



# **The Pituitary Foundation Support Group Volunteer Handbook**

A role specific handbook for volunteers running  
support groups

Last updated June 2023

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## **1.1 Volunteers Running Support Groups**

Our Support Groups have been a major support for people living with or affected by pituitary patients, with some groups running for longer than 20 years. The Pituitary Foundation has over 20 successful support groups and we are pleased that you are willing to expand the network and reach more people.

The groups differ in size, formality and main focus and we are really proud of this network inside the pituitary community as no other country in the world has a programme of similar size.

Groups meet to listen to speakers, learn more about specific conditions and treatments or simply socialise with people with a similar experience. Some groups also like to get involved with spreading awareness and raising funds.

Please read through this and the general handbook carefully and make sure you understand all policies. Whilst all content is important to give you the necessary information to volunteer, we need to make sure you've read all relevant policies before you start your role.

### **1.1.1 What's involved in running a support group?**

Running a support group is a significant responsibility that requires time and dedication but it also incredibly rewarding.

When running a support group, we expect that you run at least 4 meetings per year, either online or in person. You can decide for yourself if you want to offer any additional services like a newsletter or Facebook group.

Groups should be welcoming, and open to everyone, and you should pro-actively invite people to meetings who may not have attended before.

Each Support Group has its own webpage on the Foundation site. Enquiries come into the website and are directed to your nominated email address. People can enquire about your meetings via our website.

Your role at the meetings is really important – everyone should feel welcome and able to speak. You must ensure that the meeting is positive, and while difficult experiences are discussed people come away feeling supported and uplifted. The Foundation's services should be signposted and updates about our work given.

It is very important that the meetings are supportive and non-directive. In your role you must not advise, recommend or try to solve people's dilemmas. You should also ensure this does not happen in meetings. Support Group leads should not offer a helpline or support service, and should direct people to the Foundation's support line where staff and volunteers are specifically trained.

When you sign up as a volunteer to run a new support group or take over an existing one, we ask you to commit to at least 2 years after which your volunteer contract with us will have to be renewed. This is the only way we can ensure that you are up to date with current training.

We can support you with material, contacts and tips for any of these and are always happy to help. We can also give you the contact of former or current volunteers running support groups who can share their experience with you.

### **Description of overall role:**

Overseeing the organisation of meetings of local pituitary patients, carers and friends; liaising with The Foundation staff; and communicating with the local pituitary community about group meetings and events. Lots of groups end up with a couple of committee members who can help Support Group leads by taking on tasks, but the overall responsibility still lies with the you. In starting a new group, as the co-ordinator of the group, you can create a meeting and activities schedule based on the time you can commit to the role.

### **1.1.2 How Support Groups work**

We are changing the way support groups are run. Groups established from 2023 onwards will be led by a volunteer who has overall responsibility for delivering the meetings, safely and in line with relevant policies and laws.

We are still working on the best way to organise funds for current new support groups and will let you know as soon as possible once we can present the new procedure to you. Our aim is to make it as easy for you whilst staying withing the regulations of charity funds.

Groups established before 2023 often have a different structure, with their own bank accounts and a chair and treasurer. If this is still the case for you, biannual returns must be submitted by the group to the Foundation to ensure our financial compliance.

The lead volunteer may wish to find someone to work with them on running the group, perhaps taking on responsibilities for a newsletter, organising specific activities or finding meeting venues.

### **1.1.3 Running Group Meetings**

If you're new to this position, please contact Kim Wegner, Volunteer Coordinator before the first meeting.

For every meeting, be it the first or the 100<sup>th</sup>, it is helpful to go through some points to ensure everything is prepared and people know where to go and feel welcomed.

#### **Planning**

- o Arrange venues and/or speakers for meetings and events. Venues should be accessible (i.e. with lift or ramped access) and easy to find. Nearby parking is helpful.
- o You will need to do a simple risk assessment of the venue. A template is included at the end.
- o Send out invites to members.
- o Tell the Volunteer Coordinator about the meeting dates so we can update the website.

#### **At the Meeting**

- o Make sure the meeting room is set up/ prepare for an online meeting.
- o Ensure people have directions to the meeting room with posters showing the way/ a link to the online meeting is available and working.
- o Provide light refreshments if you are able, or let people know that they can purchase their own.
- o Greet members warmly and introduce people to each other.
- o Create a welcoming atmosphere by letting everyone speak and be themselves.

