

Fibromyalgia Friends Together Annual General Meeting (AGM)

calling notice and agenda

Thursday 15th December 2022 at 1.15pm at The Manor, Shuttlewood Clarke Foundation The Manor, Shuttlewood Clarke Foundation. Priory Lane. Ulverscroft. Markfield. Leicestershire. LE67 9PH.

For directions use this Google Maps link:

https://www.google.co.uk/maps/place/Shuttlewood+Clarke+The+Manor+and+ Activity+Centre/@52.6962633,-1.285726,15z/data=!4m5!3m4!1s0x48775f59ad951c85:0xb8ae18bea60cebef! 8m2!3d52.6956924!4d-1.2737688

If you are unable to find us, then please call the Chair on: 07741 538773

Refreshments, including hot and cold food and drinks are available for purchase before the meeting at the Manor.

If you are unable to make this meeting in person, you can join us online through this link: (Please use Microsoft Teams)

Join the conversation (microsoft.com)

Item number	Item topic	Led by
1	Welcome and introductions	Chair
2	Apologies	Secretary
3	Approval of the minutes of the last meeting	Secretary
4	Officer reports on activity of the last year	All officers of the Steering Group
	 a) Chair b) Secretary c) Treasurer d) Membership officer e) Activities and Fundraising Co-ordinator 	
	f) Moderator (Social media)	
5	Self-nomination and appointment to the following roles a) Chair b) Vice-Chair c) Secretary d) Treasurer e) Membership Officer f) Activities and Fundraising Co-ordinators g) Moderator (Social media) h) Social Media and Website Officer i) Publicity Officer	Secretary
6	Group review of the last year	Chair
7	Planning for 2023	Chair
8	Any other business	Chair

Meeting papers

Item 1

Welcome and introductions

Item 2

Apologies

Item 3

Approval of the minutes of the previous meeting

Minutes of the Annual General Meeting held on 16/09/2021

Fibromyalgia Friends Together Annual General Meeting 16/09/2021 Place – The Manor Shuttlewood Clarke Foundation, Priory Lane, Ulverscroft, Leics, LE67 9PH Present Chair – Mark Farmer Secretary – Janet Hall Treasurer – Sandra Webster Events/ Fund-raising – Trevor and Pat Jordan Membership Officer – Gill Youngs Moderator(Social Media) – Diane Stephens Group Member – Janet Hall

Apologies

Apologies were received from Publicity Officer – Deborah Aydinli

Chair

Mark Farmer opened the meeting by welcoming everyone and thanking them for the work that had made the group a success. Mark presented his detailed report. In short the group had been badly affected by covid, they had been unable to have face to face meetings, but had been successful through social media. Treasurer

Sandra Webster presented her accounts and report. In view of covid, all forecasts of expenditure had not been realised.

The accounts were unanimously agreed, and any monies unspent being carried forward to the next accounting year.

Secretary

The secretary reported that there had been little activity for her to report on. Dr Vasu Rheumatologist had never reply to letters issued to him, before covid restrictions and because of covid there was no point in pursuing him further. The chair and the secretary were unable to have a face to face meeting, to review the constitution, again because of covid. The reason for the review was to ensure the constitution was in order to apply for charity status.

Events and Fund-raising

Trevor Jordan presented his detailed report of events. Unfortunately so many of the events were cancelled in view of covid. Trevor reported that there was however people visiting the web site and reported the figures.

Membership Officer

Gill Youngs present details of the membership for the year.

Facebook Moderator

Diane Stephens presented her report on the numbers visiting facebook. Diane found that she was receiving requests for the whereabouts of support groups in their own area. She was not sure of what she should say to them.

Nominations For Roles

The publicity officer Deborah Aydinli was absent due to ill health and found she was no longer able to continue. There were no nominations for this post. All other post holders agreed to continue, were nominated and seconded.

Any Other Business

Group member Janet Hall explained that her local WI, who had recently formed were willing to host a talk from the group. Trevor was prepared to deliver a talk, with help. Secretary Janet Hall said that she was not sure if the WI, had a defined process for speakers to go through and she would make enquiries. Janet Hall secretary under took to look at the web site fibromyalgia uk, whose umbrella the group worked to see if there was information about local support groups, for Diane Stephens to be assisted.

