

**Devin J. Starlanyl Remarks
Invisible Illnesses Conference
Washington, DC
May 11, 2002**

Thanks for Tracy Loeffler, Melanie Woodruff, and all the other wonderful people who have taken so much time and effort to bring about this event. Look around you. Most of us here, those with chronic invisible illnesses, share more with each other than we do with our blood relatives. About 10 years ago, I created a word, FMily, to express the bond that we share. It's not just people with fibromyalgia and chronic myofascial pain that share this bond. We all have in common invisible illness, and many of us have more than one. We are a FAMILY, as close as any troops who have been through war together and survived. Welcome, everyone, to the first National Family Reunion.

Immobility is difficult for us. It's okay to move around, stretch, or whatever you need to be as comfortable as possible. I do understand. I'll teach you a few tricks to help. Contract the muscles on one side of your buttocks, and then relax them, and then do the same with the other side — it will help keep the blood flowing in the areas you compress when you sit. If your seat is too high for your body and your feet don't touch the ground, you need to improvise a footrest so that your hamstring muscles, under your thighs, aren't compressed. A tennis ball under the hamstrings moved around will stretch them a little.

I didn't start out to become a fibromyalgia and myofascial pain educator and advocate. I had other plans. I enjoyed being an ER doctor and technical director in pharmaceuticals. My husband and I had found the perfect place to live the dream of the 60s. We put our home on the market and planned a move to northern New England. Just before that move, after I left my job, I was rear-ended at an intersection. I was going less than 5 miles an hour with my foot on the brake, and a car came up behind me and lifted up the back of my car. That car's windshield shattered, but my body absorbed the bulk of the impact. When that car pulled back, my car fell back to the pavement. Double whiplash. I didn't know how drastically my life had been changed at that moment. I wasn't surprised at the severe headaches that resulted, nor the aches and pains. I did expect that, in time, they would go away. The crippling headache that lasted for over a month did ebb, but it was replaced by a bewildering set of symptoms. I began charting specific pain patterns, but test after test came back negative. I saw doctor after doctor, only to be told that such pain patterns didn't and couldn't exist. I was hit with episodes of confusion and other cognitive deficits. A cognitive deficit is something that is missing from your normal mental abilities. I was a Mensan, in the top 2% IQ bracket, and yet I would get lost driving around our small town. I was told I might have post-traumatic stress syndrome, or

that I was burned out from working the ER and looking for an excuse to quit. One doctor told me I was just out of shape, gave me repetitive exercises and told to "work it off". I weighed 105 lbs. at the time. I had been extremely active, often working over 80 hours a week at jobs I loved, and played goalie in ice hockey games. I became *really* confused. I knew I was impaired, but the doctors that I was seeing seemed even *more* impaired. I did my own research.

Eventually, I found the medical texts "Myofascial Pain and Dysfunction: The Trigger Point Manuals" by Drs. Janet Travell and David Simons. *There* were the exact pain patterns I had been describing. One myofascial trigger point after another, complete with referral pattern and associated symptoms, were revealed in page after page of these texts. Here is the trigger point, this is what causes it, this can perpetuate it and this is how to diagnose and treat it. This is how you can prevent it. Relief flooded my whole being. That was replaced by anger. Why didn't those doctors know this information? Most of you here have myofascial trigger points, and many of you don't know about them either.

One night in 1993 I visited the nearby small city of Keene, NH, because their hospital had advertised a fibromyalgia support group. The group facilitator didn't show up that night, and they were turning the people away. I knew what it took to get out to a meeting at night when you had fibromyalgia. I spotted a hospital VP who knew me. I explained the situation to him, and I held the meeting. I started talking and listening and found that although these folks had been meeting for over a year, they knew very little about fibromyalgia, most of that was incorrect, and they had never heard of myofascial pain or trigger points. One of the people followed me out to the parking lot and insisted I start a group in Brattleboro. We started the group a few weeks later, and it is still going.

By then, I had hooked up with David Simons, one of the authors of the medical texts that had opened my eyes. He has been my mentor, advisor and friend ever since. I started writing handouts for the support group. Dr. Simon looked at my first symptoms list, discussed it with Janet Travell, and said, no, you've got to separate the symptoms of myofascial pain from fibromyalgia, even if patients have both, because they must be treated differently. I found that the few doctors who knew about myofascial trigger points knew little or nothing about fibromyalgia. The doctors working on fibromyalgia knew little or nothing about myofascial pain. This is *still* the case, but it is getting better.

