

Neuropathy News®

Together, we can beat this disease

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Editor Mary Ann Donovan
Associate Editors Irene H. Beer
Josh Justin
Leila Lieberman
Medical Advisor Norman Latov, M.D., Ph.D.

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A Twenty-Five Year Medical Nightmare

by William D. Haupt III

Twenty-five years ago, while on vacation in Hawaii, I woke up and felt like I had swallowed a watermelon. My stomach was as swollen as if I had just eaten a nine-course turkey dinner that needed to come out. It never did. For the next few days I tried everything to relieve the pressure. Nothing worked. Not only was my abdomen bulging like an over-inflated inner tube, but I had chronic constipation, with a very uncomfortable numbness/tingling all over my body. The pressure in my abdomen was intense, and I could not relieve it in any way.

After returning to the mainland, and numerous trips to four different doctors, which included everything from blood tests to "barium enemies"(sic) (upper and lower GI's) I was informed by my gastroenterologist that I had a chronic case of IBS - (irritable bowel syndrome) and depression and stress, but ---nothing more. I was told I needed to reduce the "stress in your life and you will be fine." He gave me laxatives and sent me to a biofeedback program for stress therapy.

For the next twenty-five years I chased the medical "bluebird of gastroenterological paradise", trying to

find a cure for this "non-classic case" of IBS that never got any better. I was sent to psychologists, psychiatrists, acupuncturists, herbalists, internists, pain therapists, biofeedback professionals, stress management specialists, hypnotists, witch doctors, and anyone else who received me by default. Nothing helped to relieve my symptoms. In fact they continued to get worse on a daily basis.

During this time, I continually informed my family doctor as well as my gastroenterologist of my daily unwavering symptoms: swollen abdomen, heat intolerance, nausea, passing of undigested food, early satiety, constipation, dizziness after standing, easy bruisability, urinary incontinence (overflow), slow healing, etc. All of these symptoms were dismissed as chronic IBS, depression and stress, but--- only that. I was told that all "fair haired, light complexioned people bruise easily." When I alluded to the fact that I could no longer eat any solid food, they reiterated that it was all in my head. "Go back and tell your psychiatrist, because he is the only one who can help you."

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Autonomic Neuropathy

Diagnosis and Treatment

by Louis H. Weimer, M.D.

Director, Clinical Autonomic Laboratory,
Columbia-Presbyterian Medical Center

INTRODUCTION

The term Autonomic Neuropathy (AN) is used when ever the autonomic fibers, alone or in combination with other parts of the peripheral nerves are impaired. Its manifestations in most patients with Neuropathy are mild, but in some cases, it can be life threatening or debilitating.

The autonomic nervous system (ANS) is comprised of a collection of nerve centers in the brain, spinal cord and peripheral nerves. Their function is to control the 'automatic' body functions such as blood pressure, heart rate, eye focusing, sweating, gastrointestinal motility and others, which are not under conscious control. Under everyday conditions, virtually every organ and system in the body is under some autonomic control, with opposing autonomic fibers (cholinergic and sympathetic) producing a balance that is also affected by such body or environmental conditions as temperature, mood, medications, food intake and rest or exercise. The autonomic fibers in the peripheral nerves carry information from the brain and spinal cord to the internal organs and their involvement in Peripheral Neuropathy can lead to symptoms resulting from over or under activity of the end organs

SYMPTOMS

Successful intervention and treatment requires that the Autonomic Neuropathy is suspected and diagnosed. The following are the types of symptoms that can result from Autonomic Neuropathy:

- **Dry Eyes and Mouth.** AN can lead to disruption of adequate tear and saliva formation, producing dry eyes and mouth. Numerous medications produce the same effect by blocking the autonomic nerve signals, e.g., certain antidepressants. Avoidance or substitution, if possible, of these medications that may worsen the condition is important. Common sense treatments such

(continued on page 4)

Living with Autonomic Neuropathy

by Lizzie Abbot

My husband found me lying on top of a pile of boxes outside of Bloomingdale's. It was not the first time he had gotten a call from me that I couldn't get home on my own. He was used to finding me prone in strange places. We almost had it down to a routine. He would wrap me up in a blanket and take me home. Then, like Peter Rabbit, I would be given a cup of chamomile tea and put to bed. By the time he brought me the tea, I would be out for the duration. Sometimes I slept for 12-14 hours. During this time I would not move or roll over. I would stay so still, my self-winding watch stopped. When my husband would try to wake me, I could not be roused.

This was Autonomic Neuropathy at work. Autonomic Neuropathy is a failure in the signals that control our breathing, heart rate, blood pressure and digestive system, those parts of our body over which we have little or no conscious control. Although I had other symptoms, my most dramatic were near faints. I've been known to lie down nearly anywhere, from the bench in the locker room where I swim to the sidewalk. My neuropathy affected my blood pressure. When it dropped, my whole body felt it. If I didn't get enough blood to my head, I couldn't think. I became dopey. I dropped things. I fell down. Sometimes my balance was so affected, I staggered like a drunk. Simple tasks were difficult. Once I sat down on the floor and cried because I couldn't get the key in the lock to my apartment. (I was on the wrong floor.) There were other signs I was losing it. When I put popcorn in a bowl, it ended up on the counter. I fell down on perfectly flat sidewalks, which resulted in a scenic tour of New York City emergency rooms. I couldn't read -- my eyes were blurry. I had the attention span of a gnat. Nausea and fatigue were daily companions. My symptoms came and went.

