

# FootSteps...

TOWARDS PROGRESS

The Newsletter dedicated to finding a better way to live with erythromelalgia  
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## Pain... The Disease



By MELANIE THERNSTROM

A modern chronicler of hell might look to the lives of chronic-pain patients for inspiration. There is a special suffering, a separate chamber, the dimensions of which materialize at the New England Medical Center pain clinic in downtown Boston. Inside the cement tower, all sights and sounds of the neighborhood -- the swans in the Public Garden, the lanterns of Chinatown -- disappear, collapsing into a small examining room in which there are only three things: the doctor, the patient and pain. Of these, as the endless daily parade of desperation and diagnoses makes evident, it is pain whose presence predominates.

"Yes, yes," sighs Dr. Daniel Carr, who is the clinic's medical director. "Some of my patients are on the border of human life. Chronic pain is like water damage to a house -- if it goes on long enough, the house collapses. By the time most patients make their way to a pain clinic, it's very late." What the majority of doctors see in a chronic-pain patient is an overwhelming, off-putting ruin: a ruined body and a ruined life. It is Carr's job to rescue the crushed person within, to locate the original source of pain -- the leak, the structural instability -- and begin to rebuild: psychically, psychologically, socially.

For leaders in the field like Carr, this year marks a critical watershed. In January, the Joint Commission on Accreditation of Healthcare Organizations, the basic national health care review board, implemented the first national standards requiring pain assessment and control in all hospitals and nursing homes. Standards for evaluating and managing pain in lab animals have long been tightly regulated, but curiously there had never before been any legal equivalent for people. Maine took the further step last year of passing its own legislation requiring the aggressive treatment of pain, and California and other states are considering following suit.

"It's a field on the verge of an explosion," Carr says. "There's no area of medicine with more growth and more public interest. We've come far enough scientifically to see how far we have to go."

Chronic pain -- continuous pain lasting longer than six months -- afflicts an estimated 30 million to 50 million Americans, with social costs in disability and lost productivity adding up to more than \$100 billion annually. However,

only in recent years has it become a focus of research. There used to be no pain specialists because pain had always been understood as a symptom of underlying disease: treat the disease and the pain should take care of itself. Thus, specializing in pain made no more sense than specializing in fever. Yet the actual experience of patients frequently belied this assumption, for chronic pain often outlives its original causes, worsens over time and appears to take on a puzzling life of its own.

Research has begun to shed light on this: unlike ordinary or acute pain, which is a function of a healthy nervous system, chronic pain resembles a disease, a pathology of the nervous system that produces abnormal changes in the brain and spinal cord. New technology, like functional imaging, which is generating the first portraits of brains in action, is revealing the nature of pain's pathology.

Far from being simply an unpleasant experience that people should endure with a stiff upper lip, pain turns out to be harmful to the body. Pain unleashes a cascade of negative hormones like cortisol that adversely affect the immune system and kidney function. Patients treated with morphine heal more quickly after surgery. A recent study suggests that adequate cancer-pain treatment may influence the prospects for survival: rats with tumors given morphine actually live longer than those that do not receive it.

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## **Pain... The Disease** (Continued from page 1)

Paradigm shifts occur slowly; if arriving at a new medical conception of pain has been difficult and protracted, disseminating the knowledge will be more so. Pain treatment belongs primarily in the hands of ordinary physicians, most of whom know little about it. Less than 1 percent of them have been trained as pain specialists, and medical schools and textbooks give the subject very little attention. The primary painkillers -- opiates, like OxyContin -- are widely feared, misunderstood and underused. (A 1998 study of elderly women in nursing homes with metastatic breast cancer found that only a quarter received adequate pain treatment; one-quarter received no treatment at all.)

While the undertreatment of pain has led to lawsuits -- recently, a California court issued a judgment against a Bay Area internist for undertreating a terminally ill patient's cancer pain -- so has the over-prescribing of OxyContin in cases of patient abuse. It takes only a few lawsuits -- along with the threat of Drug Enforcement Administration oversight and regulation -- to exert a chilling effect on prescribing practices. "Doctors feel damned if they do and damned if they don't," says Dr. Scott Fishman, chief of the division of pain medicine at the University of California at Davis Medical Center. "The enormous confusion about pain has led to the hysteria around opiates."

Dr. James Mickle, a family doctor in rural Pennsylvania, describes the leering most physicians feel about treating pain: "Is it objective or subjective? How do you know you're not being tricked or taken advantage of to get narcotics? And chronic-pain patients are, generally, well -- a pain. Most doctors' reaction to a patient with chronic pain is to try to pass them off to someone who's sympathetic."

And what makes a doctor sympathetic to pain?