I became a consultant on the Internet support group fibrom-I, and started holding free counseling sessions in my home to help local people figure out where their symptoms were coming from. I thought there would be a finite number of people, but they kept coming. I talked with over a thousand

people on the net and in person. I was getting calls at my house at all hours, and at one time I was getting about 700 emails a day. I was also writing a science fiction. Trauma surgery is out of the question when you have a problem buttoning your blouse. I told God that if She wanted me to keep at this work, I needed a publisher or I needed to win the lottery. One person who came to see me insisted that I had to write a book on fibromyalgia and myofascial pain, because the workload was wearing me down and yet there were millions of people who needed the information. Again, I insisted that I couldn't do that, and I had told the same to many other people who had encouraged me to write down what I knew. My fingers had TrPs, and my arms, and the repetitive motion and the sitting, would be disaster for my own health. She persisted and said she would help. She had the publisher. I prayed. I told God I couldn't do it. God said I could, and I would get what I needed.

Since then, I have written 3 medical books. I even wrote science fiction that is tied in with fibromyalgia and myofascial pain. I hope it is the first of a series. (I think I love science fiction because I am looking for a planet with a 186-hour day so that I can get my work done.) I also hoped people who wouldn't read the medical self-help books, especially our companions and family members, would read the science fiction and finally "get it." My co-author, Mary Ellen Copeland, asked, "Do you realize what we are doing here?" I said, "Yes. We are trying to revolutionize medical care." We are still working on that. My mission has caused me to meet some of the top researchers in the world. I have also met many other amazing people, those with invisible illnesses. They are the ones who have been through the fire and survived. That experience changes people, and some of the changes are very positive.

Many invisible illnesses are not well understood by medical care providers and insurance companies. Just last Tuesday, one nurse wrote me that she had been diagnosed with traumatic fibromyalgia. Her doctor told her it would "burn itself out" in 5 years. That same day a man wrote that his neurologist told him he couldn't have fibromyalgia because it was a women's disease. A woman — the same day — told me her doctor said treating her myofascial trigger points didn't make sense because she had too many of them. This lack of training and misinformation must change, because we are the ones paying for our doctors' ignorance.

The media is paying more attention but is often full of misinformation. Did any of you catch Tom Brokaw reporting on "Fee-bro-malasia"? At least he *did* say something about it, and that erases some of our invisibility. Let me clarify something. *All widespread pain is not fibromyalgia*. Chronic myofascial pain can be widespread, for example, and hypothyroid, HIV and medication side effects can cause widespread pain. All people with chronic fatigue don't have Chronic Fatigue Immune Deficiency Syndrome. The two terms

should *not* be used interchangeably. People who regularly overwork may have chronic fatigue, but they have no idea what CFIDS is all about. They have never had to leave their shopping cart in the checkout isle and struggle to make it to their car before they collapsed.

Studies show over half of Gulf War veterans with unexplained musculoskeletal pain meet the criteria for fibromyalgia, and a significant number of the veterans with unexplained fatigue have CFIDS. Many doctors and patients get these conditions mixed up, and there is a lot of overlapping, although research indicates that some of this overlapping may be due to doctors misunderstanding the cause of the symptoms. I will try to clarify some of this today. Some of you diagnosed with fibromyalgia may not have it, and many of you with other invisible illnesses may have fibromyalgia and/or myofascial trigger points causing or contributing to a substantial number of your symptoms and this is important, because you may be able to do a lot for those components of your illness. Everything I am telling you today is documented by medical journal articles and texts. The reason I put so much documentation in my last book on a chapter-by-chapter basis is so that readers can educate their doctors and other care providers who may not be aware of current research. Too many of us are spending a lot of time and effort to educate our doctors and paying for the privilege. There are too many care providers out there taking your money and then saying that these conditions don't exist, or that they are all the same. The facts are the facts, and the disbelievers will just have to get over it. There is a big difference in not understanding a condition and refusing to believe it exists. Fortunately, patients now have options. More and more doctors and other care providers are hungry for information, and the research is coming out faster than anyone can integrate it all. Doctors and other care providers who insist that these conditions don't exist are simply bragging about their ignorance and warning patients to stay away from them. There are only three types of doctors: those who can treat and diagnose your illness, those who are willing to learn to diagnose and treat your illness, and your former doctors. There are options. Once these scoffers start losing patients, some will realize that it is in their own interest to educate themselves. Hit them in their money bone.

Last week at the National Fibromyalgia Partnership Orlando Seminar, Dr. Roland Staud talked about his research that shows that there are demonstrable biological changes in fibromyalgia that keep the pain sensation going. There are changes at the spinal cord level and at the gene transcription level. The central nervous system can change its response to a given stimuli, and that is what happens in FMS. The pain response gets stronger, and the pain does not decay as quickly. Eventually, the pain level does not return to normal, and then additional stimuli add on to that higher level. Fibromyalgia is not all in your mind. It is real.

