



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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A way for you to help NEMSN

What if NEMSN earned a penny every time you searched the Internet? Or how about if a percentage of every purchase you made online went to support our cause? Well, now it can! NEMSN is asking you to support our organization by using this search engine (instead of whatever you are using now, like google.com for example)-please check out: www.goodsearch.com

GoodSearch.com is a new Yahoo-powered search engine that donates half its advertising revenue, about a penny per search, to the charities its users designate. Use it just as you would any search engine, get quality search results from Yahoo, and watch the donations add up! You can add GoodSearch to your toolbar to make it easier.

GoodShop.com is a new online shopping mall which donates up to 37 percent of each purchase to your favorite cause! Hundreds of great stores including Target, Gap, Best Buy, eBay, Macy's and Barnes & Noble have

teamed up with GoodShop and every time you place an order, you'll be supporting your favorite cause.

Please go to www.goodsearch.com instead of Google or other search engines, and select "National Eosinophilia Myalgia Syndrome Network" or "NEMSN" as your designated charity, and this wonderful organization, because of its advertising revenue, will donate one cent to NEMSN for each search that you do! It is simple, it works easily and well. A penny for a search may seem like not much, but if just 100 searches total, from all NEMSN supporters across the country, are done in a day, it will mean a DOLLAR A DAY for NEMSN! The check will be sent monthly to our treasurer, Michael Bird. We are doing our best to be here for you, please be here for NEMSN. And pass the word around to anyone who is supportive.

Editors Note: You can check when you are using the search engine and see what we are earning. Every little bit helps.

**National EMS Network
Newsletter**
Published by

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Request for Contact...

Dear Sandy,

I am interested in knowing if anyone is suffering from a slow digestive system. My doctor diagnosed me about 6-8 months ago. They said it could be from EMS or being a diabetic. Please let me know if anyone has complained of a slow digestive system.

I've had EMS since 1989. It's been a long, painful time. I also suffer from numb feet and my hands are going numb, but my doctor doesn't know if it's from my EMS, being diabetic, or maybe a little of both.

In the last 10 months, I was told, after testing, I have 3 big ulcers, a big hernia that can't be operated on and they also found 2 tumors. I was operated on in September. Thank God it wasn't cancer, but I did have a complete hysterectomy. It was 6 weeks before I was able to do anything.

Thank you for listening.

Barbara Sigafos
2530 Steele Lane
Easton PA 18040-8618

Hi Jann and Sandy,

I was looking at the article titled "Are the Foods You are Eating Keeping You in Pain?" in the Sept. 2007 Newsletter and decided I should write you about my experience with food and other allergies.

After getting EMS I noticed I seemed to have allergic reactions that I didn't have before. Sometimes I would get chest pain when breathing products that had fragrance and sometimes I would walk in a room and before I

...continued page 4

Faith Rumph Joins Board of Directors

The Board of Directors is happy to appoint Faith Rumph as a new board member. Faith will be our Director of Volunteers and will coordinate volunteer activities for the organization.

NEMSNI has been looking for people to step up and fill vacant board positions. We are very pleased that Faith has agreed to join us. In early winter of 1995 Faith became Newsletter Editor of NEMSNI and held that position through September 30, 1999, when Joe Hayes took over.

During her time on the board she served as Executive Vice President as well as Newsletter Editor for much of 1997 following the retirement from the board of Dorothy Wilson, Exec. V.P., in the fall of 1996.

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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. 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.

Website: www.nemsni.org

The National EMS Network Newsletter is published quarterly in February, May, August & November by The National EMS Network, Inc., a nonprofit charitable organization under section 501 (C) (3) of the Internal Revenue Service.

Addressing The Cause And Finding A Cure: Why Cause is Everything When It Comes To Low Back Pain

by: Steve Preston

There is an epidemic, at least in the States when it comes to treating back pain. Most doctors do just that... treat back pain rather than finding and eliminating the cause.