What I hadn't told my husband (and hadn't admitted to myself) was that I often lost control of my bowels and bladder. I learned ways to cope. I kept a complete change of clothes at my office. I was frequently nauseous, and had, upon occasion, even made myself vomit hoping to feel better. Vomiting didn't help, but it did make me sleep for long stretches. Sometimes, afterwards, the nausea stopped.

My first "spell" happened after swimming. I almost passed out going up the pool ladder. I then vomited and had to lie on the bench in the locker room in my wet bathing suit. By the time I was able to get up, my bathing suit was dry. Next time I had a "spell", I was presenting plans for a renovation to a psychiatrist and his wife. He told me to see a doctor.

I didn't have one. My internist and friend of 25 years had retired. In a period of my life filled with losses this turned out to be one of the biggest. We had lost my mother, my father-in-law and my husband's brother, the last through a terrible long death from throat cancer. Each one of us had lost our best friend to other forms of cancer. We moved out of a house we loved because of my problem with the stairs and then we lost our money. Life is a journey, we said. Sometimes there are bumps along the road. We thought we'd handled them pretty well. What we didn't know was that our visit to the land of illness was only the warm-up for the grand tour. That spring, my husband was diagnosed with the same type of throat cancer that his brother had. With a whoosh, our tour bus was off.

Throat cancer is an ordeal. Each phase has its own horror. Behind each one was the shadow of my husband's brother and a feeling that perhaps we couldn't lick it. Our kids were great. We were all trying hard. Without any medical training, I was trying to care for my husband who was barely biologically viable. I was trying to run my job via laptop, e-mail and telephone. I was worn out. My muscles twitched. I had strange electric sensations. Secretly, I thought I was losing my mind. It was stress -- I'd read stories about stress. It could play tricks with your mind. I was exhausted -- it was depression, no doubt. My husband was depressed. Who wouldn't be?

The psychiatrist on the oncology unit was remarkable. Board Certified in three specialties, he was also the lead writer on the "Manual for Diagnostic Criteria for Mental Illness in the Medically Ill." We went to see him together. In no time he had my husband on track. One day as he hauled me out of the sofa, he asked what I was doing about my disease. I may have thought I was crazy, but he didn't.

I decided to call the neurologist I had seen a few years before for my burning feet. After a bevy of tests she phoned. "Your test results are back," she said. "You have a degenerative, progressive spinal cord disease. I think it is MS. I'm sorry." I was shocked. I didn't know anything about MS, but I found out fast. MS doesn't have to be, but can be debilitating. She also told me I was a "difficult" case. Before starting MS medication she wanted me to see an MS expert. He agreed with her

assessment, but he thought it could also be CIDP (Chronic Inflammatory Demyelinating Polyneuropathy). I was relieved that it might not be MS, but concerned that I could not start medication that would slow the progressive nature of my illness. We had to wait for symptoms to develop. Develop they did. My flare-ups were more frequent and severe. Somewhere in here, I decided if I didn't have a diagnosis, my doctors didn't believe I was sick. I must be crazy, I thought. I stopped calling my neurologist. When I "crashed" I went to my internist or the ER. After one long, nasty bout, my internist declared with impatience, "You have a serious medical condition! We need to do something." But there was not enough information. I was discouraged. After two and a half years, the MS expert decided I did not have MS. He didn't know what I had.

Just when I was about to give up, I got the information I needed. At my next flare-up, the physician on call was an expert on Neuropathy. After some specialized tests, he was able to give me a diagnosis-Autonomic and Small Fiber Sensory Neuropathy. My falling and dropping things was low blood pressure brought on by a peripheral rather than the central nervous system involvement that would be characteristic of MS.

I am now taking Midodrine, which is a miracle drug for hypotension (low blood pressure) even though my Neuropathy now includes an abnormal variable heart rate. With the tweaking of various medications, I am feeling better than I ever would have thought possible. Last year at this time I was out of work for eight weeks, barely able to move from my bed to a chair to look out the window. This year, I am packing my watercolor box and brushes to go painting in Tuscany (a secret fantasy). We don't know the cause of my Autonomic Neuropathy. If it is immune mediated, there are medications that can make a significant improvement. I am giving myself Enbrel, a powerful anti-inflammatory usually prescribed for rheumatoid arthritis. Some people with my symptoms have good results with it. I am hopeful I will be one of them. While I am feeling good now, I can't forget that I have a chronic illness. I need to pace myself.

Some days I believe that my visit to the land of illness has made me a richer, kinder, better person. Sometimes it just feels like a bad trip. But I do have a few tips for fellow travelers. People I expected to rely on vanished, but new friends appeared. I've been surrounded by unexpected love. Coincidences feel like miracles. It gives me comfort to believe they are. Every minute counts. I appreciate where I am today more than ever. My husband is doing well. Each morning when I wake up, I reach out, touch his fingers. I am so glad that we are here, together, today, alive.

AN

Autonomic Neuropathy

Diagnosis and Treatment

(continued from page 2)

as artificial tears and frequent small sips of water are often all that is needed.

