



Raising Awareness of Fibromyalgia Syndrome

Press release 22 September 2008

Fibromyalgia Syndrome Sufferers set up Registered National Charity

Sufferers of a painful condition called Fibromyalgia Syndrome, fed up of poor awareness in the UK, have taken matters into their own hands and set up FibroAction, a new national charity which has now achieved registered charity status.

Fibromyalgia Syndrome (Fibro) is a debilitating, chronic condition whose main symptoms are widespread chronic pain, hypersensitivity to pain and chronic fatigue. Despite the high numbers of sufferers (between 1.2 and 2.7 million people in the UK alone), awareness of the condition, and the knowledge and treatments available for it, is very low, even amongst medical professionals, and many patients are left to suffer alone.

FibroAction founder, Lindsey Middlemiss, 27, is a Fibro sufferer herself. Having developed the condition following a whiplash injury when in her final year of University, Lindsey spent over 2 years trying to get a diagnosis. However, even when a diagnosis was made, effective treatment wasn't given. In agony and absolutely desperate, feeling that her life could be over at 25, Lindsey was fortunate enough to finally see a specialist privately, who has helped her get the condition under control. She says:

"It would be bad enough developing Fibro if quick diagnosis and effective treatments were easily available, but it is common for patients to struggle to get diagnosed and then be told by supposed experts that there is nothing that can be done. People are left in utter despair and agony, despite there now being a large number of treatments available that can help control the condition."

Lindsey set up FibroAction with some fellow sufferers in order to try and raise awareness of Fibro. Despite only having been running for less than 6 months, FibroAction is already reaching out to both patients and medical professionals and the charity's input led to the NHS updating its online information on the condition this summer. For a recent UK Awareness Week, FibroAction launched a downloadable, printable patient information leaflet on its website.

The team behind FibroAction hope that the registration of FibroAction as a national charity will enable them to achieve even more and make a real difference to the millions of people in the UK with Fibro. The coming year should be an exciting time for Fibro awareness in the UK.

For more information see www.fibroaction.org

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Further information:

- The NHS Direct information on Fibro is available at:
<http://www.nhsdirect.nhs.uk/articles/article.aspx?articleId=449§ionId=1>
- **Fibromyalgia Syndrome (Fibro)** is also referred to as Fibromyalgia, FMS and FM. Fibromyalgia is pronounced Fy-bro-my-AL-gee-ah. FibroAction prefer the abbreviation, Fibro, as it is easy to pronounce, spell and remember.
- The estimate of 1.2 and 2.7 million people with Fibro in the UK is based on internationally recognised prevalence statistics of 2-4.5% of the population. The prevalence of Fibro in the UK has historically been hugely under reported.
- FibroAction (registered charity number 1125957) was set up in April 2008.
- FibroAction is an incorporated charity and as such is also a company registered in England and Wales (company number 6662336).
- FibroAction aims to educate people about Fibromyalgia Syndrome (Fibro), including people with Fibro, healthcare professionals and the general public, as well as providing support to patients.
- For more information on Fibro and FibroAction, please see the [Media Section](http://www.fibroaction.org/Pages/Media-Section.aspx) of our website:
<http://www.fibroaction.org/Pages/Media-Section.aspx>