanity some scientists created in their ignorance?

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Jeanine's Story

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this book. The name of it is "City Hawk: The Story of Pale Male." It is written by Meghan McCarthy. So, after 3 years of being in bed, I am still active.

It has been almost 20 years since I became sick with EMS, along with a few thousand other people. I am only 51, and I do not know how long I have left to live. But one thing is sure. Life will never be boring. EMS can never destroy me. It may wreck my body; but it can not touch who I am. I love life. I love the people in this world. I will make the most out of each day I have, each encounter with people I know or will get to know. There is so much beauty in life, so many blessings. If I hadn't become sick, I never would have learned to paint. I would have never learned to be a photographer. So, it is true — there is always a silver lining in every cloud. Let it shine brightly.

Jeanine Lent

Editor's note: Jeanine may be contacted through the editor.