

FND Dimensions - AGM

Date - Wednesday 21st September 2022 @ 5.15pm

Venue - via Zoom

Reporting Year - April 1st 2021 - March 31st 2022

Trustees Committee

Steve Webster - Founder/Chair (SW)

Nicolas Stone - Treasurer (NS)

Sarah Webster - Secretary (SaW)

Stephanie-Roxanne Blanco - Trustee (SRB)

Chrissie Moring - Trustee (CM)

Linda Stone - Trustee (LS)

Report on Activity - (SW)

Once again it has been a very busy year with further growth in service users of our groups, now over 1500 and with increased geographical spread. Outside interest through things like Twitter have gone from 1000 followers to just under 1200 and website enquiries have increased. This confirms we are continuing to attract people to the charity and a greater need to deliver against our charitable objectives;

(1) To promote and protect the physical and mental health of sufferers of FND (Functional Neurological Disorder) through the provision of support, information and practical advice.

(2) To advance the education of the general public in all areas relating to FND.

Group Activity

Members

Our membership numbers have grown extensively over the past year (approx. 25%). We now have 1500 members (Facebook closed group) and 1700 members (Google database) (Figures taken from March 2022). As our numbers grow we are working harder to ensure our Google contacts database is kept updated. There are two membership figures in this report, one is the number of members that have joined our Facebook closed group ("FND Dimensions Meet-Ups") and the other is the number of

members we have in our Google contacts database. We have some members that are not on Facebook and the membership numbers of our Facebook closed group can fluctuate as members leave (either intentionally or not), change their profile name, open a new profile etc. We are rarely told of name and profile changes therefore ensuring that our Google contact database is accurate can be quite challenging.

There is a written process in place for welcoming new members, allocating them to their nearest group and inputting their details onto the Google database and SW is responsible for this.

As we continue to grow, we are now seeing more unresponsive members in groups, as well as members leaving (either intentionally or accidentally). At present there is procedure as such for these situations, so we are discussing how best to address this potential issue and ensure that members are receiving the support they need.

Fundraising & Events

Funds being raised have been very limited this year (please see Treasurers report below). Most funding coming in has been the remainder of payments from 'Virgin Money Giving' resulting from Andy Varney's 'Virtual London Marathon' run and Thomas Snell's Ironman Competition.

Working with 'Edukit Solutions' (The Funded Team) an application was made to the National Lottery's - Reaching Communities Grant, to try and raise funding to support the employment of a 'Project Manager', but this was unsuccessful.

There are several other smaller donations which have been received from individuals, but the overall year after income and expenses are added and subtracted, as seen a gain of around £250 - this has to be addressed.

Applications for further funding will now be made.

Other opportunities for events had to be put on hold due to COVID restrictions, limiting the chances of raising further funding.

FND Awareness Day UK - 25TH March followed the format as shown below and was very successful, engaging people across the country.



FND AWARENESS DAY UK
25TH MARCH 2022

Online Zoom Event

Guest Speakers

Come and join us for 3 online sessions on the 25th March 2022

<p>10:30am - 11:30am Lets talk about FND</p> <p>Take this opportunity to ask a specialist general questions relating to FND. Questions will be pre-selected, followed by 15mins of live Q&A engagement.</p> <p>Hosted by: Kim Hearne, FND Action Tim Nicholson, Consultant Neuropsychiatrist & Senior Clinical Lecturer at King's College</p>	<p>13:00pm - 14:00pm South West care</p> <p>Come and hear about the support offered by FND Friends in the South West, and meet FND specialists, Dr E Mallam & Dr L Russell, who will be discussing our recent FND conference held for clinicians. Followed by a Q&A of pre-submitted questions.</p> <p>Hosted by: Mandy Hall, FND Friends</p>	<p>18:00pm - 20:00pm Social time for all</p> <p>Join us for this more light-hearted session. There will be a brief round up of what has happened during the day, a fun general knowledge quiz and followed by an informal chat on whatever subject or questions people would like to raise.</p> <p>Hosted by: Steve Webster, FND Dimensions</p>
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Free tickets will be available shortly through Eventbrite





FND Dimensions has a small team of volunteers, all of whom suffer with FND or related conditions. This invariably impacts on our 'day to day' running when members of the team are ill and not able to support our activity. We are more than grateful for the time that our volunteers give us and we formally wish to thank them for helping FND Dimensions reach the level it has during the last year.

The central admin team has particularly had health issues this year which has impacted on the level of support being given to all groups. However, we have maintained a consistent presence offering regular group 'drop in sessions', some 'face to face' meet up's and 1:1 support sessions for those with particular needs.

