

THE NEW! Fibromyalgia AWARE

The NFA Serving the Fibromyalgia Community Since 1997

2016 • Vol. 2 • Issue 3

**Men with Fibro Speak Out:
It's Hard to "Be A Man" With FM**

**Can Pain & Intimacy Coexist?
Findings from the FM Intimacy Survey**

On the Cover

Sabrina Dudley Johnson:
First Responder, Advocate, Fibro Diva

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FIBRO FORERUNNERS



LETTERS FROM 1997



BE INSPIRED, GET INVOLVED



TAKE CONTROL OF YOUR HEALTH

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FIBROMYALGIA FORERUNNERS

This section of the magazine honors those who have persevered through the adversities of living with, researching and treating this ailment. These patients, doctors and scientists have helped us face challenges with courage and kindness, they have championed the cause with hope for a better future, and they have led us away from a miserable imaginary malady to a reputable illness. These humble hard workers came forward to foster a spirit of community, a respect for research, and a commitment to the dialogue that has kept us motivated over the past 20 years. We applaud you. Thank you for your contribution to the FM community.

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If you know of an inspirational person you'd like to nominate as a Fibro Forerunner, please take a moment to click the link below and submit your suggestions. We look forward to celebrating their successes with the FM community. Together we can change the story of fibromyalgia.



WHEN PROTECT AND SERVE LEFT HER *injured and alone*

By Elizabeth Mesic, Executive Editor

"I thought I could make a difference in my own neighborhood," Sabrina Dudley Johnson reminisced as she recounted the beginning of her career as a police officer. Sabrina, with dreams of someday being a lawyer, had joined the police department with a class of cadets in 1988. At that time she lived in one of the

roughest neighborhoods in Chicago. My mother, a community organizer, and my father, a naval officer, "taught me when growing up, if you don't like how the system is operating, then learn the system and change it from within." This sentiment would shape her experiences throughout her life.

Sabrina knew being a police officer would be difficult, but she didn't anticipate the injuries that came with the job. "I was hurt six times while on the job in 1991 and 1992," she recalls. "It was during an arrest when I twisted my neck, shoulder and wrist, and that's how the fibromyalgia began." Sabrina was placed on the police department's version of workman's comp. She was told which doctors to see, what treatments to undergo, and how long she had to recover. After an entire year of treatment, she was still not well. Blamed for her pain, Sabrina was given permission to pursue her treatment with a private doctor. Her doctor diagnosed her with fibromyalgia, yet Sabrina was never told.

In 1993, this Midwestern police department didn't accept fibromyalgia as a real diagnosis. Her doctor was told to "keep looking." A compromise diagnosis of Ménière's disease was reached, as it encompassed some of her symptoms.

Sabrina sought treatment under this incomplete diagnosis with an ear, nose and throat (ENT) doctor. While preparing her for surgery this ENT doctor, looking through her chart,



causally asked, "Did anyone ever tell you, you have fibromyalgia?" Sabrina was shocked. "I felt betrayed by both the police department and my personal doctor! No matter what the circumstances, they should have kept me informed." Without the correct diagnosis Sabrina had been left ill prepared to apply for disability or accommodations for suitable work environments. "It was frustrating," she remembered. "I wanted to keep working; I just didn't know what was wrong."

The medical section chief told Sabrina, "Go back to work or go on disability." Unable to return to the rigors of her job on the police department, she was forced into early retirement. Pension administrators

The stress of proving she was sick not only to her job, but to her husband as well, was devastating.

did not want to grant full disability to Sabrina because she was the first known officer to develop fibromyalgia after a work related injury. "They just thought it was in my head or I had had it before," she explained. "They couldn't accept that fibromyalgia could be caused by an injury." Furthermore, there was no objective physical evidence. "I couldn't work,



and I couldn't get disability. I was stuck."

To make matters worse, Sabrina's doctors informed her husband that fibromyalgia was not a real illness. "He was aggravated by the doctors who told him I was lazy." Domestic violence erupted in the house, which led to their divorce. The stress of proving she was sick not only to her job, but to her husband as well, was devastating. "The ongoing battles were so debilitating that my fibromyalgia went through the roof," Sabrina recounted. She had lost her job, her position of respect within the community, and now her marriage. Sabrina had to do something.

“I am not sure which was harder to overcome, being a person of color with FM, or being a law enforcement officer with FM.”

She could not be the only public safety worker with this experience. Fibromyalgia affects an estimated 5% of the population, and at the time that was almost 11 million Americans. In addition to having little to no support for injured police officers, Sabrina faced another challenge. “I was told women of color didn’t get fibromyalgia,” she said incredulously. Yet there she was. “I am not sure which was harder to overcome: being a person of color with FM, or being a law enforcement officer with FM.” Her answer was to start the first minority and public safety officer-oriented nonprofit organization for fibromyalgia in 1997 called FACES, which stood for “Fibromyalgia Association Created for Education and Self-help.”

FACES turned out to be “one of the most successful American fibromyalgia support groups,” said Jeanne Hambleton, a fellow NFA Leader Against Pain, who wrote for [FMS Global News about the disbanding of FACES](#) in 2008. FACES ran monthly meetings, quarterly workshops, annual seminars, an e-newsletter, and even an annual television show.

“I think we were the only support group for African Americans and first responders at that time,” Sabrina explained.

Her activism continued with the submission of her 2005 paper simply entitled “FYI” to the Fraternal Order of Police Chicago Lodge 7 and the Department of Justice (DOJ). This paper highlighted the occurrence of fibromyalgia in the community and the likelihood that 5% of public safety workers were also affected. Sabrina continued to work at exposing this problem of public safety workers developing fibromyalgia as a result of on-the-job injuries. “There was no one to help an injured police officer suffering from fibromyalgia or any other chronic pain disorder with the disability process,” Sabrina remembered wistfully.

Sabrina was an original member of the NFA’s Leader’s Against Pain.

Eventually the police department accepted fibromyalgia as a disabling condition and after 11 years, Sabrina was finally granted a disability award from the DOJ. In 2012, the DOJ accepted fibromyalgia as a possible outcome of an on-the-job injury. “This was my last fight.” Sabrina smiled, “And we won it!” It’s still not a seamless process though.

Even if a public safety worker receives full-duty disability from their department, they still need to be nominated by their superintendent to the DOJ to get this award. This victory was overshadowed by Sabrina’s deteriorating health, and as a result, her work to fight for disabled cops began to diminish. With accommodations, some officers were able to continue to work with light duty. “It’s not the easy street that people believe,” Sabrina related about being a disabled cop.

Sabrina was an original member of the NFA’s Leader’s Against Pain. “The NFA had the best media outreach program,” Sabrina reminisced. FACES also co-hosted the NFA’s FAME (Fibromyalgia Awareness Means Everything) conference in Chicago in 2001. There were over 200 patients and healthcare providers on site. It was the first time in Chicago that



the patients got to mingle with the doctors. “We came away with a lot of cutting-edge research, and it did a ton to raise awareness in Chicago.”

...she worked on a program to bring the problem of injured first responders developing chronic pain conditions to the attention of the White House.

“In November 2007, my health worsened,” explained Sabrina. “I started experiencing mini strokes.” As a result, she needed to step down from her role as president of FACES, and it was during this time that the Board of Directors voted for dissolution. “Describing the reasons for voluntary dissolution...the website states the corporation



is highly associated with its founder and after the deterioration of the founder’s health, the organization now finds itself unable to function: attract dedicated and active board members, reliable volunteers, or generate ongoing funding,” reported Hambleton in Global News.

Never one to give up, Sabrina soon began to expand her work to help public servants with fibromyalgia. While volunteering with the American Pain Foundation, she worked on a program to bring the problem of injured first responders developing chronic pain conditions to the attention of the White House. In a 2009 white paper, “10-1: Officer Down – Pain, Disability and Stigma,” Sabrina requests the creation of a national public safety officer’s pain initiative that would “provide information and support to public safety officers battling to survive career-ending chronic pain disorders.”

In the paper she asserts that although data on public safety workers is collected on injuries, the information is limited. There is no good database with chronic pain outcomes and how often injuries result in career termination. Sabrina now endeavors to do just this. Her plan is to take this to lawmakers, so that she can press for research to help determine how often our public safety workers develop fibromyalgia and other chronic pain disorders after an injury. Read her white paper, “10-1: Officer Down – Pain, Disability and Stigma,” and get involved.



Sabrina Dudley Johnson is a duty-disabled police officer living with, among other things, fibromyalgia and chronic fatigue. These are the result of injuries sustained in the line of duty. Since leaving police work on disability pension, Sabrina now balances her time maintaining her health, spending time with her

granddaughter, and spreading awareness for fibromyalgia and disabled public safety officers. She founded FACES and plans to present her most recent project, “Officer Down,” to lawmakers in an attempt to gain enough support to research the occurrence of public safety workers whose careers are cut short due to chronic pain conditions.

Formerly known as Fibro Cop on Facebook, Sabrina now uses the name Fibro Diva. [Follow her on Facebook.](#)

Sabrina recommends these organizations:

[African American Fibromyalgia Foundation](#)
[Fibromyalgia Patient Education and Support Organization](#)

[Click here to write a letter of support to Vice-President Joe Biden.](#)



Meet Nick Lutes, the NFA's 2016 Men with Fibromyalgia Spokesperson

By Nick Lutes

I admit it; I've had to learn some things the hard way in life.

Sometimes it was because of stubbornness, but with my chronic illness it was because of ignorance and blind faith in doctors. Whether it was the trial and error with prescription medications, or fundamentally changing my diet, my lack of action caused me to suffer longer than I needed to and it took its toll on me.

In 2010, when my symptoms became severe, I was working 40+ hours a week, coaching youth hockey, playing hockey in an adult league, and living a very active life. The first symptom that caused me problems was actually irritable bowel syndrome. I started to miss work and other activities because my digestive system would either turn everything into a liquid state or cease movement entirely. It's kind of difficult to get a whole lot done during the day when you need to be within feet of the bathroom, and that was the case for me on many days.

A few months later I began to run out of energy before the work day even finished. I'd come home and crash on the couch immediately—and by immediately, I literally mean immediately. I'd lie down and fall asleep as if I were previously awake for days. I'd be hard to wake up and often sleep on the couch until the following morning.

No one ever took me seriously when I did speak up. It was always downplayed as growing pains, residual sports injury or fatigue...