- **Sweating and Skin.** Sweating helps control body temperature. In AN, sweating is frequently reduced or absent distally in the legs, in a similar pattern to numbness, but it can also occur in other areas of the body. Many patients do not notice this change unless called to their attention. Other areas in the skin may try to compensate producing areas of excessive sweating. Intolerance of heat may result if sweating is sufficiently reduced. Maintenance of proper skin moisture and local blood flow which affects temperature can also be affected, and patients may complain of excessively dry skin or cold hands and feet. Occasionally swelling and color changes (red, white, or blue) can occur. As a consequence, the overlying affected skin will often look different from unaffected areas with thinner, dry, shiny skin with less hair.

- **Vision:** Abnormal regulation of pupil contraction or dilation can lead to inadequate light reaction experienced as average sunlight becoming bothersome and some visual blurring or focusing difficulties despite adequate glasses.

- **Bladder:** Bladder function is under close autonomic control. Symptoms include frequent urination, difficulty initiating urination, or incomplete emptying. In more severe cases, bladder incontinence may occur. Medications that boost or block the cholinergic portion of the ANS may be used to tune bladder function depending on the symptoms.

- **Sexual function:** Sexual dysfunction is common in AN. Men may experience difficulty in obtaining or maintaining erections or in ejaculation. Women may experience inadequate vaginal lubrication.

- **Gastrointestinal functions:** Frequent symptoms include an early sense of fullness or frequent nausea after eating, abdominal cramps and pain, severe recurrent constipation, and bouts of diarrhea especially at night. Numerous medications are available to slow or enhance movement of the appropriate region of the GI tract depending on symptoms, for example enhancing stomach movement or slowing colon transit. A

A rational approach to treatment can minimize symptoms if properly diagnosed.

rational approach to treatment can minimize symptoms if properly diagnosed.

- **Heart rate/Blood pressure:** In severe cases, a combination of failures leads to an insufficient maintenance of adequate blood pressure (BP) when standing (orthostatic hypotension), resulting in dizziness or even fainting (syncope). Lesser symptoms, sometimes overlooked, include: headache, spinning sensation (vertigo), anxiety, fatigue, general weakness, palpitations, and tremulousness, that usually occur briefly after standing and relieved by sitting or lying down. Autonomic pattern dizziness is usually worse in the early morning, shortly after standing, and after a large meal, especially if high in carbohydrates. Measuring the BP lying down and at least

2 minutes after quiet standing is a simple way to measure the degree of BP drop. Medications that help maintain blood pressure are available.

DIAGNOSIS

There are a number of laboratory tests that are available to evaluate autonomic functions. These include tests that measure changes in heart rate and blood pressure upon lying and standing, or that measure sweating or autonomic skin functions.

The causes of AN are many. Mild involvement of the autonomic system occurs in many types of neuropathy, but the most common cause is diabetes, especially in juvenile cases. Other causes of prominent AN include amyloidosis, rare genetic and hereditary conditions, and certain immune-mediated, infectious, and toxic conditions.

THERAPY

The most important treatment is that directed to correct the underlying cause, if possible. Symptomatic treatment is also frequently available. For example, simple measures such as compressive stockings, elevating the legs of the head of the bed, and eating more frequent, smaller, low carbohydrate meals can minimize BP drops with standing. Also medications that increase fluid retention raise BP, and increase red blood cells are available if further treatment is needed. Similarly, management of the symptoms of poor autonomic control in each of the other systems, if sufficiently severe, is also usually available.

RESEARCH

There is some, but not enough. Hopefully as recognition of the importance of Autonomic Neuropathy increases, more funding for research and advanced treatments will follow.

AN

\$500,000 Jack Miller Gift Launches New Research Effort In Peripheral Neuropathy

Jack Miller, a member of our National Advisory Council, has made a gift of \$500,000 to The University of Chicago, which will be used to launch a concerted effort by neuroscientists there to investigate the basic biology of Peripheral Neuropathy and to find better treatments and finally, cures for this common nerve disorder. Mr. Miller, of Lincolnshire, Illinois, is the founder and president of Quill Corporation

The gift is intended as a pilot step toward establishing an eventual center for Peripheral Neuropathy to encompass basic and clinical research as well as patient care, outreach and education. The current gift will fund two, two-year research fellowships for young neuroscientists, providing them with laboratory equipment and clinical resources. One of the investigators will concentrate on the basic science of Peripheral Neuropathy and the other will perform clinical studies involving this disease.

It will also support the establishment of a Neuropathy Clinic, under the direction of Raymond Roos, M.D., Professor and Chairman of Neurology at the University of Chicago, and Betty Soliven, M.D., Associate Professor of Neurology and a member of the committee on neurobiology. The clinic, which will include neurologists along with an expert in orthotics and a physical therapist, will provide comprehensive diagnosis and treatment for people afflicted with Peripheral Neuropathy. Operation is expected to begin in early 2000. For information, or to make an appointment, please call Judy Richman, R.N. at 773-702-6221.

The Association's Medical and Scientific Director, Norman Latov, M.D. says, "This is an example of what can be accomplished when members of The Neuropathy Association work with their local neuropathy centers. We hope that others will follow suit." NV

CAN YOU TOP THIS?

Edited by Josh Justin

I read my *Neuropathy News* with great interest and think I have a story for "Can You Top This?" Like Josh Justin, I have put my watch in my sock at the swim club and found it hours later, but wait until you read this one!

