

## Public Witness Testimony

### FIBROMYALGIA SYNDROME (FMS)

Public Witness:

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#### **Public Witness Testimony by Ronald C. Kramis, Ph.D. - January 29, 1998**

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TO: The House Appropriation's Subcommittee on Labor, Health and Human Services, and Education and Related Agencies

ON BEHALF OF: Fibromyalgia Network and fibromyalgia patients nationwide

**Thank you Mr. Chairman,**

In light of your sermonettes (about budget), I would like to emphasize that your capability to direct the attention of NIH to the subject of my presentation is extremely important. There is a huge sum of information in the basic neurosciences that is yet not being applied to fibromyalgia. It is important to get the attention of NIH as well as the funding to be directed toward this painful condition.

Fibromyalgia is a persistently painful disease that costs this nation 20 billion dollars in health care and socio-economic problems. I wanted to talk to you particularly about the unremitting, life-long pain that is associated with fibromyalgia. This is a pain which destroys careers and disrupts families. It is a pain for which there is no truly effective treatment. This pain is endured, day after day, year after year, by over five million Americans. Right now, because of the progress in the basic neurosciences and the clinical neurosciences, you and the NIH have a tremendous opportunity to help these five million Americans. You can do so by focusing attention on this disease; focusing the NIH and the attention of the scientific community.

The pain of fibromyalgia is a deep and sometimes agonizing musculoskeletal pain that is perceived to occur throughout the body. Just as with many other chronically painful conditions such as severe low back pain, fibromyalgia pain occurs in the *absence* of apparent injury or disease in the tissues that are *felt* to be painful. This often raises questions of credibility for individuals suffering from fibromyalgia and for the disease itself, particularly within the health care insurance industry. Let me assure as a neuroscientist who has been studying the biological mechanisms of pain for many years, even severe and persistent pain *can* occur without pathology being present in the tissues which are felt to be painful. Many of the biological mechanisms by which this can occur are already understood. Some of them even at the molecular level.

It is a tragedy for the individuals who suffer the unremitting symptoms of fibromyalgia and other chronically painful conditions, that so few clinicians, scientists, and health care administrators understand the biological mechanisms of *pathological* pain. I would like to encourage you now, or at some other time, to try a little experiment which will help you understand how easily musculoskeletal pain can occur in the absence of tissue damage. Just reach across your chest with your thumb and all four fingers, and squeeze the large muscle that runs through the back of your neck and your shoulder. A firm squeeze, but one that is certainly not tissue damaging will become uncomfortable. If you squeeze a bit harder, and then hold that squeeze for a minute or two or even a bit longer, if you can, you will have some understanding of the pain that fibromyalgia patients go through day after day, year after year.

Two neurologically important substances, both known to be involved in the generation of persistent pain, have recently been shown to be present in pathologically high concentrations in the central nervous system of individuals with fibromyalgia. This indicates that fibromyalgia is probably a central nervous system disorder rather than a musculoskeletal disorder as originally thought. In spite of these recent discoveries, there remains no effective treatment for fibromyalgia. Even narcotic analgesics do not provide an effective remedy for fibromyalgia pain.

Fibromyalgia interferes with all aspects of a person's life. There are many symptoms that are associated with the disease other than pain itself.

1. Even the normal activities of everyday life exacerbates the pain of fibromyalgia and produces abnormally intense fatigue.
2. Fibromyalgia is severely disabling. Twenty-six percent of patients recently surveyed were receiving disability payments.
3. Fibromyalgia frequently evolves from a prior, more restricted, more localized, painful condition. In two recent studies, 25-50% of patients with chronic, localized low back pain eventually developed the total body pain of fibromyalgia.
4. Fibromyalgia occurs 8-10 times more frequently in women than in men, and is to some extent familial. This suggests a gender-linked genetic component to the disease.
5. Despite the 20 billion dollars in socio-economic and health care burden of fibromyalgia, the funding for fibromyalgia research is practically unavailable.

On behalf of the five million Americans men and women who endure fibromyalgia and on behalf of Fibromyalgia Network, their largest self-help organization, I urge you through this committee, to focus the attention of the scientific community on the fibromyalgia syndrome. As a result of the recent discoveries in the neurosciences, this is the right time to fund fibromyalgia research. Thank you very much.

**Chairman Porter:** Thank you very much for your testimony. If I understood you correctly, has anybody looked into the mental aspects of the disease or is it clear that it is physiological rather than mental?

**Dr. Kramis:** Right now there is a considerable discussion within the scientific and clinical community concerning this. In *any* chronically painful condition you are going to develop some psychologically associated conditions. But, it is very clear that there are physiological mechanisms here which are known from the basic sciences to be related to the persistent pain that is occurring in these individuals. There is really an unfortunate tendency right now, because the medical community does not have means to treat this disease and does not understand it, to say: we need the answers, it is a medical problem, but we can't treat it as a physiological problem. So there is a push to do a cost-containment study and get rid of these people and not treat them. These people have a real disease, it is not going to go away, they are going to continue to tax the socio-economic system and cost-containment alone is *not* the answer.

**Chairman Porter:** The reason I asked that question is that we had a special hearing on the role of the mind in health and healing. You mentioned back pain and related back pain problems. At this hearing there was testimony on these pain problems and it was stated that a great deal of back pain, which is a huge economic burden in our society - practically 80% of the American people experience it at some time, severe back pain, that that may be related to stress. So the reason that I asked this is to wonder if this fibromyalgia pain might also be related to stress, but you are saying that there is obviously a clear physiological cause here?

**Dr. Kramis:** There are clear physiological causes and with low back pain 90% of the cost you are talking about occurs as the result of 5% of the individuals with back pain. Those are individuals with what are called idiopathic low back pain, for which there is not an obvious physical cause. But if you look at the neurosciences, there is information in the neurosciences, there are mechanisms that just are not getting through to the clinical community that can, in fact, give good reason why pain can exist in the absence of obvious physical pathology. It is a neurological mechanism. You don't generate pain in the tissues that feel painful. You generate pain in the central nervous system. If there is disorder in the central nervous system, in fact it is a common process called central sensitization, you will get abnormal levels of pain. It doesn't require that you have a severe physical-pathological condition in the peripheral tissues in order to feel extreme pain *as if it were occurring* in those tissues.

**Chairman Porter:** Dr. Kramis, thank you very, very much for your testimony.