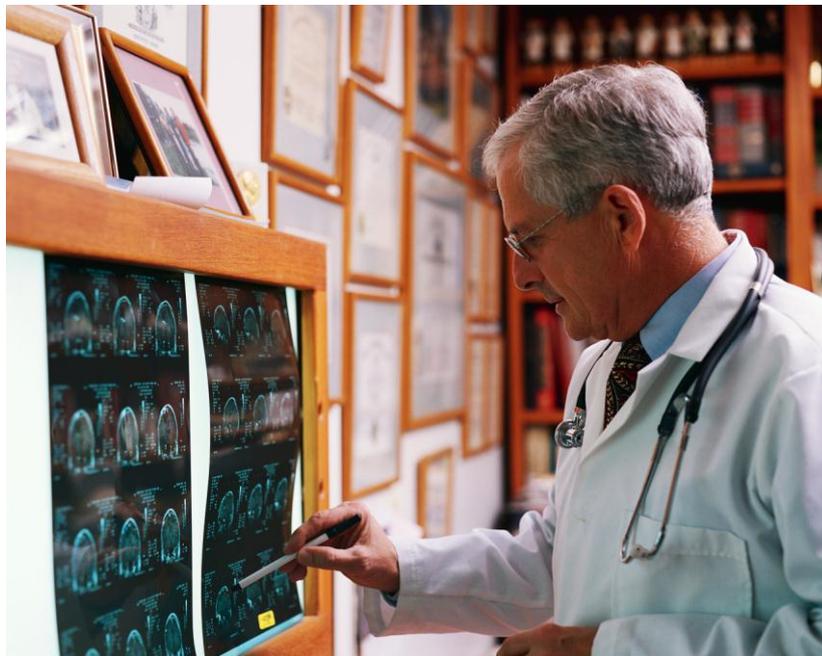


# The Fibromyalgia Regional Coordinators' Consortium UK.



**Fibromyalgia Can No Longer Be Called  
The "Invisible" Illness**

## **Introduction.**

*Fibromyalgia is a difficult condition to understand because it affects different people in different ways. Though Fibromyalgia awareness is spreading and more research is being done every year Fibromyalgia is still considered a “controversial” diagnosis by some in the medical profession.*

*This poses a problem for those of us who have it. Not only because of all the myths that surround the condition but also because some people, medical professionals and people with it, are unsure of what to call it:*

*Is it a condition? A disease? Or Simply a diagnosis?*

*Sometimes people not believing in FM can actually stem from a misunderstanding. There are a number of reputable doctors and researchers that believe that FM is not a disease, but they are not entirely sure what it is.*

*Unfortunately, the reality is that fibromyalgia is real and there are many sufferers who do not know where to turn to for answers.*

*If a patient is brushed off, by their GP, the patient should ask for a second opinion and suggest that the GP make a referral for them to see a Rheumatologist. If a patient feels that their GP is not listening to them, this can cause a breakdown in the relationship between the patient and medical professional. When this happens some patients even begin to doubt themselves.*

*The NHS expects all members of staff who are employed by them to listen and respond to a patient to the best of their ability. However sometimes, this does not happen. If you find that there are major problems in the relationship between yourself and members of your medical care team you may wish to talk to someone who is employed especially to help you. You can contact The Patient Advice and Liaison Service, known as PALS. Members of the PALS team are employed to listen to patients, their relatives, carers and friends, and answer their questions and resolve their concerns as quickly as possible.*

*Fibromyalgia is certainly not a life threatening illness but is surely life changing. Symptoms fluctuate from hour to hour and day to day and may worsen with changes in barometric pressure, humidity, cold or heat. It can be very frustrating and a little scary at times. It is a condition that is invisible to others, however research supports that FM is a distinct clinical disease. FM is formally recognised by the Department of Health and is listed on the NHS Direct website.*

*There are several medical based websites that carry well documented information about fibromyalgia, notably:*

[www.nhs.uk](http://www.nhs.uk) (NHS CHOICES)

