



# National EMS Network Newsletter

### Points of interest

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- **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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## Are the foods you are eating keeping you in pain?

by: Jesse Cannone, CFT, CPRS

### Try An Anti-Inflammatory Diet: It Could Be The Answer To Eliminating Your Pain

When I say chronic inflammation, thoughts of painful joints, muscles, swelling and loss of mobility probably comes to mind. But did you know that recent research shows that chronic inflammation in your body can lead to serious disease such as diabetes, [heart disease](#), some cancers, and Alzheimer's disease, to name just a few?

The amount of inflammation in our body varies and is dependent on many circumstances like activity level, amount of sleep or stress in our lives and even the foods we eat. Now what you have to realize is that these factors are all accumulative and as the levels increase the risk for disease increases.

Now early in life these levels can be so low that you would not even know that you have any inflammation in your body and that is because our bodies do a fair job at controlling the inflammation at least for a while, and then one day you wake up and you are in your 40s and something is just not right and then the fear sets in and you think to your self what did I do, what did I do wrong or what can I do right now to help my self.

Well, the first step is to get your C-Reactive Protein levels tested, you will need to ask your Doctor and may even demand to have the test done, all it takes is a blood sample and then have your levels evaluated by your Doctor and even by a registered dietician to help you formulate a plan of care because our diets can play a large part in achieving optimal health.

If you have pain from inflammation you may choose to take the traditional medical path for inflammation such as, non-steroidal anti-inflammatory drugs (NSAID™s), steroids and even joint replacement surgery in severe cases. The good news is that there are more natural ways to fight inflammation, and they do not have the undesirable side effects caused by most typical medical treatments.

### What You Eat Makes All The Difference

The food we eat is a critical piece of the puzzle when it comes to controlling inflammation. The average American diet consists of high fat, high sugar, loads of red meat and a frightening amount of processed foods. These are all likely to increase inflammation, not to mention contributing to obesity, yet another high-inflammatory culprit. By switching to an Anti-Inflammatory Diet plan made up of healthy, whole foods, you can actually decrease inflammation and in turn ease the pain and discomfort associated with it.

The first step is to avoid processed foods, foods high in sugar and junk food whenever

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## To The Editor

To the Editor,

I appreciated reading Bob Matney's "Update on Statins" article in the March 2009 newsletter. My interest is personal because my mother, who is not an EMS patient, was damaged by statins and continues years later to suffer leg pains, cramping and reduced muscle function. I wonder how Bob is doing now with the CoQ10 he is using to treat adverse effects of the statins? It was interesting to see Bob's analysis of various types of CoQ10 and of their various manufacturers--and of course for reminding us that CoQ10 is "barely regulated", like all supplements in the U.S.

Recently I've read that some people are genetically predisposed to be damaged by statins. I came across a New York Times article on the subject: [http://www.sciencenews.org/view/generic/id/34402/title/Statin\\_snag](http://www.sciencenews.org/view/generic/id/34402/title/Statin_snag) "STATIN SNAG: Gene variant places some people at risk of side effect from statins" by Nathan Seppa, August 16, 2008

The article cites a study published in the New England Journal of Medicine about the discovery of the gene variant that people who experience adverse effects from statins, like severe muscle pain and more, may have. It says that a certain gene "encodes a protein that shuttles compounds from the blood stream into the liver for processing. This cargo includes statins. Properly deposited, these drugs then go on to decrease the levels of LDL, the bad cholesterol. But people with the variant form of the gene make a

version of this protein that transports statins poorly, leaving an excess amount in the blood stream." It says that 5-10% of people taking statins report muscle pains at some point, sometimes severe, and that the muscles and even the kidneys can be damaged by statins.

And finally, the article states that there is a simple genetic test available to check for the gene variant that causes these horrible reactions, but this test is seldom prescribed. Apparently it "would cost less than a dollar in a standard genetics lab". WOW!

Why aren't doctors rushing to get their patients tested, before they prescribe potentially damaging drugs?

Sincerely,

Lois Vierk

### *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. NEMSNI 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 NEMSNI 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 NEMSNI 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.

## DiAnne's Story

by DiAnne Clark

On November 3, 1989 I called in sick for one day to a job where I worked as a rehab specialist for mentally disabled adults. I just figured if I could lie around for a day, then I would be okay. November 3 was the last day I worked. I was taking L-Tryptophan so I could go to sleep immediately and get up and keep going. Then I kept taking it at home after I was staying home from work thinking it was helping me to heal and get my strength back. One day I was sitting at my table and when I put the two pills near my lips my throat would immediately swell shut. I remember looking at those pills and wondering how odd that was. When I came home the first day a few months later those same two pills were lined up on the table just as I had left them.