We will be trying our best to recruit new volunteers with the relevant skills and drive to move FND Dimensions forward as we continue to grow and have received support from one of our members, Jayne Bratton who has a wealth of experience in terms of business growth and mentoring.

Financial Report - (NS)

Financial Statement for Year April 1st 2021 - March 31st 2022

(See attached for full report).

The overall summary below highlights our positive financial position, although the growth in the bottom-line figure was very small.

	2021/2022	2020/2021	2020/2021 Restricted
Income Per list (see Annex to Statement)	2,51362	1,706.96	9,320.00 COVID-19 Response NLCF 1,000.00 Albert Hunt Trust
Expenditure Per list (see Annex to Statement)	2,274.48	1,126.91	10,320.00
Carried Forward	13,571.92	12,991.87	0.00
Balance	13,811.06	13,571.92	0.00
Liabilities	0.00	0.00	

Volunteers

The recruitment of volunteers remains high on our agenda. We have 5 “senior admins” (SW/CM/SRB/Kerryn Withers-Green (KWG) and Julie Stafford (JS)) who meet regularly (via Zoom) to discuss the charity’s activities. They are also there to support and oversee the other volunteers. We currently have 20 volunteers for 61 groups. There is an obvious shortfall which we are trying to address and encourage new volunteers to come forward. KWG, with her HR experience, is working alongside other team members to iron out the recruitment procedure and ensure that this is written down and linked to the DBS checks. KWG also continues to work on the Data Barring Service procedure for volunteers. As an evergrowing charity it is important to ensure that we have documented procedures in place for our operations and SW is looking at the Safeguarding Policy. This is particularly important given the fact that all of the senior admins have FND and therefore could potentially be out of action due to ill health/symptoms. Having clear procedures in place means

that another person can pick up an individual's tasks should the need arise.

The needs of our groups continue to vary and the support that our volunteers require also varies greatly. All our volunteers have FND or are a carer for someone with FND and therefore their availability will be symptom dependent. There are also vast differences in the medical support and knowledge available in the different counties across the country which has a knock-on effect causing vast differences in the knowledge and awareness amongst volunteers. Sometimes volunteers emerge, without prompting, when a group is set up (or even when a new member joins). Some groups are very chatty and others need more encouragement. We are therefore continually reviewing how the groups are working during the senior admin meetings and thinking of ways we can best support our volunteers. We have just opened a "Volunteer Room" that is a Facebook group chat specifically for volunteers where we can share information with them and give them the opportunity to raise issues and meet other volunteers.

We would like to take this opportunity to formally thank all those volunteers who have supported FND Dimensions and the help they provide to allow us to keep growing.

Developments with the Functional Neurological Disorder Society (FNDS) have been slow as they get their own house in order. Their conference is taking place in Boston, USA in June and we have been permitted free virtual attendance.

For a long time now we have discussed changing the logo of FND Dimensions, to something more appropriate and professional looking. Likewise, we are wanting to update the FND Dimensions website. Through a contact of Jayne Bratton, Alison Cooley has offered to undertake the logo work for us 'pro bono' and will also redesign our leaflets to match. We have also received a very good offer from Jayne's husband Steven to pull the new website together for us and offer training on 'Wordpress' so we can update it regularly ourselves without too much difficulty – this offer has been taken up and the work is ongoing.

Groups

We currently have 61 groups that are split between the senior admin as follows:

SW (22 groups, including 6 shared)

North West: Cumbria

North East: Durham, Stockton-on-Tees

West Midlands: Birmingham, Coventry, Staffordshire, Telford and Shrewsbury, Worcestershire

East Midlands: Derby, Leicester (with SRB), Long Eaton, Loughborough

South West: Dorset (with Hannah Padley from FND Friends), Somerset (with FND Friends), Wiltshire (with FND Friends)

Northern Ireland (with CM)

Wales: Swansea and West, Wales South and Wales North

North West: Manchester, Merseyside, Preston, Morecambe, Chester and Wigan

South East: Berkshire, Oxfordshire

Scotland: Ayrshire (with CM), Edinburgh (with CM), Fife (with CM), Glasgow and West (with CM)

CM (25 groups, including 4 shared) - being covered by other team members currently

North West: Bury

East of England: Bedfordshire, Chelmsford, Colchester, Harlow, Hertfordshire, Ipswich, Norwich, Southend

South East: Buckinghamshire, Canterbury, Crawley, Croydon, Dartford, Portsmouth, Surrey, Sussex and Southampton

Greater London: London East, London North, London South, London West

Scotland: Ayrshire (with SW), Edinburgh (with SW), Fife (with SW), Glasgow and West (with SW)

SRB (2 groups, including 1 shared)

East Midlands: Nottingham, Leicester (with SW)

JS (3 groups)

Yorkshire and Humber: Yorkshire North, Yorkshire South, Yorkshire West

KWG (4 groups)

East of England: Cambridge, Peterborough

East Midlands: Northamptonshire, Lincoln

There are a few areas currently under development. The three Yorkshire groups have become quite large and difficult to manage. JS and CM have been looking at ways of potentially splitting the groups, so they are more focused on towns around where members are based, and hopefully recruiting local volunteers. Hopefully, this will mean that it is easier to identify an accessible meeting location for each group and the group chats will be more manageable with less people in them. (This was also in last years report, but due to illness remains to be actioned).

