

Fibro Fact Sheet

- Fibromyalgia Syndrome (Fibro) is also referred to as Fibromyalgia, FMS and FM. Fibromyalgia is pronounced Fi-bro-my-AL-gee-ah. FibroAction prefer the abbreviation, Fibro, as it is easy to pronounce, spell and remember.
- The number of people with Fibromyalgia in the UK has never been measured, but international prevalence statistics suggest that 2-4.5% of the population is a likely conservative estimate. This translates to 1.2 to 2.7 million people in the UK alone. The prevalence of Fibro in the UK has historically been hugely under reported.
- Fibro can be triggered by something as simple as a whiplash injury.
- Fibro can affect people of any age, from children to the elderly.
- **Fibro has been shown to have more of an impact on patients' lives than many other forms of widespread pain and chronic illnesses, including rheumatoid arthritis and osteoporosis.**
- There are currently thousands of people in the UK unable to return to work because of Fibro and a lack of treatment for it.
- Most doctors will see cases of Fibromyalgia during their career, yet even consultant rheumatologists, who usually diagnose Fibro, have often had little or no specific training in the condition.
- Changes in the brains of people with Fibro can be seen using PET scans and fMRIs, yet many people insist it cannot be tested for and debate the validity of the condition on this basis alone.
- **Pfizer, the world's largest research based pharmaceutical company, developed a drug called Lyrica (Pregabalin) that was the first drug to be officially licensed for Fibro by the US Food & Drug Administration. Pfizer spent \$27million promoting Lyrica in its first year, but Deutsche Bank estimates that sales of the drug in 2008 will be \$1.7billion.**
- There are many treatments that can be used to manage Fibro symptoms, yet a large proportion of Fibro patients in the UK are told that there is nothing that can be done for them and are left to suffer unnecessarily.

For more information, please see www.fibroaction.org

FibroAction Fact Sheet

- FibroAction was set up in the spring of 2008 and is registered as a national charity in England and Wales, registered charity number 1125957 (the equivalent of **501(c)(3) status in the U.S.**).
- The name, FibroAction, **was chosen to reflect the organisation's dynamism. FibroAction prefer to use the abbreviation 'Fibro' for Fibromyalgia Syndrome, as Fibro is easy to pronounce, spell and remember.**
- FibroAction was created because a group of people felt that raising awareness of Fibro in the UK was essential to the future wellbeing of everyone with the condition and that raising awareness of Fibro needed a fresh focus and a new organisation.
- **FibroAction's mission** is to educate people about Fibromyalgia Syndrome (Fibro), including: people with Fibro; their friends, family and carers; healthcare professionals; and the public at large, as well as providing support to patients.
- **FibroAction's vision** is that the needs of people with Fibro are universally recognised and met, with fast and accurate diagnoses and easy access to optimal treatment programs available to all people with Fibro.
- FibroAction is governed by a group of trustees, who also hold the roles of directors. The trustees/directors are advised by a Professional Advisory Board of experts, and are accountable to a Council of Members.

For more information, please see www.fibroaction.org

FibroAction Trustees

Lindsey Middlemiss, FibroAction Founder & Chair

Lindsey Middlemiss has had Fibromyalgia Syndrome (Fibro) since 2002, when she developed the condition following a whiplash injury during her final year of University. A trained meteorologist who was in the University slalom ski team, Lindsey had to give up on her dreams of a career in yacht racing because of Fibro.

Having struggled to get adequate treatment on the NHS, becoming severely ill because of this, Lindsey finally got treatment privately and gained much more control over her condition. Her experiences left her with an in-depth understanding of the difference awareness of Fibro can make.

A support group leader in West Berkshire (UK), Lindsey has worked to raise awareness locally and campaigned the NHS for better provision of services for Fibro sufferers. Lindsey is also the author of the blog '[Living With Fibromyalgia](#)', a source of information relating to Fibro, and has moderated on online communities for a number of years, first on helpforibs.com and then on butyoudontlooksick.com.

Lindsey is 27, married, and lives in Newbury, West Berkshire.

Emma Levick, FibroAction Founding Trustee

Emma Levick has had full-blown Fibro since 2004, but may have had the condition for even longer. Emma is an artist and was working as an art teacher when she became really ill with Fibro. At her worst, Emma was unable to even walk or talk.

Emma was responsible for the setting up of a support group in South Cheshire and has worked to raise awareness of Fibro locally. Emma has also helped to raise awareness online and has been involved with national awareness campaigns, such as the PolkaDotGals 2009 Calendar for Fibro Awareness, which she appears in.

Emma is 29, engaged, and lives in Nantwich, Cheshire.

Sue Quarrie, FibroAction Founding Trustee

Sue Quarrie is Lindsey Middlemiss' mother. A solicitor who has helped with local Fibro awareness raising events, Sue now brings her knowledge and skills to FibroAction.