- o If someone acts in a harmful way, take them outside to speak to them and make it clear that harmful behaviour is not tolerated at support group meetings.

### **Between Meetings**

- o Take calls or answer emails from current and new members.
- o Provide a newsletter (if you choose to do so).
- o Maintain a mailing/communications list of members according to our data policies
- o Make certain that group communications and publications adhere to The Foundation's Brand Guidelines
- o Organise fundraising activities when appropriate
- o Ensure all records are up-to-date

#### **1.1.4 How to reach new people**

Most people find out about support groups from our website. If you want to reach out to more people from your area, here are some ideas:

- o If there is one, build links with your local endocrine centre to encourage them to inform newly-diagnosed patients about your group. It is useful to ensure that posters are present in pituitary clinics (these can be requested from us).
- o You can find Facebook groups for people with pituitary conditions and post about your support group there.
- o Contact nearby support groups to ask if they can pass on your information. Members of the support groups might know other people living with pituitary conditions in your area.
- o We also have the ability to contact members of The Foundation living in your area and inform them of the support group. Please contact Kim Wegner, Volunteer Coordinator if you wish this to happen.

#### **1.1.5 Holding Meetings Online**

Online Meetings are a great way to connect with people living with pituitary conditions without restricting it to one specific location which might make it easier for some to attend.

##### **Zoom Account**

Zoom is an easy online service/ app to meet up with many people in an online space and works smoothly most of the time from our experience. You are welcome to use our Zoom Business account to facilitate these meetings. This will enable you to host meetings for an unlimited time instead of having to end the meeting after 40 minutes (as it's the case for private accounts.)

If you'd like to use our account, please contact the Volunteer Coordinator.

##### **Online Meeting Advice and Guidelines**

- Similar to an in-person meeting, find a topic to talk about or invite a guest speaker to the meeting.
- Before meeting online, make sure that every member has received an invite with the right zoom link, date and time. Don't share the meeting ID and password publicly to avoid non-related people disturbing the meeting. Instead, share a contact email on the website where members of the public can request the meeting link.

- Make yourself familiar with the setup before the meeting starts. That means that you enter the online meeting room, try out your speaker and microphone. If you want to share any slides or your screen, also ensure that it is working before the start time of the meeting.
- It is recommended to make someone else you trust a co-host of the meeting in case your internet connection breaks down. If this happens, the co-host can take over.
- Once the meeting started, it often makes sense to wait an additional 5 minutes to give people time to join. Ideally, say a quick hello and let those already joined know.
- After approximately five minutes, introduce yourself and the support group like you would do for an in-person meeting. Let attendants know what to expect from the meeting, approximately how long it will take, and if there will be time for questions and/ or informal chats. Inform everyone that this is a safe space and that everything said will stay in the group. Recordings are only allowed if every participant agrees to it.
- Moderate the meeting by letting everyone speak who wants to say anything (if time allows). Do not force anybody to share their camera/audio or personal story if they don't want to.
- If any participant is behaving in a harmful way to others by either constantly interrupting people or sharing offensive comments, throw them out of the meeting room.
- When the meeting comes to an end, say a few words of goodbye to everyone and let attendants know how to get in touch after the meeting if they feel the need to.

## **1.2 Support for you**

We will support you in your role as Support Group Leader where we can and like to stay in touch on a regular basis to see how it is going. If you require information that is not part of this handbook, please ask the Volunteer Coordinator or designated member of staff.

We can also give you the contact details of an established Support Group Leader who has experience running a successful support group.

In addition, we will provide you with e-mail updates from The Foundation and seasonal e-bulletins to keep you up-to-date with our work. You can also ask for copies of The Foundation's leaflets, posters or 'business cards' to hand out to clinics and at group's meetings.

## **1.3 Necessary information and guidelines**

### **1.3.1 Product Endorsement**

The Pituitary Foundation does not recommend, endorse or promote any products, treatments, consultants or companies. Nor do we offer a negative judgement on a product or person. If it is appropriate to suggest, for example, a travel insurance company it is best to offer details of more than one company.

### **1.3.2 Professional Indemnity Insurance**

To adhere to our Professional Identity Insurance, it is vital that staff and volunteers do not offer advice, and that the support offered should be taken in conjunction with medical advice from the callers GO or endocrinologist. If the Support Group leader gives callers information, advice or signposts on which the person may rely on to make significant decisions – and those decisions involve expense or distress, for which they might want to

recover damages or costs against The Foundation - The Pituitary Foundation does carry professional indemnity insurance and keeps records about the policy within the Office.

