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LOST IN THE FOG OF FIBROMYALGIA

BY

Linda Johnson

Imagine a person who is in constant, excruciating pain, but there are no outward signs of illness present to give a hint of the person's discomfort. Visualize a woman who wakes up every morning more tired than when she fell asleep the night before. Picture a man in his forties who fears he is losing his mind because he cannot focus on his work. For sufferers of fibromyalgia, such situations are everyday occurrences. Fibromyalgia is an illness that causes life-altering changes for those who are stricken with the disorder, as well as for their families. The changes in the lives of the victims and their family members can be very sudden and dramatic or they may be slow and inconspicuous to the casual observer. In either case, the changes are often devastating and permanent. The effects of Fibromyalgia Syndrome on the health of millions, the disruption of family dynamics, and the costly economic burden to the country's health and welfare system are only the tip of the iceberg.

There needs to be a greater focus on allocating increased funding for intensive research into the causes, effects, treatments, and possible cures for a misunderstood illness that may be developing into a health crisis as well as an eco-

nomie predicament, in not only the United States, but elsewhere around the world.

According to the National Institute of Arthritis and Musculoskeletal Diseases, approximately five million people in the United States alone are

afflicted with FMS. FMS is a torturous disease in a myriad of ways, but it is not a fatal disease, it is not a visible disease, nor is it a progressive disease. Because there is no widely accepted clinical test available at this time that has been shown to prove the existence of fibromyalgia, it is often diagnosed by a process in which the physician looks for a "preponderance of symptoms" simply meaning that the sufferer has many more of the symptoms associated with FMS, than not. Today's diagnosticians consider the most important criteria for diagnosing FMS to be the following indicators: persistent, diffuse pain throughout the body, extreme fatigue which is not easily remedied by rest, restless leg syndrome, and the presence of other symptoms known to be related to fibromyalgia, and ruling out other conditions that could possibly be causing the

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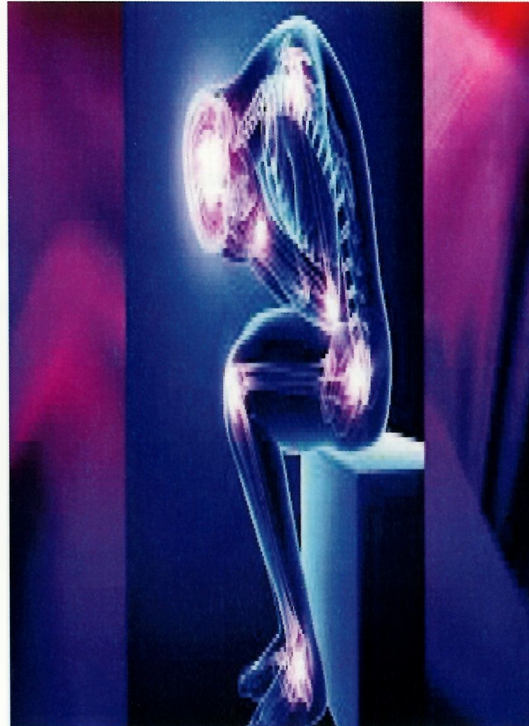
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symptoms. For many of those affected by FMS, a prevalent symptom they have in common is called “fibro fog.” A condition that slows one’s thinking processes and tends to deepen the depression of the sufferer, fibro fog is often as disturbing to the FMS victim as is the unrelenting pain he or she may be enduring. Those who experience this symptom often feel as though they are losing their mental faculties. It manifests itself as a lack of concentration, short-term memory loss, the inability to remember new information, becoming easily distracted, forgetting plans, difficulty carrying on conversations, and numerous other dysfunctions of the victim’s cognitive abilities.

Unfortunately, because most of the symptoms related to FMS are also present in a multitude of other illnesses, the diagnosis process is often very lengthy. It may take many visits to different doctors and as long as five years before one receives a determination of FMS. Researchers and experts have agreed on many possible causes for the disorder, but they are still without reliable laboratory tests to show absolute proof of the condition. Some of the causes that are most agreed upon are as follow: possible viral infections, musculoskeletal or repetitive injuries, accidents or physical traumas, illnesses or surgeries, abnormalities of the

immune system, and hormonal or brain chemical imbalances.

