



The Pituitary Foundation Volunteer Handbook

A general handbook for **all** volunteers

Last edited June 2023

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Welcome and thank you for wanting to volunteer with us!

At The Pituitary Foundation, we are grateful for all the knowledge, skills and enthusiasm our volunteers bring to their role and we constantly learn from your experiences. You play an important role in our charity and we simply could not do the work we do without you.

This is an opportunity to learn from and support each other and we look forward to welcoming you to our team!

This handbook is for you to get a clear overview of The Pituitary Foundation and your role as volunteer within it. Please read it carefully and let us know if you have any further points or questions.

You'll need to sign and agree to certain policies - there is a checklist at the end of this booklet which you'll need to return to us.

Thank you for joining our team!

2 About The Pituitary Foundation

2.1 Who We Are

We're The Pituitary Foundation. We're a dedicated team offering practical, emotional and peer support to everyone living with or impacted by a pituitary condition, so they feel empowered and live with a greater sense of wellbeing.

For over 25 years, we've been amplifying voices and striving towards positive developments for the pituitary community. We work alongside healthcare professionals, clinical research teams and specialist organisations to raise the profile of pituitary conditions, finding better solutions for everyone affected by these lifechanging illnesses now and in the future.

We believe that empowerment is crucial to living well with pituitary conditions. So, we give guidance directly via our Support and Information Helpline and specialist Endocrine Nurse Helpline, as well as offering expert, up-to-date, online resources. This helps people navigate the UK healthcare system and gain the best clinical outcome possible.

We won't stop until everyone with a pituitary disorder is getting fair, timely, effective treatment and everyone in the pituitary community has their voice heard.

2.2 What We Do

Vision

Our vision is for all people with pituitary conditions to live well, now and in the future.

Our Mission

We work with everyone with a pituitary condition, their support networks and healthcare professionals to raise pituitary awareness and reduce time to diagnosis.

We empower patients to navigate the UK healthcare system and obtain the best clinical outcomes possible, and provide support to enable everyone with a pituitary condition to live as well as possible.

Our values

We are welcoming

We are caring

We are empowering

We are trustworthy

We are collaborative

We are passionate

Our services

The services we provide include our helplines, peer support, local support groups, and relevant information which can be accessed on the website or ordered to be sent. We make sure that all these services are available to patients, family members, friends, health care professionals and the general population. Our goal is to assist everyone along their journey with information, support and understanding.

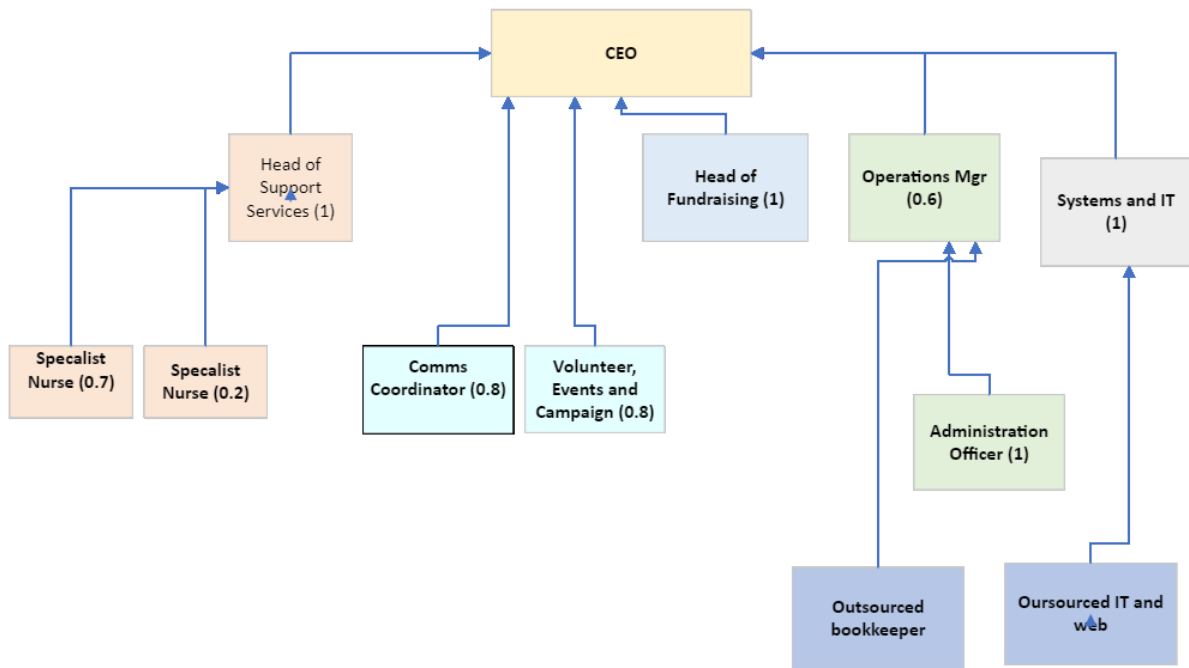
In addition to this, we put on fundraising events to bring people with pituitary conditions together and raise important funds to further support the community. We also frequently meet with medical professionals.

