



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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New Medical Advisory Council

By Lois Vierk

The Board is pleased to announce that NEMSN will soon have a Medical Advisory Council again. So far three doctors who are known as EMS researchers, namely Edward Belongia, M.D., Luis R. Espinoza, M.D. and Gerald Gleich, M.D., have agreed to be on our council. We hope to add at least one other doctor to this distinguished list, a clinician from California who regularly sees EMS patients. The Medical Advisory Council is meant to be a resource for NEMSN to call on for information and advice.

Dr. Edward Belongia is Senior Epidemiologist/Director of the Epidemiology Research Center, Marshfield Clinic Research Foundation in Marshfield, Wisconsin. According to the center's website (<http://www.marshfieldclinic.org>), "Epidemiology research focuses on population health issues. The Marshfield Epidemiology Research Center emphasizes consequential epidemiology – applied research that has a positive effect on public health and disease prevention." Dr. Belongia lists antibiotic resistance, vaccine-preventable diseases and tickborne diseases as among his current interests. In 2004 Dr. Belongia received a \$1 million award from the Centers for Disease Control for a study of influenza vaccine effectiveness.

NEMSN vice-president Jinx Engstrom writes of Dr. Belongia's early work with EMS patients as follows: "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 it was determined, he was generous to our support group. When he was presenting information at the University of Minnesota for medical staff, he allowed us to come too. So we were in on what was known early on in the epidemic. He was also very patient to explain things in terms we could understand."

Dr. Luis R. Espinoza is Chief, Section of Rheumatology, Department of Medicine, at Louisiana State University in New Orleans. He has treated many EMS patients. He has written research articles on EMS which have been published in various medical journals.

Dr. Espinoza's excellent article "Eosinophilia-Myalgia Syndrome--Long Term Complications" on our website (<http://www.nemsn.org/Articles/Espinoza2.htm>) is well worth checking out. In this article Dr. Espinoza first gives an overview of characteristics of patients who died in the 1989 epidemic. He then summarizes several articles from the mid 1990s, authored by various researchers, on long-term complications associated with EMS. He concludes that "EMS is a chronic multiorgan system disorder associated with significant morbidity, and disability - both physically and emotionally."

Dr. Gerald Gleich is recognized as one of the world's foremost experts on the eosinophil and on eosinophilia of all sorts. From 1965 to 2001 he

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From the Editor...

Dear Members,

I don't mean to harp on the same thing all the time, but another mailing of the newsletter has gone out and with it the extra cost of returned newsletters and address change cards. In one day I received a bill from the post office for \$27.06 for these address changes and for returned newsletters. Four days later, another \$10.00. It really adds up and worst of all, people don't receive their newsletters.

PLEASE!!! If you are moving or know someone with EMS who has moved, send us your/their new address, or you may call any board member to update your/their information. Their phone numbers are on the left of this column. That way, we won't get charged for a change of address card from our postal carrier, or worse yet, lose track of you because the forwarding order has expired. There are few of us as it is, and we don't want to lose track of each other. You can help to keep our costs down so that we can continue to serve our members.

I also had e-mail newsletters come back because the persons had opted for the e-mail version and then changed their e-mail account without letting me know. We want to do a good job for you so If you don't want to miss an issue, please keep your information updated.

I want to thank Faith Rumph for taking over the NEMS Connections List. She is doing a great job getting it going strong again.

We have recently welcomed a couple of new members, who just discovered NEMS on the web. One of the people was diagnosed very early

on in the epidemic, sued and won a settlement, and had never heard of us until a friend found our web site. She has submitted a question in our Request for Contact column.

Their stories have so much in common with many of our other members. They will be writing them down for future newsletters.

On another note, spring is finally here. I, for one, am really tired of SNOW and COLD weather. Maybe we will all feel a little better now that we are seeing spring flowers, green grass, buds and leaves on trees, and feeling the warmth of the sun instead of looking out at a frozen wasteland and having snow and sleet hitting us as we in the north have had all winter. It is hard not to feel blah when it is dreary and cold outside, but with the weather change, hopefully our health will change and we will all feel a little better. I hope you all have a healthy, happy and nice summer.

Sincerely,

Sandy Kintz

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. NEMS 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 NEMS Network 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 Network 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.

Request for contact...

I have a question maybe someone can answer for me. Last March, I was hospitalized with acute pancreatitis with a pseudo cyst. Not being the typical pancreatitis patient, I was wondering if there were other cases of pancreatitis in the group with EMS. No, I am not saying this is the cause or anything like that but I am curious. I had to have 80% of my pancreas removed at Duke University Hospital in November and am still in recovery, getting stronger but they keep telling me with time.

Sincerely Yours,

Sandi
skc792@mchsi.com

From Verna Hyde, whose story was in a recent newsletter.

