



# 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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## Essentials of Managing Your Chronic Illness

### The Ten Essentials of Living with Chronic Illness

By Cynthia Perkins, M.Ed.

Managing your illness means to take responsibility for the actions that are necessary for you to cope and live life as optimally as possible within the limits you are faced with. It empowers you to improve the quality of your life, reduces helplessness and hopelessness and promotes self-confidence and self-esteem.

There are many steps one can take to manage their illness, and these steps may vary greatly from week to week or from individual to individual. But, there are several essentials that are fundamental to any health care path regardless of your diagnosis.

These essentials are:

1. **Proper Nutrition** You are what you eat. What you eat has a profound impact on your mental and physical health. Eating a healthy diet is essential for optimal functioning and healing. Depending on your particular illness, this may include incorporating new foods into your diet or eliminating some favorites. At the very least you should be eliminating things such as sugar, caffeine, refined foods and unhealthy fats and replacing these with whole foods such as vegetables, whole grains, nuts and seeds, fruits and fresh or frozen meat and poultry. Preferably your diet should be free of chemicals and toxins found in the average diet such as pesticides, herbicides, additives, dyes and preservatives. Healing can't take place in a body fed with unhealthy foods and nei-

ther can maximum functioning.

2. **Exercise** Incorporating exercise into your life is crucial for the mind, body and soul. The body's natural release of endorphins, which occurs with exercise, provides wonderful emotional uplifts and is also a fantastic pain reliever. In addition to reducing heart disease, building healthy bones and muscles and managing weight, it is an excellent outlet for relieving depression, anger, stress and anxiety and also boosts self-esteem and self-confidence. Regular exercise improves energy levels, helps you sleep better and more deeply, promotes healthy bowels and boosts the immune system.

3. **Soul Nourishing** Feeding your soul healthy food is just as important as feeding your stomach. Find ways to nourish and replenish your soul. Participate in activities that make you feel whole, alive and one with universe. Neglecting your soul results in loss of joy and life fulfillment. Yoga, meditation, prayer, communing with nature, music, art, writing or deep meaningful relationships are some great sources of soul food.

4. **Take an Active Role in Your Health Care** You should play a central role in your health care treatment. Instead of passive compliance with doctor's orders this requires a partnership with your health care provider. You're with your body 24 hours a day, so no one knows how your illness or treatment

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## 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.

## CONNECTIONS UPDATE

**NEMSN Connections**, a monthly Email List of NEMSN open only to its members, exists for sharing questions about EMS and health; tips on various topics; private communications about shared hobbies or health issues; and as a vehicle for NEMSN to send worthy news items and article links to members of the group. (There are presently about 50 members.)

Faith Rumph is the Email List Coordinator. Her **new** email address for members of the group to use is [faith\\_rumph@yahoo.com](mailto:faith_rumph@yahoo.com) rather than the old AOL address. People interested in joining may write to Faith for information at the Yahoo address as well. Faith's address for **personal email** is now [MarilynR@verizon.net](mailto:MarilynR@verizon.net) instead of the old AOL address.

## Request for Contact...

I am interested in knowing if anyone has encountered calcinosis. I have been battling it for 3 years. Nothing helps, still on Prednisone, have had calcium channel blockers, steroid creams, everything. It comes through the skin, fragments, a terrible painful mess.

I have had EMS since 1989. I was diagnosed at Thomas Jefferson, Philadelphia. I have CREST. EMS mutates into everything in me. Doctors are stumped what to do about calcinosis. It is a big challenge. I've had it for 4 years, other EMS victims are starting to show signs of it. They cannot explain numb feet. My docs are at Mayo, Jacksonville, Jefferson, Philly. University of ILL. (DR. John Varga) who diagnosed me. I'm his case study. I fly out to see him yearly and e-mail.

Dee

**Editor's Note:** Contact to Dee may be made by way of the Newsletter Editor.



*From the Editor...*

Dear Friends,

*I can't believe summer is over. Another year is almost over. Here in the north the leaves are falling and many of the nights are chilly. Many of us have had a rough year, but we are still fighting and are still thankful to be alive.*

*The NEMSN Board is short two members. Won't you think about giving of your time to help us keep NEMSN strong. It really doesn't take much time and helps so many people. If you are interested in serving on the board, call or write Michael Bird, our treasurer. Please consider helping in any way you are able. Every little bit helps.*

*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. 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 and not necessarily those of the NEMSN 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.

