HOSTING AN FND HOPE EVENT

Empowering Patients to Better Health
About Us

FND Hope UK is a not-for-profit making organisation dedicated to supporting people who suffer with Functional Neurological Disorders.

Functional Neurological Disorders are due to the brain’s inability to send and receive signals properly as the result of physical and/or psychological precipitating factors. One theory suggests symptoms then possibly perpetuate because of neuroplasticity.

FND is difficult to treat because research is lacking. Lack of knowledge and understanding of functional symptoms can be detrimental to patients’ physical and mental health. This lapse in patient care and management contributes to the progression of the illness. Many patients are left to suffer with their painful and debilitating symptoms alone in silence because their doctors simply do not know how to help them.

So what does this mean for the patient? FND can be as debilitating as Parkinson’s and MS, yet without the support. FND patients suffer with a wide range of symptoms including; chronic pain, non-epileptic-seizures, sensory and balance changes, involuntary movement, paralysis/weakness and sleep disturbance. Life can be completely turned upside down for the individual and their families. Many patients lose the career they have built, and relationships are often strained.

While it is estimated that functional disorders are the second most common reason for an outpatient neurology consultation, the exact prevalence is unknown.

FND Hope UK’s motto is: “Empowering Patients to Better Health” and we currently do this by providing online support groups through Health Unlocked, and several Facebook group. We feel it is important for patients and their carers to have a community, which support them.

Be the Hope – Be the Change!
FND HOPE Fundraising and Events Planning Pack

Summary

Whether you are running an event that is small or large it is imperative that you make sure that everything is planned properly so that your event is enjoyable, runs smoothly and ultimately meets the goals that you have set for the event itself. The other key factor is that you represent the best of what FND patients and supporters can offer. Remember, you are acting as the face of FND Hope and therefore leaving a memory in those people who have come to support you and the organisation. Leave them with a positive memory, that way they may come back again in the future!

One of the phrases that it used a lot when it comes to planning an event is;

’Failing to prepare is preparing to fail’

This is not meant to scare you, but to act as a reminder that you should keep at the back of your mind. Better still, put it at the top of your ‘planning list’, treat the phrase as a friend that is there to keep you and others on track.

The following pack includes:

- FND Hope Information Sheet
- Logo’s that you should use
- Planning steps - Quick Checklist
- Ideas for events
- Job list – Volunteer Positions
- Letter of support template
- Sponsor Form
- 10 Point Planning Guide
- Sample Marketing and Communications Plan

Useful website links:

Useful logo's

Logo font
Arsenal Bold & Arsenal Regular font

Fonts used | Free downloads
Arsenal: http://www.1001freefonts.com/arsenal.font

FND Awareness Colors
Blue  #0A3C6B
Orange  #ED7223
Grey dark # 797979
Grey med  #AAAAAA
Grey light  #DDDDDD
Planning Steps – Quick Checklist

1. Got an idea
2. Plan Ahead
3. Volunteers
4. Sponsorship & Donations
5. Marketing
6. Safety Considerations
7. Legal ‘Matters’
8. The Clean-Up
9. Saying Thank You
10. Making Your Donation
Ideas for Events

There is a large range of events and ideas that you could possibly run. Here are just a few suggestions to get you thinking;

✓ Coffee Morning
✓ Cake Sale
✓ Craft Sale
✓ Tombola
✓ Car-boot Sale
✓ Raffle
✓ Sponsored Event e.g. Walk or Swim
✓ Treasure Hunt
✓ Disco
✓ Afternoon Tea
✓ Stall at Local Events
Job List – Volunteer Positions

It is vital that on the day of your event, all volunteers have a clear understanding of what it is required of them and each other. Of course the number of volunteers you have will vary depending on the size of your event. The main thing is to ensure you have enough volunteers for the activities you have taking place, rather than too few who are running round like headless chickens trying to cover all bases. Particular individuals may have taken up certain duties before the event, as shown below. When it comes to the event itself their role may change to meet the requirements of the activities taking place, so make sure they are aware of this prior to the day. It is important not to have ‘too many Chiefs and not enough Indians’. Be clear about this from the start so you don’t get any comeback.

