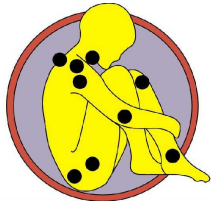


# FIBRO NEWS



MAY 2009

ISSUE NO 86

FMA UK: Contact details

Registered Charity No.1042582

FMA UK. PO Box 206, Stourbridge, West Midlands, DY9 8YL

Tel 0845 3452322 helpline 10.00 am to 4.00 pm week days

Website <http://www.fmauk.org>

Email [fmauk@hotmail.com](mailto:fmauk@hotmail.com)

## Group Charges

Group membership is £10 per annum. Each member receives a monthly newsletter by post. When attending meetings a fee of £1.50 is made to cover refreshments, a raffle and hall hire. Books can be borrowed for a returnable deposit of £1.

## North Somerset Fibromyalgia Support Group

**Chair** Mrs Betty Farron

**Tel** 0845 345 2304 **E Mail** [swfibro@yahoo.co.uk](mailto:swfibro@yahoo.co.uk)

**Newsletter Co-ordinator** Mrs Shirley Lake

**Newsletter Facilitator** Richard Sparkes

**E Mail** [richardsparkes@blueyonder.co.uk](mailto:richardsparkes@blueyonder.co.uk)

**Treasurer** Julia Mc Couaig

**Tel** 0845 345 6024 **E Mail** [joomac@live.co.uk](mailto:joomac@live.co.uk)

**Website** [www.nsomfibromyalgia.pwp.blueyonder.co.uk](http://www.nsomfibromyalgia.pwp.blueyonder.co.uk)

**Meetings are held the last Wednesday of each month**

**10.30 – 12.30 at the Folk Hall, Portishead**

**£1.50 per session**

## DIARY DATES 2009

Date	Topic	Speaker
May 27th	Growing tips and plant sale	Yvonne
June 24th	Pamper Session	all
July 29th	Antiques Road Show	Jean Hemming



*Happy Birthday  
to all of you,  
who are celebrating this month*

## Aprils Meeting

It was good to see so many members present for our AGM as we know in other situations can be somewhat boring, but ours bowled along cheerfully and with great enthusiasm.

Betty and Norman were away in Scotland ( attending a conference) so in their absence, Julia assisted by Nickie, took us purposely through the agenda.

Apologies were received from several members and a welcome was extended to two new friends of Julia and Maureen.

Our chairman's report from Betty was read and accepted by the group, as was the treasurers report from Nickie.

More details can be found in another section of this letter, together with new officers elected to serve through the coming year.

Several future events were mentioned in the "any other business" section as follows.

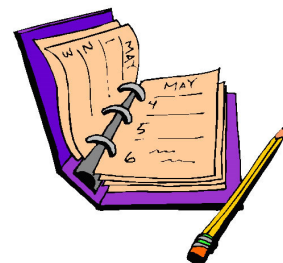
Request for volunteers to complete the tea rota please.

Next committee meeting July 14<sup>th</sup> Two ex officio members invited.

Picnic day out- Sunday 12<sup>th</sup> July Portishead Raft Race.

August meeting – a barbeque at Averil's house in Clevedon.

FM Awareness day – September at the mall.



**Make some dates in your diary's folks.**

## Presentation by Jill from (Disability Information Advice Line)

Our guest speaker this month was Jill who, with a colleague, came to tell us about DIAL, a voluntary group of dedicated team members operating from their disabled friendly base in the centre of Weston-Super-Mare, offering support, impartiality and confidential information to people with disabilities, their families and careers.

Jill, herself coping cheerfully with severe disability and a wheelchair, gave us a comprehensive guide to the 50 year old organisation, together with disability information advice line, who can use it, means of contact, help availability, advice on accessing many services as required, How the supporting and invaluable financial support is sourced and how it is spent, including providing informative newsletters to surgeries and home visits where necessary.

In the 30 years that the Weston branch has been building and working for all clients, it is obvious that an enormous amount of quality training and knowledge has made this group

Of volunteers, have matured into a professional, level headed and gentle caring team, beavering away in Weston, coping with problems of their own, yet reaching out to those in need.

Congratulations Jill and all her team for introducing the service that DIAL provides for all of us. Thank you for leaving many information leaflets with us.

If you would like to contact DIAL

- telephone No is [01934 419426](tel:01934419426)
- E Mail [mail@westondial.co.uk](mailto:mail@westondial.co.uk)
- website [www.westondial.bravehost.com](http://www.westondial.bravehost.com)
- pick up a leaflet at our next meeting
- Write to them at

**Weston & North Somerset DIAL**  
Room 5, Roselawn  
28 Walliscote Grove Road  
Weston-super-Mare  
North Somerset



May's meeting is a **PLANT SALE**  
and demonstration of **growing tips** by **Yvonne**.

Please bring along any spare plants, as all sales help with group funds.