**"Friends Supporting Friends"**

## Chuck's Story

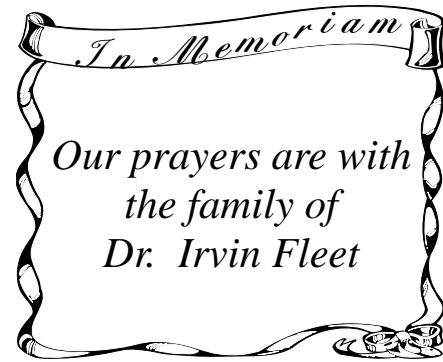
I was diagnosed with EMS in 1994 from Medical College of Augusta Ga. (oncology). At that time they thought I had Leukemia. The doctor really never heard of Eosinophilia Myalgia Syndrome. My Eosinophilia cell was at 70%.

When he diagnosed me with it he put me on high doses of prednisone. It did not really do a thing. Then he started me on interferon shots. I also took Aterax for skin rashes and itching.

I went to John Hopkins in Baltimore Md for a second opinion from Dr. Spivak in Hematology. He confirmed this was what I had. I gave myself shots three times a week for 6 months and my count dropped down to the 40% range. I then transferred to Pa. in 1995-1996 My count was stable at 40-46%. Then it started to creep back up. Dr Shaw oncology put me back on the interferon in 1999-2000. I did this 3x a week for a year. Then Dr. Spivak took me off it again because it dropped into the 40% range again.

Then in 2006 it went back up to 57%. I found a doctor in Lehigh Valley oncology dept in April of 2007. She ran extensive tests. Then she put [me] on a new pill called Gleevac 100Mg. Within three weeks my count dropped to 5%. Then within 6 weeks down to 2% normal range. I am still taking the Gleevac pill 100Mg every other day. I do not take the Aterax anymore. My skin condition has started clearing up . They dropped the dosage of Gleevac. My next visit was on Sept. 6th to see if my count stayed down. My aches and pains have subsided considerably but have not completely diminished. I am also back to work as of Aug. 20th.

The doctor dropped my dosage from 7 days a week to every other day. Then when I went back in a month and she dropped my dosage to twice a week. My Eosinophil cell count was down to normal 2%. I also was in normal range of all other counts. When I went back to see her Oct 11th she said it was still in the normal range of 3% and all other counts were still normal. She decided to take me completely off of it



for a month and then see what this will do? I have to go back in November for another check up and blood tests. She also said that she feels that my count will stay down for a while but may start to go back up. If this happens then she said I may need to take 1 to 2 tablets of Gleevac a week to maintain the count. I am still back to work . I work 12 hr days but it is a desk job. I feel 90% better than I did 4 months ago. I also was taking Atarax for the skin condition that I had. It was an itching and dry flaky skin around my nose and ears. Also a red rash under facial hair area. I had taken this pill for over 13 years and right now I am not taking it at all. All my skin rashes and itching have cleared up. I have had this problem since 1994 and the lowest they have ever gotten my Eosinophil cell count down was in the 40% range when I was taking the Interferon shots. I am very pleased with the results that I have gotten from this new drug Gleevac. But again, it may not work for everyone, just like other drugs have different effects on individuals. If this can help any one at all it would be worth the try. I will say that it did have some minimal effects on me but nothing to keep me down from every day functions.

Chuck Lecker

**Editors Note:** The first person I personally knew of with EMS had been a weightlifter and bodybuilder. I asked Chuck if he had done these things. He said he had lifted weights about that time, but had not been a bodybuilder. He had taken amino acids, which, they told him, was the cause of his EMS.

## Essentials of Managing Your Chronic Illness

By Cynthia Perkins, M.Ed. *continued from page 1*

approaches impact you and your life, better than you do. Be an active participant in treatment approaches, pursue all possible avenues, present your physician with options.

**5. Communication** Honest, direct communication with health care providers, friends, family etc., is vital to your mental and physical health as well as the quality of your relationships. You'll get the best possible care if your physician is clear about your symptoms and how the illness and treatment impacts you. Everyone gets their needs met more effectively when there is understanding of one another and this can only occur with communication. Communication prevents misunderstandings and promotes intimacy.

**6. Educate Yourself** Learn everything you possibly can about your illness and your options. Consult with physicians, nutritionists, alternative health providers, other individuals with your condition, etc. Go to the library or bookstore and read everything you can get your hands on, do research on the Internet. Saturate your mind with knowledge about all aspects of your condition so that you can make informed choices. Self-knowledge restores a sense of personal power.