A few days later, about Friday, I was diagnosed with double pneumonia. On Sunday I called my girlfriend and asked her to take me to ER. I had been on the phone with her frequently before then, so she had heard my decline, and by then I was too weak to even talk and she told me to call 911. When they arrived I had collapsed and fallen down an entire flight of stairs trying to open the door.

My eosinophil count was 71% in ER and I was told my lungs looked like lace. The nurse at the head of my gurney pushing me to ICU was another good friend. She looked down at me and I looked up at her and saw her upside down when she said, "DiAnne we all watched you get this sick, so this is what you get for burning your candles at both ends". I had been working 3 jobs and was in my senior semester in college. I never finished that particular degree. I had been a happy, enthusiastic and energetic woman just a few weeks before that.

The next day I had a near death experience and that in itself was the most important lesson I have ever learned in my life. My family doctor of about 25 years stood at the foot of my bed and I could see in his face that I was gravely ill. There was a TV in ICU and a few days later I saw that L-Tryptophan was being pulled off the market as it had killed a few, so I told a nurse I was taking it. Later I was interviewed about my health. And about two days later my doc rushed into my room waving a Cleveland paper and said I made the front page. My fifteen minutes of fame. In another day or two I was up and around and my doc told me to quit taking those pills that I would be all

right and sent me home. He retired right after that.

I could not walk and a girlfriend picked me up and took me to her house. I was so weak that I could not even make myself a cup of coffee in her microwave.

In another week or so I was so weak and sick that I could not function. Had terrible diarrhea and was beginning to rapidly lose weight at about 4-5 lbs a week. I was extremely weak when I ended up seeing a gastrointestinal specialist and I remember looking at him through the side bars of my bed when he asked me, "What is L-Tryptophan?"

In March of 1990 I was at home and my body collapsed again, however this time it went down so fast that I barely had time to call 911. I was lying face down on the cot in the ambulance begging them to hurry and pleading I would make it alive. We were on a very busy city street and it just seemed to me that the hospital was in the next state and we were not going to make it in time. When I arrived there was a trauma team waiting for me and they went to work with lightening speed. I figured this was it and was so relaxed and not afraid anymore. I was in the hospital for nearly a month after that just fighting for my life. At one point I laid in bed and watched blood being drained off internally and fill a plastic jar attached to the wall. It just seemed my life was pouring away and my body was determined to give up. It was about then that I realized I had no body left, no clothes, no home, no belongings or etc, but all that I had was my brain. It was also then that another doctor told me I would not make it past June. In my mind I defied his statement, determined I would live. And, about two years later I made my bed for the first time. About June I was diagnosed with EMS due to the ingestion of L-Tryptophan. My doctor waited that long to diagnose me because he wanted to be sure.

My decline then, and the painfully slow recovery now, seems to be an eternity. My life threatening experiences on a day to day basis became a way of life for me. My gastrointestinal doctor was and is the most wonderful man in the world and the best with bedside compassion. He spent time listening to me about my fears and holding my hand as I cried. He fought hard to save me, especially when the hospital board had given up on me as I was tak-

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## DiAnne's Story

*...continued from page 3*

ing up a bed they needed. I had purchased a home a bit later with large gardens where I could walk and where I figured I could be comfortable till the end.

Sometime in 1992 I got a terrible left-sided headache that would not let go. And in these years following, the headaches would start suddenly and last for a week or more with extreme pain. I would look in the mirror and the entire left side of my head and neck would be swollen. In about 1996 I started seeking help from neurologists who tried every different pill on the market and nothing worked. Then it was about 2000 when I saw a very prominent neurologist who was so thrilled that I was an L-Tryptophan victim and sitting in his office (like he won a trophy) it seemed like he was a child who was overcome with excitement. He ran out of his office, stuck his head back in the door and said, "Don't move."

I spent months and months in extraordinary medical testing and then he told me that my muscles on the left were already scarred from childhood head injuries and then added with eosinophils chomping on the nerves in my muscles from Eosinophilia made it worse. That was also what had happened to my digestive system. The eosinophils killed my neuro-muscular system. I also had brain damage in my left brain. It was then another year when my head and neck began to twist and turn involuntarily. He stood me in front of a wall mirror and showed me how my body was leaning and twisting to the left and it was obvious, also, that my left side was larger than my right. I was diagnosed with torticollis. Sent me for Botox injections in my neck for the pain and it was for another year of treatments before I felt the relief, less pain.

