

# Notes on completing the Support Group & Local Helpline Registration Document

Three copies of the registration document are needed, which all need to be signed by a group representative. Two copies are to be sent to the group's Regional Coordinator who will send one copy to the FMA UK office, and retain the other copy for their records. The third copy is to be retained by the group for reference.

In everything that FMA UK does, the participation of groups is critical. And in order for us to succeed in raising awareness we need to be able to communicate in all directions. Therefore we need to ensure that contact information is kept up to date at all times. **If the contact details of the group change please ensure that the office is notified. The quickest and easiest method for doing this is to change your details on our website at <http://www.fmauk.org/groupdetails>. You can copy the output of the group details form to let your RC know of these changes.**

If the details of the group leader change could the new group leader request a copy of this document to update their details and those of the group. Please also ensure that any booklets are passed on to the new group leader.

Upon sending completed documents to the Regional Coordinator, please if possible send an email to [charity@fmauk.org](mailto:charity@fmauk.org) which will inform the office that you have completed the registration document. When the office has received your completed registration document from the Regional Coordinator we will then send out a confirmation letter and a welcome pack to the group leader.

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## Document Control

## Benefits of working with FMA UK

- Groups have access to FMA UK's group insurance cover which could be saving of £350 per year. Individual cover can also be arranged through FMA UK at a discount.
- A Regional Coordinator is available to provide support and information.
- Access to a regional network of support groups and resources.
- Invitation to Regional Group Leaders' Meetings.
- All registered groups can participate in the national group leaders' meeting.
- 0844 numbers can be provided to groups. Telephone calls to your allocated 0845 number would come to your home number and therefore your home number would remain private. Your 0844 number can also be redirected to others to provide illness or holiday cover. Access to additional private resources on FMA UK's website such as the support group leaders' forum. More info: <http://www.fmauk.org/0844s>
- Access to up to date information from FMA UK that is disseminated via Regional Coordinators.
- Representation at Trustee and Regional Coordinators' meetings via the Regional Coordinators.
- Groups can request FMA UK Patient information booklets and leaflets as well as other information resources. Regional Coordinators will arrange for 20 free packs to be sent to new groups from the FMA UK office. Further packs are free but subject to postage costs.
- FMA UK merchandise is available to registered groups at a discount to prices advertised on the website.
- Opportunity to work with the UK's largest National Fibromyalgia Association FMA UK.
- Representation in Europe as FMA UK is a founder member of the European Network of Fibromyalgia Associations (ENFA.)
- A group representative can participate in a private area of the FMA UK forum to communicate ideas and information between groups all over the UK. FMA UK will also disseminate information through this forum. More Info: <http://www.fmauk.org/sgfaccess>

There are other benefits to working with FMA UK as a registered group and more will be added as FMA UK grows. FMA UK participates and is a member of other organisations like ARMA, NCVO, and the Chronic Pain Policy Coalition for example. These relationships often bring access to other information and resources that would not be possible for an unregistered group to tap into.

ARMA (Arthritis and Musculoskeletal Alliance)

<http://www.arma.uk.net/>

CPPC (Chronic Pain Policy Coalition)

<http://www.paincoalition.org.uk/>

NCVO (National Council for Voluntary Organisations)

<http://www.ncvo-vol.org.uk/>

# Registration Document for Support Group & Local Helpline

## Groups should:

1. Establish a constitution for the group. (A simple and more comprehensive draft can be obtained from FMA UK.)
2. Uphold the aims and objectives of the constitution.
3. Open a bank account in the name of the group and keep proper financial records.
4. Have two, non-related cheque signatories on the bank account (partners count as related).
5. Give FMA UK information packs to members.

## Groups & Helplines should:

6. Work with the Regional Coordinator.
7. Strive to further the Fibromyalgia cause and never bring it into disrepute.
8. Ensure all personal information is treated in a sensitive manner and remains confidential. Consider adopting the FMA UK confidentiality policy.
9. Ensure that discussions and activities promote positive attitudes.
10. Not give advice about, nor recommend (or imply that FMA UK recommends) any medication, treatment, therapy, vitamin or health supplement but may share information. No group should be established for the specific purpose of promoting and/or gaining profit from a product. Please see included example on page 4.

FMA UK is a non-funded charity and therefore requests that groups consider that each of the following:

- a) An annual donation by selling FMA UK raffle tickets, by a fundraising event, or by any other means suitable to the individual group.
- b) Make a donation to FMA UK to contribute to the cost of FMA UK's Insurance cover that they provide to groups. Typically a group's individual insurance would be between £150 - £300 but all we ask is some contribution if your group can afford it.

Together we can take the fibromyalgia cause forward, in particular, by helping those newly diagnosed, by supporting their families/carers and by action at National & European level.

**Region:** .....

**Name of Group/Helpline:** .....

**Your Name:** .....

**Position in Group:** ..... **Forum Contact:**.....

**Address:** .....

**Tel No:** ..... **Email:** .....

**Signature:** ..... **Date:** .....

Please tick this box to indicate that you have read all 4 pages of the Registration document and its notes.

For office use only:

Date Received:		Received by:	
Comments			

# Registration Document Guidance Notes

## Constitution and Finance

It may be difficult to instigate a constitution at the very beginning, but we recommend that groups, however small and informal, set something down in writing about how the group should be run. We especially find that where money is involved clear statements about its handling and use should the group cease to run are essential.

## Regional Coordinator

A Regional Coordinator is the means of keeping groups informed and giving support to groups when needed. They also bring issues to the attention of FMA UK trustees and so represent the group in their region.

## Confidentiality

It is important that any personal details held by the group or discussed within the group, or to a group member in confidence are not discussed with others. Any personal information that is processed and maintained by the group should comply with the Data Protection Act.

The group should ensure that information is processed fairly and only for the purposes of the group. This information should only be what is required, and efforts should be made to keep this information accurate and up-to-date, and ensure that it is not kept longer than required. All personal information should be kept secure and not transferred outside of the group without the permission of the members.

Further information and clarification can be sought from the Information Commissioner's Office (ICO), via their website or their helpline. Information and guidance is also available from the Charity Commission website and their helpline.

## A Positive Group

A group that constantly dwells on the trials and tribulations of fibromyalgia, without also discussing the positive strategies to overcome them becomes counter-productive.

## Advice and Information

There are clear distinctions between recommendations, and the giving of advice and information. No individual should be told that a certain treatment is going to work for them. Information about a treatment can be given with examples of those it has helped, but we are not medical professionals and do not know complete medical histories, so we should not advise or recommend. Giving advice also creates legal responsibilities for which you are not covered should any advice given lead to problems.

Please consider the following example:

*A speaker arrives at a meeting and speaks about a new drink that allows for better sleep and is made from all natural ingredients. It has been in production for years and is found to be useful for FM patients according to the supplier's research. The speaker may or may not mention the following:*

- *that it may work for some but not others*
- *that you should consult your doctor before changing treatment*
- *that it may have contraindications with meds you are on*
- *what lifestyle changes that you may have to make to accommodate the protocol*

If these elements are not covered by the speaker then the group must add them after the speaker has finished. The group should clearly state that they do not endorse or recommend this product and provide the presentation for information purposes only. Also the group should add while this treatment may benefit some it does not have the same clinical trials background of prescription medication.

While the group may accept a donation and its members may be offered a discount, the group should not be involved in the direct selling of any treatment or medication.

There is no magic potion or recipe of drugs that the consultant or GP, can give to everybody. FMA UK strongly recommends that people with fibromyalgia see their own medical professionals for help and advice before undertaking any additional treatments, over the counter medication or supplements.