One of the actions from last years AGM was to have:

- A review of 'meet up's' to date with a questionnaire that allows participants the opportunity to help guide the future direction of the organisation

This was done during the summer and has been acted on. We have since developed one new group for 'Parents and Carer's' which has proved very

successful. We are looking at putting on more 'outside' speakers on particular subjects. There is a whole range of subject areas and these are being developed as quickly as possible eg. Functional Diet.

We have also run a number of 'Mindfulness' courses, which have also proved popular and well received and we will be applying for funding to hold more courses throughout 2022/23.

Key areas of development and the future

The impact of COVID has severely restricted the developments we had in last years plan and all have simply moved into the new financial year. Our efforts have been concentrated on delivering support to groups and individuals. We hope to deliver more of the list below as we move forward but there are undoubtedly 'unknowns' in relation to how COVID will continue to impact our day-to-day activity and the time limitations of having a small team.

- A push for more volunteers. Ideally each group should have a local volunteer to help oversee the conversations and arrange meet-ups
- A "toolkit" or member's pack, to help members understand the FND diagnosis, including hints and tips on how to cope with symptoms, some signposting to sources of further help etc
- A "toolkit" or volunteer's pack, to help volunteers with how to manage the group conversations, ideas on how to arrange meet-ups (the Facebook Messenger polls facility if available, using the charity's postcard etc.), help available for particularly isolated members (i.e. paying a taxi fare for someone to make a meet-up) etc
- Ensuring that we have the necessary documentation in place (including but not limited to, procedures and "how to" guides) to ensure continuity and consistency should a volunteer fall ill and therefore minimise any risk to the charity
- Finding the right balance between maintaining a group's individuality while still ensuring that the charity's identity is clear
- Secure the funds required to enable the charity to move forwards

There is a continued desire to develop a wider sense of 'community' across our membership and groups. Our original goal of developing 'local' support groups has undoubtedly happened (with varying success of how often the groups meet). Using the social media platforms, like Zoom, will be one way we can try and achieve this. We will also be developing ideas

for engaging with more members, that reflects their interests such as arts and crafts, as a way of bringing people together. It must be noted that this is very time consuming, hence the desire to fund two roles within the organisation, Project Manager and Administration Officer.

As we continue to grow it will be important that we ensure we keep on top of all our activity and recognise the issues we face head on.

- A review of all groups and how we can possibly change the current format from Messenger to Facebook. We need to streamline the groups in order to help develop a stronger community and levels of interaction between service users
- A clear need to increase volunteer numbers across the board within our activity
- Better use of IT to encourage greater participation by individuals who for one reason or another are unable to attend meetings and a continued roll out of 'Zoom' for meetings where possible.
- A 'toolkit' of ideas that individuals can use to help with their symptoms eg. Mindfulness Techniques. This would include general advice videos recorded by specialist doctors
- Attending more conferences to boost both the knowledge of FND and Dimensions within the wider public and with medical professionals, however COVID 19 is going to limit these opportunities and we will need to look for additional outlets to boost our promotional and FND awareness activity
- Establish a good relationship with the Functional Neurological Disorder Society, a new global group of medical professionals who are linking up to improve FND services and knowledge
- Developing links with medical bodies from local GP's to Clinical Commissioning Groups (CCG's), hospitals and other medical charities
- Develop a greater sense of 'Community' amongst our members
- Funding bids to allow for the potential employment of staffed positions within FND Dimensions itself. In particular a Project Manager (PM) and a Administration Officer (AO)
- The development of a 'bespoke' website that fully reflects all our activity
- Keep better records of all meet up's that take place and ensure the activities go out on the advertising postcards across our own & other organisations (where permitted)
- Need to look at achieving charity status in Scotland
- Continue the development of 'partnership' work with other FND charities and organisations
- Organise 'Mental Health Awareness Training' for all interested volunteers
- Review Safeguarding procedures and policy

In order to help achieve the above we have been working closely with not only our volunteers but also the 'Bratton Group' who support organisations and businesses in their growth and development. This support has been provided free of charge and has proved invaluable in helping us to plan moving forward more effectively.