[www.bupa.co.uk](http://www.bupa.co.uk)

[www.webmd.boots.com](http://www.webmd.boots.com)

[www.bmj.com](http://www.bmj.com)

[www.rheumatology.oxfordjournals.org](http://www.rheumatology.oxfordjournals.org)

[www.nhsinform.co.uk](http://www.nhsinform.co.uk)

*The WHO (World Health Organization) has recognised fibromyalgia.*

*Department for Work & Pensions (DWP) has recognised fibromyalgia*

*The Government recognises fibromyalgia as a real and potentially disabling condition*

*The European Parliament has recognised fibromyalgia*

*It is hard to know how to deal with it when someone looks you in the eye and tells you the condition that has had such a huge impact on your life does not exist. Unfortunately this is not at all an uncommon reaction. Fibromyalgia is often called the “invisible illness” because people who have FM look perfectly healthy.*

*Unsurprisingly, if you are speaking openly about the state of your health you are always going to come upon the people, who do not believe what you are saying. Whenever you are dealing with people questioning your condition, your symptoms or your honesty it is usually their ignorance of the illness that causes them to question what you are saying. They may react by narrowing their eyes, raising one eyebrow or shaking their heads.*

*If a patient has a good relationship with their medical professional care team their outlook usually is positive and they become proactive. They are willing to take ownership of their own management plan. They understand that Fibromyalgia will not cause degenerative joints; at times they could be debilitating but with exercise, proper nutrition, and medications, a person with fibromyalgia can continue their life living it to their fullest.*

*Michael McNett, MD states “Numerous studies have shown alterations in biochemical and neurological functioning in FM, including high concentrations of chemicals associated with pain in the spinal fluid, increased activity in pain-processing nerves in the spinal cord, and marked increases in activity in the brain areas where pain is perceived. These studies are irrefutable, and those doctors who persist in believing that FM is a purely psychosocial condition do so in obvious disregard of the facts”.*

*The majority of research over the past two decades indicates that FM is a real PHYSICAL condition!*

## **Fibromyalgia Can No Longer Be Called The "Invisible" Illness**

Up until recently, when a person complained of the symptoms now recognised as being accredited to fibromyalgia syndrome, a lot of people attributed the symptoms to other things. Although attitudes are changing, this still happens in some doctors' surgeries today. When doctors don't listen, or "don't believe in" FM, patients suffer.

Research validates what fibromyalgia patients have been saying for decades: it is not “in their heads.” Experts now know that it is in at least their brains and in their central nervous systems, and they feel it everywhere. When doctors listen to the patient and to the research findings instead of the myths, progress is possible. Cooperation between patient and practitioner is vital for successful management of this and other medical conditions.

There's a lot that's unknown about fibromyalgia, but researchers have learned more about it in just the past few years. In people who have fibromyalgia, the brain and spinal cord process pain signals differently; they react more strongly to touch and pressure, with a heightened sensitivity to pain. It is a real physiological and neurochemical problem.

### ***Research Evidence***

***Fact: Fibromyalgia is a physical disorder with real, measurable biological abnormalities.***

The myth that fibromyalgia is all in your imagination probably causes the most frustration to fibromyalgia patients.

After years of being told “It’s all in your head,” patients finally have proof that fibromyalgia is a very real, physical illness. Research studies have revealed a number of biological abnormalities, including:

- Decreased blood flow to specific areas of the brain, particularly the thalamus region, which may help explain the pain sensitivity and cognitive functioning problems experienced by fibromyalgia patients.
- High levels of “substance P,” a central nervous system neurotransmitter involved in pain processing.
- Low levels of nerve growth factor.
- Low levels of somatomedin C, a hormone that promotes bone and muscle growth.
- Low levels of several neurochemicals: serotonin, norepinephrine, dopamine and cortisol.
- Low levels of phosphocreatine and adenosine, muscle-cell chemicals.

