



# 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 is very informative.**
- **CHECK OUT WWW.NEMSN.ORG**

## Inside this issue:

Doctors Recommendations Needed	Page 11
Donor Honor Roll	Page 3
Editor's Note	Page 3
EMS-Like Illness	Page 3
EMS Online Sharing	Page 2
Help Wanted	Page 2
Letter to Editor	Page 12
Drug Sensitivities	
My Trip to Hell and (partway) Back	Page 5
Poem-Silently	Page 13
What Works	Page 1

## What Works? For Sam It's Exercise

Since last summer a fellow EMS patient and I have been in contact a number of times about what works for him to alleviate EMS symptoms. This person does not want his name used, so we'll call him "Sam". In our phone conversations and in emails, Sam described his daily exercise regimen. He depends on it to discover ways to relieve pain and increase physical functionality. This column reports on what helps Sam. He hopes something here might be useful for you, too.

As a kid Sam had always been athletic. He used to run marathons and play soccer, among other activities. In his 20s he began studying various kinds of martial arts including judo, kung fu, and tae kwon do. Sam was in his 30s when he got EMS in the 1989-90 outbreak. The disease debilitated him greatly. Years later, besides constant pain and a body that cramps and tightens up greatly, he reports having other continuing issues including maintaining balance. He can do things like standing on one leg and not falling off a thick low tight rope at the gym, yet in normal walking around he sometimes bumps into walls or even falls down. EMS ruined Sam's ability to participate in sports and now he cannot practice martial arts; he cannot swim or jog. However, he *does* still work out at the gym-- he can kick and punch a punching bag, for example. Sam relies on the exercising he *can* do, to help alleviate his ongoing physical problems.

Sam believes that EMS has damaged his connective tissue, including the fascia. As background information, many medical websites explain that fascia is connective tissue that covers the entire body, underneath the skin. It surrounds all the muscles, organs, nerves, bones and blood vessels. Fascia supports and lubricates all these body structures. In healthy people, fascia is elastic and relaxed, freely moving. Impairment to fascia does not show up in standard medical testing. Physical therapy websites offer information on myofascial conditions. ("Myo" refers to muscle.) For various reasons the fascia and muscles can become stuck together, resulting in pain, stiffness, and decreased range of motion. Both fascia and muscles lose functionality, and this is physically painful.

Because of Sam's long involvement in sports, he was already aware of the role that muscles and connective tissue play in injuries. He already knew of the benefits of treatments like massage in restoring functionality of muscles and fascia. After getting sick, he began to research EMS and fascia. He assesses his muscles fibers as having gotten "stuck together". Constantly experimenting with types of exercise that purport to deal with connective tissue and fascia, he has found that at least a few of these types of exercise do, in fact, relieve body tightness and allow to him feel better.

These days Sam's daily regimen includes several exercise/physical therapies: "foam rolling", basic loosening exercises, and a particular type of stretching called "compression stretching". He starts his sessions with foam rolling (a strategy for loosening up body tightness, utilizing dense foam cylinders of various sizes). Sam begins by putting one of

...continued on page 4

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**HELP WANTED:  
POSITIONS OPEN NOW:**

NEMSN's Board of Directors has 2 vacancies. The 7 current members of the Board are eager to fill these vacancies --- immediately! We hope you are eager to lend your experience and commitment to our mutual cause.

No previous experience necessary.

Monthly phone conference calls and occasional shared tasks make it easy to communicate and carry out NEMSN's mission.

Don't hesitate. Express your interest NOW. Call or email Michael Bird, NEMSN's Treasurer, at 540-368-0356 or [wiltshirebird@gmail.com](mailto:wiltshirebird@gmail.com) for more information.

**Please remember to use  
GoodSearch.com,  
GoodShop.com  
and iGive.com** when surfing the web.

Use GoodSearch when searching the web and GoodShop and iGive when making purchases online. Type in NEMSN as your charity. So far, since signing NEMSN up on these sites, we have earned \$83.71 on iGive and \$362.04 on GoodSearch and GoodShop. This money adds up, so please use these sites when possible. We need more supporters to help us earn much needed money. Thanks to all who have used these sites in our name.

**Connecting via EMS  
Sharing,  
an Online Group**

For those interested in connecting with others in the EMS community, there is an online Yahoo group called EMS Sharing, moderated by Faith Rumph. This is not a NEMSN function, but we are glad that the group exists. Faith Rumph advises that "anyone with EMS or who has a relative or other person with EMS is welcome to join. As the group is not 'advertised' or seen on search engines, it's hard to get the word out."

You can join EMS Sharing at this web address:

[http://health.groups.yahoo.com/group/EMS\\_Sharing/](http://health.groups.yahoo.com/group/EMS_Sharing/)

You can email any questions to: [faith\\_rumph@yahoo.com](mailto:faith_rumph@yahoo.com)

*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.

## An EMS-like Illness from Current Probiotic Supplements

The medical journal *Case Reports in Rheumatology* published an article in December 2012 entitled "Severe Eosinophilic Syndrome Associated with the Use of Probiotic Supplements: A New Entity?" by four doctors in Philadelphia (F.A. Mendoza, S. Purohit, L. Kenyon, S.A. Jimenez). The abstract of this article, which details two current cases of an EMS-like illness from probiotic supplements, can be found at: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3521401/>

Quoting from this medical research article:

"Severe eosinophilic syndromes related to the administration or use of unsuspected immunogenic substances have been described previously. Many of these diseases presented initially as clusters or isolated cases. The spanish toxic oil syndrome, the eosinophilia myalgia syndrome, and nephrogenic systemic fibrosis are examples of such diseases. We describe 2 cases of a severe eosinophilic syndrome characterized by marked peripheral blood eosinophilia (>15,000cells/ml), mononeuritis multiplex, and necrotizing vasculitis which developed in a close temporal association with the recent onset use of nonprescription probiotics. There was no history of a prior autoimmune disease. Although both cases had prompt response to immunosuppression with rapid resolution of peripheral blood eosinophilia and accompanying constitutional symptoms, they remained with permanent neurological deficits.