You can treat your symptoms for an eternity, and you may feel better for a short period of time. To truly get at the heart of the matter though, you have to find and eliminate the cause of low back pain.

I'll let you in on a little secret. Most chronic low back pain can be resolved in six weeks or less. It's true!

A majority of chronic low back pain is caused by simple factors including:

- Poor Posture
- Injury
- Muscle Imbalances
- Improper Lifting
- Extra Weight

Let's take a look at each of these more closely.

Poor Posture

Posture is everything when it comes to back pain. Good posture results in stability and strength. Bad posture results in back pain. Many people can alleviate chronic back pain simply by taking the time to improve their posture. You probably can too!

Injury

We are all subject to injury at one time or another. You can work toward preventing injury in certain circumstances however. A lot of the injuries

that result in low back pain are caused by improper lifting techniques. You may be lifting a heavy box, or you may be lifting a heavy weight without warming up adequately. Either way, if you injure yourself you are subject to back pain. What can you do to improve your chances for recovery? One of the best things you can do is exercise. You should incorporate stretching activities into your daily regimen. By doing so you will condition your back and are less likely to get injured, and more likely to recover faster when you do get injured.

Muscle Imbalances

Muscle Imbalances occur when two muscles that oppose each other are unequally matched. If you exercise your back regularly for example, but never exercise your stomach, your body will be in a state of imbalance. No matter how strong your back is in this situation, you are going to be subject to back pain. Eliminate the muscle imbalances through rehabilitation and proper exercise and you stand a good chance of eliminating back pain.

Improper Lifting

OK, go back and re-read the section on injury. You need to lift correctly in order to avoid injury. NEVER bend from the waist when picking something up off of the floor, even if it is a feather. Always bend from the knees, and use your leg and abdominal muscles to support you when lifting an object. Many improper lifting inju-

ries actually occur in the gym. This happens when a person attempts to lift a weight that is too heavy or fails to warm up properly. You can avoid these injuries by paying close attention to technique at all times.

Extra Weight

Carrying around a few extra pounds may not seem like a big deal, but when it comes to back pain it could mean the difference between no back pain and chronic back pain. Even if you are carrying around just ten extra pounds, your body will have to shift and redistribute itself to accommodate the extra weight. Consider losing the extra weight, and you may realize your back pain soon follows.

About The Author

Steve Preston, President of Fast Fitness has been training and counseling clients for 15 years. He offers personal fitness training, metabolic testing and customized fitness and nutrition plans. His new guide "The Better Back Guide: 6 Weeks to Improving Strength and Reducing Pain Without Surgery" teaches people how to reduce, eliminate and prevent chronic back pain using a six week program. You can read more about his guide and his other fitness guides and services at: <http://www.fast-fitness.net>. Learn more about Back Pain at: <http://www.backpainworkout.com>. We thank him for allowing us to reprint his article.

Request for Contact

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left, my ears would ring and my skin and muscles would get a sort of burning sensation. I started wondering if I could have allergies, even food allergies, that were making my EMS symptoms worse, so I went to a doctor that specialized in allergies.

It turned out that he had a lot of fibromyalgia patients and was interested in auto-immune diseases. I was given an allergy test called ELISA ACT and found that I had several food allergies. The foods were not your typical ones like wheat or dairy.

One example is that I'm allergic to spinach. Everyone develops different allergies. I didn't eat spinach for a couple of years and then one day I decided I would eat a spinach salad. I couldn't imagine that I would still be allergic to it. I ate it, thought I felt fine and forgot about it. That night I slept terrible. My muscles ached and I had burning sensations. The medication that I take for EMS wasn't working as well as it usually did. I couldn't figure out why I felt so bad until my husband reminded me that I had eaten spinach.