"Someone who has pain himself," Mickle says. "Or has an intellectual interest -- who isn't interested in immediate results, doesn't want to make money, has a lot of degrees. There's one in a lot of communities, but then they get all the pain patients sent to them and eventually they burn out and quit."

Daniel Carr's interest in pain began as an intellectual one. After training as an internist and endocrinologist, he published a landmark study in 1981 of runners, which showed that exercise stimulates beta-endorphin production, leading to a "runner's high" that temporarily anesthetizes the runner. He began to wonder: if the runner's high is an example of how a healthy body successfully modulates pain, what abnormality leads to chronic pain? He did a third residency in anesthesia and pain medicine, became a founder of the multidisciplinary pain clinic at Massachusetts General Hospital and a director of the American Pain Society. Six years ago, he moved to Tufts and set up a pain clinic (which loses money) and created the country's first master's program in pain for health professionals.

Every pain patient is a testament to the dangers of the conservative wait-it-out approach to pain, as a day spent in Carr's clinic demonstrates. But it is the last patient of the day, Lee Burke, whose story proves the most instructive, because her diagnosis turns out to be so simple, while the forces that worked against it being made earlier were so complex. Seven years ago, Burke -- a delicately featured 56-year-old woman in a blue cotton sweater that picks up the blue of her eyes and the gray in her hair -- learned she had one of the most survivable varieties of brain tumors, a growth known as an acoustic neuroma behind her left ear. The recovery period from the surgery to remove it was supposed to be a mere seven weeks. Instead, she awoke from surgery with an unforeseen problem. She had headaches -- lancinating lightning, hot pain -- that knocked her out for periods ranging from four hours to four days. She never returned to her job as an executive at a real-estate company. When pain came between her and her husband, she left him -- and her money and her home. "It was easier to be alone with the pain," Burke says.

Carr asks her to describe the headaches. Like most of the 100-odd patients I observed in various pain clinics trying to describe their suffering, Burke seems stumped by the question. Therein lies a specific damnation of pain. As Elaine Scarry writes in her seminal book, "The Body in Pain," pain is not a linguistic experience; it returns us to "the world of cries and whispers." Patients grope at far-fetched metaphors. "A hot, banging pain, like an ice pick," says one. "It heats up and then sticks it in, again and again."

Says Burke: "It's like being slammed into a wall and totally destroyed. It makes you want to pull every hair out of your head. There's nothing I can do to defend myself." She looks at Carr with the particular stricken bewilderment -- why and why me? -- that I saw on the faces of so many pain patients. Pain, from the Latin word for punishment, poena, can feel like the work of a torturer who must have -- but won't reveal -- a purpose. "It's like knives are going through my eyes," she says, starting to weep.

While she blots her face, Carr sits calmly, his concentration fixed, his hands folded reassuringly across his lap, with the equable, impersonal kindness of a priest or a cop. Almost all of the patients during the long day have broken down in their appointments. Perhaps because their lives echo the chaos in his own blue-collar Irish-Catholic upbringing as the son of an alcoholic bartender, he says, he isn't alarmed when patients scream at him. He is neither indifferent to emotion nor distracted by it; you sense at all times that his focus is on the culprit -- the shape-shifter, the pain. Carr asks Burke to close her eyes and taps her head with the corner of an unopened alcohol wipe. Within a few minutes he has found a clear pattern of numbness that suggests that one of the main nerves in her face -- the occipital nerve -- was severed or damaged during her surgery. It is clear from their differing expressions that Carr regards this as revelation -- the demystification of her pain -- and that Burke has no idea why. (continued on page 3)

## **Pain... The Disease** (Continued from page 2)

Pain makes a child of everyone. Her voice becomes small as she asks, "If the nerve was cut, why does it cause pain?"

It is a question researchers have only recently been able to answer. Doctors used to be so confident that severed nerves could not transmit pain -- they're severed! -- that nerve cutting was commonly prescribed as a treatment for pain. But while cut motor nerves can be counted on to cause paralysis, sensory nerves are tricky. Sometimes they stay dead, causing only numbness. But sometimes they grow back irregularly or begin firing spontaneously and produce stabbing, electrical or shooting sensations.

Picture the pain wiring of the nervous system as an alarm, the body's evolutionary warning system that protects it from tissue injury or disease. Acute pain is like a properly working alarm system: the pain proportionally matches the amount of damage, and it disappears when the underlying problem does. Chronic pain is like a broken alarm: a wire is cut and the entire system goes haywire. "This is true pathology -- the repair doesn't occur, because the system itself is damaged," explains Clifford Woolf, an M.D.-Ph.D. pain researcher and the director of Mass. General's neuroplasticity lab. It is called Neuropathic pain because it is a pathology of the nervous system.

