



# 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.**
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## Medical Advisory Panel Q & A

Edward A. Belongia, MD, has been involved with EMS and EMS patients from the beginning. Currently he is Senior Epidemiologist and Director of the Epidemiology Research Center of the Marshfield Clinic Research Foundation in Marshfield, Wisconsin. Dr. Belongia is both a clinician and a researcher and has published numerous articles. His medical and scientific interests include the epidemiology of infectious diseases, applied public health research for the prevention and control of infectious diseases, vaccine safety and effectiveness, Lyme disease, among others.



NEMSN vice-president Jinx Engstrom writes of Dr. Belongia's early work with EMS patients: "He was an epidemiologist here in Minnesota when the initial outbreak happened in 1989. He was a huge help in determining what was making so many people sick. Then after that was determined, he was generous to our support group."

We are honored to have Dr. Belongia on our Medical Advisory Panel and pleased to present his answers to questions from NEMSN members.

**Q.** EMS patients have been asking about the advisability of getting various vaccinations. Since our immune systems aren't functioning right, is it a good idea or a bad idea? Do you have any thoughts about Shingles Vaccine? Flu Vaccine? Others?

**A.** I don't think anyone knows if patients with EMS respond differently to vaccines. In general, vaccines are still recommended for individuals with chronic diseases, including immune system disorders. The flu vaccine in particular is very safe and has been used for many years. The flu can be a very serious disease, especially in people with chronic disease, so vaccination is a good idea. The shingles vaccine is newer, but it has been shown to be very effective and appears to be quite safe. However, I would encourage everyone with EMS to discuss these issues with their doctor.

**Q.** The EMS outbreak of 1989-90 is often likened to the Toxic Oil Syndrome outbreak in Spain in 1981, brought on by contaminated cooking oil. The diseases seem to be similar. Could you comment on this?

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767 Tower Boulevard  
Lorain, OH 44052-5213

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### Board of Directors

\*

Jann Heston.....President  
155 Delaware Avenue  
Lexington, OH 44904  
419-884-7120  
Email: Nemsn2005@aol.com or  
jheston@gmail.com

\*

Jinx Engstrom.....VP/Web Administrator  
4036 Aldrich Avenue South  
Minneapolis, MN 55409  
612-825-9135  
Schubert.Engstrom879@gmail.com

\*

Ann Flaherty.....Secretary  
2727 Shakespeare Lane  
Avon, OH 44011  
440-937-1537  
Email: aflaherty225@yahoo.com

\*

Michael Bird.....Treasurer  
219 Twin Lakes Drive  
Fredericksburg, VA 22401  
540-368-0356  
Email: wiltshirebird@gmail.com

\*

Sandy Kintz.....Newsletter Editor  
767 Tower Boulevard  
Lorain, OH 44052-5213  
440-960-5910  
Email: NEMSNewseditor@gmail.com

\*

Nancy Grant.....Med/Research Director  
4308 Alcove Avenue Unit 104  
Studio City, CA 91604  
818-623-9199  
Email: nancy.grant@juno.com

\*

Lois Vierk.....Public Relations Director  
P.O. Box 4171, Monitor Station  
West New York, NJ 07093  
201-868-9572 Fax: 201-854-6450  
Email: elveevee@aol.com

\*

Robin Burkin.....Web Master  
203-388-5943  
Email: rburkin@comcast.net

\*

Website: [www.nemsn.org](http://www.nemsn.org)

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## Advisory Panel Q & A

...continued from page 1

**A.** EMS and TOS are indeed very similar, and that may hold important clues regarding the cause. The early symptoms of toxic oil were usually pulmonary, but many patients with toxic oil syndrome progressed to a chronic phase that closely resembled EMS. A contaminant in Showa Denko L-T called PAA is chemically similar to another chemical that was found in the toxic oil. The discovery of closely related chemicals in both L-T and toxic oil suggests that the two conditions may have shared a common trigger. Later research has shown that liver cells, when exposed to these agents, produce a common breakdown product that may be the link between EMS and TOS. The breakdown process in the liver may generate other potentially hazardous molecules as well. It is still not well understood.

**Q.** How are the TOS survivors doing today?

**A.** A study published in 2005 found that the long term quality of life was poor for people who were severely affected by TOS, and the level of disability was high. The abstract is available at <http://www.ncbi.nlm.nih.gov/pubmed/>. Type in the article ID in the search box: 15926964.

**Q.** Have there been more EMS-like epidemics?

**A.** To date we have not seen any other outbreaks similar to EMS, but concern remains because there is currently no way to screen products since the specific trigger and mechanism is not known.

