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National Eosinophilia-Myalgia Syndrome Network, Inc.
http:www.nemsn.org

National EMS Network Newsletter

Points of interest

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- **Your continued donations have kept this Newsletter and NEMSN alive. Please keep those donations coming no matter how large or small. Our thanks.**

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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.**

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- **We are interested in your story. Please take the time to write it and send to us for our newsletter.**

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- **If you have not seen our web site yet, it's improved and holds a lot of information.**
- **CHECK OUT WWW.NEMSN.ORG**

Inside this issue:

What Works?
For Linda Storey it's "Water Water Water, Walk Walk Walk"

In this, our second ***What Works?*** *column, Linda Storey of Cumberland, ME shares how, with tremendous perseverance, she fought through physically and emotionally devastating EMS symptoms, and eventually experienced significant improvement in her health and quality of life. Linda had begun taking L-Tryptophan in October 1989 and had used it only a few weeks, until it was pulled off the market. Here is what she has to say, in her own words.*

When I read the NEMSN newsletter at the 20 year mark I was appalled that so many were still suffering from this debilitating illness. I thought at that time of writing about some of the things that had helped me with the pain, muscle spasms and loss of mobility from EMS. I didn't write then, but with "What Works?" I guess now is the time.

In late '89 to early '90 I became severely ill with EMS. I lost 30-50% mobility over my entire body. The pain was tremendous, with extreme tenderness and constant muscle spasms. I could barely walk. I had trouble with balance and coordination and also suffered substantial cognitive dysfunction. I had lost most of the use of my hands (until Dec. '89 I had been working as a dental hygienist). Now I could hardly write. I had difficulty doing almost anything for myself - I couldn't even tie my sneakers.

I WAS IN TROUBLE.

Thanks to my husband I kept myself walking. He took me out one day in January '90 and we walked up the street for a half mile and back. It took me an hour, but after that I knew I could do it myself. Every day I walked, sometimes twice a day. One step at a time, one foot in front of the other. My family called it my "turtle walk".

The problem was that when I finished my walk I was absolutely exhausted. Exhausted to the point of fatigue. All I could do at that time was to lie down. I found lying on my son's water bed was the best for me. The warmth was comforting and there was less pressure on my body. I would usually sleep for a while until my muscles would protest, and then the muscle spasms would begin in earnest. At that point it was time to soak

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From The Editor

Correction: In our last newsletter we thanked Merzbach Law Offices, P.C. of Albany, NY, for pro bono legal work on behalf of NEMSN. We apologize. Merzbach Law Offices are actually in Rochester, NY. We are sorry for our error and again, we want to thank them for their help. It was very much appreciated.

Thank you to Faith Rumph for her many years of work for NEMSN. Faith recently resigned from producing N Connections. We appreciate all she has done and wish her the best in the future. She will be very much missed.

Doctor's recommendation needed.

Does anyone have a doctor in the Maryland/DC area to recommend for your EMS treatment? Please e-mail or call me with your referrals for us to pass on. We also need doctor recommendations from any part of the country, so if you have a doctor who you recommend for treating you with your EMS symptoms. please let us know their contact information.

Please remember to use GoodSearch.com, GoodShop.com and iGive.com when surfing the web. Use GoodSearch when searching the web and GoodShop and iGive when making purchases online. Type in NEMSN as your charity. So far, since signing NEMSN up on these sites, we have earned $65.93 on iGive and $340.80 on GoodSearch and GoodShop. This money adds up, so please use these sites when possible. We need more supporters to help us earn much needed money. Thanks to all who have used these sites in our name.

Caution: L-Tryptophan products on market may cause adverse reactions.

Tryptophan is legally back on the market in many forms. NEMSN reports that recently a number of different people have contacted us and have told of adverse reactions which they attribute to L-Tryptophan supplements, 5-HTP supplements (which are chemically similar to L-T), or other L-Tryptophan-containing products, since the beginning of last year.

Our Medical Advisory Panel has been monitoring the situation and has asked to be informed if any new cases come along. If you know of anyone who has become sick from taking a product that contains L-Tryptophan or 5-HTP, tell them to save the product and contact NEMSN

Mission Statement

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

What Works? *(continued from page 1)*

in the tub.