Story Ideas

A few suggestions for angles to take with media coverage.

NHS Failing 2 million Britons

Most people with Fibro in the UK struggle to receive decent treatment on the NHS. Diagnosis can take years and is often a lottery of which doctor you get to see; many patients are diagnosed and then left to struggle alone, with little or no medical help. This is despite there being probably between 1.2 and 2.7 million Fibro sufferers in the UK, if not more: it is hardly a rare condition. There is also plenty of scientific evidence backing up treatments for the condition, but many UK doctors are unaware of how much is known about Fibro and how to manage it. FibroAction Chair, Lindsey Middlemiss, became severely ill and desperate because of her poor treatment under the NHS and because of this much of her twenties were wasted in pain and fatigue. Lindsey finally found private treatment and has improved immensely, allowing her to lead a more normal life. It is a scandal that, in a country with an NHS, many Fibro sufferers are in **Lindsey's situation of having to pay in order to get any treatment at all.**

Young Women with Chronic Illness start National Charity

Lindsey Middlemiss and Emma Levick are both only in their late twenties and both have the debilitating illness, Fibromyalgia Syndrome (Fibro). Yet, frustrated with the lack of awareness and the lack of support available, they have set up a national charity to make a difference for everyone with the condition.

Struck down at the peak of life: it could happen to anyone

Lindsey Middlemiss was an incredibly fit and active young woman who was in the University sailing and ski clubs and the slalom ski team. Lindsey worked out regularly, did yoga and raced yachts whenever her studies permitted, planning to become a professional yacht racer after graduating. Her ambition was the race yachts around the world, but her career was cut off before it had even properly started when she developed Fibro during her final year at University.

Emma Levick was a young schoolteacher, with a career she loved that she was doing well in. Fibro has stopped her from working and has often even prevented her from enjoying her passion: painting.

Story Ideas

A few suggestions for angles to take with media coverage.

Fibromyalgia Syndrome: an invisible, but devastating condition

Fibromyalgia Syndrome (Fibro) has been shown to have more of an impact on patients' lives than many other forms of widespread pain and chronic illnesses, including rheumatoid arthritis and osteoporosis. Yet it has no outward effect and many sufferers do not look sick at all. Dealing with an invisible illness has its own issues, including: how to make people understand how you feel, when you can look great despite agonising symptoms; and how to avoid or deal with discrimination and even abuse for not looking sick as a disabled person..

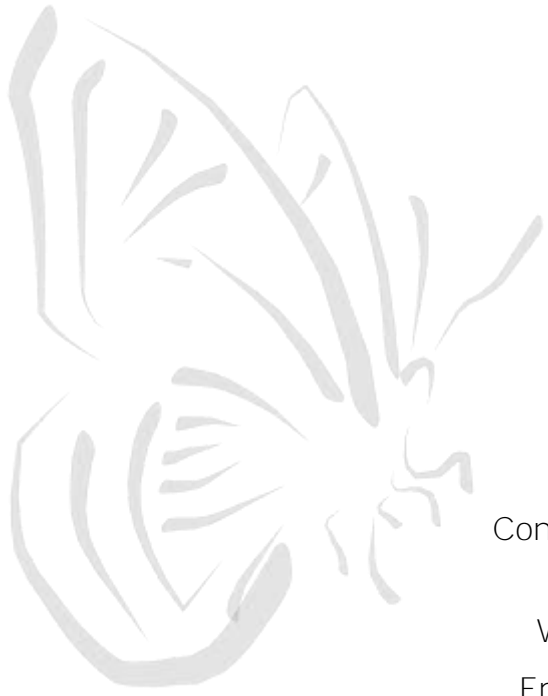
The Internet and health issues

Many doctors still deprecate the use of the internet in investigating health issues. Yet, in this day and age, it is possible to carry out a scientific literature review from the comfort of your home, and connect with fellow sufferers around the globe at any time of day and night.

Lindsey Middlemiss, FibroAction's chair, considers that she owes not just her control over her Irritable Bowel Syndrome, but also her final diagnosis of Fibro, to the IBS patient-expert Heather Van Vorous, whom Lindsey became acquainted with through Heather's website, helpforibs.com.

Lindsey has been heavily involved in online communities for years now and has counselled hundreds, if not thousands, of Fibro patients via her work as a moderator on the popular US website butyoudontlooksick.com. As the author of the blog 'Living With Fibromyalgia' at linzworld.wordpress.com, Lindsey is also a part of the Medical Blogosphere, a modern phenomenon of patients and experts blogging about health issues and sharing expertise and insight.

FibroAction aims to become a "one-stop" shop for information relating to Fibro, particularly in the UK, with news, research, awareness events and advice articles all available on the FibroAction website fibroaction.org.



Raising Awareness of Fibromyalgia Syndrome

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