Despite the scientific evidence, some medical professionals continue to dismiss fibromyalgia as a psychological problem, insisting that the symptoms are caused by depression. The fact is that the percentage of FM patients who suffer from **depression** is no higher than for any other chronic illness. Unfortunately, since it takes an average of 17 years for new research to become part of mainstream medicine, we're probably going to be fighting this myth for several more years.

- **Richard Gracely, Ph.D.**, and **Daniel Clauw, M.D.**, of the University of Michigan in Ann Arbor, used fMRI to study fibromyalgia patients with and without depression.<sup>2</sup> They found that different areas of the brain were activated when patients processed the sensory dimension of pain as opposed to those that were activated for depression (viewed as the *affective* component of pain because it has to do with how much emotional relevance a person attaches to their pain). They concluded, "Evaluation of these sensory and affective dimensions in patients with chronic pain is likely to improve diagnosis, choice of treatment, and treatment efficacy."
- The above findings are highly relevant in light of the common prescription of antidepressants for treating fibromyalgia. A 12-week treatment trial of the antidepressant, Effexor, revealed that fibromyalgia patients with depression benefited with improved mood.<sup>3</sup> However, the pain of fibromyalgia was unfazed by the drug.
- A separate report by Gracely and Clauw's team measured the response to experimental pain stimuli in fibromyalgia patients and healthy controls.<sup>4</sup> Interestingly, the healthy controls rated the stimuli to be significantly more unpleasant than the patients. Distress, anxiety or depression did not influence the patient's unpleasantness ratings. The study's authors suggest that the presence of chronic pain can alter one's perception of experimental pain (perhaps as part of the brain's reorganization process), which may pale in comparison to the day-to-day pain of fibromyalgia.
- **Ali Gur, M.D.**, of Turkey found an important cytokine chemical, IL-8, to be elevated in patients with fibromyalgia.<sup>5</sup> Correlating this chemical with brain function, he found that fibromyalgia patients with little to no depression had higher IL-8 levels and more impaired brain blood flow than those with severe depression. In keeping with the concept that fibromyalgia and depression cause different alterations in brain function, Gur was able to tease out the chemical change caused by fibromyalgia (IL-8) and the compounding issue of feeling depressed.

Eric Guedj, M.D using single photon emission computed tomography (SPECT); lead a team of researchers in France who were able to detect functional abnormalities in certain regions in the brains of patients diagnosed with fibromyalgia, reinforcing the idea that symptoms of the disorder are related to a dysfunction in those parts of the brain where pain is processed.

"Fibromyalgia is frequently considered an 'invisible syndrome' since musculoskeletal imaging is negative," said Eric Guedj, M.D., and lead author of the study. "Past imaging studies of patients with the syndrome, however, have shown above-normal cerebral blood

flow (brain perfusion) in some areas of the brain and below-normal in other areas. After performing whole-brain scans on the participants, we used a statistical analysis to study the relationship between functional activity in even the smallest area of the brain and various parameters related to pain, disability and anxiety/depression."

**In the study, which was reported in the November issue of *The Journal of Nuclear Medicine*, 20 women diagnosed with fibromyalgia and 10 healthy women as a control group responded to questionnaires to determine levels of pain, disability, anxiety and depression. SPECT was then performed, and positive and negative correlations were determined.**

The researchers confirmed that patients with the syndrome exhibited brain perfusion abnormalities in comparison to the healthy subjects. Further, these abnormalities were found to be directly correlated with the severity of the disease. An increase in perfusion (hyperperfusion) was found in that region of the brain known to discriminate pain intensity, and a decrease (hypoperfusion) was found within those areas thought to be involved in emotional responses to pain.