Last year I visited my friends in Arizona who live on a golf course. My brother is an avid golfer, so the golf balls that come over the wall into their yard, I collected and brought home for him. I threw 20 golf balls in my suitcase and when I arrived home, I found only 19. Thinking I had miscounted, I rearranged my suitcase and left five days later for Williamsburg, VA. While walking around the first day there, my shoe was squeaking and I was walking funny. After three hours, my friend, Anne, said, "You better check your shoe." Lo and behold, there was the 20th golf ball. It was lodged in front of my big toe and the toe was bent at the first joint. We thought it was funny until that night at the motel when I took off my sock. There was a huge ulcer on the top of my big toe. Fortunately, I have a wonderful, caring podiatrist and an excellent shoe man, and between the two of them, my toe was saved.

I have suffered from Peripheral Neuropathy for fifteen years and developed diabetes four years ago. I have learned so much from your newsletter. It certainly is an unusual disease and as your readers know, people just can't believe you have no feeling in your feet. But it is real and I have a golf ball to prove it.

Pat Tallon
2515 Circle Drive
Cedar Bonnet Island
Manahawkin, NJ 08050

(Do you have a story for Can You Top This? Josh would welcome it.)

Other patient associations that provide support for particular types of neuropathy:

Charcot Marie Tooth Association, 800-606-CMTA ; Guillain Barre Syndrome Foundation, 610-667-0131; NORD, 203-746-6518; Sjogren's Syndrome Foundation, 516-933-6365. National Ovarian Cancer Coalition, 888-OVARIAN

On April 1st, The Neuropathy Association sent the following press release to the major press services and the medical columnists of the country's major newspapers:

THE NEUROPATHY ASSOCIATION QUESTIONS THE U.S. ATTORNEY'S OFFICE INVESTIGATION INTO WARNER LAMBERT CO.'S PROMOTION OF NEURONTIN FOR OFF-LABEL USE IN PERIPHERAL NEUROPATHY.

The U.S. Attorney's office in Boston has initiated an investigation into Warner Lambert Co.'s promotional activities of Neurontin for Peripheral Neuropathy. (The Wall Street Journal 3/30/00). Neurontin has the Food and Drug Administration's (FDA) approval for use in Epilepsy, but is increasingly used for the treatment of painful neuropathy, a condition which can be debilitating and resistant to treatment by other medications. There are approximately 20 million people in the United States who suffer with neuropathy, and, according to our survey on The Neuropathy Association web site, approximately 30% of our members indicated that they are taking this medication.

It is ironic that the U.S. Attorney's office, whose function is to protect the public, is taking steps that could ultimately hurt millions of patients in need of proper treatment. The situation, however, is not atypical, and highlights the inadequacies of FDA's current regulations governing the "off-label" use of drugs in conditions for which they were not originally approved. FDA requires that companies conduct extensive trials in order to obtain approval for new indications, but these are extremely costly and are sometimes impractical, as when the new indication is uncommon, or if it becomes apparent when the drug's patent is about to expire, as is the case for

Neurontin. There is no question as to Neurontin's effectiveness, but the existing studies demonstrating its efficacy in neuropathy are not sufficiently elaborate for FDA approval.

Lacking FDA approval, off-label indications cannot be listed in the Physician's Desk Reference, the profession's standard guide, and dissemination of information to physicians and pharmacists is limited. Consequently, physicians may be unaware of a drug's potential benefit, or do not know how to prescribe it properly. In the case of Neurontin, many physicians were told about it by their patients, who learned about its benefits from fellow members on The Neuropathy Association's bulletin board. Additional issues are raised by the practice of managed care companies, who seize on the lack of FDA approval as an excuse to deny their patients reimbursement for their treatments.

There is a need for the FDA to develop more reasonable regulations and guidelines for "off-label" drug use which are more realistic and consistent with current medical practice. Suggestions include: requiring less costly studies for new indications which focus on efficacy, or accepting guidelines developed by professional physicians' organizations, which in this case would be the American Academy of Neurology. Lacking the needed reforms, however, we are likely to continue to see more misguided efforts, as is the one by Boston U.S. Attorney's office, which are doomed to waste valuable taxpayers' money and deny patients the help they need.

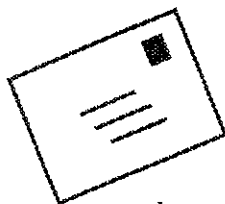
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Letters to the Editors

Here are a few of the many letters we receive. If you don't see your letter here, it could appear in a future issue. We reserve the right to edit letters for space and clarity. Please keep on writing, regular mail or E-mail. If it's regular mail, be sure to put your name, address and phone number on your manuscript. Your letters inspire us all. Write: Editors, Neuropathy News, 60 E. 42 St., Suite 942, NY, NY 10165 or info @neuropathy.org.

It gives us a bond with one another.

I received the holiday issue of *Neuropathy News* and was very impressed with all the articles, because everything in that issue pertained to me and my awful suffering. It seems my family of people don't realize how painful and heart-breaking this disease is and no cure, but your news gives us hope and we realize we are not alone.

I was especially touched by that most wonderful prayer that Judy Droste wrote. It touched my heart and soul because it says it all. The Nun's Story by Dolores Hart was really a masterpiece. I remember her when she was a movie star. She was very beautiful. I really was touched to tears by her article.