Years ago after I had the ELISA ACT test I eliminated the foods I was allergic to and in two weeks or so my pain level was cut in half. I was thrilled. It's not a cure, but it sure has helped to have had that test. On the ELISA ACT web site there are testimonials from people who have fibromyalgia & chronic fatigue. The web site is www.elisaact.com

Could you pass this info on? If anyone wants to reach me they can e-mail me at

rhondamitch@suddenlink.net

Thanks,

Rhonda

Dear EMSers

Besides EMS, I have Fibromyalgia and a condition called TMD that causes awful pain of the jaws, gums, teeth, face, and sometimes it causes a dull headache or ear problems, etc. I don't have TMJ. This condition developed around the year 2000 and causes a lot of trouble from clenching but not grinding of the teeth at night. I wear a special night guard that used to help me, though I had relapses, but lately, it is not working (from Splintek). Do others of you have this condition and if so, what have you found helpful? My regular dentist has been supportive but of minimal help. Thanks for any suggestions and shared experiences. Faith faith_rumph@yahoo.com

Dear fellow EMSers & Medical advisors

I was taking an anti-cholesterol drug Lovastatin and of course got whatever disease this thing is causing. As the symptoms were exactly the same as EMS I just thought I was in an EMS relapse and old age. In the mornings my feet hurt so bad I couldn't walk. I would lean on the bed and move my weight from one foot to the other until the stiffness and pain subsided enough I could walk. I stopped taking it on 12-12-2007 and by the 16th felt much better, from the 17th through the 20th had feelings of euphoria. Turned out statins cause depression and I guess my brain was rebounding.

Anyway, researching this new disaster I came across a possible link between statin drug & EMS side effects.

An article states the statin drug turns on the gene "atrogen-1" that causes muscle wasting. It also states that every disease they've tested with muscle wasting has this gene turned off.

Question: Does anyone know if any EMSer has been tested for this gene problem?

Theory: If certain people don't have the "atrogen-1" gene that might explain why some people developed EMS and others didn't. I'm sure you intelligent people can come up with more than this one theory. It'll give you something to think about.

Sincerely,

Robert A. Matney.
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3114 122nd Ave. East
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Faith Rumph Joins

Board ...continued from page 2

Faith briefly served as President from early spring 1999 until mid-summer 1999 while also serving as Newsletter Editor. She decided to step down from the board because of personal reasons and declining health in the fall of 1999. We are so happy to have her back on the board.

Editor's Note: In the fall of this year, all board positions will be submitted to the membership for a vote. Please take the time to submit your vote when the time comes.

FERN'S STORY

Hi Sandy,

Thanks for a great newsletter. I have been thinking lately that everyone that responds and writes letters to you have EMS much worse than I do. I have a girlfriend who cries before she gets out of bed in the morning, so I thought that I was pretty fortunate.

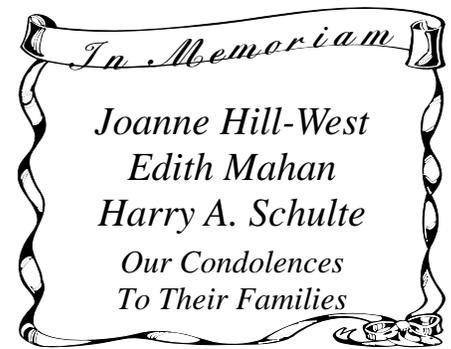
Well, this month (October) has been terrible. I wake up at night to take a painkiller. With the help of my doctor, we managed to get my eosinophil count to zero and were very happy with those results. I started to itch, especially on the legs, in July of 2005. I've had hives for years but just stocked that up to part of the EMS. My ailments go in cycles and one week I can hardly walk for pain and the next week I'll be much better in that respect but have terrible hives and the next week may be just fine with lots of energy. This syndrome is so frustrating.

