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What is Fibromyalgia?

Invisible, unpredictable, frustrating, and oftentimes torturous. The painful, diffuse symptoms of fibromyalgia have no boundaries. This disease does more than rob you of restful sleep. You wake up each morning feeling as though you have been punched around by the fibromyalgia monster that inhabits every inch of your body. Your muscles are stiff, your brain is dead, and you're exhausted before the day begins.

Fibromyalgia may affect every system, every cell in your body, but you don't have any lab tests to prove your long list of miserable symptoms. You look normal and feel awful; living with fibromyalgia is a constant struggle that others can't begin to fathom.

Quick Facts

- Affects 3 to 5 percent of the general population
- Occurs in people of all ages, including children
- Men develop fibromyalgia too, although more women are diagnosed with it
- Symptoms are chronic but may fluctuate throughout the day
- Roughly one-quarter of fibromyalgia patients are work-disabled
- Three drugs are FDA-approved for fibromyalgia, but have low efficacy and high side effects

AFSA Membership is Free

Get the latest treatment and research news on fibromyalgia. AFSA interviews the researchers and physicians, and compiles this info into patient-friendly articles. We are ad-free and unbiased. Visit our website at fibromyalgiafund.org and **Join Today!**

For daily postings to help you cope with the symptoms of fibromyalgia, visit our supportive community of patients at facebook.com/AFSAfund.



An all-volunteer nonprofit organization dedicated to funding research on the causes and treatments for fibromyalgia and empowering patients through education.

Over 90% of your donations go to support our missions.

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About AFSA

The American Fibromyalgia Syndrome Association (AFSA) has two missions:

- fund superior quality biomedical research on fibromyalgia
- educate patients about this serious, life-impacting disease

We are an all-volunteer 501(c)3 charity and have been assisting people with fibromyalgia since 1994.

Research

AFSA is the nation's only nonprofit organization dedicated to funding research that accelerates the pace of medical discoveries on fibromyalgia. We don't just say we support research; we have been funding high-quality studies on this disease since 1995.

Our research grants (up to \$85,000) enable scientists to collect the vital data needed to receive large sums of money from the National Institutes of Health (NIH) or other agencies. In addition, most AFSA awards have generated at least one research paper in a peer-reviewed medical journal. So, funding from AFSA accomplishes two goals: (1) expands research in targeted areas important for helping patients and (2) educating other scientists and treating physicians about advances in fibromyalgia.

By stepping up research on the causes of and treatments for fibromyalgia, AFSA and its generous contributors are working together to make a difference in the lives of millions.

Education

The average person with fibromyalgia struggles with this disease for five years before being diagnosed with it. And once patients are handed this diagnosis, they are often told that there is little that can be done to relieve their painful and fatiguing symptoms. Not true.

A variety of treatment options are available to reduce the symptoms of fibromyalgia. Learning about each approach places patients in the driver's seat to open a dialog with their healthcare team. Some therapies are expensive, while the scientific evidence supporting others is flimsy. The point is, patients deserve to know what the medical literature says about the various treatment options for fibromyalgia.

Part of the battle of living with fibromyalgia is that it produces so many symptoms. Reading about

*Education for today.
Funding research for a
better tomorrow.*

research studies that help explain the symptoms can be both validating and relieving to patients. The same holds true for reading about the possible causes of fibromyalgia, especially when they are based on published research studies and interviews with the lead investigators.

AFSA's education mission is not to replace a patient's doctor or other healthcare providers; that's not possible. Fibromyalgia patients need to consult with their medical team for care. But in an era of the ten-minute office visit, the information on AFSA's website can empower patients to make the most out of their healthcare appointments.

Research Priorities

The American Fibromyalgia Syndrome Association (AFSA) funds research proposals that fall into one of the following categories:

- Identify the physiological mechanisms that cause the symptoms of fibromyalgia.
- Test therapeutic interventions or agents for reducing fibromyalgia symptoms.
- Identify/develop lab markers or other test measures that can be used for diagnostic and clinical evaluation purposes.

Identifying the possible causes of fibromyalgia is essential for developing highly effective therapies. Although patients have many treatment options, none of them provide substantial relief of the symptoms. At best, any one approach helps a minority of people with fibromyalgia by reducing one or two symptoms by 30 percent. And the only way to determine which patient might respond favorably to a given therapy is trial and error. This is unacceptable.

Figuring out what causes fibromyalgia could take years, possibly decades. In the meantime, novel treatments based on new information regarding the physiology of this disease need to be tested to reduce patient suffering. The goal is to find therapies that help patients today to minimize disability down the road.

The lag time between the onset of fibromyalgia symptoms and eventually being diagnosed with this disease is shameful. Adults can lose their careers and relationships; young people can lose out on an

education and social development. The invisible symptoms of fibromyalgia make it even more important that objective diagnostic lab markers be developed. Otherwise, patients will continue to face a credibility dilemma – in the doctor's office, at work (or school), and with family and friends.

AFSA does NOT fund:

- behavioral interventions
- psychosocial or survey-driven assessments
- self-help or lifestyle change strategies
- movement therapies (e.g., any form of exercise)

None of the above studies will generate new physiological findings, better treatments, or objective lab markers for people with fibromyalgia. Besides, the medical journals are already replete with reports that falsely place the blame on patients, implying that all they need to do is exercise more and think happy thoughts.

In addition, AFSA does not fund the testing of expensive experimental treatments that are out-of-reach financially to most patients living in the United States. Nor do we fund projects that test therapies designed to benefit a third-party corporation (e.g., they have patented a device and they want AFSA to pay for testing it). Although we do fund researchers outside the United States, we are particularly sensitive to the needs of patients living in this country.

Why Donate?

Effective treatments for fibromyalgia are sorely lacking.

Government funding institutions should do more, but they don't. That's why AFSA's grants are essential for helping researchers collect data to successfully compete for large-scale government awards.

Learn more on our website at:

www.fibromyalgiafund.org

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This brochure is for informational purposes only. Patients should always consult their physician for medical advice and treatment.