Thank you very much for *Neuropathy News*. It gives us a bond with one another.

Helen Zak
60 Homewood Pl, Elma, NY 14059

Suddenly he had that old spark in his eyes.

My father has suffered with Idiopathic Peripheral Neuropathy for over 12 years. He has been to many doctors who all try to help, but end up giving up. Then my father received *Neuropathy News* the other day. He brought it to my place to show me. He had a glimmer of the old spark in his eyes like he had before his days were filled with pain. You have given him hope, and it has helped him to know that he is not alone in his suffering. Thank you, Thank you, thank you!

Leann
klwilson@world-link.com.au

Blessings on you and all your members!

Last week I received your package containing a lot of hope, good information and support. I must admit I was blown away by the presentation, content and even the format. Awesome!

I am 67 years old and was diagnosed with Peripheral Neuropathy about 18 months ago, my doctor not able (or willing) to help. Since I live by myself with my German Shepherd, I really felt alone with this problem. The cause was tentatively attributed to blood pressure medication interacting with Paxil. It was a horrible 6 months until things settled down to a more or less bearable level. My puppy, at the onset of this problem, was only 9 weeks old, so I had to keep active, but it was an uphill trip. My friends live too far away to be readily accessible although the phone does help on the darker days.

My adult son has told me that he is too busy to help with the odd chore, has never called to inquire how things are, so "family support" is non-existent. Enter The Neuropathy Association, blessings upon you and your members.

Eleanor J. Rossler
1173 Wooded In Dr.,
Mississauga, ON L5H 2T7 Canada

Pineapple does the trick—again!

I was diagnosed about 5 years ago with Peripheral Neuropathy, and have been in a wheelchair. I read your newsletter about how pineapple does the trick and

also bromalin capsules, (Ed: Newsletter 6, 8/99, pg. 3, E-Mail from Herb Bischoff.) So I started on both on October 2, 1999. At that time, on a scale of 1 to 10, my pain was a 10. I also went to a new neurologist in Richmond, VA. He put me on Zostrix Cream, which I rub into my feet and legs for three weeks and then Zostrix Cream High Potency. He also put me on Neurontin. Today I am walking normally with no pain. I am 72 years old and feel 20 years younger. I would like to thank pineapple, Bromalin, Zostrix, Neurontin and especially my doctor.

Louis P. Haboush
9210 Lydell Dr., Richmond, VA 23228

And again!

The cocktail of 2 slices pineapple, one orange, one carrot has reduced the burning feet by at least 50%.

pdmatt@tds.net

An off-label use for Viagra

Because of my age (60 in June) and the medications I take for diabetes and Peripheral Neuropathy, I find Viagra useful for the rare serious romantic evening. Besides the expected results, I find that Viagra has also helped my Peripheral Neuropathy for 4 to 5 hours after taking it. My prescription for Viagra was for a small amount because of its previous rare use. I have, however, gotten the pharmacy to increase the prescription size, and I am going to try it on some really bad PN days. I would be interested to know if any other men have had the same results.

Tim Woodbury, 314-963-1709
TWO01@MSN.COM

A Twenty-Five Year Medical Nightmare

(continued from page 1)

I suffered through two hernia surgeries (as a result of the chronic bloating and constipation), continual colon and stomach scoping and probing, hemorrhoid and rectum surgeries, as well as numerous undignified procedures during the course of this 25-year medical fiasco. At one point, my surgeon told me that I must have "swallowed a devil" who was creating this voluminous havoc in my intestinal tract. (Reminisces of ET.)

As the years went on, my family and friends, not being able to comprehend the severity of my ailment and its socially unacceptable ramifications, started "deserting me like rats from a sinking ship." I was accused of being unsociable because I could not eat meals with them, labeled as an egotistical hypochondriac, and accused of being just plain demented and crazy! Everyone told me all of these ailments were "just in my head." This included many of my less compromising doctors. I was told that I needed major psychological help---and that there was nothing wrong with my digestive system that could be treated.

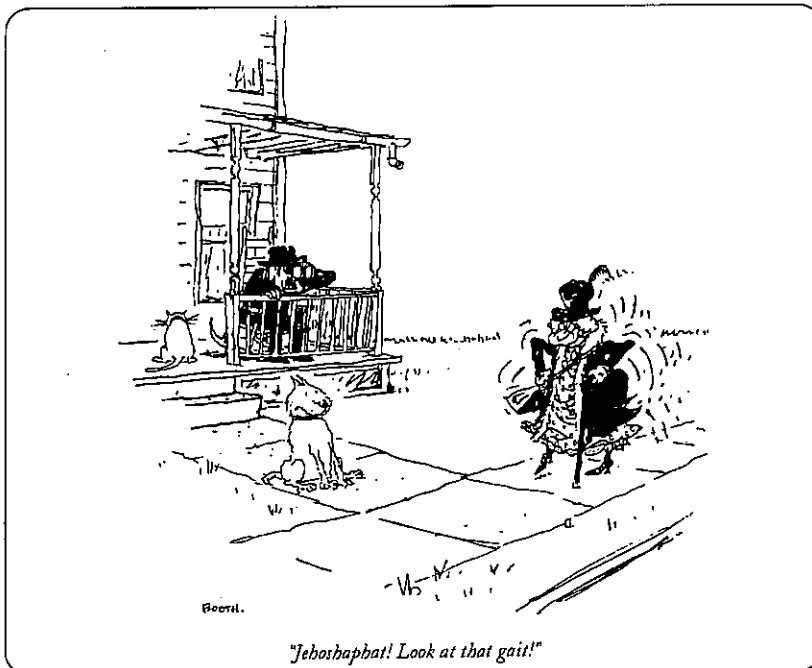
Six years ago while in Seattle, Washington, I ended up in the hospital for two days. My legs gave out, (refused to work) and I literally felt as though I had been run over by a truck. My "psychosomatic IBS symptoms" had now traveled down to my legs and up into my arms. My extremities felt very heavy, numb, and painful. After another barrage of tests, it was determined that along with the "IBSD" (and Depression) I now had developed Chronic Fatigue Syndrome, and Fibromyalgia. (Yes, more symptomatic, untreatable, and incurable mystery ailments.)