A majority of FMS victims experience deep depression and moderate to severe sleep disorders, both of which tend to exacerbate the continuous and intense fatigue that plagues most sufferers. However, some experts disagree as to whether the presence of the depression and sleep disturbances are



symptoms or possible causes of FMS. Research strongly suggests that the cause of the malady is most likely an amalgam of factors. The University Of Maryland Medical Center gives a general description of possible causes of FMS which include genetics, illnesses or infections, extreme stress--either physical or emotional—and post-traumatic stress disorder or PT. Presently, the majority of people diagnosed with FMS are women. The ratio for women to men suffering from FMS is ten to one. Men are diagnosed with FMS much less than women are, but according to health reporter, Matt McMillen, that may be because men are under more pressure by the mores of society not to complain or to show pain.

Although the word “Fibromyalgia” is relatively recent in medical terminology, there is evidence that the disorder is not a new disease. De-

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descriptions of ailments resembling FMS have been alluded to for many years. In medical literature dating as far back as the early 1800s, there were references to and descriptions of illnesses and afflictions that shared many of the same symptoms that are currently associated with FMS. According to Bret Stetka, MD, in the Old Testament story of Job, he speaks of his personal suffering of pain, depression, and long, sleepless nights. Stetka makes the observation that, "Job's ailment does sound a lot like the modern interpretation of fibromyalgia." FMS was officially recognized as an illness by the American Medical Association until 1987, but despite that official recognition of the disorder, there still existed widespread skepticism in the medical community concerning the legitimacy of FMS. In those early days, many physicians continued to doubt the existence of FMS, and in addition, many who were willing to believe in the possibility of its existence did not know how to define it. They wondered, was it a physical disease, disorder, or syndrome or was it purely a psychological ailment?

The first time I ever heard the word "Fibromyalgia" was when my sister, Louise, told our family that she had just been diagnosed with the condition. Some of us were very skeptical because she looked so healthy and had always been so energetic and upbeat. I admit that I was unconvinced that there was re-

"I admit that I was unconvinced that there was really anything wrong with Louise . . . she looked so healthy"

ally anything wrong with Louise. However, I changed my mind about six years after her announcement when I was diagnosed with FMS shortly following a major surgery of my own. I was extremely fortunate because the doctor I saw was very progressive in his belief that FMS was a real, physical condition and not a mental problem. I did not want to have fibromyalgia:

not because it was a painful and chronic disorder, but primarily because I thought no one would believe that I was actually suffering from a real disease. It is ironic how quickly one can become a believer when one becomes affected. After many years of experiencing to some degree most of the symptoms of FMS, I can tell you that it is real and it can affect a person in subtle and serious ways that one never imagines.

As if the physical and psychological difficulties of the disease were not arduous enough to cope with, another hardship for FMS victims and their families is the financial burden that the ailment frequently places upon them. For those who are dealing with FMS and continuing to work, the possibility of applying for disability benefits may seem like the answer to their problems. However, doctors will often suggest to their patients that they continue to work if at all possible in order to keep themselves from feeling

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more depressed and isolated. For those who are no longer able to work, in addition to losing their income, they will often also lose their medical insurance coverage. Add to that, the fact that it can be particularly difficult to qualify for disability benefits stemming from a diagnosis of fibromyalgia. If either breadwinner in a family is unable to work, and cannot receive disability benefits, it puts the burden of supporting the family on the shoulders of the remaining family members. In many cases, those family members may be children still at home. Furthermore, the loss of laborers to our nation's workforce, as well as the loss of breadwinners for many families, is a great blow to our national economy. Estimates of the costs in the United States due to FMS have run as high as 12-14 billion dollars per year.

At this time, what can be done to address this health dilemma? There is research in progress to learn more about the causes of FMS and also to find treatments and hopefully cures. There has been at least one potential breakthrough that shows promise for possible use as a method to diagnose and treat FMS. However, much of what is known about fibromyalgia today is "old news"—information that researchers have known for many years. New discov-

eries are few and far between. Unfortunately, the funds for fibromyalgia research are woefully lacking. In 2012, the actual cost of fibromyalgia research funds spent was reported as 13 million dollars. The estimated research funds for the year 2017 have dropped to nine million dollars.

Consider that one prominent cause of FMS is believed to be genetic in origin. Should there not be more research in that area just to keep up with the birth rates in families that have shown the genetic predisposition for FMS? Fibromyalgia is not going away. There needs to be a greater focus on allocating increased funding for intensive research into the causes, effects, treatments, and possible cures for a misunderstood illness that may be developing into a global health crisis, in not only the United States, but also around the world. Therefore, when one takes into consideration not only the alarming number of people who suffer

from fibromyalgia syndrome, but also the very substantial financial cost to the nation's economy, we should seriously consider the real possibility that FMS should be considered to be a national health crisis. Our government needs to fund more vigorous research to find a cure for this debilitating and costly disease that seems only to be increasing in our country and around the world.