In the past, some researchers have thought that the pain reported by fibromyalgia patients was the result of depression rather than symptoms of a disorder. "Interestingly, we found that these functional abnormalities were independent of anxiety and depression status,"

**"Fibromyalgia may be related to a global dysfunction of cerebral pain-processing," Guedj added. "This study demonstrates that these patients exhibit modifications of brain perfusion not found in healthy subjects and reinforces the idea that fibromyalgia is a 'real disease/disorder.'" 8**

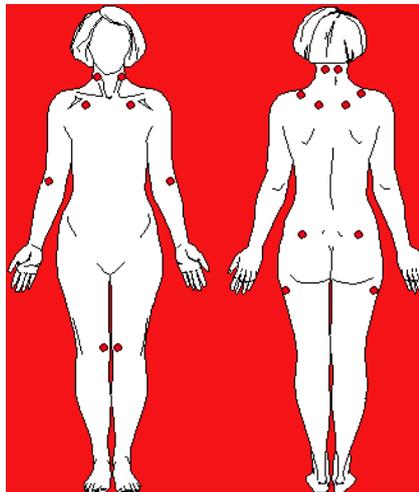
**Richard Podell, MD, MPH Clinical Professor, UMDNJ-Robert Wood Johnson Medical School** records in his lecture to the American Conference Institute's 10th National Advanced Forum on Resolving Disability Insurance Claims and Litigation, June 2007:

***Definition of Fibromyalgia:*** The American College of Rheumatology Criteria For Fibromyalgia Requires:

- 1) *History of widespread chronic pain in 4 quadrants of the body and*
- 2) *Abnormal tenderness at 11 or more of 18 designated anatomic sites, called tender points.*
- 3) *Appropriate Rule/outs*

***Clarification:*** Tender points are areas of muscle/tendon insertion. These "points" are normally more sensitive to painful stimuli than other sites. To be abnormal the patient must report pain, not just tenderness. Examine pressing with the thumb using a force that just makes thumbnail blanch.

Tender point counts can vary from day to day. Psychological distress makes tender points more painful. A person who has chronic widespread pain but < 11 of 18 tender points meet the definition for chronic pain syndrome. Technically, fibromyalgia is a sub-class of chronic pain syndrome.



Fibromyalgia Tender Points

Please note: The formal definition of fibromyalgia provides no guide to assessing disease severity or disability.

One can be disabled from fibromyalgia despite having only 11 positive tender points on a given day. Or one might be able to work despite having 18 out of 18 positive tender points.

**Other than tender points there are no objective finding to be looked for on physical examination or standard laboratory tests that measures the severity of fibromyalgia.**

However certain findings, when present, do provide evidence that illness is major. For example, abnormal results on formal neurocognitive testing; low blood pressure, increased heart rate and/or fall in blood pressure with prolonged standing.

There are no specific findings on physical exam or lab that reliably measures disease severity. There are no specific findings on physical exam or lab that distinguish between one person with fibromyalgia or chronic fatigue syndrome who is able to work from another person with fibromyalgia or chronic fatigue syndrome who is, in fact, disabled.

So far as the physical exam and standard lab tests are concerned, both persons can appear exactly the same. Yet despite the same appearance, one person has the stamina to sustain a regular level of function for five days a week. The other person cannot.

***What is the “Objective” Evidence (besides the patient’s self-report) that the Pain of Fibromyalgia is in Fact “Objectively” Real?***

In principle, an individual patient could fake or exaggerate his or her report of pain on the tender point exam. *However, many research studies now show that, as a group, fibromyalgia*

*patients do accurately report the pain that they feel. Objective research studies confirm that fibromyalgia patients:*

*1) Feel pain when exposed to much lower levels of minor trauma/adverse stimuli compared to normals.*

*2) Experience a more rapid increase in pain levels when traumatic or noxious stimuli are repeated*

*3) Have a slower decay/decline of pain levels after the experimental stimulus is removed*

*4) Have a halt or reversal of the decline of pay after experimental stimulus stops, if even a very small adverse stimulus is reintroduced. In contrast, among normals, adding such small adverse stimuli do not prevent the pain's decline and resolution.*

***These research articles are relevant to establishing that -- Fibromyalgia is real.***

- Fibromyalgia is mediated through physical mechanisms. Psychological factors can trigger and/or exacerbate or result from fibromyalgia; but the primary nature of this disease is physical.
- The main “end organ damage” of fibromyalgia affects the pain signalling pathways within the central nervous system (spinal cord and brain).
- Fibromyalgia patients, for the most part, accurately report on their symptoms.