Minutes taken by the Group Secretary, Janet Hall, for approval at our 2022 AGM.

Item 4

Officer's reports on the activity of the last year

Chair's report

Mark Farmer

2022 has been another busy year for the group and for me as Chair. Numbers attending our group meetings have been steadily increasing, it is good to see people are starting to feel confident enough to attend face to face meetings once more.

Across the year, I have led sessions, amongst others on:

- Claiming for PIP
- Developing national pain priorities
- Sleeping with pain

As well as chairing the group, I also chair the officer group, that manages the group's business, called the Steering Group. The reports of Steering Group Officers, follow this report.

Janet, our group Secretary and I, continue to support people with their PIP applications, with us over the last few years securing ten of thousands of pounds in yearly income to the people we help.

This year saw the launch our new Whatsapp messaging and mobile phone text messaging support number 07741 538773. We will promote this number for people to text and to get support from us in 2023.

In October 2022, I became unwell with Covid, with other group officers keeping the group running. I was reminded, that we have such a friendly and supportive group of officers, who work so hard to run the group, promote our work, raise awareness of Fibromyalgia and support those with Fibromyalgia and their carers- Trevor, Pat, Sandra, Gill, Diane, Janet- A BIG thank you.

November 2022 was a particularly busy month. I presented to the medical profession in Liverpool, at the Royal College of Physicians on how I thought the medical profession could better support those with Fibromyalgia. Over 500 people attended the session.

I met with Cara, a lady who has ME, who lives in the Uppingham area, who has moved back to the area having completed her degree, to talk about her taking on the management of our website. She very kindly agreed to do this and help with content for our Social Media pages. You will start to see improvements to the website in the coming months. If you have anything you would like added to our website, then please contact Cara at: <u>cara@fibro.org.uk</u>

I helped promote the group and raise awareness the Christmas Light Switch on in Loughborough. Thank you to Trevor and Pat for organising this and getting up early in the morning to set-up our stall.

I met with a researcher and lecturer at Loughborough University, who we have now agreed a bid for research funds to use professional artists to help us visual and describe what it is like living with Fibromyalgia. We wait to hear the outcome of this funding and will keep the group updated accordingly.

We continue to offer Mental Health First Aid to anyone who requires it. Janet, Trevor and I are all qualified mental health first aiders. We are trained to help with immediate mental health issues and can help connect you with the right people. You can contact us through: <u>chair@fibro.org.uk</u> or call or text us using the numbers, call on 0116 2988007 and 07741 538773.

With the help of Trevor, we have been running the group's website and I have been working to promote our presence on social media. Here are some statistics:

Total website views this year to date:

9,947

Total all time website views:

40,342

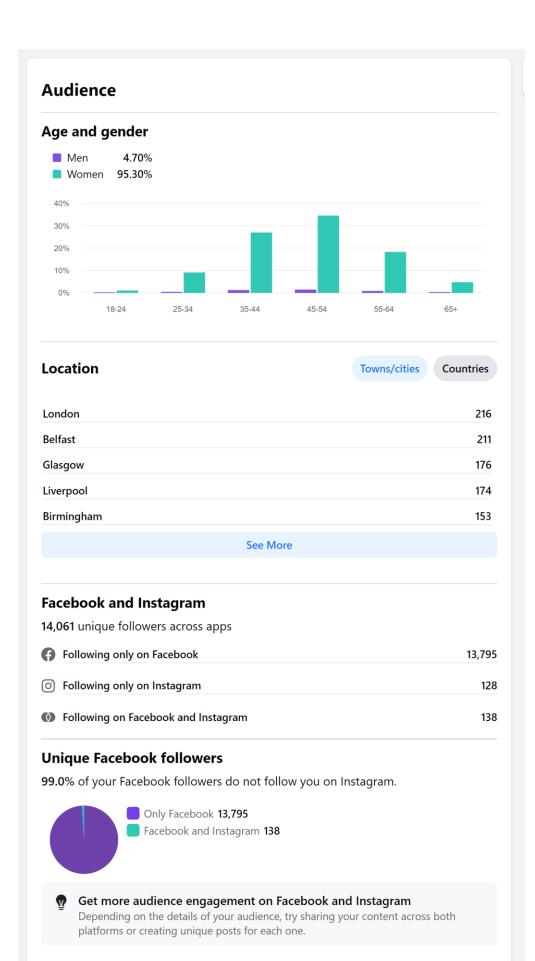
These figures are lower than the actual figure- as we had website technical or problems for several months this year, where the system was not recording the number of visitors. We are currently getting between 30 to 40 views per day.