You will not necessarily need all the positions that are suggested below. However, it gives you an idea of the sort of roles volunteers can take up and what their responsibilities should be. If the event is small, then an individual may be happy to take on more duties. The bigger the event gets, the more people you will need to carry out those duties.

**REMEMBER** – Your volunteers are your best resource, treat them well and they will hopefully be willing to help again in the future. Abuse their time and efforts, you lose them and give FND Hope a bad reputation.

**Event Co-ordinator**

As ‘Event Co-ordinator’ it is your role to ensure that the ‘event plan’ has been followed and implemented and that all volunteers are clear about their roles and responsibilities. You need to make sure that each individual who is in charge of a particular area has the resources and support required for them to carry out their role, prior to and during the event. On the day, you want to ensure that you have as little amount of problems as possible and that you can enjoy the efforts you have put into getting things organised. Ensure other people know how to get hold of you during the event. As lead, you will also be required to ensure that all legal matters such as licenses or agreements are agreed in writing and the appropriate paperwork kept to hand as proof on the day. Maintain contact throughout the event with volunteers, ensuring they have had a break where they can and they get something to eat and drink.

**Event Co-ordinator (no.2)**

In this role, you need to know all the same details as the main co-ordinator above. If this person is ill, then you will hopefully be in a position where you can step into the breach and take over without any fuss. You will also act as a key support person during the build-up process, it is always useful to have a second person to bounce ideas off and help carry some of the burden. On the day itself, you can be more flexible and help to step in to cover where necessary.
Sponsorship / Donations Support – Volunteers  
(again, depending on the size of your event you may need one or two people in this role).

It will be your job to get as much support for the event as possible from the local business, community, family and friends. The more ‘in-kind’ support you get or donations of any sort, makes for bigger profits on the day and more money to support FND Hope projects. Keep a clear record of who you have written to, phoned and any offers they make. Ensure you inform the ‘Event Co-ordinator’ of any progress and also the Marketing person as sponsors may want you to include their logo in any information that goes out to the media or is advertised on the day.

Marketing Volunteer  
You will have the role of spreading the news to as many people as possible about the event, through as many types of media as possible. Be clear about information regarding FND Hope, what FND is and how proceeds from the event will support future FND Hope projects. Obviously, event details such date, time, venue and activities available will be crucial in getting the message across to your potential attendees.

Safety Volunteer  
This role will need to be carried out in conjunction with the ‘Event Co-ordinator’ as they will be the one with responsibility for any licenses/agreements that need to be held onto. During the event, you will need to be on duty ensuring all safety requirements of any buildings or areas of land you are using are being adhered to.

Kitchen Volunteers  
If you are serving refreshments and the event is busy, you will undoubtedly have a busy role. Try and keep things as tidy as possible, it will make your job easier and also looks good in front of customers. Safety is a priority so try and have a system in place, where helpers are not constantly crossing each-others paths, food areas are clean and money is looked after. If necessary, agree with the ‘Event Co-ordinator’ a rota system so you are not stuck behind the same busy counter for the whole event.

General Volunteers  
There is always a need for some people who are willing to pitch in wherever on the day. This could involve setting up rooms and seating areas, assisting on stalls, selling raffle tickets and cleaning up at the end of the day. If you have this role it makes you know less important than anyone else. However, be prepared to jump into any given situation where required. If you do not want to be involved in a particular activity, make this clear to the ‘Event Co-ordinator’, preferably before the event day, allowing them a chance to plan accordingly.
SAMPLE EVENT REQUEST FORM

YOUR NAME
- Marketing FND

YOUR EMAIL
- marketing@fndhope.org

Name of event
Clarify the purpose or focus of your event. E.g. fundraiser, race, golf tournament

Location of your event
Country / State, City

When do you want to have your event?
Most events are successful with a generous timeline of 3-6 months or more

Why would people be interested in this event or initiative?
Identify the value proposition for your target audience(s).

Who is your targeted audience?
- Internal Audiences within a school, foundation or business
- External Audiences (e.g. corporate business community, special groups, , runners, golfers, etc.
- Sponsors

What do you want them to do?
Reach out to stakeholders, partners, and potential sponsors to help further define what you are planning.