...

"Prior experience in unveiling the etiology of the eosinophilic syndromes has shown that a high index of suspicion is required. The description of these two cases may allow the recognition of similar cases and remind the medical community that the widespread use of agents seemingly considered to be beneficial and free of side effects may occasionally have serious consequences."

*Editor's Note: NEMSN has learned from Fabian Mendoza, MD, Associate Director of the Scleroderma Center at Thomas Jefferson University Hospital in Philadelphia and article author, that he and his MD colleagues at Thomas Jefferson do see eosinophilia patients. If anyone in the Philadelphia area is looking for medical advice, this might be a resource for you.*

### Caution:

L-Tryptophan products and other supplements on market may cause adverse reactions.

Tryptophan is legally on the market now in many forms. NEMSN reports ongoing contacts from people who tell of adverse reactions which they attribute to supplements which contain L-Tryptophan, to 5-HTP supplements (which are chemically similar to L-T), or to other supplements. Our Medical Advisory Panel has been monitoring the situation and has asked to be informed if any new cases come along. If you know of anyone who has become sick from products containing L-Tryptophan, from 5-HTP supplements, or from other supplements, tell them to save the product and contact NEMSN.

### To contact NEMSN about anything in this newsletter please send an email

to us at [nemsn.org@aol.com](mailto:nemsn.org@aol.com), or phone our Public Relations Director, Lois Vierk, at [201-868-9572](tel:201-868-9572), or you may send US mail to NEMSN, 767 Tower Blvd., Lorain, OH 44052-5213.

## Donor Honor Roll

through June 20, 2013

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

Michael Lawson

James & Roberta Shaver in memory of Joe Kintz

### Contributors (Sustaining) \$50 - \$99

In memory of Joe Kintz...

Ann Flaherty, Michael Valentine & Andrea Valentine

Lois Vierk

Michael Bird & Dayna Tolley

### Contributors (Friends) \$100 - \$249

Tiffin Metal Products in memory of Joe Kintz

## What Works *continued from page 1*

his cylinders on the floor. He targets whatever is hurting and tight at the moment--his back, his leg, whatever--and positions it on top of the cylinder. For up to five minutes at a time, he rolls himself back and forth over the cylinder until he feels relief. Sam makes his own foam rolls from inexpensive 5-inch PVC pipe which he wraps with foam rubber mats. He has made cylinders of different sizes and hardnesses. It's also easy to find exercise foam rolls for sale online and at some sports equipment stores.

After foam rolling, Sam does loosening exercises for a few minutes. These include easy arm swings, loose and easy leg swings, easy joint rotations of the wrists and shoulders. Finally he moves on to stretching. He has borrowed techniques from "compression stretching", a type of fascial stretching therapy. A definition found online (<http://www.livestrong.com/article/163642-compression-stretches-for-the-shoulder/>) states that "[c]ompression stretching is a form of exercise therapy that combines pressure and massage techniques with assisted manipulated stretches. This particular technique is frequently used by physical therapists and massage therapists, to enhance joint range of motion and warm up muscle tissue . . ." Sam himself does not go to a physical or massage therapist. He has developed techniques which he can do by himself with an exercise ball. Instead of having a therapist immobilize a body part by physically holding it down or applying pressure, Sam puts a hurting arm or leg, for example, under an exercise ball and puts some of his body weight onto the ball. He then gently pulls the immobilized part, stretching out a joint or other soft tissue, and this further eases pain and tightness.

The book *Stretch to Win* by Ann and Chris Frederick is highly recommended by Sam for more specific information on helpful techniques for any individual person. Sam says this book is available in many libraries. It is geared towards athletes but he advises it could be useful to anyone. As an aside, author Ann Frederick developed her therapeutic methods of fascial stretching therapy from a therapy developed in the US in the 1940s called Proprioceptive Neuromuscular Facilitation or "PNF". It was originally used to treat patients with musculoskeletal and neurological deficits, including polio.

Back to Sam -- he does his foam rolling/loosening exercises/stretching routine several times a day. It takes

him about 10 minutes each time. He also works out at the gym. I asked him why he does all that. His answer was simple and right to the point. He feels better and has less pain. His body functions better. He can move better. He is less prone to injury and has more strength.

Thank you, Sam!

### TO YOU IN SAM'S OWN WORDS:

**"I don't want the prolonged painful life and death other EMS patients have suffered. I feel that potential eating away at me every moment of every day. Because I have the knowledge to treat some of this, it gives me a choice. Others didn't get that opportunity, and this makes me feel obligated to continue. EMS life is an experiment."**

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### PLEASE SEND US YOUR OWN STORIES!

*What Works?* is a place to share experiences about what works to help relieve EMS symptoms. If there are things you do, routines you follow, treatments you take, etc. that help you, please get in touch so we can write it up here. Reading about what is good for you may help someone else find a way to ease the pain or get through the day better.

We know that the health of different EMS patients runs the gamut from being debilitated and incapacitated, to actually doing quite well. Whatever your condition, we'd like to hear from you.