Woolf was the first to answer an old puzzle: why does chronic pain often worsen over time? Why doesn't the body develop tolerance? Woolf's research demonstrated that physical pain changes the body in the same way that emotional loss watermarks the soul. The body's pain system is plastic and therefore can be molded by pain to cause, yes, more pain. An oft-used metaphor is that of an alarm continually reset to be more sensitive: first it is triggered by a cat, then a breeze and then for no reason it begins to ring randomly or continuously. As recent research by Allan Basbaum at the University of California at San Francisco has shown, with prolonged injury progressively deeper levels of pain cells in the spinal cord are activated. Pain nerves recruit others in a "chronic-pain windup," and the whole central nervous system revs up and undergoes what Woolf calls "central sensitization."

Lee Burke's records do not even note whether her occipital nerve was cut, and her surgeon may not have noticed the dental-floss-size nerve. It took more than a year of complaints before she was referred to Dr. Martin Acquadro, the director of cancer pain at Mass. General, who noted that she had severe muscle spasms in her head, neck and shoulders. It was a classic pain misinterpretation: he seized on muscular pain as the primary problem, rather than a secondary symptom, and diagnosed tension headaches.

He treated her with Botox injections, tricyclic antidepressants and migraine medications. She tried range-of-motion physical therapy, stress-reduction courses, psychiatric treatment, yoga and meditation and consumed 3,200 milligrams of ibuprofen a day, along with 12 cups of coffee (caffeine is a treatment for migraines). He steered her away from opiates with warnings about their addictive qualities.

Until recently, opiates were the only serious pain drug available. But neuropathic pain is the kind of pain for which opiates are the least effective. In the past few years, however, an alternative has come along. A new antiseizure drug, Neurontin, has been found to also act as a nerve stabilizer that can quiet the misfiring nerves responsible for neuropathic pain.

When I call her four months after the appointment with Carr, Burke says she feels 50 percent better from a combination of Neurontin and other drugs. The muscle spasms -- so rigid that Acquadro compared them to railroad tracks -- had melted. She no longer needed a snorkel for her daily swim because she could move her head from side to side again. Of course, you have to be in terrible pain to find the side effects of pain drugs tolerable. But while her headaches sometimes required so much Neurontin that she was too dazed to walk, she was glad to be able to sit up to watch television instead of simply lying prone in agony.

"Dr. Carr is my savior," she says. I recall the way she left the appointment, clasping his hand as if she wanted to kiss it and looking at him with hope so intense it was hard to watch.

"There's tremendous ignorance about neuropathic pain," Woolf says. "Most doctors don't know to look for it." One confusing factor is that not all patients with similar conditions develop chronic pain. Neuropathic pain seems to require genetic vulnerability. Pain clinics are filled with patients with ordinary conditions and extraordinary pain. M.R.I.'s show only bones and tissue; doctors might look at a patient's scan and say, "Your back looks fine -- the muscle swelling is gone" or "The bone's all healed," and conclude there is no reason for pain. But the pain is not in the muscles or bones; it is in the invisible hydra of the nerves.

Of course, not all chronic pain is neuropathic -- there is inflammatory pain, for example, or muscular pain. But many chronic-pain conditions, like backache, which was once assumed to be wholly musculoskeletal, are now thought to have a neuropathic component.

About 10 percent of women used to complain of chronic pain following radical mastectomies. Their pain had always been interpreted as a psychological phenomenon: they were just "missing" their breasts. But in the early 1980's, Dr. Kathleen Foley at Memorial Sloan-Kettering Cancer Center in New York identified the pain as being caused by the severing of a major thoracic nerve during surgery, and the technique was revised. (Continued on Page 4)

## **Pain... The Disease** (Continued from page 3)

Doctors warn patients of many risks, from death to scarring, but rarely mention the not-uncommon side effect of chronic pain. The life of one of Carr's patients was ruined by having a nerve nicked during plastic surgery to correct protruding ears. Another acquired chronic chest pain after being treated in a hospital for a collapsed lung when a tube was inserted in her chest -- one of the most nerve-rich areas in the body. One especially poignant category of patients in pain clinics is that of those who have had surgery specifically to treat chronic -- usually back -- pain where the surgery leads to new, worse pain, an outcome for which they say they had no warning.

Pain doctors have many theories about why these kinds of things happen, but the dialogue is frustratingly one-sided. There are no spokesmen for under treating pain -- no one advocates not treating pain. Although I contacted many of the former doctors of pain patients, it was rare that one was willing to examine his decisions thoughtfully, as Martin Acquadro did. It was immediately clear to me that Acquadro, a licensed dentist as well as an anesthesiologist, was both competent and caring and that the forces that delayed Burke's treatment were not personal shortcomings but genuine, pervasive confusions about pain.

