



National EMS Network Newsletter

Points of interest

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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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- **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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EMS Twenty Years Later: Reflections of Eight NEMSN Members, Part 1

Introduction by Faith Rumph

I don't know about you, but 20 years ago in August I was happily married with a son who was 12 years old, and I felt that life was going along pretty well. There were new friends in my life, new interests, I was getting over the depression I had felt over several family deaths, and I thought that things were "looking up" as people say. At age 39, I was forging ahead.

Then August 17, 1989 dawned. I awoke with a symmetrical hives-like rash on my inner thighs.

And that is how my EMS Odyssey began.

It's been a long 20 years in many ways. In other ways, I am astounded how fast the time has gone by. At times it seems incredible that I am still alive. After all, I'd been told to prepare to die at one point by one doctor. But I dared to hope that this novel disease Eosinophilia-Myalgia Syndrome might go away like an allergic reaction. I immersed myself a few hours a day in reading Russian literature and studying Russian and figured it might help me keep my mind busy. Looking back, I find that period of time somewhat surreal.

I was unaware for the most part of those dying of EMS, and I was blessedly ignorant of the years to come filled with more and more medical diagnoses secondary to EMS, increasing pain and disability. For instance, I never really thought I'd have to use a wheelchair in public like now. I thought I'd live or die, not become a crippled person for the rest of my life,

struggling and looking back on memories of days of ease of movement. It was unimaginable to me in 1989 what 2009 with or without EMS might be like, to be honest.

Following are the brief Stories and Reflections of eight persons with EMS who have written about their lives these past 20 years. When I began this project for NEMSN, I invited about 12 persons to write because I knew that not all of them would say "yes." I am so pleased that eight persons did say "yes." Their combined words make a full-length article of 2000 words. The writers come from states from coast to coast, from cities, suburbs, and from a farm; from those who are retired, to a few who manage with great difficulty to work jobs yet; from a few a bit younger (earlier or mid- 50s) to a person almost 80 years old. They are people who have backgrounds in business, the arts, social work, farming, and in other areas. They are, like you, survivors of this awful disease that came into our lives in 1989 or in earlier years. Like you, they struggle, they have setbacks, they have some triumphs, and they have mourned what was taken from them by EMS. And everyone wonders about the future.

So, I thank them for writing and helping to remember this *milestone of 20 years since the recognition and naming of EMS.*

Here's to you, one and all, for you have

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From The Editor...

I hope you will enjoy this newsletter and the one coming out in December, our two issues on the 20th anniversary of the outbreak of EMS. It has been a pleasure working with Faith Rumph on this issue. She proposed the project of publishing members' EMS stories and reflections and she gathered all the materials. We really appreciate all she has done so that our 20th year is remembered. The next issue will have articles from the doctors on our advisory panel and perhaps more reflections from our members.

I, along with the board of directors, want to thank Dr. Gleich for his generous donation to NEMSN.

We are fast losing members to moving with no forwarding addresses. Here is a list of the latest. If you know the following members and their new addresses, I would appreciate you sending them on to me. The states following the names are the last we have for these members.

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Sandy

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.

EMS Twenty Years Later: Reflections of NEMSN Members *continued from page 1*

made it to this 20th year. And here's to the friends, loved ones, doctors, counselors, members of the clergy and any others who helped us all along the journey so far.

As Aleksandr Solzhenitsyn wrote in his great book *The Cancer Ward*, "It said in the book [of Tolstoy] that people live not by worrying only about their own problems but by love of others."

Faith Rumph lives in Virginia, is a former member of the NEMSN Board of Directors, and is a former music teacher, piano instructor and freelance writer. Faith volunteers for NEMSN by doing their NEMSN Connections 11 months a year. She is married, has one son and two grandchildren and may be reached at: faith_rumph@yahoo.com for information about NEMSN Connections, or her various non-NEMSN EMS sites.