Our Facebook group membership now stands at 2,788 members, this is an increase of circa 200 members since the start of December 2021.

Our Facebook and Instagram pages have circa 14,060 followers as of December 7th 2022.

We have grown both figures through utilising advertising on Facebook and promoting the group at in person events.

Graphic showing the detail of our Social Media audience:



We have circa 140 people on our group newsletter list as of December 7^{th} 2022.

Our Charnwood Lottery tickets continues to generate income for the group. Unfortunately, we have seen a reduction in the number of people purchasing tickets, no doubt, as a result of the cost-of-living crisis we are in. We would encourage everyone to purchase a ticket, as we receive 50 per of the ticket value. As a reminder, there is a top prize of £25,000 and one ticket only costs £1. We have had many winners over the years of the £250 prize and many other prizes have been won. Thanks to all that are able to purchase tickets.

The Shuttlewood Clarke Foundation is now charging a monthly fee to make use of the Manor. We need to continue to find additional resources in 2023, to cover this cost, fund our website, for advertising on social media, to purchase equipment and materials for our stalls and to pay for our telephone and texting services. We do this to ensure that there is support for people with Fibromyalgia and their carers and to raise awareness for the condition. Thank you to everyone for supporting our work and mission.

Secretary's report

Janet Hall

At the 2021 AGM two issues were discussed for consideration. I have undertaken research on these two issues.

Support groups

Diane bought to our attention that there were a number of people from outside our area who visit our Facebook page who want to know what support group is available in their area. They often asked why we do not set up a support group for them. She queried whether it would be appropriate for her to suggest they set their own support group up. Our support group is under the umbrella of Fibromyalgia Action UK. I have checked their website and they have a section for querying the whereabouts of support groups throughout the UK. Anyone asking about support groups outside area should be directed to the main website. I hope Diane and Gill find this information helpful and will be able to point people in the right direction.

Talks to the Women's Institute

It was suggested that someone from the group could give a talk to the new Women's Institute in Wymeswold. Trevor indicated that he would look at putting together a PowerPoint presentation and Mark would work with him. Janet Hall secretary was not convinced that a talk about fibromyalgia would be a welcome topic at one of the WI meetings. As secretary I have undertaken research. The Women's Institute holds an approved list of speakers for local groups to obtain their speakers. Women's Institute's in Leicestershire have a head office in Leicester. You should apply to them if you want to present a talk. Potential speakers are then invited to present the talk before a panel who vote on whether the talk can be included in the approved list. Speakers are required to give details of their expenses and any required donation, which again is considered. Fibromyalgia Friends Together need to consider the implications of doing talks to the WI and other groups. Consideration needs to be given that all information that we give is in accordance with Fibromyalgia Action UK as we are insured through them. I noticed on the Fibromyalgia Action UK website that some of the information provided has changed. It is a big task to put together a talk of about 30 minutes (the usual time). It may be best that the talk includes video clips. I am aware that each local Women's Institute can appoint their own Speaker but I have been advised that it has to be voted on by their committee. As a group we would not want to limit ourselves to one WI group and therefore a formal application to the WI would be the appropriate way forward. I would recommend that until Trevor and Mark have been able to put a talk together, with inclusions of videos to fill the time out, that has been approved by the Steering Group no ad hoc talks be undertaken as there may be a question of not fulfilling our obligations under the FMAUK insurance.

Treasurer's report

Sandra Webster

Introduction

The accounts are for the financial year to 31 st March 2022. The year before is shown for comparison.

Income 2021-22

The Charnwood lottery provided a regular monthly income totaling £576.In addition there were some regular individual donations. The Shepshed Carnival and Ibstock County fayre netted £114.