He left that hospital practice and went into private practice and saw me a few times more. I was sent to physical therapy where the therapist manipulated my neck and used hot packs. It worked for only a few hours and then the pain came right back. He sent me back to another pain specialist and then seeking help for myself became muddy for me. In the next years that doc tried all sorts of pills, most of which made me sick, dopey or crazy. There was even a thought of putting electrodes in my brain which I quickly shot down. What if they did not work? I told that neurologist that he would not be able to work if he had my headaches. And, since I have told others the same.

I started looking for a new doc. Whenever I would tell them what my diagnoses were they would not believe me and went off on their own ideas, giving me more pills and more crazy diagnoses. One spine specialist told me everyone has it when they get older and I was to deal with it like everyone else and he walked out the door. At one point, my new family doctor told me that he did not want to hear L-Tryptophan any more from me and walked out of the room. I went to another neurologist and was told that I have Chronic Pain Syndrome due to Addiction to Pain Killers (which I rarely take).

(Another doctor had also told me that same thing years earlier and I was also accused of being addicted to coffee, also. Decaf.) I was not being believed. Another doctor has now sent me to physical therapy and I am rebelling. If it never worked before, why would it work now? I am losing faith in the medical profession. I started seeing a psychologist specializing in patients with chronic pain. And a few weeks ago she told me that my muscles are knotted and hard on the left from stress that I create and when I move my left arm, I break the knot and get a headache, that I have to move the arm and work through the pain. It is all I can do to restrain myself.

I learned not to use my left arm a few years ago and the headaches never start, or stay at such a minimum pain that I could just take an OTC pill. I just feel now I am against the wall. I joined a successful meditation study with a monk and a neurologist a few months ago and found that being quiet and meditating lessens the pain considerably. The frustration and stress I have felt with the doctors I have now just make me angry. I have another brand new family doctor (the last one moved) and I said last week I wanted to talk to him about the headaches and he said he read the report from another doctor that I have chronic pain syndrome due to the addiction to pain killers and he walked out of the room. All I can do is come home and cry as I am so discouraged.

I am rearranging my life now so I can be more comfortable. I have decided to immerse myself into my arts as I am a felter and just play, have fun and enjoy life. It seems to help a lot to let go of the stressors and that makes life easier and less painful for me. At this point I simply do not know what to do about the doctors and am considering giving up on them, as I am beginning to believe that this

## Are the foods you are eating keeping you in pain?

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possible. Instead choose fresh, whole foods including anti-inflammatory varieties like lean proteins, fruits and vegetables. But choose carefully, in fact even some vegetables and pre-packaged health foods can work against you. Use this quick list of the best and worst foods in controlling inflammation:

### Anti-inflammatory foods

Atlantic Salmon- (wild)

Fresh whole fruits, vegetables

Bright multi-colored vegetables

Green tea

Water

Olive oil

Lean poultry

Nuts, legumes and seeds

Dark green leafy vegetables

Old fashioned oatmeal

Spices, especially Turmeric and Ginger

### Pro-inflammatory foods

Sugar, from any source

Processed foods

French Fries

Fast Foods

White bread

Pasta

Ice Cream

Cheddar Cheeses

Snack Foods

Oils such as vegetable and corn

Soda, caffeine and alcohol

In addition to these dietary changes it is also recommended that you:

- **Maintain a healthy weight** - There is no question that eating healthy is not easy now days, either at home or at a restaurant. But you must at least start to do these three things. Decrease your sugars, Decrease your hydrogenated oils and increase your daily intake of fiber to 35 grams, that is a ton of fiber but just try, you may hit it, you may not, the point is try to:

- **Get better sleep** - 7 to 9 hour is mandatory for optimal health and the one thing that most people do not know it that quality sleep is the key to controlling systemic inflammation.

- **Relax more often to lower stress levels** - Find time for yourself, morning, noon and night and focus on your breathing and clear the clutter in your mind, learn to stay focused on the most important tasks in your life.

- **Exercise on a regular basis** - Everyone always asks me what it is the best exercise to do and all I can say is - do something you like to do, granted you can tolerate it, shoot for 15 to 20 minutes 3 times a week.

- **Demand to have you CRP levels tested** - This simple blood test is the best indicator of the level of systemic inflammation in your body, It is recommended that you have the levels evaluated by an certified health care provider to take the most appropriate action for you and your condition.