How will you promote your event?
Social media, advertising, such as television, radio print, flyers, word of mouth, network community,

Will FND Hope be the only non-profit to benefit?
Other non-profit, charities
How will you define success?

- # people that attend event/enrollment etc., participate, buy a product
- Financial measurement—make a profit, meet budget, break even, percentage amount donated to FND Hope

Will you evaluate after event?

- Buzz created in social media before, during, and after the event (e.g.– Did people use your hashtag and retweet?)

Timelines

- Do you have a communications plan yet? Include actual dates, realistic time frames, volunteers

Other than approval of logo use is there anything you want Hope FND to do for your event?

- Add your event to our event calendar
- Link to your website/Facebook etc., Twitter
- Ask for volunteers to support you

In your opinion how does FND Hope benefit from your event?

- More awareness,
- Financial support

Thank you for supporting FND Hope.

Please allow 48 hours for approvals.
The ‘Planning Guide’ set out below is for you to use as a means of guidance. You can pick and choose which bits you deem necessary, depending on the size of your event. However, we would urge you to read through each section in order for you to be certain you have considered all eventualities, particularly any Safety & Legal obligations.

At the beginning of the ‘Fundraising and Events Planning Pack,’ the summary held within it a phrase that we would advise you to think about;

‘Failing to prepare is preparing to fail’

This is not a scare tactic, but a thought you should keep at the back of your mind and at the top of your ‘planning list’. Treat it as your friend and your mantra, something to be used and to keep yourself and others on track.

You want your event to be a successful one. This will not only bring you a personal sense of pride and fulfilment, but also credibility to FND Hope, who at the end of the day you are out there representing.

The ‘10 Point Planning Guide’ is not meant to be a heavy chain around your neck. It is here to help you think through what you are planning in a simple and pragmatic way. Likewise,

it is here to help you weigh up your options and maximise the potential of your event. Please read it and consider it carefully!
1). Got an idea

Great! Before going any further talk it through with someone you can rely on for good, honest feedback. Bounce ideas around, perhaps post something on Facebook to gauge reaction or get feedback from someone who has run a similar event. You could talk it through with one of the FND Team before you submit your event form. Remember, if you are going to do something on behalf of FND Hope, you need to let us know and we will help as much as possible.

You could think about setting yourself a goal or target of what you want to achieve or how much money you would like to raise. However, be realistic, you can never be certain of the end outcome until the end of the event itself. You need to keep yourself healthy and minimise the stress involved. At the end of the day the last person you want to let down is yourself.

2). Plan ahead

Once you have decided on an event you can start your planning process for real. At this stage there are many factors to start thinking about, but primarily they are;

- Date
- Time
- Venue
- Budget

You want to make sure that your event is not going to clash with anything else that is going on in your area. Check out all the usual places that hold events, schools, community centres, the local council or other groups who may be advertising what they are doing. Start to make a list of what you need to make your event happen and importantly what are the costs involved. Ensure you pick a venue with good access, adequate facilities and space for your event. It is now that you will start to be able to assess the amount of help you are going to need. Remember, do not put yourself under too much stress, get support and try and gather the people you need to help deliver your event successfully.

Make sure you or someone is going round with a camera and capturing images of the day’s activity. Remember, these images may be used for publicity purposes, so make sure you get agreement from people that they are happy for their picture to be used either in the local press or within FND Hope promotional material. If the photo involves a child, make sure their parents or guardians are happy for the images to be used. If not, delete the image immediately (if possible). If the child is alone at the event, avoid taking images of them!
3). Volunteers

Depending on the size of your event, it will give you an idea of the sort of help you are going to need to make it happen. (See section 5, Job List – Volunteer Positions). Volunteers are your key asset and should be respected as such. Importantly, you need someone you can rely on to act as your ‘second in command’, who if necessary can take over if you are indisposed. (This has nothing to do with the fact you are a patient with FND). In any organisation it is imperative that two people know the event inside out, in case the other one is not available for whatever reason.