Acquadro thought the pain of all acoustic neuroma patients should manifest itself similarly, and most of those he had seen did, in fact, "respond to simpler, more holistic therapies." He had not thought of Neurontin, and he feared opiates. "We don't always do patients a favor putting them on high-dose narcotics," he says. "When a patient is depressed or anxious, you're leery about narcotics or alcohol. With Lee, I guess I'd have to say I was being cautious." His voice changes -- softens and quiets -- as he gets to the real point: "I was afraid."

Like many doctors, he says he felt comfortable with anti-inflammatory drugs, although the 3,200 milligrams of ibuprofen that Burke took daily put her at risk for gastrointestinal bleeding. According to the Federal Drug Abuse Warning Network, anti-inflammatory drugs (including aspirin and Aleve) were implicated in the deaths of 16,000 people in 2000 because of bleeding ulcers and related complications. While large doses of the drugs are sometimes needed to treat inflammation, opiates are a much safer -- and generally more effective -- analgesic.

Although far fewer than 1 percent of pain patients using opiates develop any addictive behavior, opiates have a reputation for being dangerous, and social biases -- class, race and sex -- influence who is entrusted with them. Studies by Dr. Richard Payne at Sloan-Kettering show that minorities are up to three times as likely as others to receive inadequate pain relief -- and to have their requests for medication interpreted as bad "drug-seeking behavior." A study conducted by Dr. William Breitbart at Sloan-Kettering found that women with H.I.V. are twice as likely to be under treated for pain as men. Many of Carr's patients have some social strike against them that led their previous doctors to withhold treatment: two were workers' compensation cases, one was mentally ill, several had histories of substance abuse, all of them were poor and most were women.

Women tend to be either less aggressive in demanding pain treatment or to be aggressive in ways that are misinterpreted as hysteria. The longer pain goes untreated, the more desperate and crazed the patient becomes -- until those behaviors look like the problem. Burke recalls that whenever Acquadro sent her to other specialists -- headache specialists, balance specialists and behavioral pain-medicine specialists -- she would break down during the appointments in pain and frustration. "They all just figured I was a basket case," she says. "And I was. I was a basket case."

Rather than dismiss her psychic distress, Acquadro seems to have become overly focused on it, trying to explain her pain through that prism: "Lee's pain seemed to be better at the times she was happier, was forming new relationships or helping others," he says. "And even though she was motivated and worked hard on stress reduction, the fact remains, she is a tense person."

Naturally. Everyone who has chronic pain eventually develops anxiety and depression. Anxiety and depression are not merely cognitive responses to pain; they are physiologic consequences of it. Pain and depression share neural circuitry. The hormones that modulate a healthy brain, like serotonin and endorphins, are the same ones that modulate depression. Functional-imaging scans reveal similar disturbances in brain chemistry in both chronic pain and depression. "Chronic pain uses up serotonin like a car running out of gas," says Breitbart. "If the pain persists long enough, everybody runs out of gas." Thus, Acquadro's not treating Burke's pain aggressively because she was "tense" is like "not rescuing someone who is drowning because they're having a panic attack," according to Breitbart. Difficulty breathing triggers panic as reliably as pain causes depression. When serotonin is inhibited in laboratory animals, morphine ceases to have an analgesic effect on them. Medications that treat depression also treat pain. Depression or stressful events can in turn enhance pain. Since Sept. 11, pain clinics have been fuller. "If we started putting sugar in the water, it would affect the diabetics first -- pain patients respond to stress with increased pain," explains Scott Fishman, who also trained as a psychiatrist. But to make stress reduction a primary strategy for pain treatment is trying to repaint the walls of a crumbling house.

It is an easy mistake to make -- and one I made myself. I developed pain five years ago for, what seemed to me, absolutely no reason. A fiery sensation flared in my neck, flowed through my right shoulder and sizzled in my hand. It didn't feel like normal pain -- it felt like a demon had rested a hand on my shoulder. Suddenly I tasted brimstone and burning. (Continued on page 5)

## **Pain... The Disease** (Continued from page 4)

Two years later, an M.R.I. would reveal spinal stenosis, a narrowing of the spinal canal, and cervical spondylosis, a type of arthritis, both of which squeeze the nerves and cause pain to radiate into my shoulder and hand. But in the meantime, I was convinced that if I steadfastly ignored it, the pain would eventually go its own way. I tried to treat it as a psychological problem. Many pain patients have had doctors who pathologized them, told them their pain was unreal; I pathologized myself, hoping my pain was unreal -- or that it would become so if I treated it as such.

I analyzed the pain in psychotherapy. I tried acupuncture, massage and herbal remedies. I read books about conversion hysteria, the placebo effect and Sufis who thread fishhooks through their pectoral muscles. What I didn't read was anything that might have actually informed me about my symptoms, like Fishman's excellent patient-oriented book, "The War on Pain." Nor did I consult any clarifying Web sites, like [painfoundation.org](http://painfoundation.org).