People with invisible illness share more than the understanding of what it means to struggle over a hidden obstacle course while others unknowingly breeze by on the freeway of life. When you have more than one of these conditions, the combination can be disastrous, with much greater pain, fatigue and other symptoms than most doctors realize. We, on the other hand, realize this all too well. Many of us share perpetuating factors. Perpetuating factors are factors that contribute to and aggravate your illness. For all invisible illnesses, identifying and dealing with perpetuating factors is your key to achieving a better quality of life. Fibromyalgia, for example, is not progressive. If your illness is getting significantly worse with time, there are one or more perpetuating factors that have not been properly addressed. If you identify and deal with your perpetuating factors thoroughly and promptly, your symptoms should ease considerably. If you go into flare, a time when symptoms worsen and new symptoms develop and pain clouds your life, that is a sign that one or more perpetuating factors are out of control.

Drs. Janet Travell and David Simons, the founders of myofascial medicine, isolated many common perpetuating factors for myofascial pain. I'll be talking more about that condition, and them, a little later. One word of caution. Just because one person has found his or her one perpetuating factor and become symptom free, that doesn't mean they have found a cure for everyone. Each of us is unique. That's what makes treatment so complex. There is no place for cookbook medicine with these conditions. Doctors can't say, "you have such and such illness, take this medication and you will be better in such and such time". It doesn't work that way. We are not looking at one big puzzle. Each patient is one big puzzle, and we have to be willing to find all the pieces for each one until each of us is whole.

Many of us have symptoms in common. Multiple Chemical Sensitivity can include headaches, muscle weakness tremors, coughing, watery eyes and fatigue. All of these symptoms may be caused by myofascial trigger points, even in people with Multiple Chemical Sensitivity. Often, if you treat the myofascial component, it decreases the total symptom load enough so that the rest can be more easily managed. Chemical sensitivity can be a perpetuating factor of any illness. Research shows that every one of us has traces of pollutants inside his or her body. Both FMS and MCS patients may have sensitivities and odd reactions to medications. Research shows that MCS neurological sensitization is similar to that which occurs in FMS. One study found that 21% Post Traumatic Stress Syndrome patients had unsuspected fibromyalgia. I have a feeling that most of us with localized pain have myofascial trigger points.

Fibromyalgia is not the same as CFIDS, although they may both have neuroendocrine dysfunctions as part of their picture. Substance P in cerebrospinal fluid of CFIDS patients is within normal range, but it's increased in FMS

patients. Another study points out that, "In fibromyalgia, there is a condition of physiological hyperarousal. In CFIDS, a blunted response, the exact opposite, occurs." With many invisible illnesses, symptoms can vary from day to day and hour to hour. Healthy people, especially insurance companies, have difficulty understanding this. Some of them, especially fibromyalgia, have times of flare. Flare is a time of sensory overload, with overwhelming symptom intensity when you are least prepared to cope with it. Many of us with heightened sensitivity deal with sensory overload. We have so much neurotransmitter traffic and it is so dysfunctional, the brain has great difficulty dealing with the input.

MCS: Multiple Chemical Sensitivity is a chronic condition with symptoms that recur reproducibly, in response to low levels of exposure to multiple unrelated chemicals that improve when the chemicals are removed. This may include symptoms affecting multiple organ systems. For example, muscle pain can be a symptom of MCS if muscles are the target organ. A state health dept survey in NM and CA found 2-6% of the civilian population have a diagnosis of MCS, with higher rates among the military. 16% of civilians reported unusual sensitivity to common everyday chemicals. American Lung Assn, AMA, US Environmental Protection Agency, US Consumer Product Safety Commission state, "...complaints [of MCS] should not be dismissed as psychogenic, and that a thorough work up is essential". They recommend that MCS be formally diagnosed — in addition to other disorders that may be present. In one study on environmental chemical intolerance (CI), they found a possible relationship to CFIDS and Fibromyalgia, wherein individual differences in susceptibility to neurohormonal sensitization (amplification) of responses may add a disabling intensity to multi-system dysfunctions in CI. Fibromyalgia is the commonest cause of widespread pain (Bennett, 1995), yet it usually remains undiagnosed for years, during which the patient is untreated, mistreated or undertreated, or a combination thereof. Fibromyalgia, like many other conditions, is not *curable* right now, but it is very *treatable*, and there are many different ways in which you can regain some measure of control in your life, and considerably improve your health and quality of life. FMS is not musculoskeletal. A recent study titled, "Is fibromyalgia a neurological disease?" The answer was a resounding YES!