To avoid such a situation, it is important to remember that the confidentiality of the patient should be kept intact and that you make no recommendation or endorsement. However, if a caller brings to your attention that there is an issue with something you may have noted, please bring this to the urgent attention of the Head of Support Services or the Volunteer Coordinator.

### **1.3.3 Finances and Bank Returns – June 2023**

In the past, LSGs have had their own bank accounts and could use that money to book rooms, buy refreshments etc.

The process is currently under review and this handbook will be updated with new information as soon as possible.

For all queries and help regarding setting up accounts, establishing trustees as signatories, and submitting returns please contact our Office & Finance Manager, Gabrielle Welland, on 0117 370 1322 or email: [gabrielle@pituitary.org.uk](mailto:gabrielle@pituitary.org.uk).

### **Guidelines for Appropriate Use of Funds – June 2023**

We are also updating the guidelines for using funds. The section below can be used as a general direction when in doubt but should not be used as a direct quote. New information will be added to this handbook as soon as possible.

The following are some general guidelines for using funds raised for or donated to your group. This is not a definitive listing and we invite you to contact the Volunteer Coordinator should you have any questions or concerns. As a registered charity, we must be very mindful about the utilisation of all monies raised on behalf of or by volunteers of The Pituitary Foundation, including support groups.

We always hugely appreciate donations from the support groups directly to our charity as it allows us to continue providing our core services. If you would like to donate towards a specific project or booklet reprint please get in touch and we can let you know what projects we specifically need funding towards.

#### **Appropriate:**

- Venue Hire, Catering for group meetings for patients and families (teas, coffees, biscuits/snacks approx. £1-5 per head) Venue hire can vary depending on the area but hire is usually £20 - £80. (The London group are of course subject to much higher room charges).
- The costs of creating, printing and distributing newsletters.
- Transportation costs for group members who have real difficulty getting to meetings or paying for their own transport. (Reasonable public transport receipts, car travel can be paid at 45p per mile).
- Transport, accommodation and delegate fees for your support group leader, or members who have financial difficulties, to attend Pituitary Foundation Conferences.
- Speaker fees and related expenses for meetings if claimed. (It is good to enquire about how much an outside speaker may charge if they do not live locally to ensure your group is happy offering to cover expenses before inviting the speaker).

Reasonable public transport receipts should be covered, car travel should be paid at 45p per mile).

- Basic expenses for staging a fundraising or awareness event. (Up to £50)
- Offering a condolence or get-well gift to a group member or a part of your local group (for example, flowers, cards, chocolates, etc.).

**Inappropriate:**

- Costly dinners or events for the whole group but especially select persons of the group (for example, a meal provided for committee members only). Especially be careful about 'luxuries' like several course meals, providing wine or other alcoholic beverages, etc.
- Donations to other organisations, be they clinics, groups, individuals or other charities. It is important to note that it is best practice that monies raised for an organisation stay within that organisation and are not donated to another unless this is specifically noted while raising the funds. If you wish to raise funds to give to other organisations or an individual, you must obtain prior approval from the Trustees. If approval is granted, please talk to a member of The Foundation staff for guidelines on how to raise funds that will be donated outside the organisation. For example, your group decides to stage an event that would offer a new booklet stand to your local endocrine clinic. You would need first to obtain permission from the Trustees to raise these funds. If granted, you would then need to be clear to your donors that you are utilising the funds raised in order to give something to the NHS. This is also noted in the Constitution guidelines.
- Training, travel or expenses that do not benefit the Group

Again, these are basic guidelines and we ask only that you use your best judgement and call Foundation staff if you have questions.



## 1.4 Practical help and tips for running a support group

### 1.4.1 Risk assessment template

Please fill out the risk assessment template below for every new meeting you're planning.

This risk assessment is a great way for you to think about possible risks and keep everyone safe. We always do risk assessments for every event we host, and it helps us being prepared and making sure we do everything to prevent accidents.

If any accidents do occur, this risk assessment shows that you have taken steps to make the meeting a safe space and prevent risks as much as possible.