Not too long after the fatigue had set in, the pain settled in and knocked me completely out of action. I began to miss work, and naturally, many thought I was faking. Once I started missing out on my own

hockey games, those who knew me well knew that something was seriously wrong. To say hockey is my number-one passion is an understatement. Being unable to play and coach are still the losses that cut deepest to this day.

Since getting many answers at the Mayo Clinic in Rochester, Minnesota in September of 2013, I've learned that I've actually had fibromyalgia



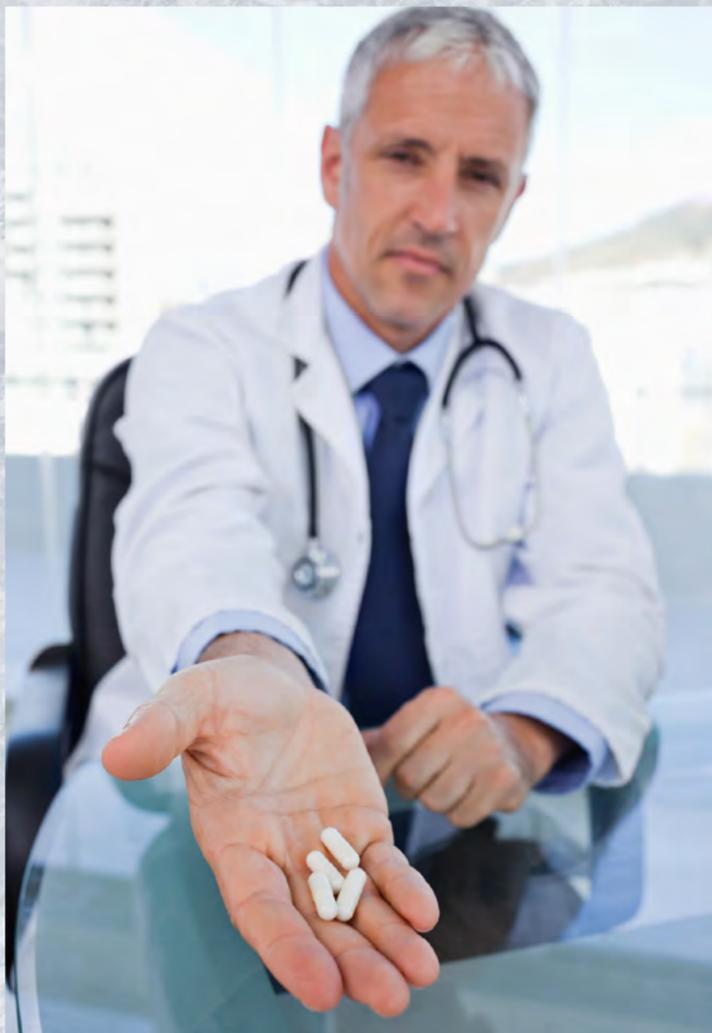
I kept waiting for someone to step in and save the day, either by a “magic pill” or instructions on what I needed to do to get better.

since I was around 10 or 11 years old. The pain wasn’t debilitating, but I wondered, even at that age, if constant pain of some sort was normal. No one ever took me seriously when I did speak up. It was always

downplayed as growing pains, residual sports injury or fatigue, or some other logical assumption. I often wonder what my life would’ve held for me had I been diagnosed earlier in life.

One thing I soon learned was that I was too dependent on doctors and those in the medical profession in general. I assumed I was ailing from something they’d all seen before and thought they’d identify and treat it immediately. I was also too slow to educate myself on things like my possible illnesses, the impact my diet has on my health, and the treatments and remedies I could explore on my own. I kept waiting for someone to step in and save the day, either by a “magic pill” or instructions on what I needed to do to get better. When no one showed up, the realization that I needed to take it upon myself slowly became clear.

I started to research daily and began

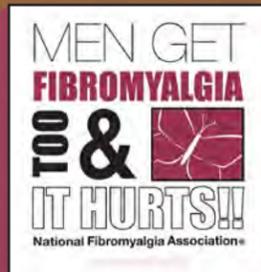


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educating myself with the help of the Internet. I also decided that I had to be my own guinea pig to find answers and treatments for myself. Once I started to find little answers that helped me a few percent at a time, I wondered if others had a similarly difficult time getting help and answers.

If I'm going to hurt no matter what, it might as well be for a good reason...

Because of my natural tendency to teach others, I started up a Facebook page called "Fibromyalgia: Not Just For Little Old Ladies Anymore." I intended to help and support other fibro fighters who were newly diagnosed and in the same boat as me. Soon after starting my page, another fibro fighter offered me control of the page called "Fibro for Us," and I took him up on the offer. Fibro for Us had ten times the audience that my first page had, so naturally, I figured I could help more people.

After several months of daily educational and humor-related posts, Facebook changed the way it showed a page's posts to its audience, and I found that I'd have to pay to get my posts seen by more than the 10% who were actually still seeing them

regularly. Unable to work, I had no disposable income to spare, so I took to Twitter with the intent of promoting my Facebook pages. I planned to increase my audience by bringing in Twitter tweeters who would know the quality of the content they could find on my pages. They'd seek my pages out daily and I'd find a way around paying Facebook.

Slowly and surely I gained a Twitter following of over 2,500 people and over 4,300 total Facebook likes between my two pages. Reaching and helping that many people has given a purpose to the pain and fatigue I battle daily. I hope to help others avoid the things I had to learn the hard way. The daily mantra I live by is: "If I'm going to hurt no matter what, it might as well be for a good reason," and I can think of no better reason than helping others to improve their quality of life!



About the Author:

Nick Lutes is currently battling fibromyalgia, chronic fatigue syndrome and other health issues. He completed high school and a 5-year apprenticeship in refrigeration service. He worked 15 years in the heating and air conditioning field and 8 years coaching youth hockey. He has studied his chronic illnesses for the past 5 years and has worked for the past 3 years to help others battling similar ailments through his pages on Facebook and through Twitter. His latest project is utilizing his mechanical skills by making art and "spoonie" items from spoons and other silverware to raise awareness for chronic illness and generate income.

Learn more about Nick's work here:

[Fibro for Us](#)

[Fibromyalgia: Not Just For Little Old Ladies Anymore](#)

[Nicholas Lutes \(Facebook artist page\)](#)

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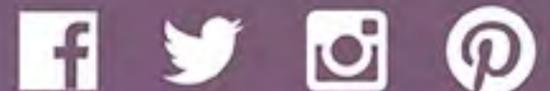
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Facing FM Past and Present

Living with fibromyalgia has its ups and downs. We all seem to know the downs so well, but it can be difficult to also notice the ups. Between the pain, sleepless nights, continual fatigue, lost income, and the unpredictability of life with chronic illness, we can easily become downhearted. We recognize how important it is to share both the ups and the downs, the past and the present, all with the hope that you will relate to these stories and be inspired to participate in the FM community.

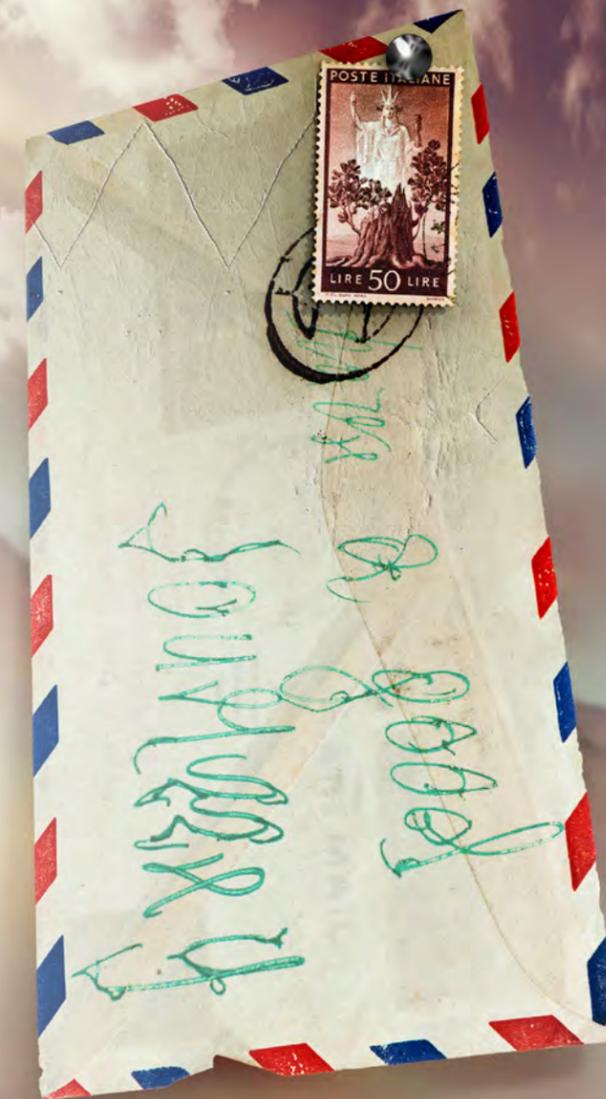
In this issue, we focus on topics of interest to men with fibromyalgia, as well as discussion of sex and intimacy for all people with FM. We can see that in 1997, the struggle for men was much the same as today: how to live with fibromyalgia and still feel like a man. And for everyone, we find that chronic pain and fatigue do not mesh easily with intimacy. So, how do we connect with our partners when we have pain and fatigue?

Read these letters from almost 20 years ago and

They help remind us how far we've come as a community, and how much we have to be thankful for.

It is with that hope that we revisit letters from the 100 Letter Campaign of 1997. These time capsules were written by men and women with FM to raise awareness and gain media attention. They help remind us how far we've come as a community, and how much we have to be thankful for. Fibromyalgia is much more visible today. Yes, it is still a long way from being universally accepted, but it is now part of our cultural dialogue.

join the discussion by sharing on the magazine's Facebook page. Together we can change the face of fibromyalgia to include all who suffer. As the newest NFA spokesperson, **Nick Lutes**, notes, "It's not just for little old ladies anymore."



It's All in the #s for Bob

How did I get FMS? Try following this my FMS friends:

- Polio @ 16 – Not supposed to walk – I did and I played basketball 16 months later! Though not as well.
- At age 21, I had my first of 3 drunks – whiplash of my body from behind. It's ok though as this is where and how I met my wife of 34 great years. (She happened to be our support group leader.)
- Slip and fall getting out of the newest craze – a conversion van – spine hits housing of front wheel – two surgeries and 7 months later back to work!