Of course it's true that what's good for one person may not be appropriate or helpful for another, and NEMSN does not recommend anything in particular for a given individual. However, if you've found something that works to help, please get in touch with NEMSN, using the contact information on page 3.

This forum will not focus on medicines or the like. You're welcome to write to us about this topic too, but send it as a Letter to the Editor. *What Works?* will not be a place to advertise a particular product of any sort, though it's fine to mention products that you use.

Please get in touch and share your own story.

*by Lois Vierk with special thanks to Nancy Grant*

*...continued on page 5*

**Editor's Note:** The following is the story of Vivian Degani, EMS patient in New York City, who got sick in the 1989-90 epidemic. Vivian wrote this piece herself though it was never published in her lifetime. She passed away in 2002 from causes seemingly unrelated to EMS. Her sister, Lynne Mochon, recently found Vivian's handwritten manuscript and had it typed up, and then Lynne sent it to us.

We thank you, Lynne, for sharing your sister's words with us. It is clear that Vivian Degani was a brave woman with much determination to live life to the fullest, even as she faced this bewildering and debilitating disease, EMS.

## My Trip to Hell and (partway) Back

*By Vivian Degani, March 1991*

I guess it began the day I mulched. Now, I'm a city girl through and through. I agree with Fran Liebowitz's definition of outdoors: it's the space between your apartment and the taxi cab. This particular summer day in 1989 I was visiting my friend Carol up at her house in Elmsford in suburban Westchester County, New York. A few years ago, Carol, a childless divorcee, bought a huge 4-bedroom house sitting on about half an acre of land. She had a number of reasons for making this purchase. One of which was to enjoy country life, which is difficult for me to understand.

There is a long path leading from the street to Carol's porch and Carol had bought a bunch of marigold plants to line this walk on both sides. My assignment was to cover the soil with mulch before the marigolds were planted. I never did understand the purpose of this and in fact it's unimportant except for understanding the physical positions one has to assume to mulch properly. First one enters the garage where there already has been unloaded a big bag of mulch bought at the gardening store. With a small shovel, I had to shovel out a bunch and put it in a small bucket. I then had to walk with this bucket which probably weighed 5 pounds down the walk. I then had to squat and shovel out the mulch and spread it on the soil. I was to repeat this action until the whole walk was covered on both sides.

I didn't make it.

After a relatively short period of time I begged off this job complaining about the difficulty I had squatting and the heaviness of the pail. Instead I sat on the porch rocking in

a rocking chair, puffing on my Marlboro and sipping Diet Coke. Carol assumed that Vivian was being a princess. Didn't want to do any work that might make her sweat and her hands dirty. In truth, I agreed with this assessment and didn't think much of it at the time. Little did I know that I was beginning to exhibit signs of a neuro-muscular disease that could have proved fatal to me – indeed it did take 28 lives. [Editor's note: Eventually, as we know, over 40 deaths were officially attributed to the epidemic.]

There was nothing strange about me shirking heavy work. However, there were some strange symptoms that began to appear late that summer. First I started to itch. I was itchy over virtually every part of my body. I scratched so violently that much of my body turned black and blue. I went to a local clinic where I was tested for a host of diseases including Lyme disease and Epstein-Barr. All tests were negative. There was however one funny result that kept appearing in my blood work. I had a very high eosinophil count. An eosinophil is a type of white blood cell. Normally a person has a count of less than 500 in his blood. My count at various times went as high as 2,000. No one was clear on why, but thought it might be an allergic reaction to a drug called mellaril which had recently been prescribed for me.

The doctor at the local clinic referred me to a dermatologist who tried various combinations of anti-itch body creams and anti-histamines. Eventually the itching stopped but an even more ominous happening occurred. In all the areas where I had been itchy I now felt terrible pain. I couldn't be sure but it seemed to be muscle pain, a condition I had never experienced, since exercise was never high on my priority list. I was in pain all over my body. Now it was time to call out the big guns. I made an appointment with my internist Dr. Charles Friedlander. He was stumped as to what the problem was and in late August 1989 sent me for a consultation with a rheumatologist named Dr. H. Michael Belmont. Belmont was seriously uninterested in my case. At 140 pounds standing only 5'3" he surmised that I was severely out of shape and in dire need of a better diet and more (read any) exercise. I couldn't very well argue with this evaluation. That summer my stomach was so large that on a number of occasions people asked me when the baby was due. Indeed, one day I got on a cross-town bus and a gentleman stood up to give the pregnant lady a seat, while at the same time an elderly woman hung on to a pole for dear life.

*...continued on page 6*

## My Trip to Hell and (part way) Back ... *continued*

So here I was with an enormous gut, muscle pain, a high eosinophil count and no idea what was the matter. Dr. Friedlander next referred me to a neurologist named Dr. Gobinthan. He performed a battery of neurological tests on me and found nothing wrong. He casually mentioned that he could perform an EMG but it was a very painful test and he didn't think it would show anything anyway. As soon as I heard that miserable 4 letter word – PAIN- I concurred with him, wrote out another in what would be a long series of checks and went on my way.

Dr. Friedlander implored me to give Dr. Belmont another chance so I went back to him in September.

At this point he also noticed that I was losing weight – I was down to 118 without my shoes and he began to show some concern. He decided to send me to physical therapy and together we found a physical therapy clinic in the Ansonia Hotel near my apartment on 75<sup>th</sup> Street.