When the pain depressed me, I focused on the depression. I adopted Dr. John E. Sarno's popular creed that muscular tension syndrome is the source of most back ills and faithfully scrutinized my life for stress. It is one of those circular self-confirming hypotheses: when I was happy and my pain light, I took it as confirmation of the correlation; when I was happy but had a lot of pain, I wondered if I didn't want to be happy. I recall how, strapped inside the white crypt of the M.R.I. machine for more than an hour, I tried to calm myself by repeating the motto of my Christian Scientist grandparents: "There is no life, truth, intelligence nor substance in matter. All is infinite Mind and its infinite manifestation." But I sensed the machine was seeing my pain in its own way and that its report would be irrefutable. My pain would no longer be a tree falling in the forest with no one to hear it. The greatest fear pain patients have, doctors sometimes say, is that it is "all in their heads." But infinitely scarier, I thought as I lay there, is the fear that it isn't. This is the new frontier of medicine," Clifford Woolf says heatedly in his clipped South African accent. "What we're learning is that chronic pain is not just a sensory or affective or cognitive state. It's a biologic disease afflicting millions of people. We're not on the verge of curing cancer or heart disease, but we are closing in on pain. Very soon, I believe, there will be effective treatment for pain because, for the first time in history, the tools are coming together to understand and treat it."

The most important tool in his lab at Mass. General -- a vast landscape of test tubes filled with rat DNA -- is the new "gene chip" technology that identifies which genes become active when neurons respond to pain. "In the past 30 years of pain research, we've looked for pain-related genes, one at a time, and come up with 60. In the past year, using gene-chip technology, we've come up with 1,500," Woolf says happily. "We're drowning in new information. All we have to do is read it all -- to prioritize, to find the key gene, the master switch that drives others."

Woolf is particularly interested in certain abnormal sodium ion channels that are only expressed in sensory neurons that have been damaged. He believes he is close -- perhaps a year away -- from identifying which among these channels is the most important one. Then -- if his animal data applies to humans -- pharmaceutical companies could design blockers for these channels, and after the years it takes to develop a new drug, there could be a cure for neuropathic pain.

On the table before us in Woolf's lab, a graduate student is piercing the sciatic nerve of a white rat. The rat is of a pain-sensitive variety, one prone to developing neuropathic pain. In 10 days, when Woolf cuts open the rat's brain, he will be able to discern the imprint of the sciatic nerve injury. There will be corresponding maladaptive changes in the way the brain processes and generates pain.

The biggest question of pain research is whether this pathological cortical reorganization can be undone. A 1997 University of Toronto study has shown disturbing implications. Anna Taddio compared the pain responses of groups of infant boys who had been circumcised with and without anesthesia. Four to six months later, the latter group had a lowered pain threshold, crying more at their first inoculations -- providing evidence that there is cellular pain memory of damage to the immature nervous system.

Terms like "pathological cortical reorganization" and "cellular pain memory" have a very ominous ring. Are these children really doomed to be more sensitive to pain their entire lives? Will a cure for neuropathic pain help all the people who already have it -- or only prevent others from developing it?

Woolf looks at me and hesitates. "We don't really know," he says tactfully. Another pause. "In the present state, no." However, he says, even if the damage cannot be undone, treatment could still help suppress the abnormal sensitivity. "But obviously, it's going to be much easier to prevent the establishment of abnormal channels than to treat the ones already there." He sighs, rests his head against his hand. "Obviously."

I want to ask another question, but I'm overcome by a rare unreporterly desire. I want him to get back to work.

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*Editor's Note: We have reprinted the article in its entirety. Please note that the article is provided for you for educational purposes only and is not to be reprinted or to be used in any commercial way. However, this article seems to apply so well to many of us, that we felt it an important addition to our private "libraries" of information about the illness we all share. We hope you enjoy this opportunity.*

## We Still Need a Few Good Folks!

We still need your help! The TEA Board of Directors is in need to fill one more vacant Board Member Seat. While we have recently filled two seats, one more has come open, not to mention various other positions that need some attention. The TEA Board is a small group of members, some have EM, and others don't, who give of their time to work towards the education and research into erythromelalgia. We meet once a month, via the Internet, and typically handle issues like the governing of this non-profit organization, new items of interest to our members, and the advancement towards EM research and treatments. Won't you join us and be a part of this pioneering institution... dedicated to improving the lives of those who are afflicted with EM? We'd like to hear from you and answer any questions you may have about this task. The qualifications are simple...