- Drunk #2 puts me in the hospital for 11 weeks. Back to work 10 days later. Only something was becoming more difficult. Oh well – onward I must go!
- Episode #1 of 7 kidney stone attacks: ouchie. Yes, but I kept going without morphine or stone crushers! (But we FMSers have a low pain tolerance, or so they say.)

Tried for 18 months to get back to 80% productivity, to produce 1/2 of what I earn and 5 times as much as I am getting on SSDI!

- Little drunk pushes me into condo pool as a joke HA HA. 13 weeks in hospital and doctor tells me that most of my lingering pain is due to "tight hamstrings and a LACK of SEX!" Good Grief! It takes me 5 more weeks to get back to work. Tried for 18 months to get back to 80% productivity, to produce 1/2 of what I earn and 5 times as much as I am getting on SSDI!*

August 1, 1997



I sat and stared at my 5 walls and forced myself back to try to WORK. I also tried about every pain clinic- biofeedback-self relaxation-voodoo BS there was and they all got richer as I got worse! So just for the hell of it, I had a couple of physical relapses and 13 more weeks in a damn hospital! (This is 1982, folks!)

Finally one day someone told me about a kind and understanding "special FMS doctor" at Peoria** School of Medicine who had a whole new concept about repeated muscle damage. His name? Muhammad Yunus! After a 2-1/2 hour exam and various tests, mental and physical, he told us that I had the "F word." It took me 2 years to pronounce it. Do not stay as stupid as long as I did. Go educate yourself and always say fibromyalgia the right way >> fi-bro-my-al-jah!

From Bob

* Social Security Disability Income

** University of Illinois College of Medicine at Peoria

FACTS & MYTHS

Myths about Men and Fibromyalgia

By Kevin White, MD, PhD

I call fibromyalgia the disease of a thousand myths because so much misinformation exists about it. One myth is that it only affects women. In fact, roughly 1-2 million American boys and men will develop fibro at some point. One reason many doctors don't know this is that almost all the early research was done on women. Add to this that men are less willing to go to doctors and admit to pain, and the problem is compounded. Here's what I have learned about fibromyalgia in men, both from my own research and the research of others.

Like women, men can develop fibromyalgia at any age, including childhood and adolescence. In our own large study, roughly one in four men with

fibro had developed it by age 30. The symptoms are virtually the same in men as in women, including widespread pain, severe fatigue, non-restful sleep, frank insomnia, headaches and many other symptoms. And, in both sexes, symptoms range from mild to severe and disabling.

I call fibromyalgia the disease of a thousand myths.

The bad news is that... Certain sad realities exist specifically for men with fibro. First, as hard as it is for many women to be believed, it's typically harder for men, because so many still think of it as a woman's

disease. Men with fibro are often stigmatized as wimpy, or whiners, or lazy and opportunistic. Some doctors think all they want is drugs. Men also tend to remain undiagnosed longer.

Another problem concerns work, especially among men with more physically demanding jobs. How does someone continue heavy manual labor when they hurt all over and are exhausted all the time? Do you really want someone driving big trucks or handling heavy machinery if they are exhausted? Yet employers and insurers often deny men their disability claims because they either remain undiagnosed or their doctors remain doubtful. And because men still tend to have the largest share of

income in families, this means their entire family may suffer financial ruin.

...it's typically harder for men...

Finally, remember that young boys get fibromyalgia too. Picture a 12-year-old girl with fibromyalgia and it's tragic. But a 12-year-old boy with it might be even worse because of how the pain, tenderness and fatigue can totally derail all attempts at sports, potentially leading to ridicule



and bullying by peers, who typically will not understand.

The good news is that... There is more and more information about fibromyalgia in males on the Internet, including several really good

websites for men with FM to go to for up-to-date information and support, like the **National Fibromyalgia Association's Men and Fibromyalgia** page, the **Fibromyalgia Support for Men** Facebook group, and the website **Men with Fibromyalgia**.

I recommend that all men with fibro and those who support

them visit these sites to learn as much as possible, largely from men who actually have the disease and have found ways to deal with it. With support and treatment, many men can obtain some degree

Men with fibro are often stigmatized as wimpy, or whiners, or lazy and opportunistic.

of relief from their pain and other symptoms. The starting point, however, is recognizing fibromyalgia as the problem and breaking through all the myths about what it is... and isn't.



About the Author:

Dr. Kevin White is a world expert in fibromyalgia research and treatment, a staunch fibromyalgia patient advocate who tours Canada, the U.S. and Europe educating people about the realities of fibromyalgia, and author of the award-winning book *Breaking Thru the Fibro*

Fog: Scientific Proof Fibromyalgia Is Real. Visit his [website](#) or purchase his best-selling book in printed soft-cover or eBook at [Amazon.com](#) and bookstores worldwide.

Can Men Have Fibromyalgia?

Paul's Struggle to Survive with Fibro

I suspect that what is now fibromyalgia, started off as chronic fatigue syndrome in 1988. I was working as a field service rep in Los Angeles at the time. My average workday was 16 hours, with lots of stress because somebody's computer just had to be working within the next 30 minutes, or the world would end.

I had aches in my bones and muscles that felt like a truck had hit me.



I developed irritable bowel syndrome, followed by fatigue so intense and pervasive that I would fall asleep driving on the freeway and working on a computer. The doctors I saw at that time gave me the impression they really didn't believe in CFS, and the symptoms I was relating to them. I had migraine headaches virtually all the time. Sometimes they lasted for days on end, and I had to seek out a doctor that would give me something to make me sleep for a few hours. I had aches in my bones and muscles that felt like a truck had hit me.

I moved to Georgia in 1990, still working for the same computer company, still working 16-hour days. Now I was doing phone support instead of driving from site to site. Desk bound and stressed out. Other symptoms began to manifest themselves.

Stairs are an obstacle that I don't relish.

Both of my knees have excruciatingly sharp pain that at times causes me to scream out in pain and buckle to the floor. The left knee and right ankle are

August 10, 1997



the worst. This doesn't happen very often, but when it does, it catches me off guard and startles anyone viewing me and hearing me cry out in pain.

Over the last few years, I have learned how to tense up various muscles in my legs, feet, and back so that I can walk almost normally. I walk softly and carefully, paying attention to how I place my feet, and the angle of the knees. Stairs are an obstacle that I don't relish.

I have had to give up walking, soccer, scuba diving, baseball, riding a bicycle and anything else that requires standing or running. Even sitting caused intense pain in my hip joints, back, and neck. I have a 9-year-old son that I cannot join in sports. This is the most demoralizing of all.

There are times that just touching my right ankle, my back, or either of my knees is more pain that I can stand. Icy Hot, Deep Heat, or Mineral Ice types of gel seem to take my mind off of the severe pain for a while, but the deep underlying pain is always there.



Sleep is something that I crave all the time because I can't sleep for more than an hour or so. I almost always bend my legs when I sleep, and this causes extreme pain in my left knee, which then causes me to wake up over and over. I am tired and sleepy all the time.

exercise. Every time I did, I was laid up for days with pain that can't be described, and that no pill would make go away.

I think I have tried every non-steroid, over-the-counter pill there is. Some helped, most had no effect at all on the pain and stiffness, or the joint

Various doctors that I have gone to are either mystified, or tell me that I must exercise more since that seems to be the only thing that helps fibromyalgia. Easy for them to say; they don't have the pain. Don't get me wrong, I haven't given up doing most everything "normal" people do, but I sure as hell don't go to the gym and deliberately

pain. Some caused excruciating heartburn that was more painful than the joint pain. I am taking Pepcid AC and Alka-Seltzer frequently after meals, and sometimes in between meals to combat an overly acidic stomach.

I have eliminated red meat and even chicken from my diet because I have discovered by experimenting that grease in even small amounts causes agonizing heart burn, stomach distention from gas, and an intense burning sensation in my lower esophagus. I suffer from bouts of diarrhea that go on for days. Then there are days of constipation.

*I have a 9-year-old son that I cannot join in sports.
This is the most demoralizing of all.*





Then, in May of 1997, for reasons I don't understand, I began experiencing intense pain in all of my joints and in my leg muscles. The pain went on 24 hours a day. After three weeks of this pain, and no sleep, I was contemplating suicide to escape the pain. I don't mean to sound melodramatic when I mention suicide, but until you have suffered days of severe pain, no sleep, and every indication that the pain will not go away, death does not seem such a bad thing.

Nobody will understand the pain fibromyalgia can cause unless they have this condition. I no longer complain or explain to people anymore because they look at me like I am making it up or that the pain and other symptoms can't be as bad as I claim.

...until you have suffered days of severe pain, no sleep, and every indication that the pain will not go away, death does not seem such a bad thing.

A coworker that sits across from me could see that I was in agony, and she suggested I try an herbal supplement. I agreed, she brought some in, and I tried it. Leaping lizards!! It actually removed about 90% of the burning pain in the first 24 hours!! For the first time in years I was able to walk almost without thinking about how I place my feet or position my knees.

I was a bit concerned that one of the ingredients in these pills is belladonna (deadly nightshade), but I was desperate. I would have rubbed manure

on my joints if I thought that would help. Other ingredients in this supplement are Arnica montana, Rhus toxicodendron, Hypericum perforatum, Ruta graveolens.

I have given up coffee, tea, chili, hamburgers, or any other beef. I have given up milk, because of the havoc it plays with the stomach and bowels. Oriental food of almost any kind makes me feel nauseated. Greasy or oil-rich food of any kind causes intense heartburn within 30 minutes. Actually, it is easier to list what I can eat without causing problems.

Paul of Georgia



Top 5 Foods for Fibromyalgia Relief

By Leah E. McCullough



While it takes more than food to recover from fibromyalgia, one cannot heal without giving the body the building blocks it needs. This list is an unconventional approach, using the traditional foods that our ancestors utilized for healing and to maintain health. Choose organic, pasture-raised or grass-fed foods.

- **Chicken Broth**

Also known as “Jewish penicillin,” broth has been a healing food for several millennia. Broths are an important source of gelatin, which is difficult to obtain from other foods. The minerals of broth are needed for all cellular functions, but the anti-inflammatory gelatin is quite important for the lining of the gut and for the joints and cartilage. For more information check out this free recipe: [Raise the Dead Chicken Broth](#).