***The following research articles support these conclusions. Podell offers representative quotations from various research abstracts.***

**Cook D, Lange G Ciccone D et. Al., Functional imaging of pain in patients with primary fibromyalgia, J Rheumatol 2004;31:364-78**

“Subjects underwent fMRI scanning while receiving painful and no painful heat stimuli... fMRI data indicated that the FM group exhibited greater activity than controls over multiple brain regions in response to both no painful and painful stimuli ( $p < 0.01$ ). ... *Data from the practice session indicated brain activity in pain-relevant areas for the FM group but not for controls. CONCLUSION: Our results provide further evidence for a physiological explanation for FM pain.*

**Staud R and Rodriguez M, Mechanisms of Disease: pain in fibromyalgia syndrome, Nature Clinical Practice Rheumatology, 2005; 3: 90-98**

*“Persistent or intense nociception (noxious stimuli) can lead to transcriptional and translational changes in the spinal cord and brain resulting in central sensitization and pain. This mechanism represents a hall mark of fibromyalgia and many other chronic pain syndromes...”*

**Harris R and Clauw D, How Do We Know That the Pain in Fibromyalgia is “Real”? , Current Pain and Headache Reports 2006; 10:403-7**

*“...neurobiological studies indicate that fibromyalgia patients have abnormalities within central brain structures that normally encode pain sensations in healthy pain-free controls...There are now multiple, converging lines of evidence confirming that the pain of fibromyalgia is “real” and that there are strong neurobiological underpinnings to this condition.”*

**Gracely R, Petzke F, Wolfe M, Clauw D Functional magnetic resonance imaging evidence of augmented Pain Processing in Fibromyalgia, Arthritis & Rheumatism 2002:46: 1333-43**

*“In FM patients, application of mild pressure produced subjective pain reports and cerebral responses that were qualitatively and quantitatively similar to many of the effects produced by application of at least twice the pressure in control subjects.”*

**Dr Poddle summarises by saying “ Fibromyalgia was first recognised by rheumatology/arthritis specialists. It was first thought to involve mainly the muscles and joints. However, as research has developed, we now know that a major part of this illness affects the pain signalling pathways of the central nervous system—the brain and the spine. This is the main site of the “end-organ damage”. This distortion of neural pain pathways has been given the name “neural sensitization”.**

A useful way of thinking about neural sensitization is to imagine a radio with the volume dial turned up very high, and the station selection knob being slightly off frequency. Hence, the amplification and distortion of pain signalling to the brain. 9.

**Karen Lee Richards, Co-Founder of the American National Fibromyalgia Association (NFA) is constantly looking for and disseminating evidence which establishes that fibromyalgia is real and not something in a person’s imagination. She makes reference to the research mentioned earlier in this document (page2) conducted by Researchers from Massachusetts General Hospital and the University of Michigan (Richard Gracely PhD and Daniel Clauw, M.D.) and reports;**

Researchers have discovered a new clue in the mystery of what causes fibromyalgia pain. The [study, published in the August 2010 issue of the journal \*Arthritis & Rheumatism\*](#), found That fibromyalgia patients have more "connectivity" between brain networks and regions of the brain involved in pain processing.

### **Study Methods**

A total of 36 women – 18 fibromyalgia patients and 18 healthy controls – took part in the study. Fibromyalgia participants were asked to rate the intensity of their pain at the time of the test on a scale of 0-10, where 0 is equivalent to "no pain present" and 10 is equivalent to "the worst pain they could imagine." Reported pain scores ranged from 0 to 8.1. Next, participants each underwent six minutes of resting-state brain scans - functional magnetic resonance imaging (fMRI).

### **Results and Conclusions**

The brain scans showed that the neural activity (connectivity) between certain brain networks and the insular cortex – a region of the brain involved in pain processing – was greater in the women with FM than in the healthy controls. The connectivity to the insular cortex was notably stronger in those who reported higher pain levels.

