



National EMS Network Newsletter

YOUR ATTENTION SOUGHT AND PARTICIPATION WANTED AS 2020 COMMENCES

by Michael Bird

This newsletter seeks your participation in important matters that affect NEMSN's operations. First, you have the opportunity to elect individuals who will serve as members of our Board of Directors (see page 2). Second, you have the opportunity to vote for or against NEMSN by-law changes recommended by the Board of Directors (see pages 2 and 3). Third, our occasional request for contributions to keep our organization humming is made below (page 1). Finally, alternative means for receiving NEMSN newsletters and correspondence are discussed below.

EVERY DOLLAR COUNTS. MORE DOLLARS NEEDED. To be blunt, a contribution from you in any amount would get NEMSN off to a good financial start in 2020. The organization intends to publish newsletters more frequently and continue with updates/improvements to our website. Basic operating costs, interaction with our medical advisors and conduct of our periodic meetings also dent our organizational checking account. We enter 2020 with slightly more than \$3,400 in the bank. That makes us a small, yet effective, prudent and active entity. That amount, however, probably limits just how much we can do. Be as generous as possible for every dollar you contribute is wisely applied and is acknowledged with a handwritten thank you and receipt.

Recent Contributors: \$1-\$99: ALISON ADLER, DR. EDWARD BELONGIA, JEAN KINSELLA, SUSAN LUTTRELL (in honor of Nancy Campbell) AND ERNEST & NORA VIERK.

Recent Contributors: \$100 or more: MONA ROBERTS AND BERNADETTE ZIGALO

Please make a contribution today. All you need to do is write out a check and send it to the address on the form at the end of this newsletter. It's that easy!!!

NEMSN'S ANNUAL MEETING. It will be conducted on Sunday, March 15 at 7:00 p.m. The meeting will be held via conference call. Any member who would like to participate should indicate so on the form at the end of this newsletter. Board of Director election results and by-law change votes will be announced at the March meeting. Other business will follow.

MORE COMMUNICATION OPTIONS FOR YOU. For the most part, NEMSN newsletters are mailed to members. Some have individually requested they be sent electronically. So, if you would prefer to receive NEMSN newsletters and other communications electronically (or electronically and by mail), please send a note to us through NemsnTalk@aol.com (see form at the end of this newsletter).

The electronic option will obviously help save money so we can continue to send our newsletter to those wanting current information on EMS and related health issues. The most recent newsletter cost about \$1,300 in printing and mailing costs. This was higher than normal because with the recent passing of board member Sandy Keating, we lost our long-time layout person and had to rely on the printer for layout work. If you don't have an email we will gladly continue to mail copies to you. And a friendly reminder: all NEMSN newsletters from the most recent back to 2006 are accessible on NEMSN's website.

2020 ELECTION FOR THE NEMSN BOARD OF DIRECTORS

There are five seats on NEMSN'S nine-member board due for election in 2020. In our December 2019 newsletter, we asked that any individuals interested in serving on our Board acknowledge their interest and submit a short bio for your consideration. The following three individuals have expressed interest in serving a term that would extend from 2020 to 2024 (if by-law changes on next page are approved; if not, then the term of office is 2020-2022).

MICHAEL BIRD

For a decade and a half, I've had the honor of serving as a NEMSN board member and as its Treasurer. Keeping the lines of communication open and updated among all victims, families, friends and medical providers is key. Providing access to all pertinent medical research completed and pending is pivotal. And having NEMSN serve as a resource for those experiencing EMS-like symptoms remains an essential activity. I'd like to continue these activities and make whatever contributions I can as the spouse of an EMS survivor, Dayna Tolley, and on your behalf. Thank you.

NANCY GRANT

To serve on the NEMSN Board is a privilege. EMS is a rare and nearly forgotten disease/syndrome. This very small organization provides an essential role in connecting new and old EMS patients with their community, resources, and information. I became a member of the NEMSN Board sometime in the early years of 2000 after attending the NEMSN San Diego Conference in California. Over the years I have worked on many newsletters, either writing for them or editing the words of other authors. I would like to continue to serve NEMSN in this way.