As a volunteer, you can get involved in all these areas and help us improve the lives of people impacted by a pituitary condition.

2.3 Our People

The Charity is governed by a board of Trustees. We are delighted to have a Medical Committee who support our clinical work and a newly formed Patient Committee who inform our service development.

We are a small team of staff. The structure is as follows:



Whenever you have a question or want to know more about one area, you can use the following list to know who to contact.

CEO	<p>Ren Renwick - CEO ren@pituitary.org.uk 0117 370 1318</p> <ul style="list-style-type: none"> - Manages the running of the charity and all staff - Responsible for policy changes, campaigns, and strategies - Oversees external affairs and governance 	
	<p>Pat McBride - Head of Support Services pat@pituitary.org.uk 0117 370 1315</p> <ul style="list-style-type: none"> - Leads Support Services team - Delivers helpline services - Produces <i>Pituitary Life</i> - Leads Medical Committee 	
	<p>Pauline Whittingham - Endocrine Specialist Nurse pauline@pituitary.org.uk 0117 370 1317</p> <ul style="list-style-type: none"> - Medical enquiries - Scheduled helpline hours 	

	<p>Darshna Patel - Endocrine Specialist Nurse darshna@pituitary.org.uk 0117 370 1317</p> <ul style="list-style-type: none"> - Medical queries - Scheduled helpline hours 	
	<p>Jay Sheppard - Head of Fundraising jay@pituitary.org.uk 0117 370 1314</p> <ul style="list-style-type: none"> - Manages fundraising events - Corporate relations and legacies - Coordinates trusts funding, lottery, and raffle 	
	<p>Lottie Storey - Communications Officer lottie@pituitary.org.uk 0117 370 1312</p> <ul style="list-style-type: none"> - Oversees communications schedule - Develops engagement with our key audience - Posts on social media - Updates the website 	
	<p>Kim Wegner, Volunteer, Events and Campaigns Coordinator kim@pituitary.org.uk 0117 370 1310</p> <ul style="list-style-type: none"> - Volunteer management - Supports development and delivery of online events - Supports delivery of campaigns 	
	<p>James Charlick - Administrator james@pituitary.org.uk 0117 370 1316</p> <ul style="list-style-type: none"> - Coordinates administration in all departments - Schedules helpline shifts - Organises memberships, merchandise, and booklet orders 	
	<p>Martin Cookson - IT & Systems Manager martin@pituitary.org.uk 0117 370 1311</p> <ul style="list-style-type: none"> - Manages databases and IT, including data protection - Support membership, fundraising and finance functions 	

Gabrielle Welland - Office & Finance Manager
gabrielle@pituitary.org.uk
0117 370 1322

- Leads on office management, including HR, suppliers and finance



3 Being a Volunteer

3.1 What we expect from you – and what you can expect from us

Volunteers are often the first point of contact for members of the public who haven't yet heard of us and play a big role in representing our values as well as the charity as a whole.

Throughout someone's journey with a pituitary condition, volunteers are the ones inviting them for a coffee and chat in local support groups, provide valuable advice on the phone or make sure that important information like booklets reaches them in time when they need it.

We simply could not do the work we do without you, so thank you for wanting to volunteer with us.

Before you can start volunteering, there are a few things to go through.

What we expect from our volunteers

As a volunteer, we ask you to follow our guidelines and represent the charity in the best possible way to ensure everyone engaging with us can always expect the same high standard. We expect you to work in partnership with staff and other volunteers to support our community, and live our values (welcoming, caring, empowering, trustworthy, collaborative, passionate).