Please understand that I hadn't been in a gymnasium since 1971 when I was a member of Elaine Powers. I had joined that club on a "special 2 for 1" membership drive with my friend Patti who had just had a baby and needed to lose weight for that reason. I went to Elaine Powers for a couple of months and made friends with a few of the exercise instructors, one of whom told me about a diet doctor on the west side who easily and gladly supplied diet pills for a relatively inexpensive fee. After I started seeing Dr. Konigsberg I completely stopped going to the gym. (Patti meanwhile lost the weight went on to have a second daughter and remains my friend and looks terrific to this very day.)

I went faithfully to the physical therapist twice a week and to my surprise did the exercises at home which were advised. My boss was not all that happy about my leaving work early and I quickly was using up my sick time and eventually vacation time. When I was at work it was difficult to concentrate on any of my projects. I worked for the NY Division of Tourism as the assistant to the New York City Regional Tourism Director.. Together we labored to encourage travel to both New York State and City. My job duties involved very detail-oriented assignments. I was finding it hard to concentrate. After a few weeks of this activity my physical therapist made an important observation: I wasn't getting any better! In reality I was losing ground and life was becoming more miserable daily. I

went to work, came home, slept and started this dreary sequence again the next day. I didn't eat much because it took too much energy to prepare a meal – which in my case meant calling a restaurant and ordering food already prepared and delivered.

Getting to work became a nightmare. My habit was to walk a few blocks from my apartment to the IRT subway station. I then took the train two stops to Times Square. Disembarking from the train I had to walk up two flights of stairs to reach the sidewalk and then it was, yes a two block walk to work. My office was on the 51<sup>st</sup> floor of a modern building on Broadway at 44<sup>th</sup> Street.

By September I found I was having trouble walking up the two flights of stairs at 42<sup>nd</sup> Street. By the time I reached the street level I was gasping for breath and my legs both ached and felt like rubber. The two blocks to the office building were murder and it was only by the time I reached 44<sup>th</sup> Street that I began to feel normal again. I attributed this new problem to 20 years of smoking finally catching up with me and began thinking that I might have to eventually consider giving up tobacco.

By mid-September I was no longer physically able to travel by subways. I switched to buses, only the ones with "kneeling" front steps which describes most of the Manhattan buses. I'd wait for a kneeling bus, ask the driver to lower the steps which most did non-to-gladly. There were only 3 steps to deal with but it quickly became hard to even handle those. A number of times I'd ask a fellow passenger, a stranger, to stand behind me as I climbed those few stairs and give me a push if needed, which at times actually happened. I had to allow an hour to get to work by bus whereas the subway took me half that time. I would only get on the previously described kneeling buses and then only those that were empty enough to afford me a seat which takes some doing and waiting on a weekday morning at 8:30.

Eventually I had to give up buses because I couldn't climb up the three stairs to the fare box. I could only get to work by cabs, usually gypsy cabs, which is a costly and difficult enterprise.

In September I started to experience other strange events. One night I took a bath which felt soothing on my skin, only to realize that I could not get out of the bathtub. It took 20 minutes using all combinations of leg and arm motions to propel myself from the tub. From then on I

*...continued on page 7*

## My Trip to Hell ... *continued from page 6*

took only showers. I washed my hair daily as usual but found I didn't have enough strength in my arms to blow-dry my short do. I let it dry naturally and it looked it. I stopped putting on makeup. This alarmed my friends and family to no end. When I was a baby my first word was "mascara". I really believe that beauty is not from the inside but from Revlon. My giving up makeup was tantamount to Donald Trump giving up his ego, Madonna swearing off sex, you get the idea. I just didn't have the strength in my arms or coordination in my hands to apply makeup properly.

Other incidents were equally scary. One day, again in September, I was crossing 14th Street heading towards my first day of class at a course I was taking at the New School. While waiting for the light to change, my legs all of a sudden gave way and I fell in a pile in the gutter of the street. I scraped my arm and knee and they both bled. My tote bag and pocketbook also landed in dirty water in the gutter. A few passersby walked over to me and helped me get in a standing position. I reeked from the dirty water. I collected myself and continued to the New School where I shakily explained to my course advisor why I would be missing the first day of class. Tearfully, I walked one block west to Sixth Avenue and found a cab to take me uptown.

My trip to hell was just beginning.

By October my life was out of control. I could only travel by cab. I was in constant pain. I had no energy. I was losing weight and not even enjoying it.

One morning I was alone in my apartment preparing for work and I dropped a book. I bent down to retrieve it and again my legs gave way. I tumbled backwards and landed on my back with my head crashing onto the floor. I couldn't get up. I got onto my knees and tried to draw myself into a standing position by holding on to something – the bed, the bookcase, anything solid. Nothing worked, so I crawled all the way around the bed till I could reach the phone. I called my next-door neighbor Mary who thankfully was still home. She used her key to let herself into my apartment and was able to pick me up from under the shoulders until I was standing. I sat on the bed shaking as Mary left for work. Finally I was composed enough to get downstairs and find a gypsy cab to take me to my office.

In the office I had been running into all sorts of logistic

problems. When I had lunch in the cafeteria, I couldn't always get up from the chair by myself. The same was true at my desk and to my embarrassment in the ladies room. Someone finally suggested that I use the handicapped bathroom which turned out to be a life-saver. Using the bars on either side of the commode I could pull myself into an erect position. I was grateful that I was in a modern building which had been constructed with the disabled in mind. (Little did I know at the time that I was just beginning my journey in to the world of the physically handicapped.)