But anyway, about the same time that I started the medication that we had hoped was taking the eosinophil count to normal, my lower leg started to lose its colour. Pigment was disappearing and I thought it was damage to the skin because of it being so itchy. So I continued using creams and even alternative medicines and trying to stay away from any chemicals that may have been causing the hives. My legs started to get worse and the doctor finally sent me to a second dermatologist who took one look at my legs and said I was allergic to a drug. He guessed it was hydrochlorothiazide. I had been prescribed this for edema and also was on a high blood pressure medi-

cation for that. I stopped taking the hydrochlorothiazide but the itching didn't stop and was on high doses of antihistamines but they didn't even seem to help. Our medical insurance questioned my use of the Singular, prescribed for my eosinophil count. It's actually a medication for asthma but I was taking very high dosage of it. The insurance company needed an explanation for his giving it to me and they didn't accept the answer so they refused to pay for it. It was \$80 a week and so I stopped taking it (couldn't afford it) and have had no itching of my legs since. But my legs look awful with a huge patch of no pigment in both legs and the surrounding skin is black. The dermatologist said that I may never get the dark parts to lighten or the white parts to regain their pigment so I am left with ugly legs.

So, I am just writing to say that you should watch what you take for medication from your doctor. EMS is something that few doctors will be able to help because of its complexities. If you find one who will try his hardest to treat it, you have found a gem. I look for articles on the internet and he is very open to reading them and trying new stuff but made a boo-boo when it came to that medication but we didn't think all this time it was that that caused the allergy problem.

I am now off all medications for the eosinophilia and high blood pressure and am taking alternative medications such as antioxidants and vitamins and minerals to cleanse my system of all the drugs. I haven't had a blood test to see if my blood count is back up but I am just feeling good



NEMSN would like to thank the family of Harry Schulte for listing NEMSN as a charity for contributions in his obituary, and to the many family and friends for their generous contributions upon his death. We are such a small group and every little bit helps us to continue our work.

about not putting so many drugs into my system. I still suffer with muscle pain and try to exercise as much as I can but find it difficult. Also, trying to lose 20 pounds but it's hard without exercise.

I know everyone has different problems that go along with their EMS. (it is such a strange ailment) but I am grateful that I finally have a name attached to this and would like to know if anyone else has similar problems. I believe my EMS started in 1981.

Thanks for listening to my problems.

Fern

Editor's Note:

At Thanksgiving time, Fern wrote that her "blood eosinophil count is still almost at normal and it's been a few months now since I stopped the medication so other than the myalgia symptoms, I am doing well".

If anyone wants to contact Fern, you may do so by e-mailing, writing or calling the editor.

High Cholesterol? Problems Taking Statin Drugs?

EMSers, Here we go again!

Wish we could say it ain't so but it is. Many EMSers developed high cholesterol with EMS, mine went from less than 110 to as high as 320. Drs. proscribed statin drugs, mine was Lovastatin, and indeed levels came down. But, and this is a big one, statins can give you a EMS similar disorder with the exact same symptoms including memory loss with very painful muscle and joint pain. FYI: Severe skeletal muscle breakdown is known as rhabdomyolysis. This is so new that it doesn't even have a name but [is] referred to as statin-related muscle toxicity. Maybe like EMS they'll call it a syndrome. And like EMS it seems to go into remission only to return again. My left arm is so sore picking up a pencil is painful. I started the drug last March and stopped on December 12th when I discovered it caused serious side effects. After 4 days off the drug I experienced mania several days and much of the muscle soreness subsided. Unfortunately the mania went away and some pain returned.

The online article stated we should have a blood test done for creatine kinase (CK) as elevated levels strongly indicate the disorder. I was tested 4 weeks after ceasing the drug and my CK level was 280 when 200 should be its maximum. Additionally, Drs. discovered that every muscle wasting disease they had tested showed the atrogen-1 gene had been turned on. Obviously EMSers would make a perfect test group for this. However, after a few emails to Drs. they told me there is no reliable test for atrogen-1 levels and no laboratory performs such measurements. Additionally, atrogen-1 is found IN muscle, and measurements requires a muscle biopsy. All is not lost.