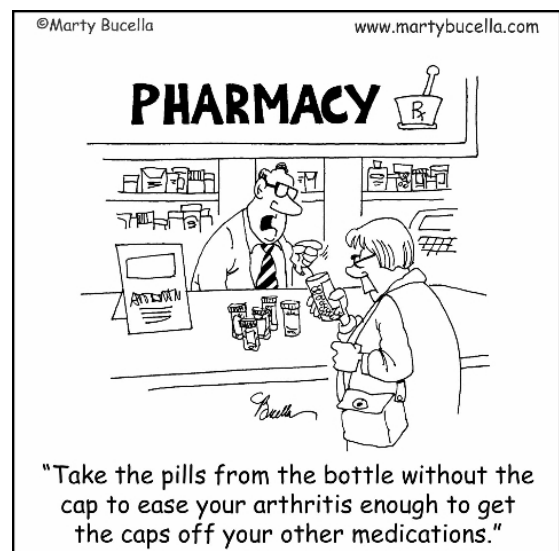
So if you are in pain and you are going to make a conscious choice to help your self get better then making these changes to your diet and lifestyle will most certainly improve your overall health and help reduce the pain from inflammation. If you would like more information about reducing inflammation naturally and effectively go to the link below to learn more. <http://www.losethebackpain.com>

<p>

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## EMS/FM Story

By Patty Bell

I was healthy, and then EMS/FM hit me and it took two years and three doctors to find out what I had. I now have a doctor who believes that I have EMS and Fibromyalgia (FM) as a result of the EMS. He says all my problems that I have and any I get from now on are from the EMS/FM. My body is giving up little by little.

My sleep pattern is so abnormal. Like most people with EMS/FM, I wish I could get a good 8 hours of sleep like I had before my illness set in. Now I sleep one or two hours at most at a time, (total of 4 hours sleep a night), and my pain is so bad at night that I don't get to bed until around 4 a.m. I do take a cat nap in the afternoon - not by choice. My body just falls asleep without warning in the afternoon around 3 p.m.... sleep for an hour. I do not drive anymore during the afternoon because I drop off to sleep without warning!

My pain is constant 24/7 - the worst part of having the EMS/FM. The burning pain goes from my neck to the bottom of my feet and is worse during the winter months due to the cold. I am housebound during the winter; if I get any kind of chill, I suffer greatly. Now with all this said, I must add that I have developed a lot of medical problems. My doctor says it is a result of EMS/FM because of the constant pain and lack of sleep. Chronic fatigue is a big problem.

I have sensitivity to touch. Everyone knows not to touch me. I miss not having the bear hugs from family members! Just the slightest touch sends shooting pain throughout my body.

I had a small stroke in January 2005 which affected my memory loss, but I was having problems with memory before the stroke. My memory has gotten worse. My doctor has said that due to the lack of sleep and constant pain from EMS/FM that fatigue and sleep problems are the results. We are not giving our brain time to rest. And he has told me that without proper sleep to give our bodies time to recover, we will have medical problems on an ongoing basis.



I also have problems with my gastric system, such as diarrhea. Not much has helped that. I do eat a lot of fiber foods to help, but they do not help totally. My stomach aches from the fiber, I think - don't know for sure. I am a mess!

I have problems with balance and walking and problems with my body regulating temperature. I was not approved for a scooter and can't afford to buy one. I use a cane for balance and can only walk short distances. I do not go anywhere due to not having the ability to get around.

I developed diabetes just two years ago and take a pill to control that. Just two months ago, tests came back that my thyroid is not working like it is supposed to, so I take a pill for that - doctors' solutions to everything is to take a pill.

I did develop dryness and itchiness of the skin also just about one year ago. I do not have anything wrong with my face. No problems there. Just from my neck down I have the pain.

Severe shortness of breath is my recent problem. I had x-rays of my lungs and have good clear lungs - healthy there. My doc can not give me a reason for the breathing problem. It's not due to any meds I am taking either, so he just marks it down to the EMS/FM.

I thank the Lord for every day I am alive! I feel some days like giving up, but then I think about missing my grandson's smiles and stories (he's five years old). I do not like to complain about my illness, so this is hard for me to write. I will endure my pain and sleepless nights, plus all the other problems, just to have one more day with my grandson, and to see the sun and all the wonders of nature that God has given to us.

*Patty Bell lives in Iowa.*

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