- ◆ **Must have Internet or e-mail capabilities.**
- ◆ Must be a current TEA member.
- ◆ Must have interest and enthusiasm for the opportunity.
- ◆ Must be willing and able to dedicate adequate time to the job (may equal 2-6 hours per month).
- ◆ Helpful, ...but definitely not necessary, is to have some past experience in any type of non-profit or voluntary organization.



### Changes, Changes, ...Everywhere!

With May comes several changes in the way TEA will be meeting new and current members. Included in the bundle of changes are the new introduction letter, brochures, and membership contact (Beth Coimbra). In addition to these changes, TEA is planning some major overhauls to the website. On the "drawing board" are changes in the password system, the graphic appearance of the site, and added information for our members. Because of our limited staff of volunteers, these things will take time to implement, but have patience... we're excited to see TEA blossoming into a better organization for you!

### New Members

*"Make new friends, but keep the old,  
One is silver and the other gold"*



*The following list is of the members that have newly joined since November 2001. This brings our membership to over 225 members. And, on this occasion, we would like to extend a great big hug of a welcome to them all!*

Suzanne Kerkstra, David Eckert, Christine Larch, Eloise Masters, Thomas Loynd, Vincent Cox, William Woodfin, MD, Barbara and Daniel McDonald, Carol Kanter, Martha Douglas, Helen Van Oijen, Dorothy DeCoster, Zack Collar, Ruth Spratt, Sher Perkins, Teresa Eckert, Marie Materi, Corrie Camp, Roberta Miller, Virginia Phillips, Elizabeth Egan, Sue Davis, Mildred Weddingfeld, Theresa Hoffman, James Seesz, Russell Flynn, Colin Heaton, Betty Backer, Joy and Nathan Taylor, Jeanne Johnson, Helen Bean-Eckstrom, Hermann Weber, Helen and Norman Longley, Geralynn Deller, Doreen Irish, Virginia Anderson, Kathleen Weaver, Mrs. R.K. Carless, Roger Johnson, Judie Huddleston Deborah Preble, Tillie Miller, Joanne Smith, and Michael McGinn

**Welcome! We're glad you've joined us!!**



# Your Stories... and everyone has one!

TEA has been asking its members to write brief stories about their EM or daily lives.

Several members have responded and we are printing a few of them here for you. We would love to hear your story too! Please send them to Nancy Mabry at :209 Ridglea, Midland, TX 79701

**My name is Viola Tumiel.** I am 77 years young, and still as active as any normal person. The redness, swelling, and burning in my feet started around 1977. My primary care physician had never seen this condition and sent me to a vascular surgeon, Dr. Leary. He also didn't know what it was, and performed Doppler tests, which came out negative. In 1988 I took myself to a podiatrist, Dr. Campenelli, who prescribed Isoxophrene and recommended I see a Neurologist, Dr. Lall. He conducted electromyography study on lower extremities. This showed mild to moderate axonal peripheral neuropathy. Further tests showed carpal tunnel syndrome. I also had cat scans and an MRI. He prescribed 3 carbamazepine (Tegretol), 9 Motrin, 2 vitamin B complex, and 2 multi-vitamins daily, along with physical therapy. No visible help. In 1999, I went to a dermatologist, Dr. John Martinez, for hives. He determined I was taking too many unnecessary medications, and had me discontinue everything except heart and osteoporosis medications. He added Zirtec. At first this seemed to help both the hives and the feet, but all too soon the burning and soaking in cold water became a regular routine again. In December, 1999, I was referred to a Surgical Podiatrist, Dr. Tiberia. He was the first doctor to give my foot condition a name. He said, "We have good news and bad news. Good news - we have a name for your condition, erythromelalgia; bad news, we don't know what to do about it."

I continued soaking my feet in 58 to 60 degree water several times during the day. Usually my feet would burn so badly during the night, that I would wake and soak them up to 3 times every night! I carried ice packs with me wherever I went. If I was visiting family, I would carry my foot basin. This will be the memory my grandchildren will always have - Grandma with her feet in a basin of water!

In 2000-2001, Dr. Novelli suggested I see a Rheumatologist, Dr. Carlos Martinez. He seemed very interested, and said he had seen this condition once before in his 'fledgling' years. Though he, too, didn't know the answer, he said he loves a challenge. He was the first to give me any hope. He has prescribed a compound salve prepared especially for me. 60.00CD Neurontin 10% Lido 10%, and I am happy to report I seldom have to soak! The redness, swelling, and burning have been greatly reduced! Directions on the salve say to "apply sparingly." I only apply the salve to my feet well below my ankles. It seems to keep my lower legs cold and therefore my feet don't flare up as much as they used to. I only wear shoes when I absolutely have to, and then it's sandals, even in the winter. I also wear support knee highs. As for my hands, they tingle so badly that it is painful. They are either painfully hot or extremely cold. Summer weather is better for me. Winter seems worse. Wishing everyone in our group GOOD HEALTH!! É