Hot water. As hot as I could stand it. I kept the hot water running all the time I was in the tub, usually about two hours. Then I was out and would start the process all over - exercise or movement of some sort, rest (on water), soak in hot water. It was a cycle I followed usually four times a day. (That was eight hours a day of soaking in hot water!! Plus more time sleeping on water.) In February '90 my husband bought us our own water bed.

In spring of '90 I started physical therapy, about three times a week, to try to gain back some mobility. Because physical manipulation hurt so much, the only way I could stand it was to stretch in a warm water pool. Water, especially warm water, became my friend. I was sleeping on a water bed, soaking in the tub, exercising in a warm pool. Eventually I slowed down on the physical therapy and started exercising in a regular pool. This was a major factor in regaining my balance and coordination. Again it was exercise, rest and water that helped.

My final effort was to try and gain back the use of my hands. In January '94 I started making towel paintings. Not an easy chore with muscle spasms but I decided if after all this time I still had to continue therapy I was to do something I really enjoyed. I learned to paint with a wet paper towel in my left hand so I could correct mistakes when my right hand and arm decided to not cooperate and to do their own thing. It took a lot of reconditioning to gain back muscle control, strength and coordination. Fortunately it eventually worked, and I found another hobby.

To this day my husband and I still sleep on a water bed. I can sleep on a regular mattress now but I am always glad to get home, home to my water bed. If I have a day when I have muscle spasms, not often but now and then, the water bed always helps. Eventually we got a hot tub which I still use, although much more randomly now. I continue to exercise, mostly walking. Last September I actually completed a half marathon. Not bad for a sixty-something.

My life today is fairly normal. I pretty much do what I want to do. My husband and I travel, often to the Caribbean or to Mexico. This August we spent 10 days in the Grand Tetons and Yellowstone. We motorcycle, including making numerous long distance trips - from Maine to Tennessee, from Maine to Ohio - from Maine to Canada to Wisconsin to Ohio. A hobby we both enjoy. I work full time, not as a dental hygienist but as an office manager for my daughter's pediatric clinic. I enjoy our three children and their children, our six grand children [three babies since January 2011].

I have been hesitant to write because my life seems so "normal". I almost feel guilty that I came out of this as well as I have. It took years of therapy with lots of intense physical work while I was dealing with tremendous pain but somehow most of that went away. I have no overall pain, take no pain meds. I feel so thankful and so blessed.

Today when I think of my life and my health issues I actually think in terms of breast cancer rather than EMS. (I was diagnosed with breast cancer in Dec. '93 and again in Sept. '98. In Oct. '98 I opted for a bilateral mastectomy and reconstruction.)

Through all of this my faith played a very important part in my healing. There were many that times I didn't think I had the strength to go on. I was too sick, in too much pain, just too exhausted. Those were the times that I just put myself in God's hands. I couldn't do it on my own. He was always, ALWAYS. there.

I hope this will help someone. There really is hope. I was SO SICK yet now my life is so full and so routine. Busy, but routine. My recommendation: Use your faith as best you can - then - water, water, water - walk, walk, walk.

--Linda Storey

...continued on page 4

What Works? *(continued from page 3)*

In a phone conversation with Linda, I asked a couple more questions. I wanted to know if she had found any doctors or health care practitioners who were now or who had been particularly helpful. She said that on the contrary she came up with her own recovery plan. Her primary care physician diagnosed her EMS early on but had little treatment to offer save pain medication (which numbed the pain a little but made her feel "loopy") and prednisone. Linda was sent to a hematologist and she says that the best thing he did for her was to take her off the medication. It was not easy for her to stop taking prednisone because her body had become dependent on it. It look 16 painful months to be weaned off prednisone.

I asked a little bit more about the physical therapy in the warm pool which Linda used to do three times a week. The physical therapist actually got into the pool with Linda, and together they worked on stretching out her body in the warm water.