In gathering your willing hands, whether they are family, friends or neighbours you will need to show a friendly degree of leadership and delegation of roles. Ensure people are happy with and understand their job description and what it entails. Agree a pattern of communication e.g a weekly phone call or get together that allows the person to get on with their role, but allows you to keep a check on what is developing. At the end of the day, you are in charge of the event and the buck stops with you, but the pressures can be shared out and the more your volunteers feel joint ownership of the event, the more successful and enjoyable the experience will hopefully prove.

Your volunteers must realise that they are representing FND Hope and as such need to think and act in a way that maintains and enhances the reputation of the organisation.

4). Sponsorship & Donations

The more sponsorship or donations towards the event you can get the more money you are going to raise and the greater the profile of FND Hope. Make a list of all the local business you feel most appropriate to be able to help. Where possible try and find a named person within a particular company who you could write to directly. They are much more likely to respond in a positive way because of this. Cold calling and letters to ‘whom it may concern’, are usually not welcome and are often ignored.

Once you establish a relationship with a business, try and maintain contact for potential support in future events. Inform them about progress that has been made due to the support they have given previously.

Does your local council offer grants or venues at cheap rates for ‘Charity Events’? Are there any local grant giving Trusts that you can apply to? Can you get a local dignitary along to open or support the event?

Remember, these things can take time to organise. Venues need to be booked well in advance where possible. Local Trust, will probably only meet every quarter to make decisions about grant awards. Local dignitaries usually have busy diaries, so again try and book them well in advance.
Family and friends are often the first people we turn to for support in some way. This is fine to a point, but be careful not to ask for too much, too often. Some will always want to chip in and help, which is fine. Others may not, be wary of this!

5). Marketing

If your event is going to be successful, then you need to ensure that you attract people to come along. Therefore, the ‘marketing’ is key and you need to use every medium possible to get your message out. Details you send out need to include;

- Who?
- What?
- Where?
- When?
- Why?
- How?

Make your message clear, succinct and positive. Highlight aims, objectives and activities taking place. Ensure you have clear contact details and tell the world about what you are doing.

Advertise wherever possible, the list is long, Facebook, Twitter, Email, Posters, Leaflets, Local Radio and the Local Newspaper. Advertise, through schools, community centres, GP’s, shop windows and public notice boards.

Again, depending on the size of your event, will focus your attention on what is realistic and manageable. If you only have small venue, you don’t want hundreds of people showing up at the same time. If your event is aimed at a particular group, publicise your event accordingly.

(The next two areas of ‘event planning’ can be quite involved and stressful if not approached correctly. However, there is an easy way round them. In terms of both ‘Safety Considerations’ and ‘Legal Matters’, one much easier idea is to let someone else worry about it. You can do this by ‘piggy backing’ another event such as a School Fete or Car Boot sale for example. You may have to pay for a stall, or often with school fete’s pay a percentage of your takings towards the school Parent/Teacher Association (PTA) but at least the worry is theirs. Just make sure you are operating within their guidelines to avoid any misunderstandings).

6). Safety Considerations
Whatever you are doing, these are a MUST for any event! They are also closely linked to the next subject of Legal Requirements.

Once again, this is an area that you have to keep proportionate to the size of your event. The best way to be sure is to work through your local council / authority, who will be able to tell you what is required depending on the type of event you are running. One useful website is:

http://www.hse.gov.uk/event-safety

There are some basic things you can think about doing though.

✔ Food preparation areas must be kept clean and ‘perishables’ refrigerated where necessary.
✔ For smaller events held at someone’s home, then basic hygiene should be considered as part of the welfare of your guests. Also, remember your neighbours and keeping them happy. Warn them of the potential of maybe a few more cars around than normal or more noise that may noticeable. It may sound simple, but if not considered, you might find yourself being reported to Environmental Health if you have not kept people informed of your plans.
✔ In terms of the ‘Health & Safety’ of your volunteers, other more basic things are probably going to be just as important. Make sure you allow for volunteers to get a break and something to eat and drink.
✔ Ensure money is kept locked up and out of reach.
✔ First Aid – if you are running an event that is open to the general public then you must have First Aid cover available. To be more thorough and have a clear and visual First Aid presence at the event, then organisations like St John’s Ambulance are available to book; https://www.sja.org.uk/. Costs will vary depending on the size of your event and the timings involved, but if the event is outside you must provide a dry, clean, undercover area for them to operate from.
✔ If you are bringing in outside equipment, ensure that it is in good working order and has been maintained properly. You will need to see that paperwork covering these areas is available from the supplier, if not, don’t touch it! Again your local council will be able to advise you about trusted suppliers.
✔ If hiring a venue, check what the limitations are on numbers that are allowed in the building at any one time. The venue should have a list of what you can and cannot do and what their requirements are in terms of Health & Safety.
✔ Always ensure that if you are using a building, fire regulations are up-to-date, fire alarms are working and fire exits are kept clear and are well sign posted.
✔ You may need to consider things like, ‘Wet Weather’ contingency plans, which could mean as a worse-case scenario, cancelling your event.
7). Legal ‘Matters’