That day that I fell continued to get worse and worse. I got to work but couldn't concentrate on any of my assignments, even the simplest tasks. Finally, I sat at my desk and broke down crying. My friends will all tell you that it takes a lot to get me to cry. Even in the worst of my depressions I am sullen, maybe angry, distant, but I don't cry. This day I bawled my heart out. The phone rang and it was Renay. She heard me sobbing and was instantly alarmed. She asked what the matter was. I exclaimed about how much pain I was in, and how weak I was and the worst part is I didn't know what was happening to me. Renay remarked that for me to cry, I must be feeling horribly. I got off the phone and called my mom. We agreed that someone would put me in a cab and she would meet me in front of her apartment building on West 123<sup>rd</sup> Street. Diane Emery led me down in the elevator and through the lobby out to Broadway. She found me a cab and placed me inside by myself, shaking and crying. I started the half hour journey uptown.

It was Friday the 13<sup>th</sup> of October.

I spent a week at my mom's apartment, my situation constantly deteriorating. I couldn't get off the couch by myself. I couldn't walk alone to the bathroom at the end of the hall. My doctors had no idea what to do with me.

Finally, on October 21, 1989 I was admitted to University Hospital, part of the New York University Medical Center. At the time I didn't know that my doctors gave me a 50/50 chance of living. At the time, I didn't know that it would be the better part of a year before I was to go home again. At the time, I was just happy to be in a medical facility where my condition, whatever it was, could be monitored and there were nurses and aides around to help with the simplest of tasks which were becoming increasingly difficult.

*...continued on page 8*

## My Trip to Hell ... *continued from page 7*

At this point I'd like to interject a funny thought, but frankly nothing funny was happening at that time.

In the hospital I continued to worsen. The muscles around my lungs were beginning to weaken and there was some talk of possible respiratory failure. (This greatly interfered with my smoking which caused added tension. Since I could barely walk I was having a tough time getting into the ladies room to light up. Many of you might not understand, but the four smokers left in the world will relate to this dilemma.)

A chunk of muscle was taken out of my right thigh and biopsied. After much study and deliberation the good doctors came up with a diagnosis: POLIMYIOSTTIS. This is a disease of the arthritis family I was told the symptoms and the treatment. It sounded just like what I had. What a relief to know that I had a real, although rare disease. I contacted the arthritis foundation and they sent me info about this ailment. The course of treatment included two main factors: the use of a steroid, usually prednisone, and physical therapy. They started me on prednisone, 60 milligrams a day, and began sending a physical and later an occupational therapist to my bedside. Get well cards started arriving to my room along with a few bouquets of flowers from co-workers and friends. My mother's staff collected money on my behalf and wanted to buy something for me. I nobly suggested the money be donated to the arthritis foundation, my new cause.

Life went on in the hospital. People visited, calls were made and although I continued to deteriorate slightly there seemed to be some feeling that the illness had been arrested.

November [1989] arrived. One morning there was a column in the New York Times health section about a new condition brought on by the consumption of an amino acid called L-Tryptophan (L-T). Dr. Friedlander called and asked if by any chance I had been taking L-T? I said yes. He exclaimed "My God, I think we know what is really wrong with you!"

It appears that a new disease was in the process of being discovered and the culprit was this manufactured form of a naturally occurring amino acid called L-Tryptophan. Tryptophan (the natural form) is found in many common foods and drinks and is considered a die-

tary aide. When you drink a glass of warm milk, that makes you drowsy. On Thanksgiving Day when you feel tired after the big feast it is the Tryptophan in the turkey that poops you out. Tryptophan is found in many other often used foods such as tomatoes and other fruits.

All of my life I've had problems with sleeping and I've tried a host of remedies for this most unpleasant condition. In April of 1989 a doctor whom I was seeing recommended L-T for insomnia. L-T is not a drug and supposedly has no side effects and is completely safe(!). It is an over-the-counter product sold in health food stores and pharmacies. I took L-T for 6 months from April 1989 until I went into the hospital that October. It was interesting how this disease was discovered in the first place.

It seems that a number of people in New Mexico were exhibiting symptoms that describe my condition as well. These include muscle and joint pain, a high count of eosinophil, fatigue, weakness, skin abnormalities, shortness of breath and so on. Doctors in New Mexico were alarmed by this outbreak and contacted a specialist at the Mayo Clinic. The one common factor that kept appearing in this original group was the use of L-T. Soon there were cases of this strange new disease, which was named Eosinophilia Myalgia Syndrome (EMS), popping up all over the country.

On November 11, 1989 the Food and Drug Administration issued an alert to the public to stop taking L-T. Shortly after that the New York State Department of Health called for the removal of L-T from all stores in the state.

By late November I had been in University Hospital for a month. The good news was that my doctors now knew what was wrong with me. The bad news was that my condition was worsening. When I entered the hospital I could still walk albeit with difficulty. A month later I was confined to a wheelchair. I would work out daily with the therapist who was sent to my bedside. At this point Dr. Belmont assumed control of my medical condition. He contacted the Mayo Clinic, too, as well as other doctors whose names were in the articles appearing in the press. The early word on treating EMS was the use of prednisone which I was already taking, the discontinuation of L-T and lots of physical therapy.

To this end it was decided that I should be transferred next door to the Rusk Institute of Rehabilitation Medicine. Rusk is a world famous rehabilitation hospital and, I found

*...continued on page 9*

## My Trip to Hell ... *continued from page 8*

out, difficult to enter due to its popularity.

