

Sheffield ME and Fibromyalgia Group AGM 2023 - 12/05/2023

Conference room 2 - The Circle. Chaired by Carolyn Leary.

In Attendance

Carolyn Leary
Gillian Johnson
Claudia Geo
Rebecca Gransbury
Shehla Ali
Laura McDonnell
Manuchehr Maleki-Dizaji
Isobel Hemmings
Richard Souter
Elaine Souter
Jacqueline Ryan
Beatrice Greenfield
Victoria Millins
Alison Millar
Angela Colton
Carol Watchorn
Michele Young
Steven Wilson
Duraiya Kapasi
Simon Briggs

Apologies

Sheila Broadhead, Treasurer

Staff in attendance:

Amy Palmer, Charity Manager
Emma Kirby, Senior Benefits Advisor
Ayan Farah, Benefits Advisor
Maddy Whitby, Charity Administrator (secretary)
Pippa Line, Engagement Officer

Introduction - Carolyn Leary, Chair

- Fairly short AGM part.
- Lunch.
- Followed by a presentation by Adam Lowe, poet, and on the NICE guideline committee.
- All staff COVID tested. Masks and LFTs available.

AGM

Anyone interested in running as a trustee, please do get in touch!

Reporting back from 2022

- Anyone interested in writing up the history of the group and recording the early days, please do come forward.
- Most trustees are either living with ME, Fibromyalgia or Long COVID, or carers for those who are.
- Thank you to all volunteers involved this year.
- Our membership has risen dramatically, to around 520 by the end of December.
- However, our membership is not as diverse as it could be, according to the statistics in Sheffield. We particularly need to reach out to BAME communities, low income and other marginalised groups who may not have easy access to our resources.
- Thank you to Ayan, Pippa, Holly and Elyane for all their outreach work this year,
- What we try to offer is a wide range of activities. We have heard how some enjoy wellbeing activities, but also how some activities unrelated to ME/Fibromyalgia/Long COVID are enjoyed too, e.g. French, arts and crafts, photography
- Being around others who you don't have to explain your condition to is part of the uniqueness of our charity
- Befriending service ongoing
- We run a Members-only group on Facebook with 350 people on it. Moderated by Carolyn and Mandy among others. Useful forum for members wanting to talk about others experiences.
- Benefits service. We are one of the largest local ME groups in the UK, and our benefits work is unique and makes life-changing differences to members..
- Having someone to help one through the benefits system is extremely useful and please do use it!
- Massive amount of work done by Becca curating the quarterly magazine
- Please contribute to the magazine!
- We hosted a series of four "Science to Sofa" talks and q&a bringing world-class science to the homes of those living with conditions, watched by international audiences
- Decode ME study - biggest genome study relating to ME. Please sign up for this.
- Major "Speak Up" project this year which was effective in opening doors to speak with commissioners of services.
- Art exhibition in the Winter Gardens was very popular- funding by Marie.

- Nutrition - one of our trustees is a nutritional therapist, lots of work done here
- Outcome of the benefits service available on report - increase in weekly income and significant back-dated awards for members.

Changes

- Elyane headed off, passed on to Amy as Charity Manager.
- Welcome to Amy, Emma and Maddy, new joiners for the team.

Accounts

- Financial statements available to read
- We receive grants to do specific things, and grants that are “unrestricted”. Our main funders this year are the Lottery, the ME Derby group (which has sadly folded), Postcode trust, and the tackling inequalities fund. Healthwatch Sheffield also funded specific projects.
- Staff costs are the major expenditure. Also office rent and upkeep.
- More online things is financially benefiting the charity
- Lottery funding runs to the end of December. Bid for continued funding has already been put in.

No Questions.

Election of new trustees

- Simon Briggs stepping down for a break - will be greatly missed.
- Becca Gransbury is standing again
- Beatrice Greenfield rejoined in Nov 22 and standing again
- Isabel Hemmings standing again
- Duraiya Kapasi will be stepping down - massive thank you for your contribution.
- Alison Millar will be standing again
- Emma Saville will be standing again
- Ellen Roy will be standing for trustee, returning from a break
- Carolyn Leary is standing again
- Huge thank you to Sheila Broadhead (treasurer).

Ellen said:

- Was part of trustees, rejoining after period of illness
- Likely to be mostly online but excited to rejoin

VOTE:

For this board: All

Against: 0

Abstentions:0

Vote passed. Board is elected as trustees.

Questions

Is Carolyn standing as Chair?

A: Carolyn will stand for Chair at the first trustee meeting. Would love to have a co-chair or vice chair - or happy to step aside if someone else would like to take on the role.

Feedback from members

- Yoga groups - Friday mornings, online. Great.
- Positive feedback about the breadth of what we offer and wellbeing gained from volunteering.
- Being mindful of the state of play with benefits and welfare. Being more aware of it.
- Open facebook group is very useful, but we need more information on how to join the private Facebook group.
- Want to see more in-person meetings rather than on zoom.
- Enjoy qigong and parlons Francais.
- Issues with emails going to junk.
- Could we transition from clapping to jazz hands in future as it can trigger conditions.
- Good to see the strength of the organisation continue. Guided walk around Norfolk park was a great idea to get people to talk to each other.
- The organisation is very online focused now, and for people with visual impairment it is excluding. Art therapy and poetry writing in-person groups would be welcomed back.
- Having a community like this where people with these conditions can be together is very useful.
- We would love to pay for taxi fares but it is unfortunately very expensive and we don't currently have a fund to do this.
- Need more than 8-10 people to justify having a tutor, so it would be useful to gauge interest.
- Pippa will look into a hybrid arts and crafts session, with people joining online and in person.
- Lots of interest for in person Tai Chi.
- The facebook membership/private group system is quite confusing - a more accessible/less confusing system would be ideal.

LUNCH

Celebration of World ME day

Adam Lowe's performance of selected poems from his book, "Patterflash".

Discussion of NICE guidelines

Why did you become a layperson for NICE?

- Did a scoping workshop
- Family history of activism inspired him
- Successfully elected
- Personal connections to people with ME
- Saw that fitness did not improve PEM.

Tell us who is who on the committee and what did they learn, and what was implemented?

- Can't say
- Wide range of opinions on ME and related conditions on the committee
- Often beliefs that were considered ableist weren't expressed because the people with the conditions were in the room with them
- First priority was removing the experience that every interaction with the NHS was

torture so people can actually access care.

Upcoming general election - what do you think will happen with Labour (if they get in)?

- Lots of new Labour policies negatively impacted healthcare
- Keir Starmer seems to agree with a lot of Conservative policies
- Awful benefits system that can't cope which Labour might be better suited to deal with

Is there a health statistician on the guidelines group?

- Yes, and they tend to cut through a lot of aggrandising

What replaces CBT for example in the NICE guidelines now?

- CBT is still in there, but now optional and transitioned to "supportive CBT"
- Graded exercise therapy is gone
- Lymphatic drainage is not in there due to a lack of evidence
- No evidence for nutritional supplements
- Lots of support around energy management
- There is little good research into ME.

Why are we celebrating world ME day?

- Went into NICE expecting the worst
- Was about consensus and listening to each other
- Want to celebrate that
- Want to look ahead to the challenges and celebrate the gains we've made, while also thinking of those who we've lost
- It is an opportunity for others to get involved

Thank you and take care!