**My name is Illiana.** I live in Denmark. My EM started with a rash that increased over a period of 1 year. I saw a dermatologist for this and he first thought of a certain rash, for which I cannot find an English word. By the end of one year my feet and ankles were

very, very swollen and the skin cracked many places. My face and neck were also very hot. I couldn't walk very well, and had great pain. When I had to go shopping (this in wintertime with snow and ice) I used my sandals (no stockings) and even the sandals were too much. I couldn't even fasten the straps on the sandals, as the feet were too big for that. The last half of that one-year period, I lived in my living room as I couldn't tolerate the heat of my bed. I had my feet into ice cold water with an ice block into the water and that took the swelling down, but in the end it didn't do any good either and I became worried, because the feet turned into an ugly purple color! I wondered if that was very bad.

After having lived in ice water, so to speak, and not having any sleep for 2 weeks, I called the dermatologist and demanded to go to the hospital. He had to see me first and I went there in great pain. When he saw my feet he was greatly shocked and admitted me to a hospital for skin disease at once. (I have to put in here that in Denmark there is a very long waiting time for having an appointment by a dermatologist even if one is seeing one regularly, so he hadn't seen my feet in this state before.) When I arrived at the hospital it only took the doctors a split second to determine the cause for my feet...EM!!! They called several doctors to watch them, and took a lot of pictures and the next day I attended a conference of students so that they also could watch the case. I was given a kind of aspirin, which didn't do any good.

The next time I saw the dermatologist at the hospital, she suggested I discontinue taking the antidepressant Edronax (reboxetin) which I had taken for about 2 years. I got another drug, Seroxat (paroxetine as paroxetinhydrochlorid). In the next 6 weeks I began to have a sky high blood pressure, and my pulse raced down from 86 to 58 (and I am not a sports woman!!!!) and my depression sent me downhill into a black hole. Now for the exciting part...The EM disappeared 100%!! Unfortunately, because of the blood pressure drop, and the depression, I had to go back to Edronax and now the EM is turning its ugly face onto me again. I have decided that I will rather live with the EM than a bad depression. So now I have started to use Gabapentin (Pfizer) 300 mg. 3 x per day! Only time will show how things will turn out. É

**Your Stories...** (continued from page 7)

**Hi! My name is Marilyn Wade.** I live with my husband, Dave, and my son, Steve, in Troutdale, Oregon, USA. We have four children, two girls and two boys, in that order. We also have four granddaughters, and by the time this is published we will have a grandson. My hobbies are writing, mostly religious stories, and cross-stitching. I was diagnosed with EM in 1985, the same year I was diagnosed with diabetes, by Dr. Terry Kennedy, a podiatrist in Gresham, Oregon.

My life was very active - working, babysitting, shopping, going to the library, out to lunch with friends, going to dinner with my husband, and vacationing at the beach or with family. Today, I don't babysit, shop, or go out to eat. Food sensitivities like spices and chocolate became a problem since the EM. I don't drink, so alcohol's not a factor. I couldn't do much of anything if it weren't for my husband and family. They help me in everything I need to do, including housework, preparing meals, and taking me where I need to go, especially to the doctors. Also, we've hired a housekeeper who comes in every other week to do the heavy cleaning. É

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**My name is Furman Mayberry.** I am 81 years old. I am a retired Electrical Inspector with the State of South Carolina. I am a retired member of the International Association of Electrical Workers. I retired at age 65. I was diagnosed with EM by Dr. Thomas Brothers of the Vascular Research Department of Medical College of South Carolina. I have also been a Type II diabetic for about 18 years. Since taking the American Diabetes course in 1992, I have kept my blood sugar under good control. EM has radically changed all aspects of my life. I am not able to travel, as I did before. I get very little sleep (day or night). My main problem is extreme body heat, from my feet to the top of my head. My head sometimes gets so hot, my vision becomes blurred. My body heat affects my left ear and causes stomach problems. The heat is worse at night, or when trying to sleep in the daytime. The heat usually starts around 8:30 PM, and by bedtime, it feels like there are worms in my toes.