*Many thanks Dr. Belongia for his answers. As always, consult your own physician(s) for your own medical condition(s).*

*If you would like to have your questions submitted to our panel, please e-mail them to:*

*NEMSNewseditor@gmail.com or mail them to:*

*Sandy Kintz  
NEMS News Editor  
767 Tower Boulevard  
Lorain, OH 44052-5213  
440-960-5910*

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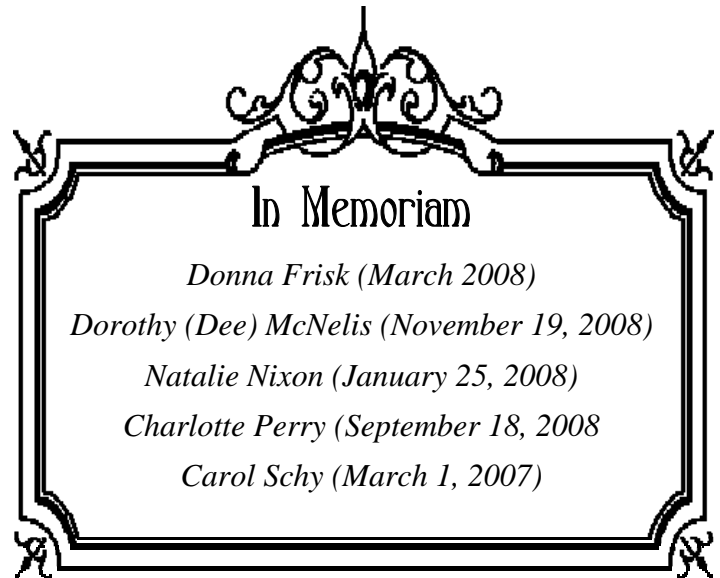
The National Eosinophilia-Myalgia Syndrome Network, Inc., is a non-profit organization dedicated to helping EMS survivors and their families by offering educational information and peer support. NEMS is also committed to encouraging research to improve treatment for L-tryptophan-induced EMS and to increasing

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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.

## NEMSN Connections may be just the thing for you.

Would you like to belong to an online email group of NEMSN members who receive monthly information on health and EMS? If so, NEMSN Connections, produced by Faith Rumph, is for you. Faith presents health tips each month. Members can connect with other EMS patients to share their own questions and answers, and NEMSN presents current news items of interest. You may also share recipes, if you like. For information on how to join, please contact Faith: [faith\\_rumph@yahoo.com](mailto:faith_rumph@yahoo.com)



## A Practical Guide: How To Save Money On Prescription Drugs

*By: Richard Brommer*

Needing a prescription drug should not be a matter of cost, but unfortunately it is. With the cost of prescription drugs at unreachable heights the under and uninsured individuals of the world often do without their medication, both ordinary and life saving. What many people doing without their prescribed medications do not realize is that there are opportunities for prescription discounts in a number of different places.

### State Assistance

Many people are eligible for state assistance programs that will help them with their medical costs, including prescription drugs costs. Naturally, there are the obvious programs such as Medicare and Medicaid. However, other programs may exist through state assistance. Your state government website or county social service office can help direct you to prescription drug programs that you are eligible for.

### Patient Assistant Programs

One of the best ways to get discounts on your prescription drugs is through patient assistance programs. These programs are operated by the major pharmaceutical companies like Glaxo, Astra Zeneca, and Pfizer. These programs provide prescription drugs to individuals without insurance for free or low cost. These programs cover some of the most widely prescribed popular prescription

drugs on the market and the programs are not government run.

The patient prescription assistance programs work in a fairly easy way. A person in need of a certain drug can go online to the drug manufacturer's website and find out if they offer prescriptions assistance for the drug. They can also call the pharmaceutical company directly. They will either print an application or request that an application be sent to them. They will then take the application for prescription assistance to their prescribing physician. Most of these programs require that your doctor complete and mail in the form on your behalf. Once your application is approved the drugs will either be mailed to you or dispensed to your physician. In addition, most patient assistance programs require that you reapply every few months.

### Discount Prescription Cards

There are many groups that offer prescription discount cards. These cards allow the card holder to get a percentage off prescription drugs when they take the script to be filled at the pharmacy. The percentage off varies and is based on the actual drug in question. Some of these prescription discount cards are based on membership to programs like AARP. However, others are provided to people who have no insurance for free, like the Together Rx Access program.

## Statin Update

By Bob Matney

In a past newsletter I wrote statins (anti cholesterol medications) can potentially cause "statin disease", it has no official name. FYI Red Yeast Rice is chemically the same as the medication Lovastatin. Resultant abnormalities in liver function and skyrocketed Creatine Kinase (or phosphokinase, a muscle enzyme) cause incredibly painful muscles & joints, myalgia, fatigue, dyspnea, memory loss, depression and peripheral neuropathy. Any of this sound familiar? A little over 1% of statin users become disabled and surprisingly not a single law suite.

