



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.**
- **Volunteer Application Please take the time to fill it out if you are able to give the gift of your time.**
- **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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Message from your President

Another year ends, a new year begins. As President of NEMSN I would like to welcome you to our first new issue of 2006.

To recap 2005, we have undergone many changes and devoted many hours to bring new and informative articles to you, our members.

A new revision of NEMSN bylaws and a Volunteer Application follow in this issue.

We have also brought back comment and question areas for those wishing to ask about specific areas you may be experiencing, and wish to share or have email contact about. For privacy reasons, please use an anonymous email address, if wanted, in the newsletter. For those with internet service please email comments or subjects to our new editor, Sandy at: NEMSNnewseditor@gmail.com or for those without internet service, to myself at: NEMSN President, PO Box 3016, 155 Delaware Ave., Lexington, Ohio 44904-1212.

We will make certain that requests or contact information for you will appear in the following newsletter. Names will be OMITTED unless otherwise requested. In 2005, we have also lost some board members due to retirement or other avenues in their personal lives.

In Honorable mention and Thanks :

Julie Allender - Our Volunteer Coordinator- Her practice is taking up much more of her time and energy than thought.

Rhonda Farro - Who worked closely with our volunteers.

Nancy Grant - A current Board member in Medical Research but possibly will be moving into Fund Raising.

Joe Hayes, Our past newsletter Editor who's personal business has taken off and we congratulate him on his personal successes.

For an organization maintained only by EMS sufferers and/or family members,

I feel we are doing an outstanding job. Even though as we all know, new recruit volunteers are ESSENTIAL to maintain and grow. I would like to ask for anyone who may have a few hours or more per week to make use of the volunteer application inside and become a volunteer. We can only continue with your individual assistance.

I personally find it a health benefit to reach out in support as well as keep busy. Volunteering is a very helpful solution to boredom or the feeling of being unneeded. Friends Supporting Friends is a good motto.

We are currently gearing up for our new year elections. We will have a brief personal info section of each candidate for selection and need nominations. Ballots will be forthcoming so please send or email your choices to our Treasurer - Michael Bird, when received.

We have also found a few ways of cutting expenses. Changing our board

Continued next page...

**National
EMS Network
Newsletter**
Published by

The National EMS Network, Inc.
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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.

From your President (Cont'd)

conference call company as well as finding a new print service for our newsletters. Every little cut helps and we appreciate your continued donations in making our endeavors meet your expectations or needs.

Please let us know things you would like to read about and we will make every attempt to bring it to you. Personal stories are appreciated along with helpful suggestions on what has helped you. Exercises that we can manage, healthy eating, ways of doing things around the house or work that has helped, etc.

This new year is dedicated to you, our members. I look forward to this year as President in maintaining NEMSN with quality and growth, support and closer friendship with all.

Comments and Suggestions always welcome.

Cordially,



NEMS2005@aol.com
www.nemsn.org

**Smiling
will help
you feel
better.**



Request for Contact

We hope to have this column in every issue of the newsletter. If you have the desire to hear from others regarding EMS info, other health info or just need to hear from others about a problem you are experiencing, e-mail the editor with your question/request and let us know if we may use your name or just your e-mail address.

detroittiger552@hotmail.com would like to hear from anyone that has had or is contemplating gastric bypass surgery.

q2jonmypo6@yahoo.com in Pleasant Grove, Utah is seeking the name of a caring doctor "who knows something about EMS" and who will be helpful and supportive. Does anyone out there know the name of such a doctor in her area?

Verna Hyde is recovering from breast cancer surgery and would welcome your thoughts and prayers.

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.

DISCLAIMER

The NEMSN 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 & not necessarily those of the NEMSN Board of Directors or its committee or sub-committee heads, nor of the Editor. Information is intended merely to inform readers. Drugs & treatments & legal issues should be discussed with readers' own physicians & attorneys.

By-law Amendments

The following amendments to the by-laws have been adopted by the board and need your approval. The approval form is on page 5 along with the ballot for the board of directors. You may send it back in the donation envelope, along with any donation you care to make. If you would like, you may e-mail your vote to Jann Heston at NEMSN2005@aol.com.