**7. Pace Yourself** Set priorities with your time and your energy. Break down your tasks and activities into hard and easy categories and list them according to priority. Do the things that are urgent or most important first and then the others when you are capable. Break long-term goals down into several short-term goals. Permit yourself to achieve the goal in small steps instead of all at once. Always allow yourself to rest when needed and give yourself permission to leave the list unfinished. Be flexible and accept your limits. Allow yourself time to recuperate when you have participated in a draining activity.

**8. Humor and Inspiration** Humor and inspiration are good for the soul and the immune system and necessary to help us keep things in perspective and out of negativity. They improve mood and make life a little lighter and more manageable. Feed yourself with humor and inspiration daily. Keep quotes, nature pictures or jokes in your daily space for frequent viewing, with things like calendars, or if you have Internet access you can receive quotes of the day or jokes of the day delivered to your email box. You can also watch funny films, read cartoons or read inspira-

tional magazines or books.

**9. Nurture Primary Relationships** Everyone needs love and support and it is especially important for those with chronic illness. It assists in the acceptance and adjustment process, helps you cope and relationships are what makes life worth living. There is nothing more fulfilling than loving and being loved. Chronic illness will undoubtedly be a strain and stress on relationships and has the potential to erode or destroy them if left unchecked. It will be necessary to make a conscious effort to nourish them. Make those most important to you a priority and reserve quality time for them. Encourage open communication of feelings. Deal with the impact the illness has on your relationships directly and honestly. People have a tendency to try and spare one another's feelings by avoiding these types of discussions, and although you may avoid the discomfort of the moment, in the long run this is destructive to the relationship. Seek friends who are supportive and understanding.

**10. Reduce Stress** Life is stressful and there is no way to eliminate it, but keeping stress to a minimum and finding ways to deal effectively with your stress on a daily basis is essential to preventing it from overburdening your already limited physical and emotional capacities. Delegate responsibilities and chores to others in your life if possible. Shorten duration of visits and activities when necessary. Participate in soothing, relaxing activities like massage, meditation, prayer and exercise. Don't allow yourself to get caught up in the vicious rat race of life by trying to live up to others' expectations. Most of society lives a very unhealthy pace of life. Keep life simple; enjoy the simple things of life.

### About the Author

Cynthia Perkins, M.Ed. is an author and holistic health counselor helping individuals living with chronic illness or chronic pain to live life to the fullest. She is also author of the inspirational E-Book "Finding Life Fulfillment when Living with Chronic Illness-A Spiritual Journey". Cynthia's services are available by telephone and she may be contacted by visiting <http://www.holistichelp.net/> or calling 1-866-343-7714. We thank her for allowing the reprinting of her article.

## FDA NEWS

Consumer Inquiries:  
888-INFO-FDA

### FDA Issues Dietary Supplements Final Rule

The U.S. Food and Drug Administration today (June 22, 2007) announced a final rule establishing regulations to require current good manufacturing practices (cGMP) for dietary supplements. The rule ensures that dietary supplements are produced in a quality manner, do not contain contaminants or impurities, and are accurately labeled.

"This rule helps to ensure the quality of dietary supplements so that consumers can be confident that the products they purchase contain what is on the label," said Commissioner of Food and Drugs Andrew C. von Eschenbach, M.D. "In addition, as a result of recent amendments to the Federal Food, Drug, and Cosmetic Act, by the end of the year, industry will be required to report all serious dietary supplement related adverse events to FDA."

The regulations establish the cGMP needed to ensure quality throughout the manufacturing, packaging, labeling, and storing of dietary supplements. The final rule includes requirements for establishing quality control procedures, designing and constructing manufacturing plants, and testing ingredients and the finished product. It also includes requirements for recordkeeping and handling consumer product complaints.

"The final rule will help ensure that dietary supplements are manufactured with controls that result in a consistent product free of contamination, with accurate labeling," said Robert E. Brackett, Ph.D., director of FDA's Center for Food Safety and Applied Nutrition.

Under the final rule, manufacturers are required to evaluate the identity, purity, strength, and composition of their dietary supplements. If dietary supplements contain contaminants or do not contain the dietary ingredient they are represented to contain, FDA would consider those products to be adulterated or misbranded.