‘Legal Requirements’ are also another must for any event and are going to be based on the size and type of event you are running. Your Local Council / Authority will have guidelines about what you do and don’t need a license for. Check their website and search under Business & Licenses. Alternatively, give them a ring and speak to someone directly who can inform you of your best way forward.

There are some basic principles that apply, which on the whole will probably cover the sort of event you will be running. For example;

- If you intend to run a ‘Raffle’, as long as the tickets are all sold on the same day, at the same price and at the same venue and the draw is made before the end of the event, then you do not require a license.
- However, if you intend to run a ‘Raffle’, where tickets are sold at multiple sights and before the event itself, then you will require a ‘Small Society’ License. This should cost around £40 and is often then renewable each year for half the original cost.
- If you are running an ‘Awareness Event’ and collecting money or selling items on behalf of the charity on a privately owned site, such as a Supermarket, then no license is required at all. However, you will require written permission from the site owner.
- Street Collections may vary in terms of a need for a License. However, you must inform your Local Council of your intentions and agree a date. All collectors must have Identification Badges with the Charity Number included. Note, no-one under the age of 16 years old is permitted to collect money by law.

If you are planning a ‘PrizeDraw’ this will require a lot more detail and preferably a sponsor who can act as Guarantor of the prizes available. Tickets will need to be printed, numbered and clearly labelled. They will need to show who the promoter is i.e FND Hope, show the charity number. Most importantly be registered under the Gambling Act 2005. (This sort of event is more likely to be run directly by FND Hope itself).

Larger events take you into a whole new ball game in ensuring you are covered by ‘Public Liability Insurance’. For this get advice from your Local Council and check out the Health & Safety Executive website [http://www.hse.gov.uk/](http://www.hse.gov.uk/)
8). The ‘Clean-Up’

At the end of a busy event one of the last things you want to do is, clean-up. However, it doesn’t matter whether the event is at someone’s house or a hired hall, it has to be done, so it’s all hands to the pump in getting it done as quickly and thoroughly as possible.

If you have hired somewhere, you may be contractually obliged to ensure that the room is left as you found it. Ensure all rubbish is binned or taken to the local tip if you have to dispense of it elsewhere.

Remember, you are acting on behalf of FND Hope and as such will be leaving behind an impression of the organisation – let it be a good one!

9). Saying ‘Thank You’

Two little words which mean so much! As ‘Event Co-ordinator’ it is advisable to gather all your volunteers together at the start of the day. This will give you the opportunity to update them as to any changes or to give them any last minute words of encouragement. It will also allow them to ask any questions on things they want clarifying. It will also give you the chance to thank them before the event starts and to let them know how much you appreciate their efforts.

It is also important during the event that you thank any sponsors, people who have donated goods and dignitaries that have attended as well as the local community for their support. Remember, follow these up with letters of thanks and maybe a few pictures of the event. This will help build and hopefully maintain that relationship in the future and in turn brings kudos, respect and credibility to FND Hope.

10). Making Your Donation

Once the event is over it is vital that you gather in all monies collected as soon as possible and add it all up. Do not do this by yourself. Have someone check and double check your figures. Get the money into a bank account and once it has cleared, go to the FND Hope website and make your donation. Inform someone within the FND Hope team that the money has been paid in and they will be able to double check this for you to give you peace of mind.

You can now relax and look forward to your next event!

GOOD LUCK!
We Thank You for Your Support