EMS Twenty Years Later: Reflections of Eight NEMSN Members

By Terry L. Zarate

I contracted EMS 20 years ago, but it took me 7 years to get diagnosed. Most specialists thought I had a psychosomatic illness, as did my family. The first two years of my illness I was in great pain, weak, and it felt as though I was in a haze. It was difficult to think. I felt I was dying. Because I didn't have a diagnosis, I got no help for the pain. When I was finally diagnosed, my doctor gave me a very grim prognosis, which ended with me as an invalid and my husband caring for me.

EMS mimics other diseases and, at various times, the doctors thought I had Carpal Tunnel Syndrome, MS, and Herpes. Tests proved each one to be false. I am very tired most of the time. EMS pain includes different kinds of pain – stabbing, aching, throbbing, nerve pain, as well as a tingling sensation all over. Some days I have a low grade fever with chills and a dead tired feeling. Nothing seems to help it but time.

I have no idea what my prognosis is. I have a good doctor who treats symptoms as they come up. Some days I struggle to get through and other days I feel almost like a normal person. I try very hard not to dwell on what might have been and to concentrate on the positive in my

life. I am one of the lucky ones, for sure. I have a good life and a wonderful supportive husband. We will see what the future holds.

By Ernestine Priester

Twenty years! I am 69 years old and definitely not getting better. I think EMS and Lyme disease are merged. (I was diagnosed with Lyme disease in 2007.) I don't know which is which, and I am sensitive to most medications I have been prescribed for Lyme.

My short term memory is definitely worse. I struggle to put small thoughts together to write anything. The thought of trying overwhelms me.

For the past 3 months, I have thrown myself into different modalities of exercise at least three days a week. This makes me exhausted, yet if I don't do it, my pain and nerves are worse.

Twenty years! I am still angry at times because of what happened. EMS - The silent killer of my "before EMS life." I stay so....very....tired. I miss my life pre-EMS, and I know my husband of 47 years does, too. Thankfully, our grandchildren light up my life.

For 18 of the past 20 years, I hung onto the attitude, I WILL GET BETTER! I CAN ALMOST TOUCH IT! THE HOPE, IT'S THERE! I KNOW IT IS! THE SOMETHING THAT EXISTS! I CAN ALMOST SEE IT! I WILL FIND IT!

That feeling changed in the 18th year. I finally told myself that it wasn't going to happen and I am still trying to accept that sinking feeling. I told myself that IT IS NOT OUT THERE! I WILL NOT GET BETTER! Perhaps, instead, the way I deal with EMS will get better.

Tallahassee, Florida
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By Jo

I am a person with pre-epidemic EMS who's been living with this disease for more than 20 years.

In the summer of 1988 I started feeling awful. After many doctors' visits I was first diagnosed with Eosinophilic Fasciitis. By spring 1990 my diagnosis was changed to Eosinophilia Myalgia Syndrome.

Before EMS, I enjoyed walking for exercise as it was

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like exploring. Since the onset of EMS my legs and feet hurt continuously, and just a 5-minute walk increased that noticeably.

Because my feet and legs always hurt, my house is not as clean as it used to be. I don't cook the same quality of meals because of the length of time it takes while standing.

I see other people my age out working in their gardens—on the rare time I do that I have to keep it at about 10 minutes once, maybe twice, a week at the most, or the pain is unbearable. That is just not enough to even keep up with the weeding in my small front yard.

When I tried to get disability my doctor would not support me because he ignorantly thought I no longer had EMS because the eosinophils were no longer elevated.

I am still angry at times at not being able to do things I want to do. I don't think I would have settled for such a low amount of money with Showa Denko if I'd have realized how this would have impacted me for the rest of my entire life.

Pleasant Grove, Utah
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By Elene Decker

When I was told that I had EMS, I waited two days before I told my husband. I knew it was serious and I dreaded telling him. Life has never been the same. This disorder sounded so serious I was sure I would die from it. I was never hospitalized, and had very little treatment. My doctor simply treated the symptoms and let my body heal itself. I learned to compensate for the pain and weakness by slowing down. My life, though slower, has been much the same. It took about a year for my blood values to normalize.