There was no new grant income.

Expenditure 2021-22

The main expenditure last year was on training-£810 was spent on mental health training for 3 officers. In addition, YouTube learning premium subscription was £180.

The remaining expenditure mainly related to annual subscriptions for IT packages and licenses. Facebook advertising expenditure was much less than the previous year at £45.

Cash Reserves

At 31st March 2022 the group had £5104 left in cash reserves. Included within this balance was the unspent LCFC grant of £2100. The rest of the cash grants received in previous years has been spent.

There are some running costs which are recurrent in nature e.g. website and software packages. In total these amount to under £500.

From 1 st April 2022 the group has agreed to a request from the Shuttlewood Clarke Foundation for a room hire fee for meetings held at the Manor. This is £24 per meeting or £288 per year.

The group therefore has sufficient cash reserves at 31st March 2022 for the time being. In the longer term however, there is a need to generate regular sources of income. At the present time, an annual income target of £1000 would cover annual recurrent running costs.

Membership Officer's report

Gill Youngs

I continue to welcome new members and give out welcome packs, now that the monthly meetings are back to normal. There are currently 143 contacts. The Facebook page continues to grow, current numbers are 2,700. The amount of conversations show that the page is still popular and of benefit to the members.

Activities and Fundraising Coordinator's report

Trevor and Pat Jordan

Fibromyalgia Friends Together

AGM December 2022

Activities and Fundraising

Introduction

This is a report for the past year 2022 outlining the activities and fundraising events the group has taken part in. This report is compiled by Trev and Pat Jordan joint Activities and Fundraising Co-Ordinator's for Fibromyalgia Friends Together.



Outdoor Awareness Display

Pat and I decided that because Covid was still with us we were not happy attending awareness displays indoors at Supermarkets, but we would attend the outdoor summer fairs. This still left the group able to raise money through the Charnwood Lottery scheme, recycling empty ink cartridges, grants, and donations.

<u>Events</u>

Wednesday 29th June. Manor Day Visit.

This event was attended by fourteen of us. This included arriving at around 10:30am and being served with coffee and biscuits. A hot lunch was served at 12:30pm which consisted of a main course and a sweet. Tea and cakes were served at 2:30pm prior to leaving for home at approximately 3:00pm. All this

for a suggested donation of £7.50. Excellent day out, value for money and plenty of time to chat and meet people.

Sunday 21st August. Ibstock Country Fair.

This event again was well attended. We were approached by twenty-five to thirty people who showed an interest in what we were all about and either had Fibromyalgia or knew someone who was suffering with Fibromyalgia. We also have had two people attend our meetings who we met at this event.

Monday 29th August. Shepshed Lions Carnival.

This also was well attended with a good response from the public who showed an interest in the information we had for them on our stall. Again, about twenty people showing they were also sufferers with Fibromyalgia.

Sunday 20th November. Loughborough Christmas Lights Switch On.

A chilly day but the event was well attended, so loads of opportunity to meet people and give them our leaflets.

Do not forget to check out our website

www.fibro.org.uk

To finish off this report I would like to thank everyone that have helped us make this such a rewarding year Thank You

Trev & Pat Jordan, Activities and Fundraising Co-ordinators for Fibromyalgia Friends Together



Moderator's report (Social Media)

Diane Stephens

We currently have 2.8K members.

Our membership is continuing to grow steadily, with peeks for joining following advertising campaigns and where we have had a stand promoting our group.

Most conversations and posts are relevant and helpful to everyone in our group. Now & again we get a series of scam posts which get removed and the poster blocked as soon as we become aware. I continue to monitor on an 'ad hoc' basis to try and limit this happening.

All in all a popular, beneficial group.

Item 5 Self-nomination and appointment to the following roles

- a) Chair
- b) Vice-Chair
- c) Secretary
- d) Treasurer
- e) Membership Officer
- f) Activities and Fundraising

Co-ordinators

- g) Moderator (Social media)
- h) Social Media and Website Officer
- i) Publicity Officer

Item 6 Group review of the last year

Item 7 Planning for 2023

Item 8 Any other business