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- **Eggs**

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- **Butter (or Ghee)**

The easily digestible saturated fat in butter and ghee (clarified butter oil) helps the body to assimilate the vitamins and minerals from other foods, and will also lower the glycemic index of foods, making them have less of an impact on blood sugar. So butter your veggies.

- **Raw Sauerkraut**

Raw sauerkraut is a natural probiotic, high in vitamin C and enzymes, has antibiotic and anti-carcinogenic properties, and will even help with meal digestion.

- **Liver**

Liver is one of the most nutrient-dense foods available and can give people incredible energy. Most people balk at liver because of the strong taste. However, it is a major food source for vitamins A, D and K. An easy way to get liver into your diet without tasting it is through **desiccated liver capsules**.



About the Author:

Natural healing expert and author, Leah E. McCullough, affectionately known as **The Fibro Lady**, recovered her health from fibromyalgia, chronic fatigue and a host of coexisting conditions in a very short amount of time, using all-natural methods. She hosted the **The Healing Fibromyalgia, Chronic Fatigue, ME World Telesummit** in January 2016. You can purchase the telesummit recordings of Leah's interviews with top healing experts at **The Fibro Lady Store**.

- As a special free gift for readers of *The NEW! Fibromyalgia AWARE* magazine, you can listen to Leah's interview with NFA founder, Lynne Matallana.



Listen Audio

Kat is Thankful for Supportive Family & Friends

May 29, 1997



Wow! I've never actually sat down and explained what FMS has done to me or my life or my family! This might be a good thing for me to do!!

I'm a 39-year-old woman with two sons, 18 and 15. I'm married to a wonderful man, THANK GOD!! He puts up with my aches and pains and has truly married me for better or worse.

I must back up a few years. Around 1990, I was becoming very forgetful and dropping things because I wasn't able to hold on to a cup or such. I had told the doctor this several months prior to

dropping things and by this time stumbling and falling too.

Then one day in 1992, he told me I had fibromyalgia. "What?!" I said. I had never heard of such a thing! Surely he was wrong; it was all in my head or it was something else! At this point I had quit my job because I just couldn't keep up and was hurting so bad and my memory was getting so bad. My family was falling apart because I was always sick and trying to work also. I was coming home and taking it out on my family, so after a very long discussion with my husband, I quit my job and we went to a one-income family. YIKES!!

has so many responsibilities because I can't do much for him like I did his brother.

My husband has stuck with me all the way. It's hard on him because he feels helpless.



the next episode. My memory was scaring me because I was forgetting where my children were and I was handling money at work. The doctor suspected MS. I was very scared!! Turned out the test for MS was negative. The doctor ordered more tests to see why I was

It has helped me so much to know that there are others that have this also.

My oldest son is almost 19 and in college. He lives at home. He can remember better days when I wasn't sick. I was still able to run him around and do the supermom thing then. My youngest son is 15 and I feel he is getting cheated at being a kid! He

Both my boys worry about me and have great patience with me. I know how hard it is for them to have a mom who is always sick or taking pain meds and can't drive. It breaks my heart! But they are understanding and always let me know where they are and what they are doing.

Only my husband, children and two close friends know how much pain I am in. My other friends that I had before I became ill, just kind of faded away. I have made new friends because of it though. It has helped me so much to know that there are others that have this also. That I'm not the only one!

My husband...oh, how it's affected our marriage!! We've been married for ten and half years. When he married me I was super woman! I worked, took care of two boys and you could eat off my floors my house was so clean! I was cheerful and happy all the time. I was superwoman!

I appreciate the smaller things in life now. I don't take things for granted. I enjoy each and every moment with my children and husband.

Through the years I had been hospitalized for drug reactions, serious ones. I was in the hospital for nine days once! My husband has stuck with me all the way. It's hard on him because he feels helpless.



He doesn't know what to do to make me feel better. There are lots of days I have to call him at work and tell him I'm taking a day for myself and will be in bed when he gets home from

work. I miss his hugs so much, as it hurts to be hugged and he's always afraid he will hurt me. Sometimes I just say forget the pain and hug anyway!

Sex is less frequent. I am in a BUNCH of pain afterwards, so we make love less often. But when we do, we know I'm going to be in pain, so we go for the gusto! The rheumatologist told us we were lucky we still were able to make love because so many FMS patients he has aren't able to anymore.

I appreciate the smaller things in life now. I don't take things for granted. I enjoy each and every moment with my children and husband. So what if you can't eat off my floors anymore? Who was going



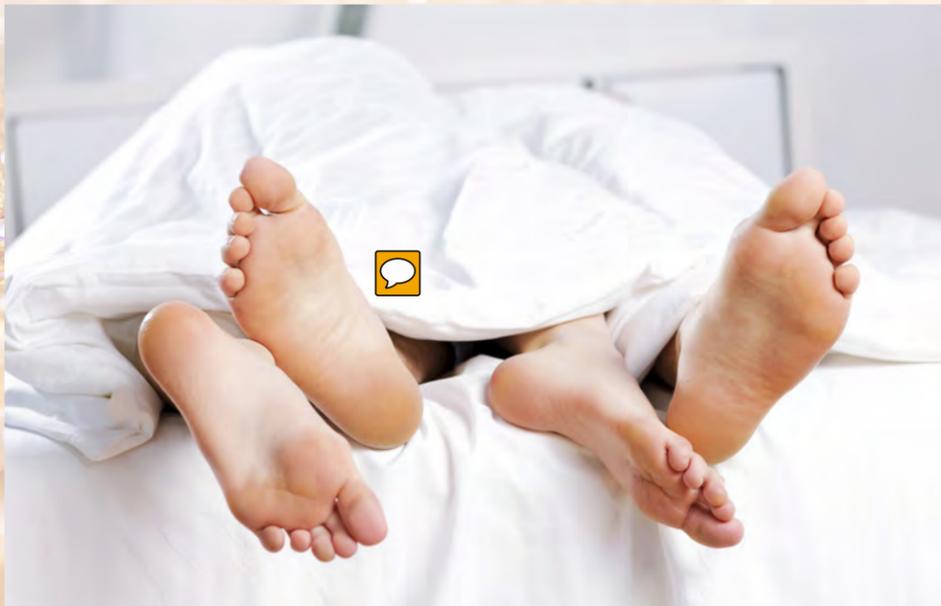
to in the first place? If I am having a good day, I go and do what I want! I enjoy what I can! So what if the laundry is piled up! Guess what? It will be there later or someone else will do it! I don't have to do everything! But these are things I have to remind myself of.

KAT

Top 10: Reasons People with Fibromyalgia Should Have Sex

By Amanda Kimberly

When one thinks of fibromyalgia, pain and fatigue are usually the first things that come to mind, not intimacy. But should we consider it a little more? It may sound daunting to someone newly diagnosed that any type of relationship is feasible. But it is not only possible to have a healthy sexual relationship, but it is an achievable goal that one with fibromyalgia should strongly consider as a form of pain management, since the benefits may help alleviate some FM symptoms.



Here are the top 10 reasons why people with fibromyalgia should engage in sex regularly.

1. Sex is Exercise

Sex is not only fun, but it is a form of exercise that increases the heart rate. If done regularly (once or twice a week), you can improve your cardiovascular health, have an increase of strength and flexibility in your muscles, and gain balance in your body.

2. You Burn Calories while Having Sex

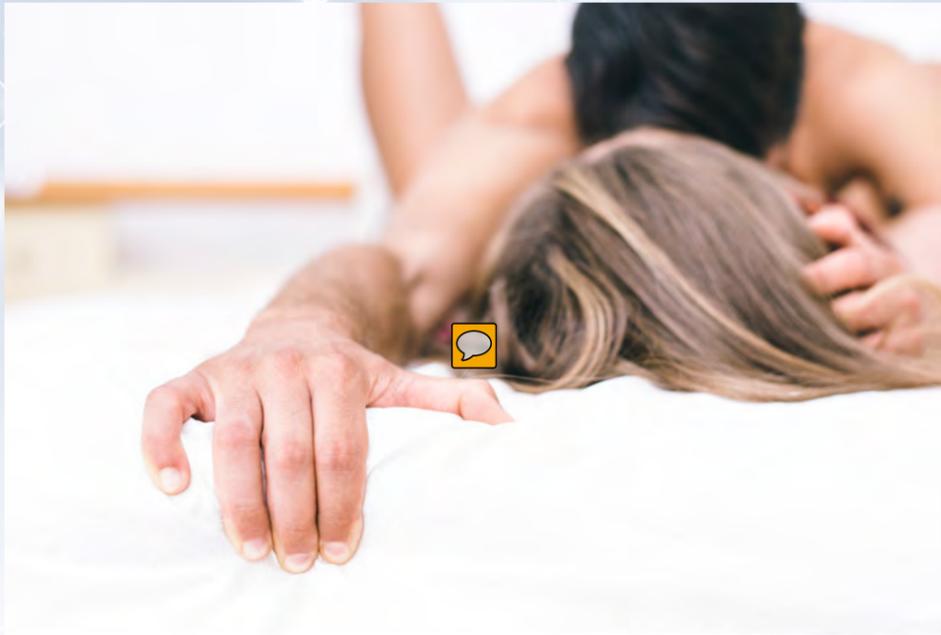
It may seem hard to fathom, but it is estimated that you burn 85 calories per hour kissing, 25 calories are burned for every 15 minutes of foreplay and 80 an hour while giving a massage. If you are having a particularly "good day" why not spend half an hour dirty dancing? You can burn 170+ calories pretending to be Patrick Swayze and Jennifer Grey. The actual sex act burns 100-200 calories, and for each orgasm, 60-100 calories.

3. Sex May Help with Cognitive Thinking

Exercise helps to increase blood flow to all organs, including the brain. This in turn gives you an extra boost of glucose that the brain can use as energy, which helps to improve memory, task coordination, and scheduling and planning, **several studies** show. This is very positive for people who suffer from fibro fog because engaging in sex may alleviate some of those symptoms.

4. It Gives Your Immune System a Boost

Sexually active people have a better immune defense against germs, viruses and other nasty things that can make you sick. According to a **study** done on college students' saliva by researchers at Wilkes University in Pennsylvania, students who were having sex one to two times a week had higher levels of immunoglobulin A antibodies (the body's first line of defense against cold viruses), as opposed to their counterparts



who were having sex less often. People with fibromyalgia are thought to have a weakened immune system, so the release of this antibody may help.