LOIS VIERK

I've been honored to serve as a Board member for about 12 years and as President since 2017. Facilitating communication and information flow among EMS patients, Medical Advisors and Board members has been a rewarding duty. Life with EMS is very tough for many of us, long-time members and new patients alike. We're fortunate today because after many years there's meaningful research on EMS and toxins that cause it. Perhaps we can dare hope for expanded treatment options, for more understanding by doctors, and for prevention of new cases. I'd like to continue on the Board to help achieve this.

***PLEASE COMPLETE THE BALLOT THAT IS FOUND AT THE END OF
THIS NEWSLETTER AND SUBMIT BY FEBRUARY 20, 2020.***

RECOMMENDED CHANGES TO THE NEMSN BY-LAWS

During 2019, the NEMSN Board of Directors did a thorough review of its by-laws. This was the first comprehensive review carried out in nearly two decades. The review resulted in several recommendations detailed in the December 2019 NEMSN newsletter. The Board sought comment and suggested edits/further changes from the NEMSN membership. That done, it is now time for you to vote on the recommended by-laws modifications. The recommended changes are:

1. Add **"maintenance and updating of an organizational website"** to the stated purposes of NEMSN. There is no mention of this activity in the current by-laws.
2. Add **"persons with or without an EMS diagnosis and having EMS-like symptoms and medical issues from having taken L-Tryptophan, 5-HTP and/or Melatonin"** to the list of individuals who can be members of NEMSN and those who are served by the organization. Current by-laws allow only individuals with an EMS diagnosis, their family members, caregivers and significant others as well as professional persons engaged in treatment, research and legal issues connected with EMS to be members of and served by the organization. In recent years, NEMSN has been contacted by numerous individuals who report an EMS-like condition after taking current supplements, but often the patients cannot find a physician who knows enough about EMS to diagnose.
3. Change the grandfather date for qualifying for NEMSN membership via receipt of the organization's newsletter from January 1, 2000 to **"January 1, 2020."**

4. Change the terms of office for membership on the NEMSN Board of Directors from an unlimited number of two-year terms to a **“maximum of three four-year terms.”** This maximum number of terms could be waived if there are insufficient numbers of candidates for vacant Board positions.
5. Change the frequency of Board meetings from 10 per year (July and December excepted) to **“one meeting each quarter of each year”** (or a minimum of four). Approving this change would keep the current March annual meeting and it would retain Board authority to call additional meetings as needed.
6. Change the distribution of NEMSN's assets should dissolution occur to **“The National Organization for Rare Disorders (NORD) and the American Partnership for Eosinophilic Disorders (APFED).”** Current by-laws name The National Arthritis Foundation, The Scleroderma Foundation and the Chronic Fatigue Syndrome Association, organizations with which NEMSN does not interact today.

PLEASE COMPLETE THE BY-LAWS BALLOT THAT IS FOUND AT THE END OF THIS NEWSLETTER AND SUBMIT BY FEBRUARY 20, 2020.

NEMSN MEMBER RESPONSE FORM

1. **BOARD OF DIRECTORS ELECTION.** (You have the option of voting for up to three candidates. Please circle the names of those you vote for.)

Michael Bird

Nancy Grant

Lois Vierk

2. **NEMSN BY-LAWS CHANGES.** (Please circle your preference.)

YES

NO

ABSTAIN

3. **PREFER TO RECEIVE NEMSN NEWSLETTERS ELECTRONICALLY?** (Please circle your preference.)

YES

NO

(IF YES, PLEASE ENTER YOUR NAME AND EMAIL ADDRESS _____)

4. **WANT TO PARTICIPATE IN MARCH 15, 2020 NEMSN ANNUAL MEETING?** (Please circle your preference.)

YES

NO

(IF YES, PLEASE ENTER YOUR EMAIL ADDRESS AND/OR PHONE NUMBER SO WE CAN CONTACT YOU WITH CALL-IN INFORMATION _____)

5. **WANT TO MAKE A CONTRIBUTION TO NEMSN?** (Please circle your preference.)

YES

NO

ONCE YOU HAVE COMPLETED THIS FORM, PLEASE MAIL TO:

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315 West Kirkwood Avenue, Apt. 403

Bloomington, Indiana 47404

OR EMAIL YOUR RESPONSES TO #1, #2, #3 AND #4 TO: ***NemsnTalk@aol.com***.

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