Amendments to the By Laws of NEMSN were proposed by Sharron Lobaugh and Jinx Engstrom and voted upon favorably by the NEMSN Board of Directors in October 2005. The entire text may be obtained by contacting the President. The approval form is on page 5, along with the ballot for the board members. You may include it with any donation you might make, in the donation envelope or send it to

In summary, these are the changes:

Article IV "Board of Directors, section 2 a: Officers the following was added: *"The Officers are elected annually from among the members of the Board of Directors."* Section b: was amended to read: *"The Board elects officers annually before the end*

of the first quarter of each new year following the annual election of board members." The time of election of officers was amended in Section c. *"Officers assume their official duties following the close of the meeting at which they are declared elected and will serve for one year and may be re-elected."* Section 3 Removal of Board Members the following was added: *" b. Non attendance at three regularly scheduled or called meetings of the Board of Directors in a year shall constitute a resignation."*

To Article V, Election. Section 1.Nominating Committee, subsection "a" the words *"shall be appointed by the President"* were added and a new subsection d: *"The President may recommend nominees to the nominations committee but does not serve on the committee."* Persons running for office are asked to submit a statement *"not to exceed 100" words.* in Section 2 subsection c.

To Article VI Duties of the Officers, Section 1. President the words *"is responsible for official correspondence"* were added to his/her duties. And under Section 4, Treasurer sub-part b was deleted.

Article VII Meetings, Section 2. Annual Meeting was changed to: *"The annual meeting is the last meeting of the sitting Board of Directors before the official election of new board members and new officers. The annual meeting is generally before the end of the first quarter of each new year. The annual meeting may be held by telephone conference call."* Subsection b. was clarified: *The purpose of the annual meeting is to provide members a summary of the annual President's report; set goals and policies for the coming year; announce the results of the election; and to carry out any other business to come before the Corporation.* Another subsection was added: *c Members who are not board members wishing to participate must give their telephone numbers to the Recording Secretary at least two days prior to the meeting. The Corporation may bear the cost of the telephonic hookup for all members who desire to participate".*

Article VIII. Committees was amended by adding: Section 2 Special Committees b. Audit: *The board of directors shall appoint or select an auditor when the office of the treasurer changes hands.*



I agree _____ I disagree _____ with the amendments to the bylaws of NEMSN as presented in the Feb. 06 NEMSN Newsletter.

Name: _____

Address: _____

City: _____ State: _____ Zip: _____ - _____

E-mail address: _____

Please return in donation envelope or e-mail vote to Michael Bird, Treasurer

Meet your new editor

Hello to all my fellow EMS survivors.

My name is Sandy Kintz and I live in Lorain,

Ohio. I am a retired registered x-ray technologist of 42 years, past classic bowler and bowling instructor, past newspaper sports columnist for our local newspaper and vocalist for local bands for many years. I also played ladies softball as a catcher and coached the girls softball program for the city I lived in at the time.

I was a registered x-ray technologist and physician's office manager when EMS hit me in the fall of 1989. L-tryptophan had been prescribed by the Cleveland Clinic for my fibromyalgia. It started out with severe pain in my left back and shoulder blade area and then progressed to a severe lung infection, muscle aches, spasms, and being so tired I could hardly function. The worst part for me was the hair loss. I had very thick hair and it has never come back as thick as it was pre EMS. Vanity, thy name is woman.

I hadn't been paying any attention to the TV news, so didn't know about the epidemic. My daughter saw the story on TV and told me to get off the L-tryptophan right away. I thought she was crazy and didn't do it until I kept feeling worse and one of our patients told us about someone she knew that had the problem.

I talked to my boss right away and she told me she was sure it wasn't that, but she would draw blood and do the tests just to make me feel bet-



ter about it. Surprise, I did have it and she immediately called the CDC and the FDA. I was the 3rd person diagnosed in Ohio according to them. Her husband was also on L-tryptophan but he didn't get EMS. He was one of the lucky ones.

I went to the Cleveland Clinic and had muscle biopsies by a rheumatologist named Dr. Wilke. Except for steroid injections in my back when I was first diagnosed and antibiotics and steroids because of my lung symptoms, I have taken no drugs for my EMS. I have just lived with the symptoms. I ended up with cognitive problems and couldn't read for at least two years, as I couldn't make sense of what I was reading. I still get pain over my shoulder blade area and spasms in my hands, back, legs, etc., but am able to read again, which was a big thing for me as I was and am a voracious reader.

The physician I worked for told me to keep a diary and to make sure I rated my pain and symptoms on a scale of 1-10 every day. She further told me to make sure I saved my remaining pills. Thanks to her advice, Showa Denko settled with me very early on.

