

Fibromyalgia Association UK (FMA UK)

NEWSLETTER WINTER 2011

Welcome to the winter newsletter from the trustees of FMA UK.

Present Situation

Trustees

At the moment we are continuing to work with 4 Trustees, their areas of responsibility being:

- Pam Stewart: Chair of the Board of Trustees
- Des Quinn, Vice Chair of the Board of Trustees, Webmaster
- Janet Horton, Benefits Advisor, web contact for general & benefits information, benefits helpline
- Gerry Crossley, National Helpline Co-ordinator & Gift Aid

The Board of Trustees are working extremely hard to cover all aspects of work which is involved with running the National Charity. They would be delighted to welcome new Trustees to the Board. If there are any professionals out there who would be willing to spend time and effort to help the fibromyalgia cause we would love to hear from you.

Any appointment to the Board of Trustees would be supported during their induction period. FMA UK prides itself on being a supportive organisation. Positions are open to anyone but having an understanding of fibromyalgia would be an advantage but is not a requirement.

We have been actively seeking someone that would be able to take on the role of Treasurer for the charity and we are pleased to announce that Jo Butterick has agreed to take on this role. Jo will not be a Trustee of the charity but will focus on the Treasurer role. We are very grateful to Jo for coming on board as this will relieve some of the workload.

Regional Co-ordinators (RCs)

At the present time we do not have a full complement of RC's and ARC's in place. The table below shows the current situations. There are a number of regions without dedicated RC's and some RC's have to cover multiple regions. Ideally we want to have a RC dedicated to each region with their assistant able to provide them with support in their role.

If anyone in the fibromyalgia community would like to be considered for the vacant positions, the Board of Trustees would like to hear from you. We are looking for candidates who:

- Have (or are willing to work towards possessing) a sound knowledge of the structure of FMA UK and the way in which it is organised and works
- Has previous experience of working as part of the management structure of a local support group or similar
- Has the ability and is willing to work alongside other people as part of a support team
- Is open to sharing skills and information

- Has the enthusiasm to promote high standards in ethics, workmanship and a willingness to raise the profile and understanding of fibromyalgia with Health Professionals, the Government, the patient and their family members and the general public by working closely with the local groups in their area

Induction will be available to the successful candidates, and they will be provided with a mentor. A comprehensive handbook is also provided

Table 1 Current List of (A)RC's and vacancies

Region	RC Name	Status
Beds and Herts	Christine Brown	Covering
ARC		Vacancy
Berks, Bucks, Oxon, Hants & IoW	Jeanne Hambleton	Covering
ARC		Vacancy
<i>ARC Special</i>	Jo Bourgaize	Covering Channel Islands
East Anglia & Essex	Madeleine Hempstead	
ARC	Helen Watts	
Greater London	Pam Stewart	Covering
ARC		Vacancy
Kent	Margaret Robson	
ARC		Vacancy
Midlands	Christine Brown	
ARC		Vacancy
North East	Angela Campbell	
ARC		Vacancy
North West	Nicola Southwell	
ARC	Ruth Spicer	
Scotland	Janet McFarlane	
ARC	Alastair McFarlane	Covering
South West	Jeanne Hambleton (SW)	Covering
ARC		Vacancy
Surrey, East / West Sussex (SE4)	Jeanne Hambleton (S&S)	
ARC	Stella Bernardi	
Wales	Bev Pope	
ARC		Vacancy
Yorkshire and Humberside	Jean Crossley	
ARC	June Chivers	

Development of a Care Plan for people with fibromyalgia

This document has been produced by RC Consortium members; its target audience is people who have been diagnosed with fibromyalgia. It is intended to be used as a tool to help people put together their own care management plan. It is hoped that this will empower people to take ownership of their condition.

The document has been reviewed by the members of the Medical Advisory Board who provided guidance as to how the document could be improved, the changes have been put in place and the document is now being trialled by members of a local support group.

The document has been presented to some members of the medical profession who are based at the local hospital where members of the trial group are treated. It has been well received by those who have seen it.

It is hoped at the end of the trial that we will be able to enter into discussion with the members of the hospital team and some of the support group who have trialled the document to assess how this document could be best used in a hospital situation and as a self-management tool

Fibrofocus Magazine

It is with regret that the trustees have found it necessary to cease the publication of FibroFocus. Unfortunately the circulation did not reach a necessary level for us to continue.

Group Leaders' Meeting

A successful group leaders' meeting was held in June in Halesowen. Those present were given an update of association news from the trustees, and group leaders were able to exchange ideas about group activities. There was a presentation about flyer design from Jean Crossley & Christine Brown, and a lively presentation on funding from June Chivers.

Christine Brown & Jean Crossley also spoke about the role of the RC and the way in which they work for the benefit of the members of the fibromyalgia community in their regions as well as having contact with medical professionals. They highlighted the material which had been produced by members of the Regional Co-ordinators Consortium for use in local groups and awareness events. This material is available to download from a restricted area on the website available to registered support groups.