You don't need to share the risk assessment with us but please keep it on your records. It might also be useful for writing the next risk assessment for the next meeting. Usually, filling out a risk assessment doesn't take longer than 5 minutes.

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Name of venue

Date of meeting

<b>Risk</b>	<b>What the outcome could be</b>	<b>What you have done to mitigate the risk</b>
People slip or trip	People with bruising, fractures or sprains	Ensure steps are clearly marked Ensure trip hazards are cleared away (bags, clutter, cables) Ensure all wet spills are able to be swiftly mopped up
There is a fire	Significant harm or death	Understand the fire procedures and explain these at the start of the meeting
People find sharing or hearing experiences upsetting	Mental health is challenged	Clearly signpost the Foundation helpline Remain aware of triggering conversations and ensure the meeting is positive
Other risk detail here	Detail here	Detail here

### 1.4.2 Venues to meet in

Most support groups meet in hospitals as it is usually an accessible and free venue for meetings. No matter where your meeting takes place, make sure your venue is easily reached by public transport and has adequate car parking. Direction posters should be

placed, so that the meeting room can be found easily. The meeting room should also be close to toilets and/or disabled toilets.

Some people may feel uncomfortable in a hospital environment. It is a good idea to change the meeting venue at least once a year to enable that they feel comfortable for a meeting. Alternative locations are: local quiet pub, village hall, cricket/golf club room, etc.

### **1.4.3 Times of meetings**

When deciding on a convenient time for group meetings, it is important to consider other members' everyday lives and their availability. To ensure that all or most interested people can attend the meeting, you can change the day and time of meeting for every other meeting (e.g., alternate between weekends and weekdays).

### **1.4.4 Seating arrangements**

Seating arrangements play a big role in making members comfortable in support group meetings. For example, arrange chairs into a horseshow or circle so members can interact face to face instead of sitting in rows. It also helps to distribute small tables that members can put their drinks on.

### **1.4.5 Refreshments**

Most groups do offer tea, coffee and water with a biscuit. You can also encourage members to bake cakes or bring their own refreshments. It's advised to also have alternative snack options to biscuits and cakes as many people with pituitary condition might struggle with their weight. Alternatives include nectarines, bananas or plain oat biscuits.

### **1.4.6 Content of meeting**

Open meetings with a welcome and introduction to any new members. If there aren't new faces there, you could ask those present have they all had a good month, or a bad time lately? Possibly you'll receive nods at best but offer the group's support if they feel they'd like to discuss this, either now, through the meeting or quietly with you at the end.

Some support groups ask one of their members beforehand to share their story to open to floor to everyone afterwards.

If you need inspirations for topics to talk about, you can use the latest Pituitary Life magazine for inspiration.

### **1.4.7 Support group members**

Local group 'members' of your group may believe they are automatic members of the Pituitary Foundation, but they have to register with the Foundation to become a member of the charity. Membership does give entitlements to vote at the General Meeting and to receive three copies a year of Pituitary Life.

Always make sure you keep a note of new member's details and add them to your email loop for group members.

Do you circulate a newsletter, or update email, to let group members know of the next meeting? It is up to the lead to keep contact lists of group members. We suggest using email as it will keep your costs to a minimum.

### **1.4.8 Committee and Succession Planning**

We suggest having or looking for a committee so you can share responsibilities like chairing meetings, sending out newsletter, sorting out finances, finding meeting

locations, organising activities etc. Having a committee or other people with responsibilities also means that they can step in if you're not feeling well on the day of the meeting. If you or someone else wants to take some time off or retire, the committee can take over your responsibilities until a successor is found.

#### **1.4.9 Fundraising**

Fundraising is a major part of our organisation without which we could not do the work we do. If you want to support us with fundraising, please reach out to Kim, Volunteer Coordinator or Jay, Head of Fundraising with any ideas or questions. Ideas for fundraising include raffles, pub quizzes, cake sales, coffee mornings, afternoon teas,...

#### **1.4.10 Adding dates to the website and reporting**

To add dates of future meetings to the website, please email Kim, Volunteer Coordinator, all details. Please use the shared template to do so. Kim will then create the event on the website.

After the event has taken place, we ask you to submit information about how many people attended and what main topics you talked about to get an overview of support groups, support you if needed and use the data for fundraising purposes. A template to do so is shared with you. We will also share the (anonymised) data like numbers of attendees with other support group volunteers during bi-yearly catch ups.