I would like my fellow EMS people to know that my cancer came back in small spots, and it devastated me so badly.

When I wrote asking for phone calls I received some calls and some of these people, particularly one lady, called me and has become a dear friend. She and another EMS lady prayed for me before my last exam and to my surprise I became much better. My cancer "hot spots" dropped from 17 to 7.

I just wanted to say I realize how important the EMS support group is and how helpful it can be. I kept my spirits up through EMS and then through two bouts of cancer, even if it meant putting on a pretty ring and then calling my new-found friends I met through the EMS newsletter.

I have a friend who wants to be contacted the same way I wanted to be

contacted. Her name is Yvonne Ross, 22112 Capistrano Lane, Huntington Beach, California 92646. Her phone number is 714 - 962 - 3030. Her email address is KAY1958@gmail.com.

The EMS support group cannot be too large or important enough.

I also welcome more calls at the number listed below.

Verna Hyde
306 County Road 37
Central Square, New York 13036
315-668-3289

Marilyn Ruggieri, a new member who just recently found NEMSN, would like to hear from people with EMS who also have scleroderma of the scalp. She may be reached at ...

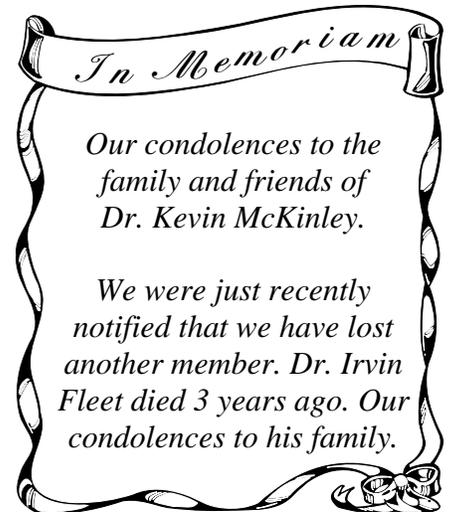
15 Hillside Village Drive
West Boylston, MA 01583
508-835-2599.

Poets or writers wanted...

Do you like to write poetry or small essays? We are looking for items for the newsletter to help take our minds off of our disease. We do not want religious items or items in bad taste that contains graphic language, violence, sexual encounters etc.....but we would like inspirational items, humorous items, items about having a chronic disease, and so on.....especially maybe humorous things might be a hit. If you would like to send us your poems or very small essays, etc., you may send them to the newsletter editor at the following addresses.

Sandy Kintz
767 Tower Boulevard
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or
NEMSMnewseditor@gmail.com



A Seed of Love

by Barbara Gartner

I planted a seed of suspicion
And watched it with tender care.
I watered it with sorry tears
And fed it with despair.

All that grew were tangled roots,
It bore no fruit at all,
So I planted another seed
And a tree grew straight and tall.

The second seed was one of love,
The branches reached for the sky.
I watched it grow with a happy heart
Unwatched, the first tree died.

Happy Birthday

by Barbara Gartner

I wish you peace and tranquility
As you travel the road to senility
I heard a comment - oh so cold!
That you're not getting better,
You're just getting old.

Editor's note: Barbara is one of our members and has graciously allowed us to reprint her poetry. If you have any poetry or short items you would like to share, please send them to our news editor.

Mary's Story

My name is Mary. I am 65 years old and reside in Huntsville, Alabama, a progressive city both culturally and industrially. I have two grown sons and I am single. I enjoy artistic endeavors and activities with my family. I spent 10 years teaching elementary school and worked in a family owned business for fifteen years. My parents and paternal grandparents lived into their 80s.

My health problems are both complex and varied. I feel that they are due largely to toxins that I have encountered; although no medical tests to date show more than a slight abnormality. This includes a vaccine at age 4 to prevent diphtheria, which my Mother declared caused me to be ill for at least one year. Dental problems have also been a cause as well.

I developed some mental depression and insomnia in late teens. It has been a lifelong problem. I began antidepressants and megavitamin therapy in my late 20s which helped somewhat. Improving my diet was also helpful. I was active and had no physical pain and walked and did aerobic exercise on regular basis for many years. The I-tryptophan saga began in 1985. I will tie it together, because all of it made me ill, in my opinion.

In 1987 I became very physically ill after taking it [tryptophan] for 3 years; complaining to my family M.D. of shooting pains in my bones, shortness of breath, weak spells, fatigue, abdominal pain and just PAIN ALL OVER MY BODY. No explanation. A few months later I was alerted to the I-tryptophan situation by watching the evening news with the late Peter Jennings. I was terrified! I had so many of the symptoms. (I had purchased it exclusively from mail order [from] both Florida and Illinois sources.) Returning to my doctor, he did some blood work and stated that although my eosinophils were only slightly elevated, something had changed my health status greatly.