As one of our volunteers, you will have the privilege of speaking with patients who may share personal, sometimes difficult experiences. We expect all employees and volunteers to show respect for each other and The Foundation.

All volunteers must adhere to our policies. This may be to meet our legal requirements, or to ensure the best possible service for our community. You will be asked to agree and adhere to

- our Diversity Equality Inclusion Policy
- our Safeguarding Policy
- our Data Protection Policy and Online Safety Guidelines
- our Code of Conduct
- our Confidentiality and Disclosure Policy

Furthermore, we ask you to

- undertake training each year (at the Foundations cost),
- attend the AGM (virtually or face to face)
- communicate confidently and positively about our services,
- let your contact member of staff know if you are having any problems, if you have any complaints, concerns or feedback, and

- act responsibly and within the law

We will ask you to sign an agreement with us, and in some instances will require you to undertake DBS check.

Every volunteer role will have a minimum agreed time frame. Volunteers will be required to renew their agreement with the Foundation every two years if it is mutually agreeable.

What we offer our volunteers

In return for your effort as volunteer, we will:

- ensure you have a named staff member to support your work
- introduce you to how our organisation works and your role within it
- give you a free membership subscription throughout tenure as active volunteer
- Give you free access to all online events
- send volunteer e-bulletins and frequent updates about the charity
- offer training and support for your role
- reimburse agreed expenses
- strive to resolve any concerns fairly and reasonably, if needed we will apply our complaints procedure
- respect and listen to your feedback and inform you of any changes
- involve you in conversations about our services
- encourage a positive and supportive volunteering experience

We hope you will feel great satisfaction in your role, knowing that you are helping others. We are looking forward to working with you!

3.2 Reimbursement

If you need to travel by public transport to the office or meeting venues for your volunteering role, The Foundation will cover the costs up to a reasonable amount so long as it is agreed in advance. We ask that you keep track of your receipts and any tickets and attach them to your completed reimbursement form which can be found at the end of this handbook.

3.3 Training and support

Before you can start volunteering, there is a mandatory training that needs to be completed. Part of the training happens with a member of staff to go through the role in detail. The other part involves reading this and the handbook specific to your role.

The following outlines our training and support for volunteers:

- **Onboarding:** We welcome you to The Pituitary Foundation with this volunteer handbook so that you can learn more about the organisation, its structure, responsibilities, and the boundaries that we expect you to work within.
- **Core training:** There are essential training requirements that will ensure our practices comply with related rules and regulations. These training modules may require refreshers as rules and regulations change or improve. The core training is focused on: Introduction to safeguarding, General Data Protection Regulations (GDPR), and Equality, Diversity & Inclusion (EDI) awareness

- **Role Specific training:** In addition to this, we provide a role specific handbook to help you understand your role in more detail so you can confidently support the pituitary community.
- **Support:** The Volunteer Coordinator will provide you with additional resources and advice by request. If you need support to carry out your volunteer role, please contact the Volunteer Coordinator or your contact member of staff.
- **Networking:** Where we can, we will facilitate virtual networking opportunities for you where possible, where you can meet other volunteers from different parts of the country and share experiences and stories.

All volunteers receive the volunteer e-newsletter on a frequent basis which includes all updates on the charity and useful information for your volunteer role.

3.4 Raising concerns

We hope that there won't be any concerns, but if there is something that is worrying you, either about your role, or our work more widely, please raise it with the Volunteer Coordinator as soon as you can. We will try to resolve things as quickly as possible. We will always work to ensure you feel safe and your voice is heard.

To contact the Volunteer Coordinator, email Kim at kim@pituitary.org.uk

You can also get in touch with our CEO directly at ren@pituitary.org.uk

A formal complaint process is added as an appendix.

3.5 Ending your Volunteer Role

We are hugely grateful for all the time that you can offer us and we recognise that you will leave this position at some point.

We ask all volunteers to sign up to a minimum period. We understand that there may be reasons this is not possible; however, this minimum period is a reflection of the training investment which we will provide. We will ask that all volunteers renew their agreement with us, if mutually agreeable, every two years.

We encourage you to give us as much notice as possible and ask you to go through a short exit interview with you to help us improve our services. We are happy to write you a reference letter if you wish.