For the next six years, my life changed even more dramatically than ever before. I literally became a recluse, a prisoner in my own house. Since I had constant fatigue all over my body, I could no longer leave the house to go to work. As a result, I started working almost exclusively out of my home office. I was up and down all day-between the computer and my bed. As the years went on, my bed time increased substantially and work time decreased dramatically. On the weekends I would stay in bed and rest all day. My private, my social, and my business life fell apart completely. These combined symptoms affected every aspect of my waking life. "There was no stone unturned," and no one except my wife even tried to understand

what I was going through.

During this period, I saw at least twenty different doctors regarding these ailments. (the IBS, CFIDS and the FM). None of them offered me any suggestions as to how to treat them (let alone how to live with them). I even sent out a blanket letter to every gastroenterological teaching hospital in the nation, offering to make them "famous" if they would help me find a cure for this. I got very few positive responses. I did get plenty of unsolicited advice that there was little or nothing that could be done to help me through.

As I visited doctor after doctor and continued to expound on the salient characteristics of my numerous "mixed" symptoms, I found that none of them ever offered any suggestions for treatment or would validate anything but IBS. It was as if they had made a predisposed diagnosis and were afraid to change it during the execution. At one point during this indiscrete adventure, one doctor told me that my belly was this swollen because I had an enlarged liver, and I was rushed to the hospital for a liver scan. Naturally, the results proved to be negative. On another occasion, I was told that it was quite possible I had advanced bile duct damage since I was not digesting my food. After extensive testing and months of ambiguity and frustration, this proved to be negative also. Another doctor told me he had heard of someone who had been infected by a strange Egyptian parasite and had many of my same symptoms. (He claims he read an article in a foreign newspaper.) He suggested I contact the Public Health Department for more information. Yes, another dead-end trip down a road to nowhere. I lived in constant fear



"Jehoshaphat! Look at that gait!"

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every night that I would go to bed and not wake up because I had some very serious life-threatening disease that they had failed to diagnose. It took its toll on both my mental and physical well-being.

By this February (1999), I had lost most of the feeling in my right leg and foot. I got out of bed one morning and fell to the floor. I could not feel the rug under my feet. I stumbled to the phone and made an appointment with my family doctor immediately. She told me that it was a result of the Fibromyalgia, the Chronic Fatigue Syndrome and the Depression, and maybe a "sprain in my neck!" I was also accused of improper sleep posture. She sent me to the local ER for an x-ray of my legs and neck. She said it would probably get better in time, and, there was nothing else that she could do. (And she claimed to have studied Neurology under one of the greatest teachers in the medical profession!)

Fortunately, I had one good doctor who would listen to me—my psychologist, who has helped me more than any other doctor I have seen in the past twenty-five years. She has not only helped teach me how to communicate with these doctors, but, on the occasion when I can't, she will do it for me. When I explained these symptoms to her, she immediately referred me to a good neurologist who she knew personally and worked very closely with.

Now five months later, I have been diagnosed with Peripheral Neuropathy—and I am currently undergoing tests for Autonomic Neuropathy—which I am confident I have had for twenty-five years—not "a non-classic case of IBS" that would never go away.

Today I am in so much pain that I am confined to bed. Not only do I have intense Peripheral Neuropathy in both legs and arms, but, the symptoms of the Autonomic Neuropathy are getting worse on a daily basis. As of this writing, I have not had a bite of solid food for months. I cannot walk for more than a few feet due to the intense pain, and I can no longer work at the computer. (I am typing this document using the "hunt and peck" method on my once prolific and productive business computer.) The combination of complications from these two ailments is unbearable. None of my doctors seem overly confident that they will be able to do anything to ever get me back on my feet and free from these symptoms. I have been told the best I can expect is some type of pain control.

I have questioned many of my former doctors about their original diagnosis. I have heard just about every excuse in the book why none of them even considered autonomic nerve damage as an original diagnosis. One of my doctors told me that I did not fit into any of the profiles for that ailment—I was not a diabetic, a drug

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user or an alcoholic, so therefore, he did not feel as though it was necessary to look into it. Others have told me that it was not their field of specialty and I should have seen a doctor who specifically treats this ailment! Of course, to be the Devil's Advocate, one might ask why they didn't send me to an "autonomic nerve specialist" after they had been informed of my various symptoms which are conveniently listed in my wife's first year medical book!