The aim of the final rule is to prevent inclusion of the wrong ingredients, too much or too little of a dietary ingredient, contamination by substances such as natural toxins, bacteria, pesticides,

glass, lead and other heavy metals, as well as improper packaging and labeling.

The final rule includes flexible requirements that can evolve with improvements in scientific methods used for verifying identity, purity strength, and composition of dietary supplements.

As a companion document, FDA also is issuing an interim final rule that outlines a petition process for manufacturers to request an exemption to the cGMP requirement for 100 percent identity testing of specific dietary ingredients used in the processing of dietary supplements.

Under the interim final rule the manufacturer may be exempted from the dietary ingredient identity testing requirement if it can provide sufficient documentation that the reduced frequency of testing requested would still ensure the identity of the dietary ingredient. FDA is soliciting comment from the public on the interim final rule. There will be a 90-day comment period, ending on September 24, 2007. Comments may be addressed to the Division of Dockets Management Branch at [www.fda.gov/dockets/ecomments](http://www.fda.gov/dockets/ecomments). The final CGMP and the interim final rule are effective August 24, 2007. To limit any disruption for dietary supplements produced by small businesses, the rule has a three-year phase-in for small businesses. Companies with more than 500 employees have until June 2008 to comply, companies with less than 500 employees have until June 2009 to comply, and companies with fewer than 20 employees have until June 2010 to comply with the regulations.

Backgrounder: <http://www.cfsan.fda.gov/~dms/dscgmps7.html>

Fact Sheet: <http://www.cfsan.fda.gov/~dms/dscgmps6.html>

To see a consumer article called "Final Rule Promotes Safe Use of Dietary Supplements," visit <http://www.fda.gov/consumer/updates/dietarysupps062207.html>.

## NEMSM MEDICAL ADVISORY COUNCIL ACTIVATED

NEMSN invites you to submit medical questions to us for our Medical Advisory Council. You may send your questions to NEMSN via email ([elveeve@aol.com](mailto:elveeve@aol.com)) or US mail (NEMSN, c/o Lois Vierk, P.O. Box 4171, West New York, New Jersey 07093). We will send questions on to our advisors, and they will have the opportunity to respond to any queries that they wish to answer. We can't guarantee that everyone's question will be answered-that will be up to the doctors on our council. We suggest that your questions be stated as broadly as possible, i.e. not things that apply to your case only but that may have relevance for others as well.

Since we announced the formation of the Medical Advisory Council some months ago, we're pleased to tell you that Ketan Bhakta, M.D. has consented to join us, also. Dr. Bhakta, specialty internal medicine, is a clinician in southern California who has treated many EMS patients over the years.

Our other advisors are the well known EMS researchers Edward Belongia, M.D., Luis R. Espinoza, M.D. and Gerald Gleich, M.D.

To briefly remind you of their backgrounds, Dr. Edward Belongia is Senior Epidemiologist/Director of the Epidemiology Research Center, Marshfield Clinic Research Foundation in Marshfield, Wisconsin (<http://www.marshfieldclinic.org>). 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" can be found on our website (<http://www.nemsn.org/Articles/Espinoza2.htm>).

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 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. Dr. Gleich has authored numerous 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>).

# Donor Honor Roll

June, 2007 through November 2007

**Editor's Note:** My apologies to contributors who made contributions in June. I somehow overlooked their names in the last newsletter. I have included them here. For that reason, some names may be listed twice. We do appreciate your contributions and I am very sorry to have overlooked them in the last newsletter. Thank you for your continued support of NEMSN.

## Contributors (Regular) \$5 - \$49

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*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.

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## **NEMSN Newsletter and Connections Update**

There are now three electronic ways for people with EMS to keep up with others with EMS. There is this newsletter which can be delivered to you by US mail by sending a written request to: Sandy Kintz, 767 Tower Boulevard, Lorain, OH 44052-5213 or to save money and paper, it may be sent to you by e-mail if you request it from the editor at [NEMSNnewseditor@gmail.com](mailto:NEMSNnewseditor@gmail.com) or it may also be read online at [Nemsn.org](http://Nemsn.org)

Lastly another e-news letter/list of members is produced and can be sent to you monthly which gives you the opportunity to ask questions of others with EMS or for you to give information about what has helped you to others with EMS. This may be requested from Faith Rumph at [faith\\_rumph@yahoo.com](mailto:faith_rumph@yahoo.com)

**“Friends Supporting Friends”**