3.6 Our Policies

3.6.1 Diversity Equality and Inclusion (DEI) Policy

We are committed to equality, diversity and inclusion and acknowledge our responsibility to eliminate discrimination in all aspects of our work. We are committed to providing services that are accessible to everyone, and to create effective ways of working and partnership with our community and stakeholders.

This means that we are committed to treating all employees, volunteers, and others involved with our work, equally and to celebrate and use their differences to the advantages of the organisation. No one will be discriminated because of their age, disability, gender, race, ethnicity, partnership status, religion or belief, sex, sexual orientation, maternity, pregnancy or family leave, trade union membership, or part-time or fixed status.

These principles of valuing diversity and non-discrimination also apply to the manner in which our staff and volunteers treat supporters, service users, and other stakeholders. They apply in the workplace, but also outside the workplace in work-related contexts such as events, work-related socials or zoom meetings, whenever a member of staff or volunteer is representing the charity.

The Foundation will investigate any potential infringements of this policy and take appropriate action.

As a volunteer, you will be required to uphold our DEI policy.

Examples are:

- Someone calling up the helpline will not be judged based on their accent or any personal information they decide to disclose like their belief or religion
- Support groups are welcoming to all members of the public, no matter their background, appearance or how one presents oneself
- Volunteers are aware of holidays of all cultures when planning events or meet-ups

3.6.2 How we use your Data (Privacy Notice)

The Pituitary Foundation promises to respect any personal data you share with us and keep it safe. We aim to be clear when we collect your data and not do anything you wouldn't reasonably expect.

We process and store details relating to potential, current and previous staff and volunteers, in line with our retention policies. We do not collect more information than we need to fulfil our stated purposes and will not retain it for longer than is necessary.

We ask you for your personal details including name and contact details. We will also ask you about your previous experience, education, referees and for answers to questions relevant to the role you have applied for.

You will also be asked to provide equal opportunities information. This is not mandatory information – if you don't provide it, it will not affect your application. Any information you do provide, will be used only to produce and monitor equal opportunities statistics.

There are certain circumstances where we may be required to disclose your personal information by law, or court order, or in appropriate circumstances, with law enforcement agencies when we believe it is necessary to protect our rights, property or safety and that of our staff, volunteers and supporters.

We place a great importance on the security of all personally identifiable information associated with our supporters, service users, volunteers and staff. We have security measures in place to attempt to protect against the loss, misuse and alteration of personal data under our control.

You have the right to access your personal data and supplementary information. If you want to access your information, send a description of the information you want to see and proof of your identity by post to The Pituitary Foundation, Brunswick Court, Brunswick Square, Bristol, BS2 8PE or ask in person. We do not accept these requests by email so we can ensure that we only provide personal data to the right person.

If your contact details change, please let us know so we can update your contact.

3.6.3 Your responsibility when using other people's data (GDPR)

Everyone who works for, or on behalf of, the Company has some responsibility for ensuring data is collected, stored and handled appropriately, in line with this policy and the Company's IT policy.

As volunteer, you will be in a role to process personal data. Personal data is information which relates to a living person who can be identified from that data on its own, or when taken together with other information you can get hold of. This includes medical information, an address, phone numbers, email addresses, their full name or a photograph.

For volunteers, this specifically applies to all personal data you have access to (like our databases and internal documents) or collect, for example for newsletter sign-ups or phone numbers of helpline callers.

You must handle personal data securely and according to Data Protection Principles which are as follows:

1. Data is fairly and lawfully processed (i.e. in all ways, data is stored and used within the legal parameters)
2. Data is processed for limited purposes (e.g. you only use a person's email address for the reasons you have told them you will use it, for example sending a newsletter)
3. Your use of data is adequate, relevant and not excessive (e.g. you do not send too many emails, and you allow people to opt out easily)
4. Data is accurate (there should be an easy way for people to update their details, and, at regular intervals data should be 'cleaned' with inaccurate or old data deleted)
5. Data should not be kept for longer than necessary (as above, if people are no longer interested in a service they should, after a certain timeframe, be removed from communications)
6. Data should be processed in line with your rights (There are 8 rights that all individuals have; to be informed, to have access to their data, to change or delete their data, to stop their data being used, to move their data and to object to the use of data. You can read more [here](#))
7. Data should be kept secure (paper records should be locked away; digital records such as email addresses should be stored on encrypted drives/ documents or bespoke secure systems such as Mailchimp)
8. Data should not be transferred to countries without adequate protection (in broad terms this means no data should be shared outside of UK and Europe. There are some allowances for companies (like Mailchimp) that have agreements in place to process data)