The brain networks included were the default mode network (DMN), which is involved when you think about yourself or what's happening to you, and the executive attention network (EAN), which is involved in working memory and attention.

The researchers concluded, “Our findings indicate that resting brain activity within multiple networks is associated with spontaneous clinical pain in FM. These findings may also have broader implications for how subjective experiences such as pain arise from a complex interplay amongst multiple brain networks.” 10.

**There is abundant evidence that fibromyalgia (FM) is a very real physical disorder. FM is a difficult illness to understand. It affects different people in different ways. Accordingly, there are many approaches to its treatment and therapies which must be customised to the needs of the individual FM patient. Fibromyalgia affects men, women and children of all ages, races and economic levels.**

### **Sources of Reference:**

1. Grachev ID, *et al.* [J Neural Transm](#) 109(10):1309-34, 2002.
2. Giesecke T, *et al.* [Arthritis Rheum](#) 52(5): 1577-84, 2005.
3. Sayar K, *et al.* [Psychosomatics](#) 46(4):340-4, 2005.

4. Petzke F, *et al.* Eur J Pain 9:325-35, 2005.
5. Gur A, *et al.* Clin Exp Rheumatol 20(6):753-60, 2002.
6. Apkarian AV, *et al.* Eur J Pain 9(4):463-84, 2005.
7. Baliki MN, *et al.* Mol Pain 1(1):32, 2005
8. Medical News today [www.medicalnewstoday](http://www.medicalnewstoday.com) 04 Nov 2008

Co-authors of "Clinical Correlate of Brain SPECT Perfusion Abnormalities in Fibromyalgia" include Eric Guedj, Serge Cammilleri and Olivier Mundler, Service Central de Biophysique et de Médecine Nucléaire, AP-HM Timone; Jean Niboyet, Patricia Dupont, Eric Vidal and Jean-Pierre Dropinski, Unité d'Etude et de Traitement de la Douleur, Clinique La Phocéenne, all of Marseille, France.

**9. Adaptation of Dr. Podell's lecture to the American Conference Institute's 10th National Advanced Forum on Resolving Disability Insurance Claims and Litigation, June 2007.**

**Summary of Dr. Podell's Background Related to Fibromyalgia:**

Dr. Podell serves as clinical professor in the department of family medicine, UMDNJ-Robert Wood Johnson Medical School. He is Board Certified in both Internal Medicine and in Family Practice.

**Fibromyalgia:**

Dr. Podell is the author of two review articles for physicians on Fibromyalgia-- Podell, R, *Fibromyalgia: A Practical Guide for Diagnosis and Treatment*, accepted for publication in the Journal of Musculoskeletal Pain, 2007

Podell, R, *Fibromyalgia: Practical Treatments for the Family Physician, Perspectives*, The Journal of the New Jersey Academy of Family Physicians pages 8-13, 4Q, 2005

Dr. Podell has lectured on Fibromyalgia before the Division of Rheumatology at UMDNJ Robert Wood Johnson Medical School and other lay and professional audiences.

Dr. Podell participated in the National Institutes of Health Workshop on Fibromyalgia Research, National Institutes of Health, November, 2004

Dr. Podell is a member of the International Myopain Society, the leading international

professional organization of physicians and scientists specializing in Fibromyalgia.

Dr. Podell participated in the three most recent Scientific Assemblies of the International Myopain Society.

10. [Karen Lee Richards](#) Wednesday, August 11, 2010

[Napadow V, et al. Intrinsic Brain Connectivity in Fibromyalgia Is Associated With Chronic Pain Intensity.](#) Arthritis & Rheumatism; Published Online: April 6, 2010 (DOI: 10.1002/art.27497); Print Issue Date: August 2010.

[More Clues to Fibromyalgia Pain.](#) Drugs.com. August 5, 2010.

[Interaction of Multiple Brain Networks Provide Insight Into How Pain Occurs.](#) Medical News Today. July 31, 2010

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