5. Improves Women's Bladder Control

Many women who suffer from fibromyalgia have also suffered with incontinence issues. Orgasms may help. Having sex regularly helps your pelvic muscles strengthen with each contraction, which in turn may help to improve bladder control.

6. Lessens Pain

According to Dr. Barry R. Komisaruk, having an "orgasm can block pain." His [studies](#) with Beverly Whipple at Rutgers University in New Jersey have concluded that the act, or even the idea of orgasm, releases a hormone called oxytocin that helps to alleviate chronic back and leg pain.

Chronic pain is the most common complaint of fibro sufferers. Having sex more often may just allow you the benefit of less pain.

7. Lowers Heart Attack Risk

Everyone, including fibro sufferers, should be conscious of heart disease, since it is one of the leading causes of death. The act of intercourse increases your heart rate and keeps your estrogen and testosterone hormone levels balanced. Low levels will increase your risk for heart disease.

8. Improves Sleep

The body releases a hormone called prolactin after intercourse and it is responsible for the feelings of sleepiness and relaxation. Any fibro sufferer would love to have more sleep in their routine!



9. Eases Stress

Oxytocin—often called the love hormone—is a naturally occurring chemical in the body that not only helps to soothe sore muscles, but it also helps to lower stress, anxiety and depression, which are other common symptoms found with fibromyalgia. Having a flare and can't do the deed? Touching and hugging will also release oxytocin.

10. May Treat Migraines

"Not now honey, I have a headache," might just be a thing of the past according to researchers at the University of Munster in Germany. Their findings showed that 60% of migraine sufferers found relief when engaging in sex.



About the Author:

Award winning, best-selling, and nationally-recognized author, Amanda Kimberley, enjoys good health, good food, chocolate and romance. She is currently working on a paranormal urban fantasy romance series called Forever. You can find

out more about Amanda Kimberley on her blog [Fibro and Fabulous](#) and [her website](#).

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Make Your Purpose Greater than Your Pain

With fibromyalgia and other chronic pain conditions it helps to keep your mind focused on something other than the pain and fatigue you feel. One way to do this is to have a cause or a mission—a purpose greater than your pain—that is meaningful to you. This month we are offering an activity that you can sink your teeth into without causing a flare up.

We are so inspired by Sabrina Dudley Johnson's

work that we're posting a link to her letter campaign [here](#). She is determined to help first responders receive the long-term care they need when their careers are cut short due to on-the-job injuries.

In order to accomplish this, research must be done, but the necessary data about these folks is not available. So, she is asking us to contact our congressperson and/or the White House to request that the Department of Justice and FBI add the following categories to the annual Law Enforcement Officers Killed and Assaulted reports:

- Accidents sustained in the line of duty
- Types of injuries sustained from assaults and/or accidents
- Whether injured officers suffer ongoing chronic pain after treatment, and with what type of chronic pain conditions these officers are diagnosed (including FM)
- Number/percentage of injured law enforcement officers eventually forced to end their careers



due to in-the-line-of-duty assaults, accidents and chronic pain (including FM).

Sabrina has created a letter that you can personalize and send to your elected officials, along with information about where to send it and suggested subject lines.

Or perhaps you'd like to start your own letter writing campaign asking political leaders to include the interests of those in chronic pain in their 2016 agendas.

Be sure to share your efforts with the community on *The NEW! Fibromyalgia AWARE* magazine's Facebook page. Together we can make sure that all those who suffer from fibromyalgia and chronic pain conditions have a chance to get the care they need.





Fibromyalgia Unlocked My Purpose and Passion for Wellness

By “Captain” Mike Hastings

There is a story that comes to mind when I think about fibromyalgia. A champion swimmer, Florence Chadwick, was attempting to swim the 26-mile span from Catalina Island to the California mainland shore in 1952. A number of small boats followed her during her epic swim in case of an emergency. During her swim a dense fog settled in above the water and she became overwhelmed. Less than a mile off shore, she gave up. Everyone in the boat couldn't understand why she had quit when she was so close to the shoreline. They pulled her exhausted body out of the water and asked her why. Her reply was simple: “All I could see was the fog.” She had lost her vision of the shoreline and made a decision based on the fog. Too often, we allow our own “fibro fog” to talk us out of achieving great things that are right before us.

...most days I didn't have the energy to lift my head off my pillow.

When I was in my 20s—in the 1980s—I was busy studying at a number of universities. I was also involved with various Christian activities,

including leading a missionary team to Kenya, East Africa. Many doors opened for me during that time as I spoke to thousands of people from all over the country. From the safari plains near Mount Kilimanjaro, to the crocodile waters of Lake Victoria, my “endless energy” took me all the way to dinner with Kenya's President Moi.

This all changed in my 30s—in the 1990s—when



fibromyalgia hit me. I was stumped. It felt like my life began going in reverse rather than forward. I was very ill and practically bed-ridden. If I walked half a block each day I was doing good. In fact, most days I didn't have the energy to lift my head off my pillow. My mind was in such a fog that it was difficult to comprehend anything I read, and what I read was quickly forgotten. Suddenly, I could no longer depend on my mind to solve the problems that overwhelmed me.

To make matters worse, the people around me were busy with their own lives and had no time to spend helping me figure out why I was so ill. I remember lying in bed, looking out the window on a snowy winter day in Michigan and wondering if there was anything I could do to turn things around. It seemed that there was nothing I could do except spend the rest of my life in that bed. I felt like giving

up was pretty much my only option.

Yet despite the "fibro fog" that plagued me, I chose to continue to spend time with God each day through reading inspirational books, the Bible, and praying. I also read articles about nutrition and health. Before long, ideas began to percolate and things began to happen despite the fog!

I did not receive any supernatural flash of insight on what to do; however, as I began to spend time with God each day, I became aware in my conscience of things I needed to act on. As I followed those promptings, doors began to open. Obviously, nothing happened overnight, but in time things did begin to happen.

My steps of faith led me out of that little bedroom and eventually into the Hollywood studios where I ended up being picked for a very small part on the hit show *The West Wing*. Although my part was quite

small (about the size of a mustard seed), I was happy and chose to be grateful for what was put in my hands.

I prayed for that seed to grow, and in time it did. My tiny part got the attention of the media, as well as the medical and natural health world. Over time, my fibro story and my quest to bring attention to this mysterious illness became featured in numerous places, including a Dr. Oz article and a South Korean television broadcast that reached 10-20 million viewers.

All the media pizzazz was exciting and fun, but



...as I began to spend time with God each day, I became aware...of things I needed to act on. As I followed those promptings, doors began to open.

like all of us who suffer with fibro, what I really wanted was answers on how to get well! In 2003, I left the entertainment business and set out to find these answers. I began to set aside more time each day to pursue, study, and research nutrition and health. It eventually led me to work in numerous health food stores across the country over a period of 10 years. I learned an incredible amount of information on healing the body with natural and herbal products.

Although nothing cured my fibro, the natural products did help improve my health from many



of the layers of fibro dysfunction that I had been suffering from. This would include improvement with sleep, cognitive issues, muscle function, and gastrointestinal issues. Where I once was weak and could barely lift my head off a pillow, I could now hike a mile or two and even dance to a few songs... and enjoy it.

...we must continue to encourage one another and not give up!

The brain fog that ruled my mind for years was replaced with clarity. My decision to pursue nutrition and health definitely improved my life. I was so excited about my findings that I built a website to share some of my discoveries (www.captainhastings.com).

I realized that many fibro patients have a hard time reading and comprehending endless text in a book or on a screen, so my next step was to create a 2-hour film on fibromyalgia, which will be ready for distribution this year (2016). I hope it will help many fibro sufferers learn tips for improving their fibro life. As we all know, our fibro lives can be quite challenging at times, so we must continue to encourage one another and not give up!



About the Author:

Michael James Hastings spent 13 years in college and earned three academic degrees. He developed fibromyalgia at the age of 28 after completing his first two degrees, but by age 36 he became completely disabled. After a number of years visiting doctors, he was able to go back to work part time. This included working in various health food stores, as well as working in Hollywood, where he had a small part as "the Captain" on the hit show, *The West Wing*. Later on, Mike returned to grad school, where he finished his third degree and began working on a film about fibromyalgia.

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100,000 Reasons to Support the NFA

By Lynne Matallana, Editor-in-Chief

April 1, 2013 was the day the NFA celebrated its 100,000th member. We were so excited to meet this amazing milestone that we offered to share the story in *The NEW! Fibromyalgia AWARE* magazine. As founder of the NFA and its president for 14 years, I was honored to interview Michael Hina for this story.

When asked, “How does it feel to be the 100,000th person on the NFA’s Facebook page, Michael responded with an instant smile. “It was



very exciting,” he said as his voice rose slightly. “It’s something! I’ve followed the NFA for years now, and to be that person—it was a very proud moment.”

“It’s not getting an answer and the help that I so desperately wanted. It leaves you feeling depressed and deflated.”

We were pleased to have a man as the 100,000th follower because it helps to talk about the fact that not just women get fibromyalgia. Men are very much affected! Many undiagnosed men with fibromyalgia have similar experiences to Michael’s. He went to doctor after doctor and from test to test looking for answers. Finally, after insisting that “there is something wrong with me, I hurt!” Michael went to a rheumatologist. “He came into the room, pushed on me, and left the room again,” Michael explained with a grimace. When he returned, “he



threw a brochure on my lap and said, “You would be better off having rheumatoid arthritis.”

Feeling worse than when he walked in, Michael left the doctor’s office. “I was looking for answers.” But instead he got attitude. “It’s not getting an answer and the help that I so desperately wanted. It leaves you feeling depressed and deflated.” Yet after 10 years Michael finally had more than clues as to what was making him sick. His illness had a name.

From that point forward, Michael did research. “You cannot stop looking for answers. I found the NFA via the internet. I found some really good books, in particular *Fibromyalgia: UP Close and Personal* by Dr. Mark Pellegrino.” This was a particularly lucky discovery as Dr. Pellegrino was within an hour of Michael’s residence. “When I finally went and saw him, it all started coming together for me.”

It’s compassionate doctors who are good listeners that can really help someone with fibromyalgia. Dr.

Pellegrino was a strong resource in part because he had dealt with fibromyalgia himself. Back then, we did not hear much about men and fibromyalgia. But obviously since he experienced it himself, he knew that men could get it too.