Any brain trauma, including whiplash, can start the neurotransmitter cascade of fibromyalgia, especially if you have the genetic tendency to develop it. Doctors, and insurance companies, must understand that X-rays and other imaging studies cannot document neurotransmitter imbalances and soft tissue injuries. That makes them no less real. The American College of Rheumatology, American Medical Association, The World Health Organization, and the National Institutes of Health accept fibromyalgia as a legitimate clinical entity. There is no excuse for doctors "not believing" in its reality. At the Travell Focus on Pain Seminar 2000, I. Jon Russell, MD, the editor of the Journal of Musculoskeletal Pain, mentioned the use of the Functional MRI.

This imaging device shows the brain in action. In a healthy individual, when you pressed on a tender point site, there was a minimal response, but in a patient with fibromyalgia, "...the result was wild — the whole brain went crazy". Those Functional MRIs are documentation that something is happening to people with fibromyalgia that doesn't happen to others.

The brain perpetuates fibromyalgia, whatever the initiating trigger might have been. In a healthy brain, when a signal goes in to the thalamus or limbic system, there are filters that allow us to think about that stimulus and decide what appropriate actions are required. In Fibromyalgia, after an action or other stimulus, the filters don't work. The mechanism that allows modification of actions that result from the stimulus is impaired. The quantitative electroencephalogram (Q EEG) brain map provides hard documentation that brain dysfunction is present.

Yesterday I met with Dr. Mary Lee Esty, director of a local neurotherapy research and treatment organization in Chevy Chase. They are hot on the trail of what fibromyalgia is all about and are coming closer than anyone I know to developing a cure. In a healthy brain, brain waves are regular and even. When adults are awake, they should not have theta or delta brain wave patterns. The slower the frequency and the more times they appear, the greater the abnormality. A high variability of brain waves indicates an inefficient energy state in the brain, and this is the case in FMS patients. Delta and theta abnormalities, called EEG slowing, are common. When brain cells are damaged, these imbalances appear, regardless of the reason for the damage. Brain trauma is cumulative, and many of us have sustained countless numbers of brain bashes throughout life. Dysfunction of the autonomic nervous system is common following brain injury, and the majority of people with fibromyalgia that Dr. Esty sees have had trauma sufficient to affect brain function. She has a new therapy called SyNAPs (Synergistic Neurotherapy Adjustment Process). The treatment is painless, given through surface electrodes, and tickles the brain into remodulating its responses. During the treatment the exposure length of stimulation is modified according to the specific needs and responses of the individual patient. For more information on this, visit www.fm-research.com.

In fibromyalgia, there is a generalized disturbance of the way pain is processed by the body. Two important markers for FMS, and I'm not talking about the 11 of 18 tender points. Fibromyalgia is:

Allodynia: sensations that aren't normally painful are translated by your body and mind into pain sensations

Hyperalgesia: pain sensations are amplified.

The combination can be disastrous. Both of these changes in the way our bodies process pain seem to be worse if there is a physically traumatic initiating event (Russell, 1998). You may be sensitive to odors, sounds, lights, and vibrations that others don't even notice. Your body may at times inter-

pret touch, light, or even sound as pain. Your sleep is fragmented, and you often wake up feeling more tired than when you went to bed. You feel like you've been hit by a Mack truck. So many people mention this feeling that there was even a study about this. It was called the 18-Wheeler Sign. The study did not indicate that the manufacturer of the truck was significant :-}

One big perpetuating factor is lack of restorative sleep, and your doctor must work with you to find what you need to provide restorative sleep. Sleep, or the lack thereof, plays a crucial role in Fibromyalgia. You may not be getting enough sleep, or the right quality of sleep. You may have a host of other sleep-related problems. Besides specific tender points, allodynia and hyperalgesia, the essential symptom of Fibromyalgia is pain. A recent study found that norepinephrine can cause greater pain in about 80% of Fibromyalgia patients tested. This is another indication that the autonomic nervous system is dysfunctional in FMS. Our main regulatory system is not working as it should. The lead researcher, Dr. Martinez-Lavin, cautions that people with FMS should avoid adrenalin-like substances such as nicotine and caffeine. We should avoid preparations with norepinephrine, epinephrine, ephedra, ma huang, etc. In a recent article in Fibromyalgia Frontiers, this doctor says that anti-inflammatory medications are not very helpful in FMS. Pain should be targeted with centrally acting medications. We need anti-neuropathic medications. "It is clear that current analgesic therapy is insufficient in many cases." Thank you, Dr. Martinez-Lavin.

There is a genetic tendency to develop fibromyalgia. There are studies underway to find what genes are involved, including a total genome search for FMS-related genes. Approximately half of the children of a fibromyalgia parent will eventually develop FMS. The sooner FMS is recognized and treated, the more easily symptoms can be controlled if needs are identified and addressed. Each of us is unique and has unique needs.