At one point, when my eosinophil count went to 60%, after having been much lower, my husband and I contacted a funeral planner and made funeral arrangements. You see, we are farm people who believe in accepting life as it comes. I was thankful that my four children had all finished college and were settled with careers and families.

I never thought I would live twenty years. Someone said, "EMS is a lonely disease." This is true. EMS doesn't show, it is invisible, and I look the same. No one but my

husband, Jack, and I know the pain these years have brought. Friends and acquaintances don't see it and have forgotten I was ever sick. However, I am blessed with a wonderful family, and this ordeal has brought us all closer together. We will never take life for granted again.

Age 78 years
Kenefic, Oklahoma

By Janet O'Brien

I was 43 years old twenty years ago, with a 16 year old daughter and 11 year old son and a very busy life. We went to Palm Springs in August to see family, and on the way home I noticed that my wedding ring didn't fit any more. I thought it was swelling from the desert heat, and when muscles began to hurt, I thought it was because I had let my exercise routine lapse. I got steadily sicker, and was diagnosed with EMS sometime in November. I was terrified that I would die, and so was my family. Life would never be the same.

EMS has taught me things, mostly patience and acceptance. I learned to forgive and let go of bitterness, because it just made things worse. I gained coping skills and the knowledge that the many good things in my life should be noticed every day. I know that if today is a good day, I better enjoy it as much as possible and not worry about what tomorrow will be. Advancing age has its own challenges, which I'm sure I handle better because of 20 years of chronic illness experience. EMS is obviously a very bad thing, and I'm not a fan of pain and crazy fatigue - my two biggest problems. But I know that like all of life, it has contributed to who I am today.

Pinole, California

By Anne Parker

Twenty years ago I became sicker than I had ever been. I was sure it would pass quickly; I was only 40 years old and never dreamed my life was changed forever. Books on Tape saved my sanity, especially during the early years. Now I listen to books on my iPod, even when I am doing well enough to hold a book—I'm addicted, I'll admit!

I have learned to be much more patient with myself and

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EMS Twenty Years Later: Reflections of NEMSN Members *continued from page 4*

others, and to plan around reduced physical abilities. I still get angry and frustrated by the things I can't do, and the unpredictability of this illness. But I have learned not to get stuck there, since indulging in emotional binges leaves me exhausted, defeating my goals to do as much as possible. I remind myself that I could just as easily have gotten MS or another disabling illness.

Vacation plans include shorter flights (I went from Portland, Oregon to Miami via a night's stay in Dallas), more scheduled rest time, and travel insurance in case I can't travel. I bought a great LazyBoy recliner that goes nearly flat so I can be out of bed more during flare-ups. I use an electric scooter when needed. Of all I've lost, my professional employment was the hardest. Now I volunteer in ways that I can limit the time and energy spent as needed. Twenty years ago I thought I knew what my life would be like; now I've learned no one ever knows what tomorrow will bring.

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By Sonya Terri

I began taking L-Tryptophan for insomnia, at my Doc's recommendation, in spring of 1989. I had a great job with the California Senate, and my darling daughter was just five years old. In the fall of 1989 I was struck down with unimaginable pain and fatigue. My Doc soon diagnosed EMS, and within six months I had to quit my job.

We moved to Petaluma, and there I struggled through ten years of horrific pain, fatigue, and asthma. We managed to have good friends and community around us. I worked part-time and tried hard to make sure that my daughter had lots of positive activities. Still, I would have done so much more with her, and for her, if I had not been disabled with EMS. Eventually, I had to sell my house. Finally in 1999, I applied for S.S. Disability, which was approved after five months.

About a year ago, I moved back to Sacramento where I still have lots of family and a few dear friends. My daughter is now grown, and is attending UC Berkeley.