I visited the public library for over a year and kept up for awhile. Later I saw a rheumatologist, who diagnosed fibromyalgia. After trying several prescriptions for pain and having much stomach distress, I simply went home and decided to "be my own doctor". A nutritious diet, some vitamin supplements and rest were my main regimen. I often thought that I was dying but after about 18 months, surprisingly, it went into remission for about 3 weeks and then returned. It followed this pattern of remit and relapse

for several months, then finally,,,finally...I felt much better and was able to resume normal activities. I will regress here to state that Lithium was prescribed for depression in the early 80s and I was hospitalized with liver toxicity and nearly died from taking it. However, after approximately 6 months I fully recovered.

Having lost a tooth due to an abscess, I had a dental implant (lower right jaw) around 1988. It has now developed an abscess and is adversely affecting my health today. I also have 3 very old root canals which are suspect. In 2000 I was into water aerobics and [I was} in great shape when my neck became very stiff and painful and other signs of health problems were returning, including jerking of my legs, especially at night, and lower back and sciatic-type pain.

I had some dental work done, including the removal of two very large dental fillings which were largely drilled out. That, along with a great personal loss, seemed to catapult me into a spiral of horrible health problems again. Terrible burning pain all over, but especially feet, numbness in feet and toes, (can barely walk at times) chronic mental depression, chills, pleurisy-type pain, shortness of breath (not exertion related), allergies, again many of the same old symptoms as before. The right side of body was affected more than the left. A neurologist diagnosed demyelinating disease non-specified about a year ago.

I do have to make a decision about removing the dental implant. I have seen four oral surgeons to date. Removal is not recommended. Two surgery's [are] required and no teeth can ever be replaced, or so I am told. More investigating must be done. I have so much inflammation and PAIN that further procrastination is not wise. I must take meds for pain, either prescription or OTC [over-the-counter] daily. Also must take Synthroid for hypothyroidism and some medication for sleeping. I am presently off antidepressant meds and doing just as well. I am now very sensitive and limited in being able to tolerate most meds due to side effects.

Many questions remain. What caused all of this? (According to [the] P.D.R. [Physicians Desk Reference] some of the psychiatric meds taken over the years could cause some of these symptoms.) No compensation was paid because no law suit was filed due to lack of concrete information. Unfair?

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New Medical Advisory Council

continued from page 1

was a researcher at the Mayo Clinic, Rochester, Minnesota. At present he is Research Professor of Dermatology and Medicine at the University of Utah, Salt Lake City. His medical interests as listed on the University of Utah website (<http://uuhsc.utah.edu/derm/bios/facultybios/ggleich.htm>) include "diseases associated with eosinophilia, such as the hypereosinophilic syndrome, Churg-Strauss syndrome, the eosinophilia myalgia syndrome, the Spanish toxic oil syndrome, and the syndrome of episodic angioedema and eosinophilia. . . . Research interests include the functions of the eosinophil, the structure and function of eosinophil granule proteins, the role of the eosinophil major basic protein in primate preg-

nancy and the identification of novel treatments for allergic diseases, especially the use of topical anesthetics as anti-inflammatory agents."

Dr. Gleich has written research papers and articles which have been published in many medical journals. His article "Current Status of Research on EMS", written in 1998, can be found on our website (<http://www.nemsn.org/Articles/Gleich%20summary%2098.htm>).

We are proud to welcome these talented people to our Medical Advisory Council. We expect to be able to submit questions from our membership to them. When procedures for this are worked out, we'll let you know.

Mary's Story *continued from page 3*

You bet! I now dislike many mainstream M.D.s. In addition, I have also tried acupuncture, colonics, and chiropractics (helped somewhat).

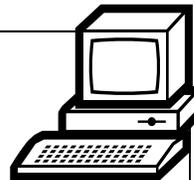
Life is still worth living most days. Glad I found your website. I welcome input and your opinions. Contact me through the editor if desired. My motto is "NEVER GIVE UP! NEVER!"

Mary

Editor's Note: We continue to print member's stories, in the hopes of showing us that we are not alone in suffering this terrible affliction, EMS. Reading how the disease has affected others may help us to understand it and our own cases a little bit more .

Join Our Email List

NEMSN Connections



An email group to help NEMSN members stay in touch, receive announcements and news from the NEMSN Board of Directors, and serve as a method to connect members in other ways, began March 1st. Faith Rumph, a former newsletter editor of NEMSN, coordinates the group. Membership updates, NEMSN news and announcements, and medical/health questions of members, are sent in email format monthly to members. Since *NEMSN Connections* is not a discussion or bulletin board

group, members do not receive multiple daily email messages and do not post messages for the entire group to read, as you might do on a Yahoo group. Instead, members communicate privately about their common concerns, and Faith sends out a monthly Update of new questions, members, email address changes, news, etc.