The National Neuropathy Web Site turned out to be a blessing in disguise, for my sanity if nothing else. When I visited this page to find out more about my current Peripheral Neuropathy ---there it was --- the answer to my twenty-five years of living hell: Autonomic Neuropathy, the ailment that has changed my life forever. The ailment that no one could diagnose. The

ailment that has been driving me crazy for twenty-five years. The mysterious ailment that has caused me more grief than one can ever imagine.

As of this writing, I do not see much future in ever getting fully recovered. The positive news is, I am now seeing a good stable of doctors who seem very much aware of my condition and seem quite sympathetic towards my personal needs. Needless to say, the logical progression of this illness continues in a negative trend on a daily basis now.

I felt very compelled to write this article, with hopes and expectations that just maybe, someone who is reading this right now, might be able to get some type of help if they have similar symptoms. I sincerely do hope that no one else will ever have to go through what I did for over two decades before they get an appropriate diagnosis. Knowing what the ailment is, is the most important thing. Going through life year after year, living with the mystery is impossible.

William D. Haupt III
2073 Crary St., Pasadena CA 91104
626-794-6647; wdh13@pacebell.net

EPILOGUE

It has been a year now since I received my diagnosis of Autonomic Neuropathy and wrote the article above. I wish I had been able to find the cause and even a cure for this debilitating ailment, but, unfortunately, I am still riding the medical roller coaster of diagnostic ambiguities, uncertainties and prototyped suspicions. My search for information on autonomic nerve damage has taken me from one end of the Internet to the other, and my current medical advisors, too.

I am now seeing an infectious disease doctor (new to my medical portfolio) who is performing some rather elaborate and extensive blood tests to see if I have some exotic or alien ailment. I also have a urologist as I have now developed urinary incontinence and continual urgency issues along with the flow control problems of before. Although there is not much he can do for me except prescribe medication, the most important thing is he recognizes my discomfort, my limitations and my distress and is trying to help me deal with it physically and emotionally.

Although I have not been able to secure much help for any of these ailments, I

find it redeeming to be able to say I am learning more and more each day about autonomic nerve damage. Understanding it makes a world of difference. Few medications contribute any significant improvement, but some do help with coping and living with it.

Most important, now I can tell people that what I have has a name, a classification and a medical definition: Autonomic and Peripheral Neuropathy. Now when I tell people that I cannot eat meals with them or tolerate other social and physical activities, I stand a chance of convincing them I am truly quite ill and not just "unsociable" or "lazy". No, it is not all in my head. Believe me, this has been my most important achievement in the past twenty plus years! A serendipity of intense magnitude!

My symptoms of Peripheral and Autonomic Neuropathy have increased over the past year (I am now confined to bed rest almost exclusively), but I find great solace in having finally found out what started this degenerative nerve process throughout my body. It has enabled me to counsel others who have similar symptoms and help provide them with some type of relevant and salient understanding and direction. I know that sharing my experience is the most important thing I can do.

When I first started on this campaign to find out what was going wrong with my body and my mind, little did I know that it would take this long to find the answer. I just hope it doesn't take me another twenty five years to find the original cause, a measure of control and the elusive cure.

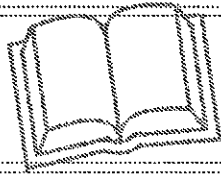
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Long Term Care Insurance— Especially for Members

Association members in 14 states—with more states to follow—may now have the opportunity to purchase difficult-to-get long term care insurance through Gene Tullio of The Long Term Care People. The states are: CA, CT, FL, MA, MT, NC, NJ, NV, NY, PA, TX, WA, WI, and WV. Mr. Tullio was introduced to The Association by Alan Schneider, a member, and represents 12 well-known insurance companies. Although not everyone will be able to qualify for a policy, Mr. Tullio says some of these carriers will seriously consider a plan for you if at all possible. In some cases, benefits may be limited. Here's how to reach Mr. Tullio:

- e-mail gtullio@aol.com.
- call 914-631-2900 X212
- fax 914-631-0526
- mail 120 White Plains Rd. Suite 204, Tarrytown, NY 10591

In all cases leave your name, address, e-mail, telephone and fax numbers.



Good Reading

Here is a book we highly recommend.

The Repetitive Strain Injury Recovery Book
 by Deborah Quilter
 Walker Publishing Company, Inc., New York, NY

Repetitive Strain Injury (RSI) refers to many separate ailments like Carpal Tunnel Syndrome and Tendonitis, affecting the nerves, muscles, and tendons of the hands, arms, shoulders and neck caused by continually repeating small hand movements. Common symptoms range

from numbness and stiffness to difficulty using one's hands. For some, the simple act of brushing their teeth or buttoning their clothes or turning a doorknob can be excruciating. Must reading for those who carry a cane, computer users, musicians, artists, and those with Peripheral Neuropathy that affects their hands.