Fibromyalgia is a biochemical disorder, and these biochemicals affect the whole body. You can't have Fibromyalgia only in your back or your hands. You either have it all over or you don't have it at all. If you have localized complaints, they are probably not caused by FMS, although it may be *amplifying* the local symptoms from another cause. Fibromyalgia is **not a catch-all, wastebasket diagnosis**. It is not just achy muscles. Fibromyalgia is not homogenous. There are many subsets of Fibromyalgia. One study has separated some subsets into meaningful categories, and this separation may be a useful tool in the future to help decide which treatment regimens are more likely to help specific patients.

Fibromyalgia is not a mental illness, and must not be categorized as such. "There is now clinical evidence that Fibromyalgia represents a distinct rheumatic disorder and should not be regarded as a somatic illness secondary to psychiatric disorder" (Dunne and Dunne 1995). Fibromyalgia is not infec-

tious. Infection from many causes can start the neurochemical cascade of fibromyalgia. This does not mean that FMS of itself is infectious. We must be very careful not to take something which may be a "finding", like a specific blood value found in some patients but not all patients, in fibromyalgia and assume it can be used as a specific *test* for fibromyalgia, separate from other conditions. This simply adds to the confusion.

The 11 out of 18 tender points of fibromyalgia came about because a group of doctors were trying to find something that all FMS patients have in common, so that they could define which patients could enter clinical studies for FMS. This criterion of 11 of 18 tender points was originally meant for patients accepted into clinical studies, not for diagnosis, so conclusions of the study would absolutely pertain to fibromyalgia. Since most FMS studies don't exclude coexisting myofascial pain, much research is suspect at any rate, because many of the symptoms often called FMS are often due to myofascial TrPs. FMS tender points hurt where pressed, but pressing a tender point does not cause pain in some other part of the body. FMS tender point count may decrease with proper medical treatment and self-care, but that doesn't mean that the FMS has been *cured*. It only means you have learned to deal with the perpetuating factors and co-existing conditions and have them under control.

There are no common specific diagnostic tests for fibromyalgia, but biochemical differences do exist. The tests are very expensive, some require a research laboratory, and the results are not specific to FMS. They show that we have metabolic abnormalities, energy producing abnormalities, and neuroendocrine imbalances. There is abnormal blood flow to regions of the brain. The cerebrospinal fluid shows discrete changes in cell differential count. Dr. Jean-Bernard Eisinger and his team in Toulon, France, may have found a *noninvasive, easy and inexpensive way to test for fibromyalgia*. His team found that patients with 11 or more of the 18 specified tender points were more sensitive to the pain of a blood pressure cuff. All of the patients that reported pain at a specific pressure had FMS, and none of the patients who didn't report pain at that pressure had FMS. The tension induced myalgia correlated to the tender point count with 90% accuracy. Sensitivity to systolic blood pressure may be a test for FMS.

Fibrofog is perhaps the most disabling, and the most life-disrupting symptom of FMS. People lose jobs, drop out of school, and are deserted by their family, become homeless. The brain can't function normally and you may not be able to describe what it is that is happening. Cobwebs have taken over all the chambers of your mind. You have lost control, and you can't explain why. And yet, to the world, you look just fine. Your family, friends and employer make impossible demands, and you feel guilty because you can't meet them.

Some of the answers may lie in glial cells. Glial cells are to the central nervous system what the myofascia is to the musculoskeletal system. They hold a key to cell permeability, which may also impact CFIDS, GWS, MCS and other invisible illnesses. Some cognitive deficits may be due to pain taking up so much of the thought-processing network that not much is left for other mental tasks. Decision-making may become nearly impossible, even for the most basic choices. Researchers at the University of Michigan have validated our cognitive deficits. They have shown that people with FMS have cognitive impairment that isn't related to age. Some cognitive functions exceed that of aging 20 years. Fibromyalgia patients reported lower memory capacity, less control over memory function, more cognitive deficits, and greater memory deterioration than a healthy group of people 20 years older, and the research showed that they were accurate in their assessments. These researchers also found that FMS patients did their very best to make the most of what they had. The deficits were not due to poor motivation. Fibromyalgia patients used more memory aids and memory improvement strategies and were highly motivated. If you feel as though you are diagonally parked in a parallel universe, this study shows that your assessment is correct. Don't ever berate yourself for not accomplishing more. Anything you do is deserving of praise. What is amazing is that in spite of insurmountable odds, so many of us succeed at moving through the obstacle course that is life as well as we do.

Fibromyalgia has a major effect on direct health costs, and as such, it is in the interest of many insurers, at least in the short term, to deny patients the health care they need. "It's All In Your Head" is a cheaper diagnosis for the insurance companies and HMOs in the short term. In the long term, this attitude costs the health care system more by creating sicker patients requiring more extensive services, further stressing medical resources.