“My family and friends were really supportive.

“You’ve got to find a way to be positive with it. If you don’t, it can defeat you.”

Of course, when I told them what I had, they didn’t really know what it was,” explained Michael as he recalled his diagnosis in the early 2000s. “It was websites like the NFA where you could actually go on and let them read” what it is like to live with fibromyalgia, and that “this is what I go through on a



daily basis. And then it kind of made sense to them.”

We know how essential it is to have a strong support group. I know when someone like a doctor or a friend would say, “you will feel better,” I believed them and that is what helped me. Michael agreed that one of the challenges of this condition is staying positive. “You’ve got to find a way to be positive with it. If you don’t, it can defeat you.”

In addition to positivity, Michael said, “You’ve really got to get out there and be your own advocate and make it happen.” The medical community continues to suggest that people with FM should find a combination of treatments that work for them individually, including medications, exercise and diet. “There is no magic pill. Not yet anyway,” Michael said with a chuckle. “We’re hoping.”

“You cannot stop looking for answers.”

Michael has a message for all the men out there with fibromyalgia. “Men have to be tough, be strong, be the breadwinner. And it’s hard with fibro.” Many men with fibromyalgia suffer more when they miss work due to their illness, and Michael has also struggled to stay employed. “How do I stay well enough to keep working? I just don’t miss work,” he explains. His philosophy sounds simple: “I can be

miserable at home, or I can be miserable at work. I’d rather be paid to be miserable.”

In the end, he wants everyone to know fibromyalgia is not just a women’s disease. It’s a people’s disease. “If you are a guy out there who has not been to a doctor, go and do it. There is a good quality of life that you can have even living with fibro.”

In 2013, the NFA reached an exciting milestone of 100,000 followers on Facebook. To commemorate this achievement, the founder of the NFA, Lynne Matallana, offered the 100,000th follower a chance to tell their story. Today, nearly three years later, we have reached a new milestone of over 200,000 followers, and counting. [Follow the NFA on Facebook.](#)

As we continue to grow, we look forward to honoring the principles the NFA has thrived upon: awareness, education, communication, and compassion. Together we can do 100,000 things to make life better for those with fibromyalgia. Become a member of the NFA (it’s FREE) and support the FM community today.

 [Join FREE](#)

 [Video](#)

Can Pain and Intimacy Coexist? 10 Tips for Doing it Right with Fibro

One of the strongest human desires and core needs is to feel loved, and intimacy is one way to receive and express love. But how can you show your love when your pain and fatigue are always with you? We asked the fibromyalgia community to take a short survey on how FM and intimacy mesh in their lives. You can still [take the survey](#), but here are some of our findings so far.

The answer is yes.

Pain and intimacy can and do coexist, which is great news for those of us struggling in the pain community. Our survey revealed that 85% of participants are married and/or in long-term relationships, so we think this discussion is important for most of us.

Here are 10 tips inspired by the answers of fellow fibro love-makers on how to keep intimacy alive in your life.

1. Keep trying new things.

A number of participants commented that sex takes more planning. Some said they needed to take pain medication ahead of time to enable them to be close. Others said the pain meds decrease sensitivity, making it harder to orgasm. Not everyone responds to FM and its treatments the same way. As your illness and treatments change, and as you age, your intimacy practices must evolve as well. So keep trying new combinations. If you can take your medications at different times, see if there is a way to manage your pain while maintaining sensitivity. Be flexible and continue to try new things until you find what works to help you enjoy physical closeness.

2. Intimacy is so much more than sex.

One respondent said, “We have become less sexual and more emotionally connected.” Try activities that bring you and your partner together like talking, reading books together, holding hands and sharing stories from your day. Be sure to plan physical touch time, like trading back rubs, cuddling, and make-out sessions. Make plans together. Abstinence is not the end. It’s possible in some cases to be able to work back into being able to have sex. Talk to your

medical team about your limitations and what might be available to help you and your partner.

“We have become less sexual and more emotionally connected.”

3. Jump on it when the time is right.

With chronic illness, it’s not just the pain and exhaustion that keep us apart from our loved



4. Connect regularly with your partner.

One survey participant wrote: “My sex drive is fine, though I am not attracted to my partner because of [his/her] insensitive behavior.” This issue is probably more common than you’d like to think, so try to remember what brought you together in the first place. Then take small steps to come back to each other. Do something nice for your partner. Forgive and get down to the good stuff. Once you can break through the resentments and find the connection you crave, the insensitivity may start to wane as well. Another participant commented: “I do hurt terribly afterwards, but





the lack of intimacy is also painful." Don't let loneliness be your marital mantra.

5. **Laugh and talk more.**

Communication can make or break your relationship, so open up to your partner regularly. If your relationship is suffering, try going out on a first date again. What would you say to your partner to introduce your desires, passions, and interests? Role playing can also be a fun way to share "new" things and reconnect. Laughter is a great way to feel close. Try watching a comedy show together, and discuss what you think the funniest part was.

6. **Focus on the pleasure.**

One participant said, "I want to feel something other than pain once in a while. Sex helps that."

Not only that, but a number of participants highlighted that "endorphins from orgasm help ease pain." The body's natural chemical response to sensual stimulation is to release dopamine and oxytocin, which produce feelings of euphoria and pain relief. So, push through the pain to the pleasure and strengthen your relationship at the same time.

"I want to feel something other than pain once in a while. Sex helps that."

7. **Schedule your intimacy and plan time for recovery.**

Eighty percent of participants indicated that the hardest thing about sex is the pain. While 34% thought that fear of pain and exhaustion were equally as challenging to overcome. Schedule your intimacy for high energy/low pain times, so you have the best chance for success. In addition to this, plan time to recuperate. Fibromyalgia slows our body's natural repair mechanisms. So you may feel pain for days following sex. One participant said simply, "It's hard to find time for

the pain and the recovery." Yes, it is hard, but tip 7 says to make the time.

8. **Pace yourself and take turns.**

Many participants commented that the way they have sex has evolved with their fibro illness. "Some positions are no longer comfortable." Changing positions regularly can help. Also, pace yourself. Slow sex can be good sex. If you know that you lose stamina quickly, try hopping to it in the beginning, then lay back and let your partner finish the work. The key to this strategy is to be vocal about how you are feeling and ask your mate to adjust for your comfort and pleasure.



9. Take time to get in the mood.

Some resources will tell you that waiting until you're in the mood to have sex is one of the biggest mistakes we make in relationships. However, in those of us with chronic pain conditions, preparing to get in the mood may be better than waiting for it to come. "I need to relax by clearing my mind of the pain before I can be in the mood," one participant reflected. Another mused, "I must be able to think beyond

"I need to relax by clearing my mind of the pain before I can be in the mood."



the pain to become aroused." This mental prep time can include visualizing sexually arousing images or memories and sensual touch (with or without your partner) to stimulate the release of dopamine, the pleasure chemical. Then, when mind and body are ready, get to it.

10. Communicate your willingness.

We noticed that comments such as, "My partner is afraid to hurt me," appeared regularly in the survey results. It is crucial to have the communication channels open, so that you and your partner know when and how to please each other. Start this conversation at a neutral time when you can talk and listen without any pressure to take immediate action. Use statements that begin with "I," such as, "I benefit most from longer foreplay, so I would like us to try that for 20 minutes." Then listen. Allow your partner to express their desires as well. No one wants to hurt the person they love during their most intimate moments, so don't be afraid to talk during sex and gently remind your partner of what feels best for you.



Thanks to everyone who took part in this survey. This is a topic that is not touched upon enough. We know it's a private, personal thing and we are so glad you told us your secrets, so we could share them with the community.



The Greatest Misconception Surrounding Men with FM: “But that’s a WOMAN’S Disease”

By Norman Hanley

I want to address one of the biggest questions men with fibromyalgia (FM) are asked. **“Isn’t fibromyalgia a woman’s disease?”** I hear it from other men all the time, from doctors, and from women with FM who believe “men are just stealing their disease.”



The answer is simple. No, it is not; and as men, no we are not. I know of no one who would choose a life of pain, constant fatigue, and having to give up so many things that we love to do! So, here are some facts.

starting sometime in 2008/2009, when I began being extra tired after physical labor, had pain lasting a little longer than it should, and I was not sleeping well. But that’s just part of getting older right? I digress.

After talking with many men and women, it is my educated guess that FM is harder on men due to “male pride.”

According to the **CDC in 2015**, 1 in 7 people who suffer from fibromyalgia are men. This is up from the CDC’s 2014 report, when it was 1 in 8. Although the 2016 report has not yet been released, in an email discussion I had with the CDC, the numbers are looking like it will be 1 in 5 people with FM are men.

After talking with many men and women, it is my educated guess that FM is harder on men due to “male pride.” I say this because I believe the greatest enemy we have is ourselves. We feel inadequate, weak, unable to provide for our families, hold a job, stay active and “be a man.” Being men, to avoid some of these feelings, we tend to push ourselves until we can go no further.

The next biggest question men with FM are often asked is: **“What makes being a man with fibromyalgia more challenging than it is for women?”** I once heard someone say, “Well, it is like Samson when Delilah cut off his hair.” It is more than this for me. Fibromyalgia was at first a slow onset,

In today’s society we can logically say that this mindset does not make sense. However, it is still ingrained in us that men are the providers, and I know for myself that not being able to provide for

my wife, or help pay the bills, or take care of even the most basic daily chores, led me into a spiral of depression.

Yes, fibromyalgia has changed my life, but it is not the end of my life.

Also, another reason that men with fibromyalgia have such a hard time is that for years many doctors believed that FM was a fake illness and even those who believed it was real, believed it to be only a woman's disease. Consequently, many of these doctors refused to diagnose a man with fibromyalgia even though he had all the symptoms.