On November 29<sup>th</sup> I finally got word that there was a bed available for me at Rusk. My mom and I packed up my belongings and commandeered a cart for the transfer. The buildings are connected so I didn't even have to go outside. One of the aides from 16 West accompanied us and our move was timed to correspond with the change of shifts at 3:30 pm. My room assignment was a quad room on the fourth floor. As our trio entered the long hall on the fourth floor of Rusk I experienced the shock of my life. All around me were wheelchairs filled with handicapped people – men missing legs, old women confused, sad looking, disabled – it was a nightmare scene from hell. I got to my new bed but found that the day and evening nurses were in report and that the aides who had just started their shift hadn't yet been told of my condition. No one could transfer me from the wheelchair to my bed. I was in pain and I just wanted to lie down, but I was confined to the chair.

My three new roommates were hanging around – Melody later named them the Golden Girls. They were all old and sick. One was terribly confused and talked to herself on the telephone. The second was a fat ugly lady who suffered from claustrophobia and wouldn't allow the curtain between our beds to be drawn – even when I needed to use the bedpan. The third was just plain nasty. She resented my having the light on and the TV playing till as late as 11 pm. She announced to all who would listen that “she would find some way to antagonize me”. Eventually the aides got word that I could be transferred into my bed. I had been in the chair for almost two hours and I ached. I've never been so scared in my life. I cried and cried and couldn't stand to look around at all the cripples. Then it dawned on me – I was one of them. I was disabled, handicapped, crippled. Then I really started to cry and was inconsolable. My mother was in shock too and didn't know what to do with me. She wanted to take me out of that horrid place but there was no place on this earth for me. I was sick, I couldn't walk. I needed help and Rusk was the place where I could get this help – if I could survive the first night.

Even though I'd already been hospitalized for over 5 weeks, my arrival at Rusk demanded a new admittance procedure including the usual EKG's, chest x-ray and a medical history with the nurses and residents. What was I doing in a place like that – it seemed surreal but it was

very real and scary. The first good news that I heard was that after this initial interview I was allowed to leave the floor. Mom and I took the elevator to the ground floor and she wheeled me into the vending machine room which was a filthy lounge surrounded on all sides by vending machines offering foods and drinks. The good news for me was that smoking was allowed in this place which would be my escape hideaway for the next few months.

By now we were hearing the end of visitor's hours so Mom had to bring me back upstairs. It broke her heart to leave me, slightly hysterical in that cold unfriendly room.

I was transferred back into bed where I spent what was left of the evening crying. Mercifully I finally fell asleep.

Life didn't improve during the next few days. I began to get assignments for physical and occupational therapies. My first class of the day was to be mat class which involved exercising on the mats in the gym. At this point in my illness I was virtually paralyzed. None of my muscles were working. It would be months before I began walking again and even then it would come to me slowly, using a platform walker and with the assistance of two therapists.

This first day I was taken to the gym on the third floor and was greeted by Stephanie Gardner who was to be my one on one physical therapist. Stephanie was a young, very pretty 21 year old in perfect shape, as were many of the other therapists in the gym. This was in marked contrast to the patients who again shocked me by the array of disabilities exhibited.

Eventually I would look on my fellow patients as a group of hard working, brave people trying desperately to improve their lot in life. I got to admire many of these folks and was inspired by their courage

But on this first day all I could see was a lot of sick people with unspeakable handicaps – people missing legs, unable to stand or walk, disfigured, handicapped.

I spent those first few days crying in the gym and again was shocked to realize that I was one of these sick people. I resisted all attempts of people helping me and didn't want to go on.

Well, days turned into weeks and weeks into months. My mom visited me every evening after she finished work which was an enormous strain on her. My friends were incredible. I don't think I could have survived those days without the support of my family and friends.

*...continued on page 10*

## My Trip to Hell ... *continued from page 9*

Soon a pattern developed. At 9 am I had mat class for an hour. At 10 am there was occupational therapy for half an hour, where we worked on upper body strength. I was free from 10:30 am until 11:30 am and often went down in my wheelchair to the vending machine room where I had my first cigarette of the day while reading a book borrowed from the patients library and treated myself to a can of tomato or V-8 juice.

At 11:30 it was back up to the third floor gym where I was strapped to a tilt table for half an hour. Then came lunch from 12 to 1 pm. My weight was becoming a source of concern to the medical staff. As my illness progressed my weight dropped until I was down to 80 pounds. The nutritionist met with me a number of times and we worked out a plan for weight gaining, including snacks in the afternoon and evening and doubles on a lot of my favorite foods.

At 1 pm I went to the greenhouse which served also as a haven of beauty away from the reality of illness surrounding me. In the greenhouse I worked with the horticultural therapists Nancy and Patrick on planting and working with the soil and cutting. This was an unbelievable help to increasing motion and capabilities in my hands in a beautiful setting. There were birds in the greenhouse and fish in a pond. All around were orchids and plants of unbelievable shapes and form. For the hours a day that I worked there I was able to work on my therapy and escape the bleak realities of my condition as well.

At 2 pm I met with Stephanie for a half hour of individual physical therapy. At first it was a 10 minute job just to transfer me from the wheelchair to the mats where we worked on stretching and exercising my sickly muscles. I loved and hated PT at the same time. A lot of what we did in this half hour was very painful. At first the progress was so slow that it was very discouraging. I couldn't move a muscle by myself. I wondered if I'd ever walk again or if I was destined to be an invalid forever.

At 2:30 pm my regular schedule for the weekday was over. Very often, however I had appointments of one sort or another. Every patient at Rusk is asked to meet with a psychologist and I was assigned to a young man named Dan McNeill. I also met with a vocational counselor, Mark Johnson, and we spent many sessions discussing the

possibilities of eventually going back to my job or possibly starting a new career keeping my disabilities in mind.