Fibromyalgia seems to be the result of many neurotransmitter cascades. A neurotransmitter cascade is like a waterfall that starts at the top and bounces off rocks and ridges on the way down, wearing down rock, moving gravel, and changing the river as it goes. The neurotransmitter cascade can cause changes throughout your body, and many of these changes start cascades of their own. Once they get going, a combination of peripheral and central factors join in to make the changes chronic, and the result is what we call fibromyalgia. Each of us may have different "informational substances", which include peptides, hormones, neuromodulators, growth factors, interleukins, cytokines, neurotransmitters and similar substances disrupted in different ways. Each informational substance may be used in many different ways in your body and brain, and may affect many other informational substances. Think of yourself as a vast network of messages going on in three dimensions at all times, even when you sleep. The system of checks and balances in the body becomes chaos. The stress response of the body, the "flight or fight", "startle" or "freeze" responses, seem to be set on high and don't turn off easily. Some of us may overreact to a sudden noise or

event and go into panic or “startle” mode. Others may “freeze” like a deer caught in the headlights of a car. It can be hard to function when you are caught in one of these response patterns.

Anything that results in tissue injury, whether from physical trauma or biochemical damage, can cause hypersensitivity at the site of the injury. If there is repeated or continued trauma, other areas may develop hypersensitivity. This can lead to a state of “central sensitization”, as your nervous system reacts to chronic, long-term pain in several ways. More nerve connections develop in your spine as a response to chemical damage caused by chronic pain. This multiplies the number of pain carrying channels you have. Neurotransmitters associated with transmission of pain also increase in number. Pain signals coming from outer areas are amplified. Your mind is constantly told that your body is being damaged and won’t let you stop feeling the pain until you do something about it. Because any number of neurotransmitters and pain receptors may be involved, you may have to try many different medications (and therapies) before finding a combination that works well for you. Many physicians give up too soon. Pain is a major perpetuating factor. You need pain relief so your body and mind have a chance to work on feeling better. Otherwise, pain itself can consume your life. You can’t concentrate on stretching exercises when someone is chewing off your leg. You need the pain under control so that you can concentrate on doing what you need to get better. Studies show that having others believe the pain of FMS is real is crucial to patients’ quality of life and ability to cope (Seers, 1996). FMS *amplifies* pain, but myofascial trigger points cause pain — and many other symptoms.

CMP: FMS is not the same as chronic myofascial pain (Gerwin, 1999). It is fundamentally different in an important way (Simons, Travell and Simons, 1999 p 18.) *There is no such thing as a fibromyalgia trigger point.* Trigger points are part of myofascial pain (Simons, Travell and Simons, 1999), not fibromyalgia. Some of you may have been diagnosed with FMS, but you don’t have it. Bodywide TrPs can give the impression of FMS. Myofascial TrPs need to be treated locally and their perpetuating factors addressed. Fibromyalgia needs to be treated centrally, and perpetuating factors addressed. All patients with one do not have the other.

Some of you may have never heard of myofascial trigger points and yet they’re the chief source of your pain. Myofascia is the white sticky stuff you see around chicken pieces in the grocery store. It wraps around your muscles too, and networks through them, wrapping around each muscle cell and fiber. When it’s healthy, it is flexible. Fascia forms a network connected from under your skin all the way down to your DNA, and can profoundly affect your health. Myofascial dysfunction is probably the most common cause of musculoskeletal pain. It is a major factor in primary medicine and just about every specialty you can think of. One change in the myofascia

can cause stress to the whole body. Myofascial restriction in one major leg joint means that it takes up to 40% more energy to walk. If two joints are restricted in the same leg, it can take 300% increase in energy expenditure just to walk. Are you feeling fatigued? This may be why. As myofascia tightens, TrPs can entrap nerves, blood and lymph vessels.

Myofascial trigger points are extremely sore areas in the muscle that you can often feel as lumps, nodules or ropy bands. Every TrP is associated with a ropy band, although you may not be able to feel it if your muscles have turned to concrete. You develop the taut band before you develop the pain. Myofascial TrPs cause weakness and muscle dysfunction before they cause pain. They cause pain at the end of the range of motion. When you stretch it hurts, so you stretch a little less, and you slowly use the use of your muscle. Active myofascial TrPs cause pain in specific referral patterns, and they also cause other symptoms. Janet Travell was JFK's White house physician. She wasn't his doctor feelgood who prescribed pain pills. She used spray and stretch and TrP injections to relieve his TrPs. She designed that rocking chair that everybody heard about, but nobody heard about the TrPs that made it necessary. Dr. David Simons was a pre-astronaut, the first man to see the curvature of the earth from space, hanging in basically a tin can suspended from a balloon. These were not two unknown doctors from East Varmint, Idaho, that nobody ever heard of. They wrote these marvelously detailed and referenced medical texts. So why isn't myofascial medicine taught in medical schools? Because it is difficult, it is complex, and it is time-consuming to learn. It takes palpation, observation and listening skills. It takes a paradigm shift in thinking. It is also marvelously cost effective and it *works*.