**MEMBERSHIP PAYMENTS ARE DUE IN APRIL EACH YEAR**

*It's now May.....*

*signed - Your friendly Neighbourhood vice Treasurer !!*

## International Fibromyalgia Awareness Day 12th May 2009

A year has passed and what has changed. In Brussels, the Written Declaration on Fibromyalgia won a majority of votes. This asks for all member states to recognise fibromyalgia and ensure diagnosis and treatment is available. It also states that research funding should be awarded for fibromyalgia. It is likely to be some time before we see the results of this as it is a slow process. In the UK, the recommendation for guidelines for the treatment of fibromyalgia were not considered to be a priority by the National Institute of Clinical Excellence (NICE). This rejection by NICE which is independent from the government is a blow for UK fibromyalgia sufferers. The annual report from the Government's Chief Medical Officer Liam Donaldson, which included a whole section on pain and especially chronic pain, gave hope that at least this area of fibromyalgia might be given some attention but it is only part of the range of symptoms and cannot be treated in isolation. We were delighted to have a debate with Ann Keen, Parliamentary Under Secretary of State in the Department of Health so that questions about the future of fibromyalgia diagnosis and treatment could be assured. This debate was secured by Rob Wilson MP for Reading East and Chair of the All Party Parliamentary Group on Fibromyalgia (APPG). It seemed that complacency with the initiatives already in place means we still have a fight on our hands. Since the Musculoskeletal Service Framework was put in place in 2006, we have not heard that treatment options have improved and we still hear of people being told to go away and live with it. We have been told that in one hospital, a mention of fibromyalgia will bar the patient access to further treatment from pain specialists, physiotherapy or other recommended treatment options! When asked about training for medical professionals, which Liam Donaldson had mentioned in his report, we were informed that we would have to take this up with the professional bodies involved in accrediting training even though deficiencies in knowledge have been acknowledged.

However, the new website [www.NHSevidence.uk](http://www.NHSevidence.uk) was mentioned by the Under Secretary. When fibromyalgia is searched for, this has the European League Against Rheumatism (EULAR) guidelines that were sent to NICE as a beginning for official UK clinical guidance. This is encouraging if medical professionals use this service. This advocates a multidisciplinary approach for the treatment of fibromyalgia. There are some centres around the country that use this but we need all PCTs to have the ability to refer patients with fibromyalgia to a multi-disciplinary team of medical professionals for appropriate treatment. It is unacceptable that these specialist clinics are not available on the NHS Choose and Book system thereby denying easy access to sufferers. We hope this debate will have raised the profile of fibromyalgia but it has highlighted that there is still much more to do. People in constant pain should have the right to effective treatment. How can between 1.7 and 2.8 million people living with such a poor quality of life be treated so badly?

### For Editors: What is 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 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”. Fibromyalgia is a common illness. In fact, it is as common as rheumatoid arthritis and can even be more painful. People with mild to moderate cases of fibromyalgia are usually able to live a normal life, given the appropriate treatment. If symptoms are severe, however, people may not be able to hold down a paying job or enjoy much of a social life. The name fibromyalgia is made up from “fibro” for fibrous tissues such as tendons and ligaments; “my” indicating muscles; and “algia” meaning pain. **Fibromyalgia Association UK** Fibromyalgia Association 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 120 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. Currently we supply information through our website, monthly magazine and professional and patient booklets. We have a national helpline for general enquiries about fibromyalgia and one specifically for benefit queries. We have also held national and regional conferences with international speakers for both people with fibromyalgia and medical professionals. Our Medical Advisory Board is comprised of expert medical professionals in various disciplines who provide information for our publications and specific queries. The All Party Parliamentary Group on Fibromyalgia was formed in 2001 and holds regular meetings to inform MPs of the problems surrounding fibromyalgia and possible solutions.

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# **Fibromyalgia Awareness Day Meeting** **at Westminster Hall London – 12 May 2009**

A good number of MPs together with representatives from FMAUK attended the meeting

## Minutes

Introduction by Rob Wilson MP

- A good week for Fibromyalgia.
- Inundated with emails following the very first debate in Parliament on Fibromyalgia in Westminster Hall on Tuesday 5 May.
- Engagement with a Health Minister – Ann Keen Parliamentary under-Secretary of State.
- Excellence attendance from MPs and supporters.
- There has been progress over the last 4 years, a greater uptake from MPs.
- There is still a long way to go, but progress is being made and targets will be met.
- Thank you to all for coming.

Pam Stewart – Chair, Fibromyalgia Association UK

- Thanks to Rob Wilson and all who took part in Westminster Hall debate.
- Attended Annual Meeting of the All Party Parliamentary Group on Chronic Pain – excellent presentations, aim is to get chronic pain recognised.
- Chief Medical Officer, Sir Liam Donaldson has stated in his annual report that pain is a priority for him.
- Negative of this week is that NICE have rejected guidelines after a two year delay.
- A lot more work to do

Rob Wilson introduces Roger Williams

Roger Williams MP

- Thanks to Rob Wilson for securing Westminster Hall debate.
- Impressive to get debate so quickly. Only disappointment was the timing with it being so early on a Tuesday morning the day after a Bank Holiday. This did mean that not all who wanted to take part, could take part.
- However, this is a continuous process.
- We will see results in the long term.

Rob Wilson closed the meeting and invited all to continue the discussion.

**Paul Swanton** Who we mentioned in our March newsletter has raised £761.77 by running in the 2009 Flora London marathon, well done Paul.