

What does FMAUK do?

FMAUK has 3-part time employees in our office but all other activities i.e. National Helpline, Benefits Helpline, Regional Co-ordinators are conducted by volunteers, without our volunteers we would not be able to provide the level of service we do. See below for a picture of people that attended our board meeting in Oct 2017.

FMAUK provides and signposts to information and resources for people who are affected by fibromyalgia. From our initial beginnings, we have seen the range of services and resources increase. What we can offer is closely tied to the level of donations we receive with most of our funding coming from fundraising/donations raised by people affected by fibromyalgia.

However below are some quick points and some weblinks as well for more info on what we try and manage to do.

- Well first of all its a focal point for support and awareness. It helps support fibromyalgia groups all over the UK and provides information, posters and literature to sufferers and medical professionals
- Free information booklets for: patient, young person, health professionals
- Sending medical professional booklets to medical professionals from the charity on behalf of patients
- About FMA UK www.fmauk.org/aboutus
- Provides medical information for sufferers and medical professionals through its Medical Advisory. Newest booklet was "Young People with Fibromyalgia" and this took quite a bit of time and effort to produce. We are currently working on an employment booklet which is at an advanced draft stage. Resource form can be found here
- We fundraise in order to finance these activities. (www.fmauk.org/fundraising)
- We provide fundraising support for local groups or people wanting to raise awareness and funds for FMA UK
- We attend medical and other conferences to raise awareness. An example of a <u>medical professionals</u> conference can be <u>found here</u>
- Awareness event support, including awareness items, e.g. posters, leaflets, t-shirts and many more items with many being offered free
- Organise and take part in European Activities through ENFA.
- Email support system where Regional Coordinators answer questions and refer people to local support
- Provide Benefits support and a general helpline (www.fmauk.org/contactsmenu/helplines)
- Provide a national helpline and offer training to helpline volunteers
- Provide website for information and support through the forum as well as a Healthunlocked forum
- Support groups across the country that are supported by FMA UK. Find one here (www.fmauk.org/groups)
- Only fibro charity that helps create and provides resources to support groups at creation and through their operation
- Providing the insurance cover required for registered fibromyalgia support groups to operate their meetings and fundraising activities
- Signposting to legal support
- Supporting regional and national conferences
- We represent fibromyalgia sufferers at various levels and to various organisations. An past example of this
 was our response to a <u>Panorama programme</u>
- An organisational chart can be <u>found here</u>

Additional items:

- Update information in other organisation's publications e.g. NHS Choices, ARC and BUPA
- Provide information and interviewees to media



- Provide participants for surveys and research projects
- Hold semi regular meetings for support group leaders.
- FMA UK sets the date for the UK fibromyalgia awareness week and organises events with groups to raise awareness of our condition

Examples of what donations can do:

Single Donations

- £2 would send a single first enquiry pack to a newly diagnosed person
- £20 could send fibro info to 10 Medical Professionals
- £99 could fund training for a helpline volunteer

Monthly Donations

- £15 would contribute to our National helpline
- £18 could pay for our JustGiving membership for a month
- £500 would pay for a part time member of staff in our office

FMA UK team of Trustees, RCs and staff.



Top to Bottom from Left to Right. Trustee(T), Regional Coordinator(R), Office(O), and Volunteer(V)
Pam Cantrell (R), Joyce Fox(R), Hazel Borland(O), Yvonne Singleton(R), Julie Powell(R), Ella Vine(O), Mo O'Donnell(O), Glen McGregor(T), and Simon Stones(T)

Janet Horton(T), Louise Dickson(V), Des Quinn(T) (& Chief), and Helen Watts(T)

About FMA UK



Fibromyalgia Action UK is a registered charity run primarily by unpaid volunteers. The majority of volunteers are also fibromyalgia sufferers who work extremely hard, despite their condition, in order to forward the cause of fibromyalgia. FMA UK was established in order to provide information and support to sufferers and their families. In addition, the charity provides medical information for professionals and operates a national helpline.

We aim to encourage NHS and other funding sources for new research projects. At present there is little research being carried out in the UK and sufferers are told there is no cure. We hope that will soon be a statement of the past.

Mission Statement

To improve the lives of people with fibromyalgia by increasing awareness of the condition throughout the UK and elsewhere, and improve the awareness of, and access to treatments for fibromyalgia.

Our History

Fibromyalgia Action UK was first established in 1992 to provide information to people with fibromyalgia. In 1997 it began working also with the 40 support groups around the country providing free information leaflets and books for sale. There are now over 150 support groups working with FMA UK and a network of regional coordinators who help set up new groups and arrange regional events such as meetings and conferences. The charity is mostly run by volunteers without whom we would not be able to provide the level of service we do. On the 1st July 2015 FMA UK and Fibroaction merged to produce Fibromyalgia Action UK.

About Fibromyalgia

Fibromyalgia is a chronic condition of widespread pain and profound fatigue. The pain tends to be felt as diffuse aching or burning, often described as head to toe. It may be worse at some times than at others. It may also change location, usually becoming more severe in parts of the body that are used the most. The fatigue ranges from feeling tired, to the exhaustion of a flu-like illness. It may come and go and people can suddenly feel drained of all energy - as if someone just "pulled the plug".

There are treatments available which can alleviate some of the symptoms but some of these are only available in the private sector and as most sufferers are forced into early retirement, or cannot work at all, the cost of such treatment is prohibitive. More info on fibromyalgia can be found here.

Charity Registration Details

Our Charity Registration number is: 1042582 Our HMRC Reference number is: available on request Company Registration number is: SC492045

Name & Registered Office:

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