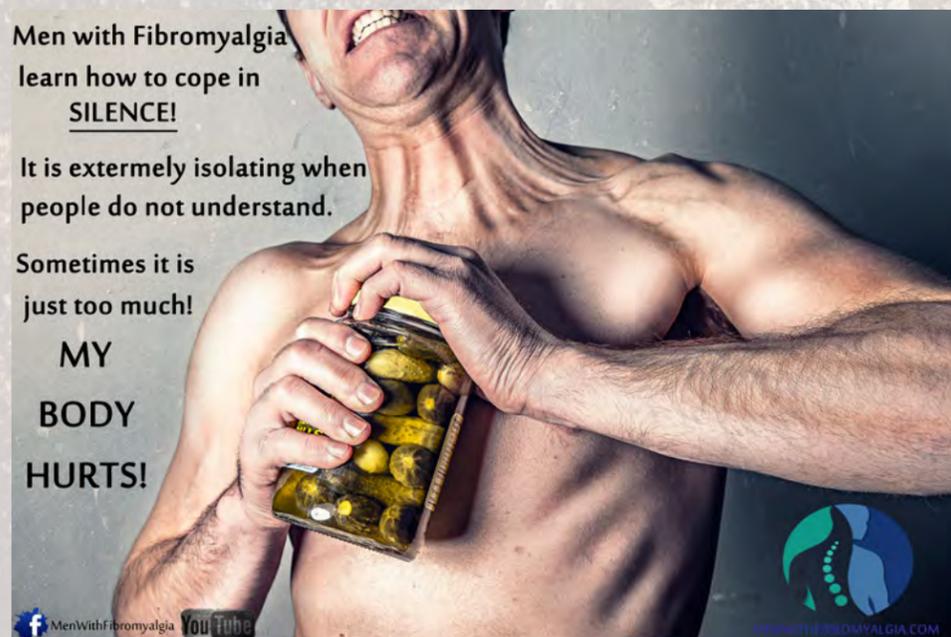
I personally went through three doctors. The first said I was too young to be this tired and in

Men with Fibromyalgia
learn how to cope in
SILENCE!

It is extremely isolating when
people do not understand.

Sometimes it is
just too much!

**MY
BODY
HURTS!**



MenWithFibromyalgia YouTube



pain all the time. The second one said I might have fibromyalgia, but that's mostly a woman's disease. It wasn't until the third doctor, and three years later, that I was actually diagnosed with fibromyalgia.

With the help of my current medical team, acceptance and commitment therapy (ACT) training **training**, meditation techniques, yoga and a very supportive spouse, within a year after my diagnosis I was able to look upon my life without the constant depression, even though I was still in pain.

Yes, fibromyalgia has changed my life, but it is not the end of my life. Like any major change in life—be it a move, new job, loss of a loved one, etc.—change can be difficult and it may take a while to adjust to a new way of living.

So, I'm dealing with my illness today and accepting that I can no longer do many of the things that I used to enjoy, such as camping, hiking, even basic chores around the house. I have learned what my new limits are and how to pace my activity. I've learned

to identify what I valued in the activities I previously enjoyed and now I find new ways to fulfill those values. For example, in camping and hiking, I valued the peace and quiet in nature, so now I do day-trip picnics, which are less stressful and still give me the outdoor quiet I am seeking.



About the Author:

Norman Hanley, a Marine veteran, lives in Tucson, Arizona with his loving wife, Stephanie, their **rescued beagles, Winchester and Luna**, as well as their two cats, Missy and Muggins.

Along with fibromyalgia, he has chronic fatigue syndrome and chronic pain from his time with the U.S. Marine Corps and three motor-vehicle accidents. He is a blogger/vlogger at SpoonGeeks.com, he administrates the [Facebook group SpoonGeeks](https://www.facebook.com/SpoonGeeks), and when he began to tell his story as a man with fibromyalgia, many other men wanted to do the same, so he started MenWithFibromyalgia.com (also on [Facebook](https://www.facebook.com/MenWithFibromyalgia)) as a place for men, their spouses and family to share their experience with the hope that spreading awareness of this devastating disease may help to find a cure.



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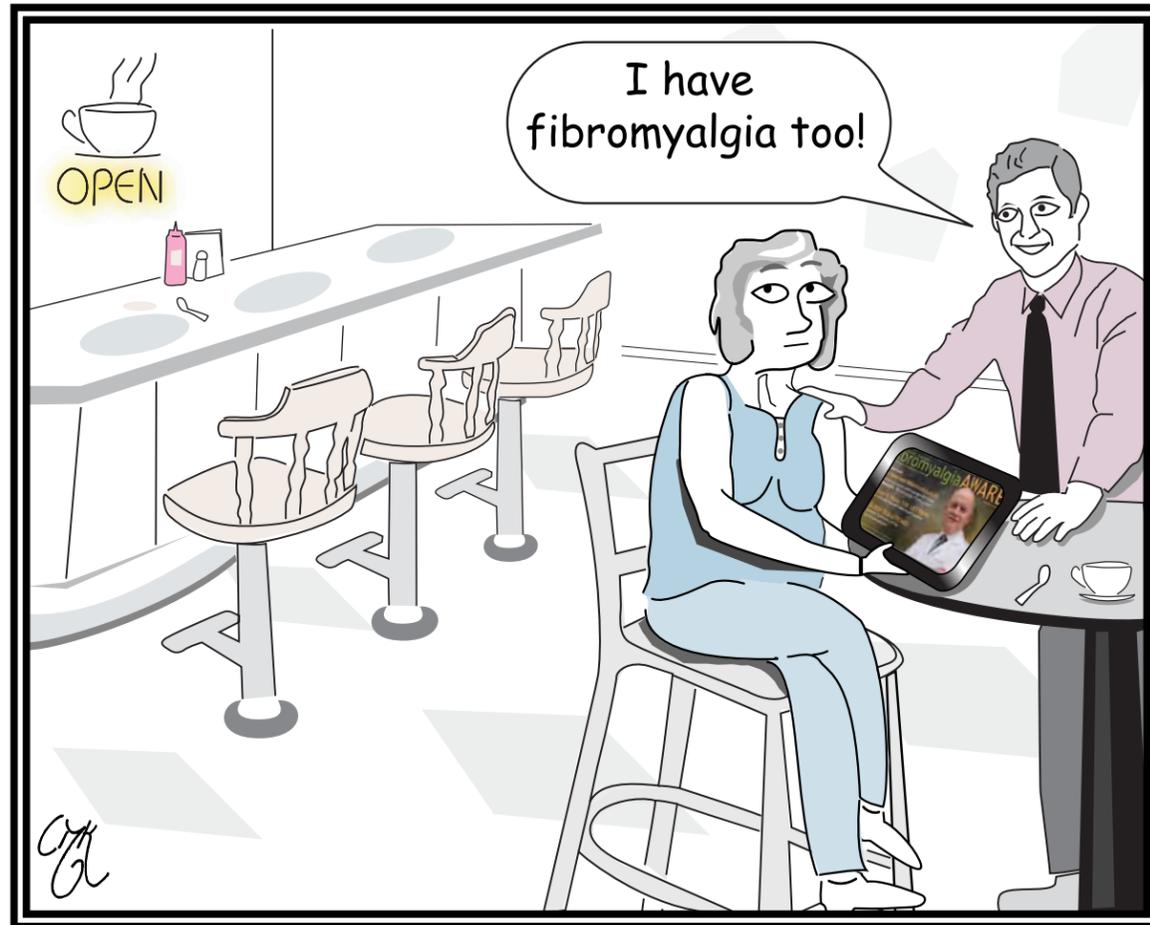


HELP SPREAD THE WORD!

Fibro Funnies

Up for a little afternoon delight?

Ms. Ima Hurtin is back to tickle your funny bone and show you ways to feel better.



"Worst Pick-up Line Ever!"

Ima needs help with her FM dating mojo. She should read our article, ["Can Pain and Intimacy Coexist?"](#) for tips and secrets that fibromites told us about their sex lives in our Fibromyalgia Intimacy Survey. You can still take the survey!

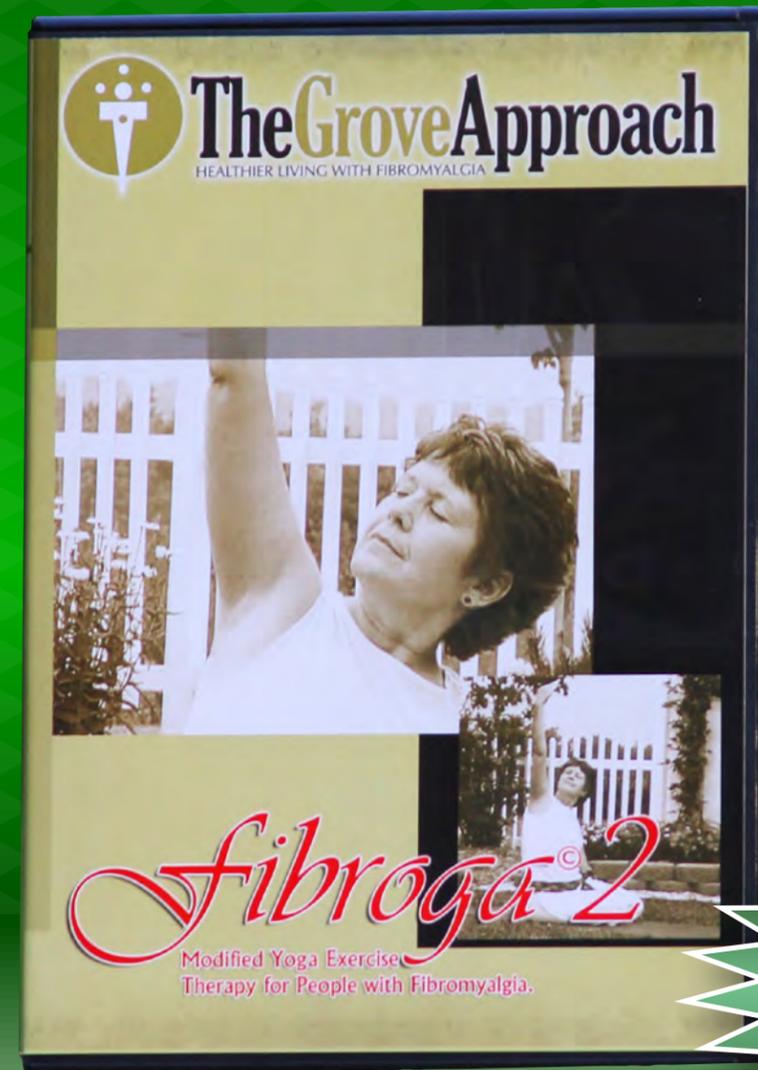


Take Survey

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Fibromyalgia

To My Fibro Family,

It's good to be back at the NFA and I look forward to charging ahead with you in 2016!