Incidentally, the RCs are looking for a volunteer who has proofreading skills to help with the production of their reference material. Please contact Christine Brown.

Trustee Meetings

Traditionally, there were three trustee meetings held annually in Stourbridge. Recently, it has been found that more frequent meetings have been necessary to get through all the business. To save costs on travelling, the trustees decided to hold monthly Skype meetings, and also to invite regional coordinators to attend, for at least part of the meeting. This is working well, and helps to disseminate information to RCs.

Physical meetings are still important to our organisation but in these times of economic hardship we must use our funds and resources wisely. As and when funding is available we will look to have more physical meetings to give us the opportunity to share ideas and experiences.

Donations

FMA UK is now able to receive text donations from your mobile. With our partners you are now able to send a text from your mobile to **70070** with the code of **FMUK01** and your amount that you would like to donate to us. For example if you would like to donate £5 to FMA UK you would text **FMUK01** £5 to **70070**. You would then be given the opportunity to add Gift Aid - meaning FMA UK benefits from an extra 25% on top of your original donation.

Work Capability Assessment.

The government announced an independent review of the methods used to assess the work fitness of those claiming incapacity-related benefits. Disability charities say the current tests are too inflexible – failing to take into account the variation in long-term conditions. The review was chaired by Professor Malcolm Harrington, who has produced an interim report with recommendations for changes.

FMA UK was asked by Professor Harrington to contribute to his 'Call for evidence' for his report. This was a further opportunity to make clear the effect current implementations are having and bring about further change. FMA UK attended a seminar chaired by Professor Harrington on 16th August. At the seminar, the following was discussed:

- The implementation of the Year 1 recommendations and the impact they are having
- What, if any, further work is required in future reviews and the face-to-face assessment

There will be further reviews and we are keen to be able to provide tangible evidence. Anyone having been through this assessment and had problems with the assessment, the report or the decision should let us know so that we can bring forward this at the next review or beforehand if we have a strong enough case.

FMA UK Links with Associated Alliances

ARMA (Arthritis & Musculoskeletal Alliance)

FMA UK continues to subscribe and be very much involved in this umbrella organisation. Collaboration with other organisations gives us a stronger voice.

ARMA would like to see the following points (amongst others) on the agenda for urgent attention:

- Adequate training of healthcare professionals (especially G.P.s)
- Better recording of chronic pain throughout the NHS to help measure its impact
- Studies on how chronic pain affects productivity & healthcare costs

Healthcare professionals should be able to refer patients to pain centres for treatment

On 4th July an End of Day Adjournment Debate was held concerning the current situation of MSD recognition and action.

Pain UK

At a recent meeting at which FMA UK was present, it was decided to set up a Pain Charities Alliance This organisation would then have representation on the embryonic Pain Alliance Europe, which was proposed at a Brussels conference chaired by Mary Baker from European Federation of Neurological Alliances (EFNA)

FMA UK attended the Pain UK inaugural meeting on 1st November and has been instrumental in helping to clarify the aims and objectives.

Mission Statement

To improve the quality of life for people living with pain in the UK

Aims

- To provide a collective voice for people with pain */living with pain* and to ensure that people with pain are at the centre of all initiatives on pain treatment and management. *'Nothing about me without me'*
- To promote the measurement of pain and patient outcome data collection to support future pain initiatives.
- To encourage the provision of adequate training on pain awareness, assessment and treatment, being included in the education of all health professionals and in particular GPs.
- To enable people with pain to have equal and early access to diagnosis, support and effective treatment/management services.
- To promote access by people with pain to appropriate and up to date information on pain services and how pain can be managed to empower individuals and promote self-management.
- To raise awareness of pain within the community, and the economic impact and stigma of pain in the workplace.
- To promote the assessment, recording and treatment of pain as a routine part of every patient contact.

The Pain UK would be able to speak with one voice at a national and international level in a way that could not be achieved by a single organisation.

Parliamentary Debate

Graham Stringer MP secured a debate on Government policy on musculoskeletal diseases. The main points that arose from the debate are as follows:

- The Minister acknowledged that there is still too much variation in MSK services and outcomes
- However, he also said that he does not believe that the case has been fully made for an outcomes strategy, but does not clearly explain why (perhaps the rest of his speech is intended to show that the government is apparently addressing many of the issues raised by ARMA, but he does not address the need for national leadership and coordination)
- The Minister said that an outcomes strategy should 'look out from the NHS to wider impacts on health and consider how those might be influenced to improve health outcomes' - so perhaps it is in this area that we need to make the case more strongly
- He explained that the NQB is meeting later this month and that 'it will decide whether it is appropriate to commission the necessary work to look at the case for a Department-led outcomes

strategy' - so it looks like we have made it on to the agenda. The transcript from the debate will also be passed to the NQB

- Also, they 'have in mind' a NICE Quality Standard on MSK conditions

Cross Party Working Group on Chronic Pain

FMA UK was represented at the Scottish Parliament's CPWG on Chronic Pain where issues such as the standards of service offered by Pain Clinics across Scotland have discussed and what could be done to improve these. The appointment of a lead clinician on chronic pain was a milestone that we would love to see replicated in the rest of the UK.

