

## **“We need you Can You Help” & “The Group and it’s Future”**

Extract from September 2014 InforME newsletter -

### **Worcestershire ME Support Group**

**AGM at Museum of Carpet, Kidderminster  
on Monday 29th September, 2014, at 2.00 pm**

### **We Need you Can you Help**

#### **AIMS OF OUR GROUP:**

- To support people suffering from, and affected by, ME, CFS, PVFS and FMS, through personal contact, meetings and information exchange;
- To raise public awareness, and promote a wider understanding, of ME, CFS, PVFS and FMS.

#### **Message from our Chairman (To members and non-members)**

Dear All,

Firstly, our thanks to Esther for taking on the job of newsletter editor (and getting it printed, enveloped, labelled and posted) plus all the paperwork for our AGM in September. Thank you.

There are changes that need to be made at the AGM:

1. We need more people to help to continue with the Group as it is.
2. How to continue with less help (we have to have more people on the committee)
3. We must have a secretary (it could be job shared)
4. Changes to area meetings as the cost of hiring rooms is one of our major expenses (6 x 10 meetings a year), and most meetings are poorly attended, e.g. less than 5 and sometimes none.

In reality after the AGM I do not expect much to change until next year, starting in February 2015. Up to December 2014 I expect we shall carry on as normal with hired rooms. I have booked Worcester/Malvern, Kidderminster for September, (except for Redditch please contact Jackie Elston - 01527 458840 for the venue address). We could then have all our monthly meetings as 'lunches' at garden centres, after the main mealtime clatter has died down, e.g. 2-3/4pm as now, or cut down on the number of meetings.

The main thing the group needs to do, if it is to continue, is to carry on the support via telephone, email, website, printed information and newsletters. Please let us know your thoughts and needs. If the group was to cease, this would be dealt with at a separate EGM and not at this AGM. However, I do not foresee this happening yet, as we still have sufficient funds, it is only help and people we lack.

All the best for now

Ian Logan

## “We need you Can You Help” & “The Group and it’s Future”

### Extract from July 2014 InforME newsletter - The Group and its Future

At our most recent group lunch we talked among other things about the group and its future, a regular topic of our conversations.

This year we have been holding our 'committee meetings' at the end of, or during, the group lunches, depending on who has come. This saves us from hiring a room for the purpose of these meetings as there are now so few of us still remaining on the committee. Group lunches, phone calls and emails serve adequately to run the group's day-to-day business and events.

Our recent ME Awareness event at the Kidderminster Museum of Carpets went ok, but only attracted 21 people who signed in during the afternoon, not many of these were new people. Most were regulars and helpers of longstanding, and I was disappointed that we didn't attract more new people. Those that did come, I think, wanted what we always supply at all our group meetings: - support, confirmation of their symptoms as 'normal', an opportunity to be listened to, suggestions of routes to follow up, and things to try to help with their symptoms. Our DVD show that was set up and ready-to-go never got an airing, but that doesn't matter.

We always have plenty of information to pass on at our group meetings, most of it free. I have always noticed that longer booklets and pamphlets are not normally wanted or are overlooked even though they can be borrowed or bought for just 1 or 2 pounds. Maybe attention span and effort is too short to take in much more information other than the most urgent of questions.

So where do we go from here? What do others want from us? Is our experience of ME/CFS/FM and running the group still required, or has the internet, etc, by-passed the need for face-to-face meetings?

Soon, we hope, ongoing research programmes and new research into Rituximab, etc, will provide proper, real relief. No more 'you can think yourself well'. Then we can retire peacefully! Not that the group employs anyone, as we are all volunteers and have given our time and precious energy for free and for many years.

And that is the problem: keeping things going with less and less help as we are getting older and still have other things which we have to do.

**At the next AGM, decisions will have to be taken on whether we can carry on at all. At present there are too few to form a committee,** as some current members intend to stand down, or have already had to do so. If we are to continue we have to fill a list of vacancies and if possible have extras to help share the load, eg secretarial duties, contacts to run meetings, a vice-chair.

Currently we have 60 normal local meetings each year (10 months x 6 venues), 1 or 2 Awareness events and 1 AGM, plus approximately 10 lunch meetings. That's a minimum of 61 rooms to hire and pay for at an average of £12 each. That, plus the newsletter printing and postal charges are our main expenses. We have been fortunate and able to cover these expenses up until now, but membership has dropped over the years and less people have come to the meetings, often only 2 or 3 visitors arrive. That makes the rooms an expensive luxury, but meeting in a public place is too noisy and not private enough. Asking for a donation towards the room is of small gain. The problem is not yet one of finance, but of supplying the needs in the best and cheapest way.

At the AGM in September, if there are enough volunteers to form a committee this problem will need to be addressed. Maybe we should become network only service. If so, I personally would only wish to continue using telephone contact, as I don't use a computer and don't wish to start. Phoning is easiest for me and very cheap using a landline, but others, of course, use email etc.

I'm sure that there is still a need for the group to exist. This is best seen when new people come to our meetings. Their relief and relaxation when they discover the information and acknowledgement by others of their dilemma and symptoms is plainly evident.

My thanks go to everyone for their help in running our group. Thank you to Esther Swinnerton for taking over as Newsletter Editor.

**So I now can only ask all:  
What shall we do after the AGM,  
and who can help?**

Best wishes to all  
Ian Logan, Chair