Dr. Belmont came to see me every other day and Dr. Kieran, my psychiatrist, came as well.

After a few days on the fourth floor I was transferred to One North where most of Dr Kieran's patients were assembled. I entered another quad room but this time was delighted to not only get a bed by the window but to have three wonderful roommates. I would spend the better part of the next year in room 124, Bed B and in all would have 17 roommates. The average length of stay for a patient at Rusk is eight weeks, some less, some more. During this long period of time and considering the serious and life challenging reasons we were all there, you really got to know people. One woman, who was to become a good friend of mine, just learned she had multiple sclerosis and she was in Rusk to recover from her first MS attack on her muscles. Another new friend lost her right leg when a car careened off the road in Brooklyn Heights and hit her while she was protecting her young son. The stories, the pain and the constant bravery displayed goes on and on. Many Rusk patients were older men and women who had suffered strokes and were working tirelessly to regain the skills that they lost. I learned a lot about strength and courage from my fellow patients. We all also supported each other's advances. When Beryl took her first step, and Dorothy uttered her first word after her stroke left her unable to speak, everyone cheered.

Time passed, sometimes slowly, sometimes too quickly. I spent many holidays in Rusk and found that all the staff went out of its way to make life more pleasant for the patients on these special days. In particular, the recreational therapy unit and the dietary staff did yeoman work to ensure as much happiness as a hospital could offer. Special meals were served and parties were planned to celebrate Christmas, Chanukah, New Years. We all received cards on Valentine's Day, matzo during Passover, hot cross buns during Lent and everything turned green on St. Patrick's Day. There is a New York State Law that a rehab cannot be closed three days in a row, so when a holiday fell on a Monday or Friday we still had classes. Eventually I was well enough to add ambulation class and the swimming pool to my schedule.

Everyone has good days and bad days and that's certainly no more true than when you're in a hospital. Prob-

*...continued on page 11*

## My Trip to Hell ... *continued from page 10*

bly my worst day came at the end of January when I learned that my 18 year old cat, Prudence, was terminally ill. I arranged to go to my mom's house to say goodbye to her, which anyone who has ever had a pet will understand is a heartbreaking experience. I had to hire an aide for the day and an ambulette to take me in my wheelchair to and from the hospital. Another low came in February. My nephew who lives in Mexico City had his Bar Mitzvah, an occasion I hated to have to miss. My mom reluctantly left me for a few days and flew to Mexico for this important event. She came back with a suspected case of Typhoid Fever and was confined to her bed at home for several weeks. During this time when she couldn't visit me, my friends were greater than ever. I'm afraid to name names and inadvertently leave someone out but I must mention Carol whose name appeared at the beginning of this story. She came practically every week for the 8½ months that I was in the hospital and I don't know what I would have done without her, especially during the period when my mom was ill. In early April, my sister Lynne flew up from Mexico and was a great help to my mom and me. The weather was beginning to get nice so Lynne took me out in my wheelchair and I got a haircut for the first time in months. I also went home for a day during her visit. This time I still needed an ambulette but I no longer needed to hire an aide. My mom and sister had learned to transfer me from place to place including the toilet, which was still very much a challenge.

As I said there were highs too and my biggest one came on May 21<sup>st</sup>, my 40<sup>th</sup> birthday. I went around the first three weeks of May telling anyone who'd listen that my birthday was approaching. The day before my birthday, I put together 80 "goody bags" filled with cookies and candy so that the therapists and fellow patients could help me celebrate. On the day itself I was overwhelmed with flowers, candy, telephone calls, presents and three separate parties with cakes. At about this time I began to walk again and showed off to my friends by walking from my room to the cafeteria in the adjoining building connected by a long corridor. That day was one of the happiest days I've ever had.

I was definitely getting better albeit slowly. I was also learning more about this disease I had, EMS. The first articles appeared in the newspapers and magazines in November 1989. On Nov. 25<sup>th</sup> I read an article in the New

York Times which discussed two theories of what happened with L-Tryptophan. One was the possibility of an addition of a contaminant. The other theory discussed the failure to remove impurities in the manufacturing process in Japan where L-T was made. In February 1990 the first law suit was filed against Showa Denko, the Japanese manufacturer, by a woman afflicted with EMS in Portland, Oregon. On March 14<sup>th</sup> the Daily News carried a story about a second lawsuit that was filed by me. The local television stations picked up on this story and three stations came to the hospital to interview me.

Throughout March articles appeared with alarming frequency about EMS-afflicted people throughout the country. I saw articles from newspapers in Washington D.C., in Boston and I read a story about EMS in *People* magazine. The most recent story I saw was an article in Reader's Digest in the April 1991 edition entitled "Anatomy of An Epidemic". The most recent figures I've read show that more than 1500 people throughout the USA were affected by EMS and 28 deaths were attributed to this disease (in the initial outbreak). I learned that I was one of the most severely affected. After months of physical therapy and steroids I was still suffering from the many symptoms of EMS and was especially bothered by muscle weakness and pain. In addition, new symptoms kept appearing and even now I do not know what to expect.

Nevertheless I was improving and on July 5, 1990 I was discharged from Rusk. I went to my mom's two bedroom apartment on Manhattan's West Side where I am still recuperating. It hurt to leave all my friends at Rusk even though I knew I would see everyone again when I came back for out-patient therapy which I continue to this day. I've been told that the prognosis for EMS patients is not very good. I don't know what this means and I don't know what the future will hold.

But that's another story.