At present what are the lingering symptoms like for Linda? The symptoms are there, but not as severe as before. For example, in the beginning of EMS she could not tolerate being on a hard floor or surface at all, either standing or sitting. Now if she must sit on a hard chair for any length of time, when she stands up she experiences leg cramping. On rare occasions she also experiences a pulsing in her lower back when she stands up, especially if she is nervous about something.

Linda herself states that the physical pain she experienced while doing her daily exercise routines was extreme, especially at the beginning, and yet she kept on pushing herself. What kept her going? She says that her three children, the oldest of whom was 15, needed her, and she wanted to be there for them.

Heartfelt thanks to Linda Storey for sharing all this with us! It is great to know that she has regained so much of her health and life. It is great to hear about the path she was able to take to get there.

--Lois Vierk, with special thanks to Nancy Grant

PLEASE SEND US YOUR OWN STORIES!

What Works? is a place to share experiences about what works to help relieve EMS symptoms. If there are things you do, routines you follow, treatments you take, etc. that help you, please get in touch so we can write it up here. Reading about what is good for you may help someone else find a way to ease the pain or get through the day better.

We know that the health of different EMS patients runs the gamut from being debilitated and incapacitated, to actually doing quite well. Whatever your condition, we'd like to hear from you.

Of course it's true that what's good for one person may not be appropriate or helpful for another, and NEMSN does not recommend anything in particular for a given individual. However, if you've found something that works to help you, please send us a letter (NEMSN, c/o Lois Vierk, P.O. Box Monitor 4171, West New York, New Jersey 07093) or an email (elveevee@aol.com). If it's too much for you to write out, let me telephone you, we can talk it over, and I will write a draft of your story. My phone number is 201-868-9572.

This forum will not focus on medicines or the like. You're welcome to write to us about this topic too, but send it as a Letter to the Editor. *What Works?* will not be a place to advertise a particular product of any sort, though it's fine to mention products that you use.

Please get in touch and share your own story.

Post-Epidemic EMS Case Documented:

Patient Became Sick in 2009 from Current L-T

In November 2011 the medical journal *Arthritis & Rheumatism* published the article "Postepidemic eosinophilia-myalgia syndrome associated with L-Tryptophan" (Volume 63, Issue 11, pages 3633–3639). This is the case report of a 44 year-old woman who began taking L-Tryptophan daily in January 2009. She took a product called "Uber Rest" distributed by Heartland Products. By August of 2009 she exhibited full-blown symptoms of EMS including severe myalgia and weakness, swelling and edema, and various progressive skin symptoms. Her eosinophil count was extremely high.

Possible causes of the patient's EMS other than ingestion of L-Tryptophan were ruled out. The L-Tryptophan was tested. Contents of the particular bottles that the patient took were not available, but samples from the same batch were. Testing revealed no impurities. (NEMSN notes that the toxin that caused EMS in the original 1989-90 EMS outbreak has never been identified.)

In closing their report, the authors state: "The present case should raise awareness for the potential for occurrence of EMS among L-TRP (Note: this is the abbreviation used in the article for L-Tryptophan) users two decades after the epidemic outbreak, and prompt continued efforts to identify the causative agent for this devastating syndrome."

The abstract of this article, "Post-epidemic eosinophilia-myalgia syndrome associated with L-Tryptophan", by Jeffrey A. Allen, Alicia Peterson, Robert Sufit, Monique E. Hinchcliff, J. Matthew Mahoney, Tammara A. Wood, Frederick W. Miller, Michael L. Whitfield, John Varga can be found online at http://onlinelibrary.wiley.com/doi/10.1002/art.30514/abstract

The full article may also be purchased at this web address.

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Bid adieu to achoo: finding relief from spring allergies

(ARA) - For many, spring signifies the budding of flowers and longer days filled with warm sunshine. But for one in five people, spring also means allergies are in full swing.

Allergies, which affect an estimated 60 million people in the United States both young and old, can really take a toll on your daily routine, and they are a nuisance both in the daily life and professionally. Whether you're affected year-round or during a specific season, learning how to manage allergy symptoms can be vital to restoring your comfort and quality of life.