If Congress wants to solve the health care crisis, this is a great place to start. Get training in myofascial medicine in medical school and at the continuing medical education levels. Dr. Robert Gerwin right here in Bethesda is an expert on this. Tap into this resource and get going. We also need insurance codes for FMS and myofascial pain. The International Myopain Society is working on this. The amount of money that can be saved in the long run may make the difference in the health care crisis.

Trigger points can cause a runny nose, swollen glands feeling, sinus congestion, headaches, stiff neck, eye tearing, blurred or double vision, staggered walk, dizziness, imbalance, ear pain, ringing of the ears, difficulty swallowing or lump in the throat, unexplained toothaches, pelvic pain, diarrhea, belching, gas and bloating, shortness of breath. They can mimic pelvic inflammatory disease, prostate trouble, or heart attack. Appendicitis type pain. Painful intercourse, urinary urgency, rectal pain. You may have an infection that activates the trigger points and then the TrPs remain and perpetuate the symptoms until they are treated, even though the infection is gone. They can cause cardiac arrhythmias. Numbness of the hand and/or fingers can be

caused by TrPs in your neck. Piriformis syndrome can be nerve entrapment and blood vessel entrapment as well as myofascial pain. They can cause carpal tunnel syndrome, thoracic outlet syndrome. Carpal Tunnel Syndrome is a description that means the nerve is being entrapped. Research shows that the most successful treatment long term is manual, not surgical. One must ask why and how the nerve is entrapped. The answer is usually myofascial. I have no idea how much needless surgery is performed on this condition alone, but research indicates that much of it can be remedied by proper manual therapy and attention to perpetuating factors. Readers of my books write me and say that they knew they had FMS because they recognized the pain patterns in my book. Those pain patterns are not FMS. They are diagrams of myofascial trigger points and their pain referral patterns. You can't have fibromyalgia in your hands or your neck or your back. If your knees are buckling and your neck is stiff, trigger points are probably at the bottom of your symptoms.

"Inactivating the related myofascial Trigger points and the elimination of their perpetuating factors appear to be important parts of early therapy to delay or abort the progression of some kinds of osteoarthritis." Simons, Travel and Simons 1999. Age doesn't cause osteoarthritis. The rest of your body is as old. Bones follow muscles. If muscles are contracted by TrPs, the bones are pulled out of alignment. Treat the TrPs and deal with the perpetuating factors.

We know the mechanism behind myofascial TrPs. They are caused by a thousand-fold increase in acetylcholine, a neurotransmitter, at the motor end plate — a place in the muscle where nerves end. This causes an excess calcium release, which can contracture the muscle. A contractured muscle isn't the same as a tense muscle. It is physiologically contractured and shortened. If your muscle is weak due to TrPs, it cannot be strengthened. Work hardening and weight training only worsen the TrPs, causing them to develop satellite and secondary TrPs and giving the impression of a progressive disease. This spread is preventable, and reversible, but we must teach medical care providers that **you cannot strengthen a muscle with a trigger point. Inappropriate care is a preventable perpetuating factor and the costs to us and to the health care system are unconscionable.**

Even single trigger points can cause excruciating torture. When you have body wide trigger points with nerve entrapment, and the pain of them is amplified by fibromyalgia and your doctor wants you to take aspirin or acetaminophen, well... While Congress is looking into the lack of myofascial training and FMS, better do something about the lack of chronic pain management.

The focus on both conditions is to restore maximum function with minimum

pain. Some doctors, pharmacists and receptionists are treating us like addicts when the real issue is that the doctor and his employees are uneducated in the current findings on opioid medication and are in denial about the amount of pain someone with a multitude of these conditions may be dealing with. At times it seems as if we are in the Dark Ages of Medicine when it comes to chronic invisible illnesses. Let's turn on the light.

Chronic pain is not something you get used to. Your body makes less endorphins with time in response to the same stimuli. Doctors need to be trained in the management of chronic pain. We need adequate medicinal and non-medicinal therapies to control pain so that we can function and have a reasonable quality of life. Returning to work should not be the only goal. Being able to attend to your needs, feed yourself and dress yourself and do food shopping does not mean that you can work a 40-hour week in a construction firm. If you work one 8 hour day and are unable to cook and eat due to pain and can't move the next day, that is not sustainable function. Cost effectiveness is important, but so is therapy effectiveness.