Slowly, I am learning to accept my twenty years with EMS although it totally altered the course of my life. I am learning to remain peaceful through pain and fatigue, and to fully enjoy every pain-free moment. Simultaneously, I

continue to seek improvement in my health and in my overall ability to "be present" for the ride.

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By Al McVicker

I was a pre-epidemic case. I had very bad arm and chest pains and was admitted to the hospital two times. No local doctor could figure out what was wrong. I then heard a story on the news a month or so later and figured it out by myself. As my employment had me moving around the country, I found it increasingly harder to find any doctors who took any interest in EMS.

I find now 20 years later that I am still having many of the same pains. Thanks to some friends in our EMS Network, I am seeing a new doctor with several EMS patients. That has been a long time coming and I am somewhat relieved.

This is a milestone that I would rather not be a part of. Looking back, it amazes me how things have changed in my life. To look at me you would never know, but to be me it's a constant battle of fatigue, pains that are what I call EMS pains, and depression. Every day is an uphill battle.

It also amazes me that I am one of the lucky ones. It's hard to imagine what some others have endured. Overall, EMS is just a part of my life. I do what I can when I can and still love life as I would have regardless.

I wouldn't mind being around for the 40th anniversary, but I am sure it will be even lonelier.

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NEMSN sends heartfelt thanks to all who have shared their experiences and feelings about living with EMS these past 20 years, and especially to Faith Rumph, who conceived of the project and put it together.

Chinese Acupuncture and Pain Regulation

Editor's Note: The following information on new research on acupuncture and pain regulation is reprinted with permission of the University of Michigan. The head researcher is Richard E. Harris, Ph.D.

August 10, 2009

Chinese acupuncture affects brain's ability to regulate pain, study shows.

Researchers at the University of Michigan Chronic Pain and Fatigue Research Center are first to provide evidence of acupuncture's effect on opioid receptors.

<http://www2.med.umich.edu/prmc/media/newsroom/details.cfm?ID=1246>

ANN ARBOR, Mich. - Acupuncture has been used in East-Asian medicine for thousands of years to treat pain, possibly by activating the body's natural painkillers. But how it works at the cellular level is largely unknown.

Using brain imaging, a University of Michigan study is the first to provide evidence that traditional Chinese acupuncture affects the brain's long-term ability to regulate pain. The results appear online ahead of publication in the September issue of *Journal of NeuroImage*.

In the study, researchers at the U-M Chronic Pain and Fatigue Research Center showed acupuncture increased the binding availability of mu-opioid receptors (MOR) in regions of the brain that process and dampen pain signals - specifically the cingulate, insula, caudate, thalamus and amygdala.

Opioid painkillers, such as morphine, codeine and other medications, are thought to work by binding to these opioid receptors in the brain and spinal cord.

"The increased binding availability of these receptors was associated with reductions in pain," says Richard E. Harris, Ph.D., researcher at the U-M Chronic Pain and Fatigue Research Center and a research assistant pro-

fessor of anesthesiology at the U-M Medical School.

One implication of this research is that patients with chronic pain treated with acupuncture might be more responsive to opioid medications since the receptors seem to have more binding availability, Harris says.

These findings could spur a new direction in the field of acupuncture research following recent controversy over large studies showing that sham acupuncture is as effective as real acupuncture in reducing chronic pain.

"Interestingly both acupuncture and sham acupuncture groups had similar reductions in clinical pain," Harris says. "But the mechanisms leading to pain relief are distinctly different."

The study participants included 20 women who had been diagnosed with fibromyalgia, a chronic pain condition, for at least a year, and experienced pain at least 50 percent of the time. During the study they agreed not to take any new medications for their fibromyalgia pain.

Patients had positron emission tomography, or PET, scans of the brain during the first treatment and then repeated a month later after the eighth treatment.

Additional authors: Jon-Kar Zubieta, M.D., Ph.D., David J. Scott, Vitaly Napadow, Richard H. Gracely, Ph.D., Daniel J. Clauw, M.D.

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