In 2003, I met A.J. Langer at a conference in Los Angeles and she introduced me to the exuberant Lynne Matallana. To this day, I still have no idea how Lynne has so much energy! I began volunteering off-and-on for the NFA, and I never felt like the most reliable volunteer. My pain, depression and other symptoms were out of control. I was finishing up college, working a part-time job and in an unsupportive relationship—life was out of control.

This year I'd like to focus on unity in the fibromyalgia community, compassion, education and empowerment.

I somehow managed to start and run the first Myspace page for the NFA, graduated in the first Leaders Against Pain class, distributed magazines and brochures to doctors' offices, attended awareness events and conferences, spoke at schools about juvenile fibromyalgia and answered supportive phone calls from FM community

members. It still never felt like enough. After taking a break from volunteering, I was never able to shake that feeling that I wished I had done more for the fibromyalgia community!

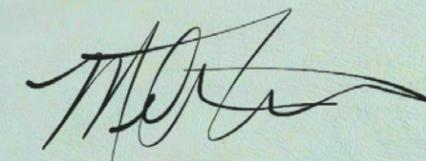
An opportunity recently presented itself and I'm ecstatic to be a part of the NFA history once again. I have lived with chronic pain for 22 years, so with me, you get an understanding, honest and resilient member of your fibromyalgia family. Yes, we are family, and we are in this together!

This year I'd like to focus on unity in the fibromyalgia community, compassion, education and empowerment. I'll be continuing the

supportive NFA programs and expanding additional resources. I invite you to attend our events and join our social media community. I know there is a lot of work ahead, but I'm ready for it, purple colored hair and all.

My purpose is greater than my pain.

Gentle hugs with love,



Melissa Talwar
NFA Director of Advocacy and Communications

Follow the NFA on [Facebook](#) and [Twitter](#)!



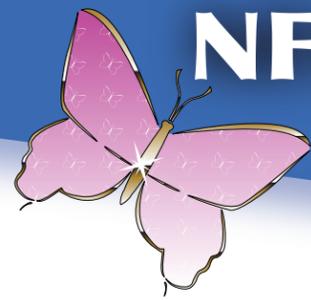


NFA PROGRAMS & ACCOMPLISHMENTS

1997-2016

- **30-Day Challenge:** Make Your Purpose Greater than Your Pain 2015
- Award Winning **NFA Website & Store**
- **Access to Care** - national letter writing campaigns
- **Advocacy Initiatives** (government support from the CDC, NIH, FDA, CA Healthcare Reform, National Healthcare Reform)
- **Advocacy Meetings & Campaigns** legislation introduced at the state & federal levels, bills introduced, language & appropriations approved
- **Advocacy Outreach** - letter writing, public hearing representation against "step programs"
- **American Academy of Family Physicians Clinical Study**
- **American Pain Foundation - Helping Hands Make a Difference Award** (for HCPs)
- American Pharmacy Association - **REMS Experts Committee**
- Annual **Fibromyalgia Awareness Day**
- **Awareness Day Walk of FAME** May 2007-2010
- **Biking for Carrie** (SF to LA) & Press Conference 2004
- **But You Don't Look Sick Campaign**
- **CA Legislative Day** - ACR-112
- **California Chronic Care Coalition**
- California Legislature Day - "Lights of Hope"
- **California Neuro Alliance Meeting**
- **Capitol Hill Days & Candlelight Vigils**
- **Circle of Care** - CME Expert Collaborative Education Program
- **Clothespin Challenge** Campaign
- **CME** - partnered with **Johns Hopkins Medical School & School of Nursing** for primary care, neurologists, rheumatologists, psychiatrists, nurse practitioners & nurses
- **Coalition for Overlapping Conditions**, NIH Research Initiative Meetings, Lynne Matallana speaker, Train-the-Trainer Programs, etc.
- **Community Surveys**
- Creation of **Fibromyalgia Awareness Day Campaigns** - 1998-2014
- **CSUF Fibromyalgia Research & Education Center** - NFA assisted in the establishment
- **DATELINE** - Maria Shriver, 12-minute segment, January 2001
- **Discovery Meeting** - August 2008
- **Education & Certification Programs for the Retail Pharmacists**
- **Eular Exhibition & Press Conference** - Europe 2008
- **Facebook Campaign "100,000 for 10 Million"**
- **FAME 2000** - first key FM patient & CME National Conference
- **FAME 2001**, Chicago Conference
- **FAME Continuing Medical Education Programs** (over 26 programs)
- **FAME on the Road** - expert think tank programs, speakers, motivational presentations, conference roundtables & health fairs
- **Feast, Friendship and Fibro-Awareness Day**, May 12-2015
- **Fibro Facts** - A collection of education articles from A to Z
- **FibroFocus** - speakers & education at national support group meetings
- **Fibromyalgia Assessment, Management & Education (FAME) Modules** (grant funding by the UniHealth Foundation)
- **Fibromyalgia AWARE Magazine** (2001-2011 print/online) - first national consumer magazine on fibromyalgia distributed at Barnes & Noble
- "**FMaware.org**" named top patient web site at the American College of Rheumatology Scientific Conference
- **FM Awareness - Biking Route 66** (1997)
- **FM Community Assistance** via phone & email (1997-2015)
- **Fibromyalgia Epidemiology Survey** (ACR Poster Presentation 2007)
- **FM Pledge to Care** - September 2008-2011
- **FM Roadmap Webinar**
- **FM Speakers Bureau** - presentations at: CME programs, web workshops, patient programs, conferences, etc.
- FM support groups: **FM Assistance & Support Connection Program**,

CONTINUED



NFA PROGRAMS & ACCOMPLISHMENTS

1997-2016

- Informational Brochure Program, Living with FM documentary, community relations, care giver outreach, media coverage
- **FM Task Force** development of statewide program to increase FM assistance
- **Healing Fibromyalgia**—Chronic Fatigue—ME **World Telesummit** - 2016 Proud Sponsor
- **HCP Educational Pieces** - booklets, brochures, pocket-cards, posters
- **HPRI** - developing exercise based protocols for FM patients with California State University at Fullerton & published findings
- **ILAP - International Leaders Against Pain** International Fibromyalgia & Pain
- **Juvenile FM Survey**
- **Know Fibro** - NFA/L. Matallana U.S. Motivational Speaking Tour
- **LAP - Leaders Against Pain** Scholarship Program (patient leadership, media & advocacy training)
- Largest FM conference ever (**FAME 2005**)
- **Living Well with FM** - programs on sleep, advocacy, patient communication, etc.
- **Make Fibro Visible** - 10-year awareness campaign, shared with & promoted by support groups around the world
- **Med-Pro** - partners with University of Wisconsin School of Medicine, first OB/GYN CME program
- **National Patient Advocate Leaders**

- Summit - Keynote Speaker**
- **The New! Fibromyalgia AWARE! Digital Magazine** 2015-2016
- **NFA Epidemiological Survey & Findings Publication** - data allowed for over 20 new medical publications
- **NFA Facebook Page:** Over 200,000 Followers - 2015
- **NFA Membership** - newsletters, e-blasts, educational podcasts, article sharing NFA on YouTube
- **NIAMS Coalition** - federal lobbying with the National Institute of Arthritis & Musculo-skeletal & Skin Diseases
- **NIAMS** research facilitation
- **NIH Roadmap** - Patient Chair
- **Nurse Practitioners Education Program**
- **OMERACT** (Outcome Measures in Rheumatology) meeting attendee
- **Omnia Education, Inc.** - fully accredited CME company, primary care including interaction with patients Optum Health Education
- **Osteopaths Education Program** - media assistance
- **P.A.I.N. Kit** - an HCP education & patient information assistance tool
- **Pain Week** 2009 - created CME & other educational programs
- **Patient Advocate Leadership Summit**
- **Patient Assessment Tool** creation
- **Patient Resource Directories**-FMaware.org
- **Pfizer PR** - L. Matallana participated in

- multiple FM educational media tours & direct-to-consumer marketing & educational pieces, including **Voices of FM**
- **Physician Survey** - access to care survey
- **Pain Month** (September)
- **Practical Clinicians Exchange** - fully accredited CME, nurse practitioner & physician assistant program
- **Proclamation Program** (over 1,500 received)
- **PROMIS** - patient survey for National Institutes of Health, teamed with **University of Michigan**
- **PSA - Lifetime documentary on FM & multiple educational videos**
- **Race Across America & All Wheels for Fibromyalgia 2008-2010**
- **Research Facilitation** - e.g., juvenile FM, FM & osteoarthritis, etc.
- **Science Behind FM** - PSA with medical animation guidelines for Sleep Well Program, poster & gift package on sleep hygiene
- **Seal of Approval** - recognizing companies working to provide effective treatments
- **Sitcom star AJ Langer** speaks out for people with fibromyalgia
- **Social Media** - over **170,000 Facebook fans**
- **Tony Terry** concert series & FM vigil song
- Top fibromyalgia researchers join the NFA's efforts 2000-2015
- **Women's Health Research** - public hearings, meetings & pain forum

Magazine Development

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About the NFA

The National Fibromyalgia Association (NFA) is the most recognized and reputable 501(c)(3) nonprofit organization serving people with fibromyalgia—a chronic pain disorder that affects an estimated 10 million people in the United States. Since 1997, the NFA has been developing and executing programs dedicated to improving the quality of life for people impacted by fibromyalgia. Headquartered in Orange County, California, the NFA focuses on patient support and education, awareness outreach, health care provider education, patient advocacy and the facilitation of scientific research. By providing an array of services, the NFA has helped to advance the understanding of this chronic pain disorder and has helped people with fibromyalgia develop skills to regain control of their life, reduce isolation and restore hope.

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Community Connections

"Thank God for the N.F.A. Your work brought help & understanding to me, an Aussie living half around the world from you. Through the knowledge you gathered & the understanding it gave to me, I found treatment & a sense of fellowship with other fibros. It probably saved my life! I know it saved my sanity! I will always be grateful to you ladies & the new editor too. I keep up with advances in fibro treatments by reading the Facebook page." – **April T. (from the magazine's Facebook page)**

"I noticed you found and printed the original letter I wrote for the 100 Letters Campaign. I still remember writing that. It was amazing to read it again and see how far we've come in our knowledge about FM as well as how much my health has improved since then. Great progress on both fronts." – **Karen Lee Richards (our first Fibro Forerunner)**



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1,700 followers on [Pinterest!](#) Check out the latest pins on fibromyalgia and its related conditions.



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