It is possible to take control of your life. No matter what your illnesses, it is possible to minimize their impact on your life. This takes support. This means that you, your medical care team, and your family and companions cannot be in denial about your illnesses, symptoms and limits. You can work within your limits to gently stretch them once you and your symptoms have been stabilized. Find out what — and who — are the perpetrating factors in your life. Develop self-advocacy skills. Build your support structure. Find or start a good support group. Support groups are for *support*. Not moan and groan clubs, but positive information sharing, compassionate and supportive structures. Pick your own support team. Find people you enjoy being with and who enjoy your company. Concentrate on positive aspects, and avoid negativity. Give your supporters space — have enough of them on your team so that you aren't always depending on one or two. Give support as well. Show interest in other people and in life itself. Join national support groups with newsletters. Use the Internet wisely. Be attentive and live mindfully. Even if you can only do a few things a day, do them well and with creativity. Modify, delegate and delete. Focus on ability instead of disability. You can exceed your limits, but know that if you push too hard too fast, there will be a price to pay.

Heroes aren't just the people who come through an acute crisis and keep going. Heroes are those who can deal with the daily grind of pain and symptoms that would wear away the hardest stone, without the support that those with more visible illnesses get readily. I am in awe of mothers who tend small children while dealing with these conditions. We contend with so many challenges just trying to make life livable, let alone tolerable, and often must make choices that are only tolerable rather than ones that are what we would really enjoy.

Having your needs met is the essential difference between disability and ability. Sometimes it may look bleak, trying to find health care providers who are can diagnose and treat our conditions. We have come a long way. It's better today than it was 20 years ago. With the research now underway, it will be even better tomorrow. Information and documentation are empowerment.

Perhaps we can prevent some of the sensitization that is happening to so many of us today. There is a great need to launch a massive training effort in medical schools and continuing medical education. Physical therapists need to learn that you cannot strengthen a muscle with a trigger pint because it is already physiologically shortened and weakened by the Trigger point. Doctors and therapists must learn to look for *why* the muscle is weak. "Chronic fatigue" is a description and not a diagnosis, and doctors must learn the difference between that and CFIDS.

Our symptoms are no less difficult to endure because they have complex causes. There is no excuse for doctors and other medical team members not knowing how to track down perpetuating factors and what options are available to reduce symptom load and restore maximum possible function. If your doctors cannot help you, they should promptly send you to people who can. There are *always* options. Just because there is no one way for everyone doesn't mean that each of us can't find ways to feel a whole lot better. Life with invisible chronic illness can be an obstacle course. Our medical and legal and other systems should not be some of those obstacles.

The importance of becoming an educated health care consumer is not the problem. You can't consume what isn't available. Many of us suffer from chronic care malnutrition. Always remember that even though some doctors deny the existence of chronic invisible illnesses, there are others who know better, and they are working to understand all aspects of these illnesses. They are also working on symptom relief. They are the light at the end of the tunnel, and it beckons us brightly. You only need to look in the right direction.

My DO just told me that they have cut the Medicare reimbursements in half. He takes Medicare patients, but a lot of doctors don't because the reimbursement level is so low. Medicare and other insurance personnel need to be educated about the reality of these conditions. Most of us are as sick as we are because the medical care system failed us. The central nervous system becomes so sensitized that the pain is incredible, and yet we are often denied the very medications and therapies that would allow us to function. We are still in the Dark Ages of chronic pain care, and it is time to turn on the lights. When the lights do go on, I guarantee that those people who finally get their eyes opened will be aghast at what they see. We have been disenfranchised. We have been disbelieved. We have been dismissed. It's time for a change.

Lumping these illnesses into what some physicians call "garbage or wastebasket diagnoses" only indicates that physicians and other care providers who call them that are uneducated and unable to diagnose and treat them. Creating a "garbage diagnoses" category only allow care providers to categorize people as garbage patients. We can no longer allow anyone to victimize our FAMILY! It's true that chronic invisible illness is a great factor in the health care crisis. But behind this is the greater problem that the majority of our health care providers are untrained in the diagnosis and treatment of these conditions. We are often undiagnosed or misdiagnosed, leading to neglect, undertreatment and mistreatment of symptoms, needless tests, procedures and therapies and even surgeries that may leave us more disabled than when we started. We are working to change this, but it is going to take all of us working together. Our illnesses are invisible. We aren't. It's time for a change. Those of us with these conditions *know* that they are real. They won't go away by pretending they aren't real, and neither will we! Thank you all for coming today. I hope you return home with hope, and empowered spirit. Use your knowledge to educate others. If we all work together, our illnesses will be invisible no more.