I'd asked if EMSers had their CK levels checked during initial EMS outbreak but only a few responded. Serendipitously while converting the 1995 EMS convention tape to DVD I discovered Dr. Elaine Lambert stating studies showed a surprising result (approximately the 36 minute mark on the tape). CK and the enzyme aldolase are both associated with muscle breakdown and elevated levels were fully expected in both but occurred only in aldolase.

POSITIVE: Surveyed patients with statin disease reported the only successful treatment, other than major pain killers, were 240-300 mg dosages of CoQ10 per day relieved some symptoms. Many EMSers are taking CoQ10 (2,3 dimethoxy-5 methyl-6-decaprenyl benzoquinone), it's an antioxidant that provides energy by making Adenosine Triphosphate (or ATP) serving as cells' major energy source and drives biological processes including muscle contraction and protein production.

I used the recommended 300 mg per day for 5 months with no noticeable improvement and was disappointed. Then in month's 6 and 7 some of the excruciating nerve pain subsided and I regained about 80% of my right arm use, progressively other pre-statin aches and pains dramatically declined but attributed it to time healing all wounds. You know nothing's that easy!

I had purchased 8 bottles of CoQ10 and waited a few months before treatment in case of contamination recall, learned from my past L-T mistake. Turned out six bottles were 100 mg capsules but two bottles were 400 mg capsules. Around month 6 instead of 100 mg capsules three times a day I unknowingly took 400 mg capsules two and three times a day totaling 800-1,200 mg. Although a huge dosage it's recommended for some breast cancers, con-

gestive heart failure patents and up to 3,000 mg per day in Mitochondrial cytopathies patients. Benefits are debated for heart patients but solid for neurological pain relief benefits, I admit results are very, very impressive. I can't find a recommended overdose limit but there is gastrointestinal upset in less than 1 percent of us and it may conflict with blood-thinning medications such as Warfarin (Coumadin) and Timolol drops, a beta-blocker medication used to treat glaucoma. So, before taking CoQ10 check with your Dr. But wait, you know nothing's that easy, it gets more convoluted!

NEGATIVE: Here's the big problem, CoQ10 is a supplement! It's barely regulated, a fermented product with nothing online completely describing the manufacturing process. And, the good stuff's made by 4 major Japanese manufactures; Kaneka (#1), Nisshin Pharma (#2) [purchased part of MGC, #4], AsahikaseiPharma (#3) and Mitsubishi Gas Chemical(MGC, #4), the bad coming from China and Mexico. For itself alone Japan supplies over 35 metric tons of raw CoQ10 and 450 metric tons world wide. CoQ10's made in one of two isomers; the 'trans' isomer is identical to naturally occurring forms in humans, whereas the 'cis' isomer, commonly found as an impurity in laboratory synthetic low grade CoQ10 (China & Mexico). Scientists have not determined if cis CoQ10 can even be utilized by humans or if it offers the same protective benefits as naturally occurring trans CoQ10. Many researchers believe the so called natural yeast-derived trans isomer CoQ10 (favored in studies) is better absorbed than synthetic formulations. I can't find if yeast-derived fermentation means genetically engineered. Kaneka manufactures one of the few trans isomer CoQ10s promoted to the supplement industry. Many supplements contain the unproven cis CoQ10 and, as usual, most bottles don't say which they're using. Assuming CoQ10's made and distributed similarly as L-Tryptophan would mean both types are sold on the spot market in large containers and mixed together thus putting consumers at risk. With an unregulated industry, bottom line is, unless you check (virtually impossible) you've no way of knowing if you took trans or cis, if they were mixed or if there was any CoQ10 in the bottle at all. And the last downside is, the stuff is incredibly expensive. Again, any of this sound familiar?

*...continued on page 5*

## Update on Statins

by Bob Matney

(continued from page 4)

Questions; would continued use of CoQ10 eliminate statin nerve pain entirely, would it take an even greater dosage, did it reduce pain at all or was it just time healing all wounds? My plan is to finish the bottles at 800 mg a day dosages, discontinue usage and wait to experience any changes, hopefully none.

\*\*\* In the study below (there's lots more) fifty patients with adverse statin effects were studied. PMID: 16873939 [PubMed - indexed for MEDLINE, East Texas Medical Center and Trinity Mother Francis Hospital, Tyler, 75701, USA. langsjoen@compuserve.com]

...a decrease in fatigue from 84% to 16%, myalgia from 64% to 6%, dyspnea from 58% to 12%, memory loss from 8% to 4% and peripheral neuropathy from 10% to 2%. Measurements of heart function either improved or remained stable in the majority of patients. We conclude that statin-related side effects, including statin cardiomyopathy, are far more common than previously published and are reversible with the combination of statin discontinuation and supplemental CoQ(10). We saw no adverse consequences from statin discontinuation.