Because of present technology limitations it's premature to do atrogen-1 tests but [they] are a future possibility. You can get a simple CK test and store results in your medical records. Even if you haven't taken an anti-cholesterol drug it could provide important future information. If EMS switched on a gene maybe future research will be able to switch it off.

To read the article go to:

www <http://www.bidmc.harvard.edu/sites/bidmc/search.asp>

Bob Matney

Former President of NEMSN Dies

Joanne Hill-West, a former president of NEMSN, passed away at the age of 61 on February 18th. Apparently, she had been suffering from a severe illness. Joanne Hill, the name by which we knew her from about 1992 through the end of 1996 when she retired from her position as president, is survived by two daughters and three grandchildren, a brother, and other relatives. Joanne was an energetic woman who helped get NEMSN incorporated and well on its path toward becoming a nonprofit organization in early 1996. Although she did not have EMS, Joanne lovingly devoted herself to NEMSN and her "EMS family." A member of NEMSN, Carmela Bottita, appropriately wrote in the online guest book: "Our Prayers are with all of the family. I have EMS. We owe Joanne a great deal. She stood up for us when we could not stand for ourselves. There is another angel in heaven tonight."

Spring Again

Spring shall come again
bringing leaves on the pin oak tree
and greener grass easy on the eyes.

The final snowfall of winter
will melt on nearby hills;
in our hearts will arise
an emotion, sweetly familiar.

Booms of thunder startle
chilled tired nerves; slowly
to a window, a door or a porch
where songs of robins reach
weary ears, we wander.... surprised
to feel a gentle touch of energy.

Not long after, respite arrives carried
on the lingering scent of lilacs and roses
or through children's laughter;
once again we remember
not even dis-ease forever closes
all recollection of beauty, of hope, of Spring.

by Marilyn Faith Rumph
Dumfries, Virginia

Donor Honor Roll

December 2, 2007 through February 27, 2008

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Deborah Rose	In memory of Harry A. Schulte
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Kathleen Quinn

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

NEMSN Contribution Form

Here is my gift to support the work of NEMSN:

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

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

Name _____ Address _____

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

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

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NEMSN Welcomes KETAN G. BHAKTA, MD to our Medical Advisory Council

Dr. Bhakta is an Internal Medicine Specialist. He began treating EMS patients in February 2003 when he assumed the medical practice of Ruth Deerfield, MD. Dr. Deerfield had developed a considerable EMS patient population through her advocacy and willingness to put in the time and energy needed to deal with the mysterious epidemic that emerged into public awareness in 1989 and was later associated with the ingestion of L-tryptophane.

Dr. Bhakta was unfamiliar with the treatment protocols for EMS patients prior to assuming Dr. Deerfield's practice, but he was a quick study and was exceptionally well suited to the task of treating the EMS patient because he has devoted his medical practice to caring for older individuals. For each patient, his goal is the same: a healthy, active life. His focus is on improving function and quality of life. He wants his patients to be able to travel and enjoy life for as long as possible.

The older patient has many potential similarities to the EMS patient. Both patients may present with multiple symptomatic complaints. It takes time, patience and careful listening to tease out the variables contributing to the patient's diagnoses. Dr. Bhakta has an extraordinarily sympathetic ear for his patients and listens to each patient's needs. He also works with family members to coordinate any services that may be necessary.

Dr. Bhakta's clinical interests include diabetes, hypertension, heart disease and dementia. Additionally, he serves as medical director for Manor Care Nursing Home in Fountain Valley, and for Heartland Hospice, in Orange, California.

Dr. Bhakta's professional qualifications include board-certification in internal medicine. He graduated from the George Washington University School of Medicine in Washington, D.C. and he completed his internship and residency training at Cedars-Sinai Medical Center in Los Angeles.

Dr. Bhakta is fluent in English and Gujarati. He is married and has two young boys. He enjoys spending time with his family, running and staying physically active. He plays basketball every Thursday night.

“Friends Supporting Friends”