My life has changed a lot since the onset, as I am sure has all of yours. I used to walk 36 holes of golf a day, carrying my bag. Now I am lucky to ride 18. Before EMS I played volleyball twice a week, racquet ball and ran at least a mile a day. Now I have so much muscle weakness that it is hard to do a lot of things that I did before, especially exercise. I am retired from x-ray and now do freelance medical transcription, a job where I

am able to sit down instead of being on my feet all the time.

I have many years experience doing newsletters for other non-profits, such as nursing homes and women's groups and am a past board member of the local American Cancer Society and past president of F.A.C.T., which is a non-profit group to help cancer patients. At this time I am past president and also president again, of a non-profit women's group in Tiffin, Ohio, that helps the local YMCA. For the past nine years I have been the co-chair of a 200 booth bazaar that earns about \$11,000 to \$12,000 each year to donate to the YMCA for scholarships, or any needed items such as exercise equipment, things for child care, etc.

This is the largest newsletter I have ever undertaken, and am excitedly looking forward to working with the board and hopefully, to do as good a job as Joe has done for the past eight years. His are big shoes to fit into, but I will try my best.

You may notice the numbering of the issues has changed. The board members have decided to bring the numbering back to the way it was in the beginning, so this Volume will be Vol.16 for the 16th year and the No. will be 1 for the first issue of the 16th year.

Here's to a healthy and happy year for all of us.

Sandy Kintz

Sandy Kintz
Newsletter Editor
NEMSNewseditor@gmail.com

Below is a volunteer application and ballot that may be used to re-elect board members. Please fill out application if you are able to share of your time with NEMSN. When finished, ballots/application may be sent back to NEMSN in the donation envelope, along with any donation you may/may not make or you may e-mail them to Michael at popsies@aol.com.



NEMSN Volunteer Application

_____ A) Serving as one of nine members on the NEMSN Board. The board meets ten times/year via teleconference. Positions on the board include it's officers, newsletter, web site, medical research, public relations and special projects. (OR)

_____ B) Serving as a support person by participating in e-mail groups or listing as a contact person on our web site NEMSN.org.

Experience: _____

Thank you so much for your willingness to share your time with NEMSN. You will be contacted by one of our officers within the next month.

Name: _____

Address: _____

City: _____ State: _____ Zip: _____ - _____

E-mail address: _____

Ballot

*** I choose to affirm the election of NEMSN Board members**

_____ Jinx Engstrom (Jinx is from Minn. and has been a board member for five years. She is running for Vice President and she serves as Web Administrator)

_____ Michael Bird (Michael is from Virginia and has served as Treasurer for the past four years)

* Note: there is one current vacancy on the Board of Directors. Director Robin Burkin has declined to run for this term. She still remains the NEMSN webmaster. Needed positions are possible Med/Res/Dir and Volunteer Coordinator. Other volunteers needed for med/res/assistance, NEMSN Connection e-mail assistant, contact persons for various regions of the U.S., writers for articles or short columns in newsletter, various topics.

2005 NEMSN INCOME AND EXPENDITURES FINAL REPORT

INCOME		\$ 493.87*	Other	----
CHECKING ACCOUNT	SAVINGS ACCOUNT	\$4,699.21	TOTAL EXPENDITURES	----
\$2,670.40	1/1/2005 Carryover			
\$3,798.00	2005 Contributions			(* Other includes tax preparation, domain registration, supplies, postage and incidentals. All expenditures make from the NEMSN checking account)
----	2005 Interest	\$ 59.49		
\$6,468.47	TOTAL AVAILABLE	\$4,530.80		
(total NEW income generated in 2005.....\$ 3,857.49)		INCOME AVAILABLE FOR 2006 AS OF JANUARY 1, 2006		
(total income available for 2005).....\$10,999.27)		Total Income Available for 2005	\$10,999.27	
		Total 2005 Expenditures	\$ 4,699.21	
		Balance as of January 1, 2006	\$ 6,300.06*	
EXPENDITURES		(Balance includes \$4,530.80 in savings and \$1,769.26 in checking. Of the amount in savings, \$2,470 is earmarked for MDL deposition.)		
\$2,704.62	Newsletter	----		
\$1,500.72	Board meetings	----		

L-Tryptophan Plaintiffs' Expense Fund Update

Dear EMS Members,
I have received verified notification of the MDL refunds. Please contact YOUR personal attorney for verification of your name and address information. In the event, ONLY, that your attorney can no longer be reached, please contact me at NEMSN2005@aol.com, Attn: Jann-MDL, and I will be happy to provide you with the information for reaching the S.C. attorney, Tom Rogers.