A different study stated statin drug use with the addition of CoQ10; "There was no significant change in creatinine phosphokinase with treatment in either group nor did these levels correlate with pain severity." CoQ10 didn't lessen CK levels but it did reduce/eliminate myopathic pain. Question, if you know the statin drug is killing you why continue taking it?

Side discussion for Drs. out there. After ceasing statin medications in December 2007 my CK dropped within normal range. In December 2008 I got food poisoning from a bad salmon patty. Within 24 hours normal allergic reactions raged but additionally when I'd cough, or even gasp a little, the pain from my neck to groin was incredible. It was as if my skin was being peeled off from the inside and then electricity radiated through the rest of my body. I've had broken bones with less pain than a single, simple cough. Another 30 hours, lots of

medication, and a blood test was finally done at my insistence. Though feeling much better (a cough produced mild pain) CK levels were still almost 40 percent above the upper limit and must have been higher at the attack's worst. Question, did statin disease cause pain and elevated CK levels from bad fish?

**Editor's Note:** Bob Matney (aka EMSBOB) became well-known in the earlier days of EMS in WA state for the colorful and interesting state newsletter he produced to which many others nationwide subscribed as word of his unique newsletter spread. He was probably one of the first EMS persons who was "wired" (online using a computer). In addition, he served as a Volunteer Listener for Project H.E.A.R. for several years, and he was the NEMSN E-mail Group Coordinator, a service now known as NEMSN Connections.



## **All You Need for Muscle Pain**

**By: Cathy Mark**

Everybody has experienced muscle pain at one point in time or another. And it is undeniable that the experience is definitely not pleasurable. It is, in fact, discomforting. But what happens when we experience muscle pain? Read on to find out.

### Myofascial pain syndrome (MPS)

More commonly known as muscle pain, Myofascial pain syndrome (MPS) refers to pain and inflammation of the body's soft tissues. It is a continuous condition that affects the fascia, the connective tissues that cover the muscle. MPS can involve a single muscle or an entire muscle group. There are even cases that the myofascial pain is displaced to a different area away from where the originally affected area is.

MPS is said to be caused by "trigger points". These are sensitive and painful areas found between the muscles and their fascia.

### What can cause myofascial pain syndrome?

- \* Sudden trauma to musculoskeletal tissues (muscles, ligaments, tendons, bursae)
  - \* Injury to intervertebral discs
  - \* Generalize fatigue
  - \* Repetitive motions; excessive exercise; Muscle strain due to over activity
  - \* Systemic conditions (eg. gall bladder inflammation, heart attack, appendicitis, stomach irritation)
  - \* Lack of activity (eg. a broken arm in a sling)
  - \* Nutritional deficiencies
  - \* Hormonal changes (eg. trigger point development during PMS or menopause)
  - \* Nervous tension or stress
  - \* Chilling of areas of the body (eg. sitting under an air conditioning duct; sleeping in front of an air conditioner)
- How is myofascial pain syndrome treated?

Treatment is only administered after a complete diagnosis of the condition has been made. There are a variety of

treatment methods that can be used to help relieve a patient of myofascial pain. These methods include:

- \* Medications. There are various prescription and over-the-counter pain relief medications available in the market in the form of tablets, capsules, creams, and gels aimed to provide long-lasting and temporary pain relief to people with MPS.
- \* Physical therapy. This method involves the use of different devices like heat/ice packs, ultrasound, and transcutaneous electrical nerve stimulation (TENS) packs to provide pain relief.
- \* Massage therapy. This method involves manipulation of the soft body tissues with the use of pressure, tension, motion, or vibration that can be done manually or with mechanical aids to reduce pain.
- \* "Stretch and spray" therapy. This form of treatment involves spraying the affected muscles and trigger points with a coolant and then slowly stretching the muscle.
- \* Trigger point injection. A small needle containing a local anesthetic is inserted into the patient's trigger point to make it inactive and alleviate the pain and discomfort.
- \* Dry-needle technique. This is administered in case an MPS sufferer is allergic to the local anesthetic used in trigger point injections.

It is natural for everybody to feel muscle pain every once in a while. You can try to administer self-care measure and see if it does any good. But if it does not help, contact your physician and ask for an assessment. Severe muscle pain is not just a simple matter that you can wait out until it goes away on its own.

### **A reminder to live 24 hours each day – not to waste a minute**

1. Throw out nonessential numbers. This includes age, weight and height. Let the doctor worry about them. That is why you pay him/her.
  2. Keep only cheerful friends. The grouches pull you down.
- ...anonymous

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