"There are a number of very effective over-the-counter treatments to address the symptoms of seasonal allergies," says Dr. William Berger, professor of allergy and immunology at the University of California, Irvine. "In fact, to help patients save money, I would recommend many of the store-brand, non-sedating antihistamines sold at leading retailers and pharmacies, such as Cetirizine or Loratadine. These products are approved by the FDA, but cost significantly less than the brand names."

According to Berger, many allergy sufferers may find better relief of their symptoms by trying one of these newer, more effective treatments now available in the aisle, like Fexofenadine, which just switched from prescription to over-the-counter in 2011

NORD Meeting in NYC Area

By Lois Vierk

Editor's Note: For a little over a year now NEMSN has been a member of NORD, the National Organization for Rare Disorders. As stated on NORD's website www.rarediseases.org), the "National Organization for Rare Disorders . . . is a unique federation of voluntary health organizations dedicated to helping people with rare 'orphan' diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service."

A rare disease is defined as one that affects fewer than 200,000 people, so EMS definitely qualifies. NORD's membership is comprised of over 160 patient advocacy organizations.

On December 2, 2011, NORD held a regional meeting at the Sheraton Hotel in Weehawken, NJ, right across the Hudson River from New York City. The location was just about 2 miles away from where one of our board members, Lois Vierk, lives. Lois attended the December 2 event and offers the following report.

There were about 34 rare disease patient advocacy organizations represented at the meeting. They ranged from relatively large groups like the Hemophilia Federation, to much smaller organizations serving those with diseases like dysautonomia, Mobius syndrome, Sturge-Weber, oxalosis & hyperoxaluria, Shwanchman Diamond Syndrome, to name a few. One of the organizations represented a disease affecting fewer than 200 people worldwide. For the first time in my life with EMS, I didn't feel out of place talking to strangers about Eosinophilia Myalgia Syndrome -- I was one of the group!

There were a number of speakers and presentations during the day. Peter Saltonstall, CEO at NORD and former hospital administrator, spoke of how NORD has plans to help organizations without patient registries to develop them. NORD plans to work on this project during 2012. (This got my attention. EMS has no patient registry. To form one, data would be collected from EMS patients who chose to join. All data would be "de-identified", meaning that no particular answer to any question could be attributed to any particular person responding.) Saltonstall said that having a registry makes it more likely that further medical research on a disease could be done. Without a registry, researchers almost automatically turn away because there is too much background work to be done before the research itself can happen. Saltonstall spoke of quite a few other matters, as well. For example, the issue of gaining access to experimental drugs and treatments is an important one for some of the other rare disease organizations. Saltonstall spoke of how NORD lobbies on Capitol Hill for various programs on behalf of its member groups.

Another major speaker was NORD Medical Officer Tim Cote. He is an epidemiologist and has worked at the CDC and FDA. He spoke of various agencies, besides CDC and FDA, which are under the US Department of Health and Human Services. He also emphasized the benefits of patient registries. When an organization has one, it is easier to connect patients with new therapies and with clinical trials. After Cote's talk I went over to speak personally with him. It turns out that he has been familiar with EMS ever since the 1989-90 outbreak. He has co-authored medical articles on EMS, the most recent of which was published in 2005. Tim Cote knows Dr. Edward Belongia, epidemiologist on our Medical Advisory Panel.

There were other presentations on topics like organizational development, community outreach, new kinds of software and social networking.

Of all I heard that day, the idea of a patient registry for EMS seems most applicable to us, most important to EMS patients. I recently phoned NORD and spoke with a staff member. She relates that NORD is planning now how to best assist groups like ours to develop registries or other types of data bases that would be useful to potential researchers. Hopefully methods will be in place later this year. NEMSN actually has a very good starting point for developing a data base, namely the 1999 survey of EMS patients, which some of you may have participated in, and the survey report authored by Karen Tonso, Ph.D. Tonso presented this paper formally at the October 2004 NIH workshop on EMS in Bethesda, MD.

NEMSN is keeping in touch with NORD as well as looking at other possibilities for developing a registry or the like. We'll let you know what we find out and how we can work together. Stay tuned!

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May 16, 2010 through August 2011

Editor's Note: A person's name will be listed every time they donate. Thank you for your continued support.

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