Not everyone who filed a claim is eligible for this refund, so please make certain you are before contacting the attorney or me. "The fact that an individual pursued and settled an L-tryptophan claim does not necessarily establish their eligibility; they need to be on the trustee's list as a contributor to the fund."

For more information, check our website at www.NEMSN.

The following contains excerpts from a letter sent to one of our EMS friends. It explains how to get reimbursement of your money if you contributed to the L-tryptophan Plaintiffs' Expense Fund (MDL).

Sincerely,



Jann

"On December 7, 1990, the Judicial Panel of Multidistrict Litigation ordered the transfer of all L-tryptophan products liability claims filed in various federal courts to the United States District Court for the District

of South Carolina under the supervision of the Honorable Matthew J. Perry for coordinated and consolidated discovery pursuant to 28 U.S.C. & 1407. Since that time, more than 1400 individual plaintiffs' claims have been prosecuted in the L-tryptophan MDL. Although the bulk of these claims were resolved within the first five years of consolidation, additional claims continued to arise with gradually decreasing frequency until 2004 and the last remaining claim was settled earlier this year.

At the present time, there are no pending claims in the L-tryptophan MDL and we do not believe there is any reasonable likelihood of additional filings. Consequently, Judge Perry has authorized Plaintiffs' Steering Committee to begin the process of returning the remaining principal in the L-tryptophan Plaintiff's Expense Fund trust account to the plaintiffs who previously contributed to that fund and their counsel.

The L-tryptophan Plaintiffs' Expense Fund was created in 1991 as an IOLTA trust with the interest accruing to the benefit of the South Carolina Bar. Each existing and later-filed plaintiff contributed \$1,000.00 to this fund as a front-end payment, which was eventually credited against a back-end assessment of 0.5% (one-half of one percent) on each settlement for common discovery expenses. Plaintiffs whose confidential settlements were greater than \$200,000.00 had their back-end assessment reduced by the amount of their front-end payment; plaintiffs whose confidential settlements were less than \$200,000.00 received a

partial rebate of this front-end payment.

At the outset of MDL, all members of the PSC agreed to seek reimbursement solely for common discovery expenses and to forego "common benefit" attorneys' fees. As a result, despite the historically low assessment, the L-tryptophan Plaintiffs' Expense Fund currently contains approximately \$550,000.00 in unused principal.

Due to defendants' confidentiality concerns, the specific settlement amounts and common fund assessments for each plaintiff are known only to the trustee. However, neither the trustee nor the PSC has been provided with contact information for the individual plaintiffs. Consequently, we must rely on the plaintiffs' attorney service list to notify plaintiffs' counsel and their clients of these reimbursement procedures.

The remaining principal in the L-tryptophan Plaintiffs' Expense Fund will be refunded on an appropriate basis as approved by Judge Perry to those plaintiffs who previously contributed to that fund and their counsel."

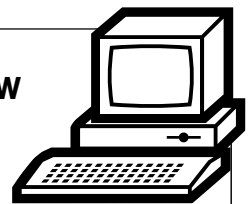
Join our new e-mail list

["The NEMSN Connection"](#)

You may use your first name, first and last name both, or you may use a pseudonym for your ID. It doesn't matter which name you use. List up to four personal interests and include your valid e-mail address.

Please JOIN and get connected.

NEMSN2005@aol.com



Donor Honor Roll

August 16, 2005 through January 31, 2005

Contributors \$5 - \$49

Allison J Adler
 Betty L. Boczar
 Dorothy H. Caviness
 Helen Clemons
 James A. Green
 Gloria Griffin
 Katherine Horton
 Verna M. Hyde

Caolyn Kee
 Michael Lawson
 Carol Loree
 Peggy Morat
 Andrea Nellius
 Natalie Nixon
 Barbara Proehl
 Marilyn A. Rizzardo

John R. Rookey
 Carolyn Roth
 Angela Selbach
 Ann Shewcraft
 Cris Swanson
 Mike Vitolo
 Mary Ann Wellard
 Ruth Yansick

Contributors \$50 - \$99

Barbara Gartner
 James P. Haire

Robert Billings Newkirk, III
 Judy Paulsen

Joseph J. Pitonak
 Gwen Y. Smith

Contributors \$100 - \$249

Virginia R. McCarty
 James & Vicki Norris

Deborah Rose
 Kathleen Sobolik

Bernadette Zigalo

Contributors \$250 - \$499

Kathleen Quinn

Contributors \$500 - \$999



 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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