### Doctor Recommendations Needed

NEMSN is trying to update its list of physicians and other healthcare providers who can diagnose EMS and who are helpful in treating symptoms. Do you have a doctor or physical therapist, massage therapist, etc. to recommend? Please let NEMSN know so we can pass the information on to others who are contacting us. The list we

*...continued on page 12*

## Letter to the Editor: Question on Drug Sensitivities

Hi,

I was diagnosed with EMS back in 1989-90. My condition has improved very little since becoming ill and seems I have a harder time with issues as I get older. I am 66 years old now, will be 67 in December. I still get the Newsletter and I'd like to thank you for that.

I have found I have developed a few problems and I was wondering if other EMS people have experienced them. Over the years I have developed a very serious and unfortunate problem with chemical sensitivity. That would be prescription medications as well as OTC medicines and even soaps and lotions. It seems whatever the doctors prescribe for me, I will have very serious reaction and despite ceasing the medications, the damage remains. A doctor had me to take Zoloft and the reaction/allergic condition to it was very wide spread and serious. The symptoms have made my pain, skin problems, fatigue and weakness much worse. Everything has intensified and appears to be permanent. It has gotten to the point that I refuse to take any new medications for fear they will make things even worse. I just can't take any more horrible reactions and/or allergic disturbances. The Zoloft did several really horrible things to me and I can't fight any more health issues or damage.

I took Darvocet until they removed it from the market. It helped me more than anything with no adverse effects. Now I am prescribed Vicodin and the best I can say for it is that it is better than nothing. I also take Xanax for the surface skin burning and depression and Elavil to help me get proper sleep. I take 2 different kinds of blood pressure medicine for my Hypertension. The pain makes my blood pressure go very high. One thing I have been using lately for the pain is a TENS Unit (machine). Transcutaneous electrical nerve stimulation (TENS) is the use of electric current produced by a device to stimulate the nerves for therapeutic purposes. The TENS Unit has helped me so much. It is a wonderful thing. I would wear it 24/7 if I could because when I take it off, the pain comes back like a brick in my head. Do you know of any one who has tried a TENS Unit? It's amazing, it really is. The burning/on fire sensation on my body goes away for awhile and it's a blessing. The TENS Unit is not the do-all, end-all solution but it does help soothe the pain in the time periods between oral medications or when the pain really intensifies.

The TENS has given me some freedom of movement and better functionality.

It is a sad thing when a person can't remember what it's like to not be in constant, excruciating, intense pain. Between the Vicodin, Xanax and the TENS Unit, I do have some comfort in my life. I do have to walk with a cane. I can't walk without it for a very long time and I walk very slow. My legs are very weak. I have also become Lactose Intolerant.

Well, I was curious about the chemical issue and wondered if this was a problem with other EMS victims and I wanted to let you know how helpful my TENS Unit is. It just may help other people with their terrible pain. Is there a Facebook home for EMS victims?

Thank You

Fay Austin, Wauseon, Ohio

*From the editor: If you have a response to Fay's questions, please get in touch with NEMSN by using the contact information on page 3. We can also put you in touch with Fay directly.*

*As for connecting with other EMS patients, see the notice in this issue about the online Yahoo group EMS Sharing. There also is a Facebook site for the EMS community. In your Facebook account, at "Find Friends", search "NEMSN". (There has not been very much activity on our site, and it would be great if more people posted.)*

*See next page for poem, Silently, was written by Fay.*

### Doctor Recommendations

*continued from page 11*

are compiling will not be published but will be available to any EMS patient who asks us for help and information. We're looking for doctors and other healthcare providers in the US and anywhere else in the world, too. Please get in touch by emailing NEMSN using the contact information on page 3.

Thank you.  
NEMSN Board of Directors

## *Silently*

*By: E. Fay Dyer-Austin*

*Pain...  
how does one explain...  
Pain?*

*It becomes as natural  
as breathing...  
it eats away at me till  
I am seething...*

*And I wonder,  
with my life asunder,  
lost to pain.  
Why do it at all?  
I'll make this call!*

*People-watching...  
I go on wondering,  
how do they dare?  
Walk without care?*

*And I am here,  
wracked with pain.  
Going insane.*

*Resentment grows...  
they'll never know.  
My pain.*

*When you have lost  
all memory of...  
living without pain.  
A way of life,  
in constant strife.  
Again.*

*Of this I'm sure,  
I'll never know...  
in joy proclaim.  
It belongs to pain.*

*So, I stand up,  
I sit down.  
I scream inside,  
yet walk around.*

*I lie in bed.  
Pray for release.  
But even then...  
it does not cease.*

*Pain...  
It's been so long.  
I can't recall.  
One moment free,  
from the burning pain,  
which devours me.*

*Is this the all...  
A constant fight,  
this dreadful plight.  
Much easier to give in,  
and let it win.*

*Yes, just sit down,  
not move an inch.  
But still I flinch,  
from the pain.*

*This must be hell.  
This I know well.  
If it were living,  
for love and giving.  
There'd be no pain.*

*In summer rain.  
Or winter snow,  
of this I know.  
It is forever,  
Yet, I endeavor...*

*To rise above,  
the power-play.  
From day to day.*

*As I do,  
and always will.  
Succumb and take,  
a little pill.  
Perhaps then smile,  
for just a while.*

*But then  
again...  
in torrent  
rain...  
that relentless  
pain.*

*Just let me stand.  
Five minutes please.  
Would be so grand!  
To stand with ease.*

*Alas, there will  
never be...  
one painless night or day  
for me.  
And as I do constantly,  
I'll suffer pain...  
silently.*

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