ENFA (European Network of Fibromyalgia Associations)

ENFA continues to strive for equality of treatment throughout Europe. At present only Germany has nationally approved guidelines for the treatment of FM. The declaration passed in 2008 has yet to be implemented in any way and ENFA has contacted the departments responsible to encourage action.

ENFA was also present at the Societal Impact of Pain Symposium at the European Parliament in Brussels.

Pam is to represent ENFA at the EULAR (European League Against Rheumatism) conference in Greece this month. Her other duties have included seminars at the EMA (European Medicines Agency), where FM is usually not mentioned as they have not approved any drugs, but this gives a chance to ensure it is brought to the attention of all concerned.

CPPC (Chronic Pain Policy Coalition)

This organisation has successfully achieved a Pain Summit held in Central Hall Westminster on 22nd November. Through our connection with this organisation, Fibromyalgia will be included in the presentations on how pain impacts on various aspects of life including work, home and society in general.

National Voices

National Voices along with all the health charities has been working on the consultation documents the government circulated during the summer. During this process we have contributed points relevant to FM for inclusion in the final recommendations for change. We have yet to find out how much is to be implemented, but many conditions have similar frustrations, especially where long term care is required and it is not life threatening.

Benefits and Work

FMAUK has group membership of Benefits and Work which means that we can provide the guides (preferably by e-mail) about ESA and DLA and how to complete the forms to give claimants the best chance of being awarded the benefit in question. Benefits and Work also provide general information and up to date information on benefits and any changes. Anyone can go to the website www.benefitsandwork.co.uk and see what is available - if it is in the 'members only' section I can access it and send it by e-mail when requested.

Online Activities

The website continues to be an important part of getting our message out to people interested in fibromyalgia. It continues to have many visitors each day and we try to keep adding new and interesting

articles. We have a recipes section which we aim to publish quite soon. We are interested in people's views on the website and if anyone has experience of using Joomla and has a few hours that they could give each week then please get in touch with Des.

Social Media

FMA UK continues to have a lively presence on Twitter & Facebook. Twitter is being to broadcast information from medical sites including PubHealth and Medworm automatically. This information and other interesting articles are then syndicated to our website automatically. This is a great way to find out about what is happening in clinical trials and medical information relating to fibromyalgia and as it is automatic it does not draw on FMA UK resources. We are also able to use Twitter to speak to people directly and have used this to help with the recent exposure on the Xfactor via The Risk as well as some fundraising events.

Our Facebook page has been retired recently by Facebook as it was an older version of a group page and while we have a new page in the process of being created we need people to manage it to allow it to be used effectively. The old page allowed events to be publicised and communication with people from all over the world. Our use of Social Media such as Twitter and Facebook are a challenge with our limited resources but they have both allowed us to reach more people with fibromyalgia and gain more opportunities for awareness.

Shop

Due to ever increasing price rises from our suppliers and Royal Mail it is unfortunate that many items sold by FMA UK will have risen in price.

We are currently seeing an amazing increase in the sale of awareness bands which we put down to their use on X Factor by the group The Risk. This is wonderful publicity and should raise awareness nationally.

Our Christmas cards are in stock which also give the chance of raising awareness to all those you send to in a subtle way and enable us to use the money from the sales to help us raise awareness and keep supplying informational material.

Future Events

Information Standard

We are in the process of attaining certification in the Information Standard scheme run by the Department of Health. This scheme was created to help the public identify and access trustworthy information about health and social care information. The process involves an audit of our systems and procedures involved in the creation and review of our publications and information delivery systems.

Information produced in line with the Standard has to be accurate and evidence based as well as being balanced and impartial. It must also be accessible and well written so that it can be used by anyone. Given the effort that goes into our existing publications and the processes that are already in place we hope to attain the standard shortly. We look forward to improving our processes and reflecting any best practice advice in our future information publications.

International Fibromyalgia Awareness Day

We have suggested holding coffee mornings on this day, but realise mornings are difficult for some, so next year how about afternoon tea? The 12th May is on a Saturday so we cannot hold our House of Commons event on the actual day and will confirm whether this will be before or after the date.

Being the weekend though means more opportunities to engage with the public or just the family and friends with tea and cakes Ritz or Mad Hatter style. Please share your ideas on our website.

An event is also being planned for the Scottish Parliament with an awareness stand in the main concourse at Holyrood. We hope to be able to have many conversations with MP's and make them more aware of what their constituents are going through.

British 10K London Run

We have six places at the London 10k run on 8th July through the centre of the City of London, including Westminster Bridge and the Houses of Parliament and Trafalgar Square. Can you persuade someone to enter and raise awareness and funds? Can you provide support to the runners and hand out leaflets along the route? More details on the website later, but book the date in your new diaries.