Quilter, who has suffered from RSI, herself, provides recovery and preventive tips and techniques for both home and work. For instance, how to sit correctly at the computer, proper placement of the hands on the keyboard; how to find a chair that fits you; typing techniques that help you avoid overuse of the mouse and space bar, the healing power of exercise and good posture, protecting your hands during daily activities. An important and highly readable guide for prevention and the recovery process. For more information and the most up to date news about RSI, visit Deborah Quilter's RSI web site, www.rsihelp.com. NN

Making Life Easier

Edited by Irene Beer

O'Riley's Rapid Release: Australian Oil of Eucalyptus

Virginia Stangel writes, "While walking through the Edison Mall in Ft. Myers, FL last May, my husband, Dwight, and I stopped at an outdoor table where a young woman was selling O'Riley's Oil of Eucalyptus from Australia. Dwight had been suffering terribly from aching calves, which were constantly twitching with the nerves jumping. And I had aching knees from osteoarthritis. The girl offered to spray our aches and then told us to walk around for 5 minutes and if the pain was gone, to come back and buy some. Well, the pain was gone! And so was Dwight's twitching. Of course, we bought a bottle and have been using it ever since. It is even good for aches from fibromyalgia. It sounds expensive, but we have used an 8 oz bottle for one year and just finally filled it back up. We believe we have found a super product that has done away with our problem and felt we should share this with others. Sure beats taking a pill!"

Dwight and Virginia Stangel
 11833 Fair Road, Sidney, Ohio 45365
 937-498-1927

(Ed: Price list: 2 oz. bottle \$12.00; 8 oz. \$25.00, Combo -16 oz. bottle with 2 oz spray bottle \$45.00. Plus \$5.00 shipping and handling. 14 day money-back guarantee. Please call or write T.R. Industries, P.O. Box 987, Lehigh Acres, FL 339701, toll free, 1-888-369-8301)

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Self-Help Support Group News

Feel better by talking to others with the same disorder and get valuable tips to help you. Join a support group. We now have 174 groups around the country, Canada and abroad. See the last issue, 12-99, of this newsletter for the one nearest you or call us about starting one. If you live in a foreign country and would like to contact other sufferers there, consider starting a support group. Phone this office for more information. 1-800-247-6968. We're open Mon. thru Fri., 9 to 5 p.m. Eastern Time.

Placer and Nevada Counties, CA. Report from Bev Anderson, Leader

Our support group has gotten so big, it now has three chapters: Auburn, Roseville and Grass Valley, and we are preparing papers in hopes of becoming a corporation affiliated with The Neuropathy Association. In February in Auburn, we heard Dr. Bob Seiwert, a local compounding pharmacist. He was tremendous. We kept him on his feet almost 90 minutes and finally called it before he dropped before us. He made a short presentation and then opened it for questions, which kept coming. This fellow has his doctorate in pharmacy with an emphasis on neurological concerns. His specialty is compounding medications for those with neurological pain, and he talked about the transdermal cream mentioned in the last issue of Neuropathy News (Ed: Issue 7, 12-99). The Auburn Journal has been very helpful to us in publishing articles and notices about our meetings. We credit their article about the compounding pharmacist with giving us a standing room only crowd at the Auburn meeting.

Minneapolis, MN. Report from Al Porte, Leader

We are in the middle of the incorporating process. We have our by-laws and have been registered here with the Secretary of State as a not-for-profit corporation, and are awaiting IRS status. Legal work is progressing.

Since 1997, we have had 28 monthly meetings (none in July and August) with excellent attendance and educational results. Mainly, our speakers are neurologists with a strong and current focus on neuropathies. For example, specialist speakers are Drs. David, Ryberg, Parry, Litchy, Kelkar, Walk, Peven, Altafullah, to name a few. They have made very useful presentations which are well accepted by attendees. One meeting this fall was conducted by Nancy Rand, a physical therapist, who explained how to maintain or regain some amount of mobility. Exercise instructions were distributed, too. Inasmuch as magnets are in the news and research is being conducted on them, another meeting featured a

demonstration of magnetic health aids in the hope that some sufferers could gain help from them. Al Porte, 2221 Minneapolis Ave., Minneapolis, MN.55406. Tel: 612-338-8805 e-mail: neuropathy-minn@usjet.net

Dallas-Fort Worth, TX. Report from Paul McBroom and Bill Wesson, Co-Leaders

We took part in the Dallas Health Fair run by the Dallas County Medical Society and Alliance which was held at North Park on February 19 and 20, 2000. At our booth, we handed out literature about Neuropathy and also had a video tape of the Dr. Latov and Mary Ann Donovan TV Interview with Dr. Walter L. Larimore on America's Health Network.. We put the book, "Numb Toes and Aching Soles" by John A. Senneff on display and had order forms for purchase. Paul McBroom made a poster which showed the Peripheral Neuropathy system. Jim Palmer also made a poster to display the symptoms of Idiopathic Neuropathy. We had a good turnout both Saturday and Sunday, talking to at least 175 people in the two days and answering their questions about Peripheral Neuropathy.

That all lead to the DFW Support Group Coalition Kick-off Event on April 2 at the Irving Public Library with Dr. Gil Wolfe as speaker. This meeting was called to give the many people who had told us they wanted to join a support group a chance to sign up for a group in their neighborhoods across the Metroplex.. The day before, we also held a training session at the Baylor Health Center for Support Group Leaders lead by Jean-Claude Wakim, Ph.D., a clinical psychologist with extensive experience in helping chronic pain patients and in conducting support groups. He originally found us at our Health Fair booth. Eighty-three people came and Gil Wolfe did an excellent job as speaker and even ran overtime. Forty-nine people signed up for support groups with one of the 4 group leaders, depending on where they live. As Paul said, "It's a Texas thang, like eating beef jerky. The more you chew, the bigger it gets."

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