To learn more about this email group and how to join, email Faith at the following address :

NEMSNConnections@aol.com

To NEMSN Members from the Board of Directors

We need you!

Our Board of Directors is currently short two members. Besides that, most of us on the board are EMS patients. So while we have lots of ideas for wonderful projects to better serve our membership, the spirit is willing but the body all too often gives out.

Do you have the interest and energy to get involved with NEMSN? Would you like to be considered for a board position? Would you like to volunteer in other ways? Would you like to just give us your ideas?

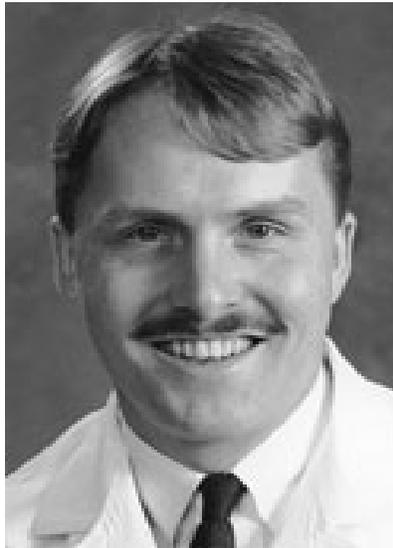
Please contact treasurer Michael Bird at popsies@aol.com

Remembering Kevin L. McKinley, M.D.

Member NEMSN'S First Medical Advisory Council

Dr. Kevin L. McKinley, chairman of the Dept. of Neurology at Ochsner Medical Center in New Orleans, passed away October 5, 2006 at the age of 45. He had served NEMSN as a member of its first Medical Advisory Council that was set up around 1998.

Although Dr. McKinley was a busy young doctor and father of three children, he made time to plan a study for EMS patients and write an article for the NEMSN Newsletter about it. He also met once with the Board of Directors and discussed his ideas with then Newsletter Editor, Faith Rumph, via telephone. From time to time he contributed to NEMSN in other ways, including answering medical questions, reading the 1999 NEMSN Questionnaire and offering input on how to improve the survey, and by doing a few Questions & Answers for the newsletter.



Dr. Kevin McKinley

Born in Missouri, Dr. McKinley earned his BA and MD degrees at the University of Missouri at Kansas City before serving his internship in internal medicine and residency in neurology at Baylor College of Medicine in Houston, Texas. While there, EMS erupted onto the medical scene, and Dr. McKinley became involved in the treatment and lives of some patients with EMS.

When he later moved to Ochsner Clinic where he was a member of the staff for 14 years, also serving as head of the Dept. of Neurology, Dr. McKinley continued to see EMS patients and to lend his expertise to their doctors as needed via consultations.

Johanne Termotto of Colorado, formerly of Texas, wrote these words about Dr. McKinley: "He was an angel for his compassion and a warrior in his fight for us against both the disease and those who caused it." Indeed, Dr. McKinley, unlike many doctors with a serious interest in EMS, had refused to take any research money from Showa Denko because he believed he could not be impartial if he used their money for research.

A man who loved music as well as medicine, Dr. McKinley "loved to synthesize his love of music with his passion for teaching" according to one of several obituaries. A colleague, Dr. Robert Fielberg, described him as a man with "a contagious joy and an encyclopedic fund of knowledge. Being with him made average moments memorable and memorable moments extraordinary. He was one of those characters who made the world better just by being himself."

Dr. McKinley loved his patients including those with EMS. As Carolyn J. Conn of Texas said, "Kevin was so good to us EMSers. He really did more than anyone ever knew. No other doctor cared about us as he did." In fact, he even served as a pall bearer at the funeral of one person with EMS when she passed away a few years ago.

Finally, I – Faith Rumph – would be wrong to close this remembrance of Dr. McKinley without stating how much he assisted me during my years on the NEMSN board and how much he meant to me personally as a kind and unpretentious physician; furthermore, I would be remiss in not telling you that he always held a special place in his heart for those with our disease. I know this is true from our talks. Some of you know it as well, and you are fortunate for having known him.

"In praise and in dispraise the same/A man of well-tempered frame."

...from "Ode on the Death of the Duke of Wellington" by Alfred, Lord Tennyson, 1852.

Editor's note: Donations in Dr. McKinley's memory may be made to NEMSN using the enclosed envelope.

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March 9, 2007 through May 3, 2007

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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 _____

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- 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.



Cheerfulness is the best
promoter of health and is as
friendly to the mind
as to the body.



...Joseph Addison



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