When I wake up really hot during the night, I will drink an 8 oz. glass of ice water. I sit with feet elevated, and I massage my legs from the knees down and also my feet, with Vaseline Intensive Care Lotion. I use the one which contains the ingredients octy methoxycinnamate, and SPF 15. For some reason this lotion cools my feet. It usually takes about an hour for my body to cool off. I then return to bed, and sleep about 2 to 2 1/2 hours, and repeat this process until 5:30 AM. I have tried about 40 different medications. Some have not helped, and many I'm allergic to. (I am constantly bothered by the hives on my stomach and chest.) I eat well. I avoid fried foods, as they cause flaring. I have tried elastic hose, but they were no help. I have tried soaking my feet in cold water with no success. I am constantly reading and experimenting. I am a member of TEA and helping out with the hope that some people may get some better relief. É



## WINTER BOARD MEETINGS

For the sake of space, we are providing only the highlights of the last 3 TEA Board of Director's meetings. If you would like to receive more complete meeting minutes, please let me know, and we'd be most happy to send them to you. The TEA address is: 4343 Roosevelt Way NE, #305, Seattle, WA 98105, or click here for the newsletter editor: FootSteps Editor

From our Secretary/Treasurer: For the period of Feb 15th to March 15th, TEA received 37 new or renewed memberships. A total of \$550.00 in donation memberships were received. Since January 1, 2002 we have enrolled 68 members. If that rate of membership continues throughout the year, TEA will have 326 members for the year 2002. Now, wouldn't that be something?!

During the same period, February 15 through March 15, the Research Fund grew by \$435.00. On March 14, the Fund had a total of \$41,035.00 and the operational account a total of \$2,761.56.

From the President: The winter months have given TEA the opportunity to rearrange a few things, like finding a new facilitator for the Medical Advisory Committee, and TEA Membership Chairman. These tasks completed, we can move on to the membership application of TEA becoming a member of NORD (National Organization of Rare Disorders). The membership with this wonderful organization will be a very good step in the right direction for TEA, as this position will allow us a better avenue of communication regarding research funding, and future project plans. Our Vice President, Ray Salza will be handling this detailed and complicated application in May. É



# Hot



# Flashes!

## Help for Disabilities:

Following is a site within the website:

[www.immunesupport.com](http://www.immunesupport.com) that has very good information on disabilities. It is written by an attorney that specializes in disability claims for those afflicted with Fibromyalgia. However, his free advice is applicable to all types of conditions. <http://www.immunesupport.com/disability/> or call: 1-800-366-6056.

Address:

Pro Health, Inc.  
2040 Alameda Padre Serra,  
Suite 101  
Santa Barbara, CA 93103

(This tip was sent in by

## Keeping up with disease

**legislation:** Visit the N.O.R.D. web site and learn what the latest activities are concerning disease legislation. [http://www.rarediseases.org/cgi-bin/nord/new/bio?id=NqXFf7AY&mv\\_pc=5](http://www.rarediseases.org/cgi-bin/nord/new/bio?id=NqXFf7AY&mv_pc=5)  
Or write to the National Organization of Rare Disorders at: P.O. Box 8923, New Fairfield, CT 06812-8923 and ask for print outs of the disease legislation and notes on the topic.

## New Membership

### Chairman, Beth Coimbra.

Beth has graciously taken on the large task of TEA Membership Chairman. In the future please send all membership inquiries to Beth Coimbra, 200 Old Castle Lane, Wallingford, PA 19086. The fee is still \$15\* per year and can be paid by check or money order, or by using the service-charge-free credit card service through "networkforgood.org" (\*this is the suggested donation and can be adjusted as needed.)



"Was that 'hummm' a hummm covered by my insurance?"

From Bunny Hoest and John Reiner in the Laugh Parade, Parade Magazine, 11/18/2001

## New MAC Facilitator, Milt LeCouteur.

Wow, is Milt ever going to be busy! Milt has accepted the post of Medical Advisory Committee Facilitator for TEA and will be conducting the first meeting very soon. Congratulations to both Milt and TEA on a great match of expertise and willingness!

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The Erythromelalgia Association,  
4343 Roosevelt Way NE, #305,  
Seattle, WA 98105, USA or contact us through our official website at <http://www.erythromelalgia.org>.

C The intent and purpose of this publication is to bring information to those suffering from erythromelalgia or their friends and family, and not, in any way, to provide medical advice.

**Close Associations:** There is a support group that may be of help to those with facial EM, redness or flushing of the face, or severe rosacea. If you are interested please contact, Meg Edelson, or go to the site called: [theredhots@yahoo.com](mailto:theredhots@yahoo.com). (This group is only available via the Internet at this time.)

## LOST MEMORY...

Two elderly ladies had been friends for many decades.. Over the years they had shared all kinds of activities and adventures. Lately, their activities had been limited to meeting a few times a week to play cards. One day they were playing cards when one looked at the other and said, "Now don't get mad at me.....I know we've been friends for a long time.... but I just can't think of your name! I've thought and thought, but I can't remember it. Please tell me what your name is. Her friend glared at her... for at least three minutes she just sat there and glared at her. Finally she said, "How soon do you need to know?"

The Erythromelalgia Association  
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Seattle, WA 98105

Are your Membership Dues Due?  
See inside for the address of our new Membership Chairman!