You should only use personal data if you need it for the work you do and only if you are authorised to do so. You should only use the data for the specified lawful purpose for which it was obtained and follow these principles:

- Do not share personal data informally; keep it secure and don't share it with unauthorised people.
- Regularly review and update personal data which you have to deal with. Update us if your own contact details change.
- If you are sending out group emails, use the blind copy (BCC) so email addresses are hidden when the email is sent. Other people should not see everyone else's email

addresses. Here is some guidance on how to use BCC in emails if you need any help with this: <https://www.wikihow.com/Use-BCC-in-an-Email>

- Do not make unnecessary copies or keep personal data. Dispose of any copies securely.
- Consider anonymising data or using separate keys/codes so that the data subject cannot be identified.
- Do not transfer personal data out of the European Economic Area except in compliance with the law and with authorisation of the person responsible for data in the Company.
- Lock drawers and filing cabinets. Do not leave papers with personal data lying about.
- Do not take personal data away from Company premises without authorisation (if you're an Office Volunteer)
- Ask for help from the person responsible for data in the Company if you are unsure about data protection or the IT Policy, or if you notice any areas we can improve upon.

Certain types of information, e.g., medical condition or ethnicity, is sensitive information and needs special protection. Sometimes, a person may tell you sensitive information informally in an email or when talking. Make sure you delete all data with their sensitive information as soon as possible (for example, after you've replied to an email where a person tells you that they have acromegaly.)

If you think that there has been a data breach, please inform the IT & Systems Manager immediately. Data breaches can include: someone has broken into your house and stolen confidential paperwork; someone has hacked your email; or you have accidentally shared personal data.

Data protection is an important suite of regulation, with significant penalties where breaches occur. It is vital that all volunteers adhere to data protection rules. If you would like to make your data more secure but don't know where to start, contact Kim Wegner, Volunteer Coordinator and she will be able to help you.

3.6.4 Keeping Safe (Safeguarding)

The Care Act defines safeguarding as follows: "People and organisations working together to prevent and stop both the risks and experience of abuse and neglect while at the same time making sure that the adult's wellbeing is promoted (...)"

We are obliged to safeguard all people, not just those considered 'vulnerable'. We are required, legally, to take reasonable steps to ensure people are safe and are at no risk of abuse or neglect.

As a representative of The Foundation, you must consider safeguarding as part of your role.

What this means for you

If you have any concerns that someone is at risk of harm, contact the safeguarding lead as soon as possible. You don't have to have proof that something is wrong; safeguarding is based on 'reasonable cause to suspect' abuse or neglect and if you feel uncomfortable with any situation where someone might be harmed or injured or anyone else approaches you with their discomfort, it is a safeguarding concern.

Examples of situations that may be a safeguarding concern. It always comes down to the context and your gut instinct:

- A caller to the helpline tells you that their doctor is not taking their symptoms seriously, bullies them and tells them that they're overreacting.
- A member at a local support group approaches you saying that they're worried about another new member. This new member was overheard making jokes about their partner hiding their emergency injection boxes.
- You are volunteering at an event where one of the attendees is in a wheelchair. This person needs to go to the toilet and another volunteer offers to go with them to help. You know that they haven't met previously, and you're worried that an uncomfortable or possibly dangerous situation will arise.

What to do

If any of these or other situations arise that identify as a safeguarding concern, first ask the person involved for consent to pass this on as a safeguarding concern. The person involved is the person possibly at risk and the person approaching you with their discomfort/ concern (if applicable). Afterwards, contact the safeguarding lead as soon as possible, ideally immediately or at least on the same day. The safeguarding lead will then go through the concern form with you and decide next steps.

You can contact the safeguarding lead even if you do not have consent. **If it is an urgent issue, always call 999.**

Please note that safeguarding concerns are very rare and have not happened in the past to our knowledge. We just want you to feel prepared in case something does happen.

You can [read the full safeguarding policy outlining child protection, risk of harm, confidentiality and whistle blowing on our website.](#)

Designated Safeguarding Officer

Our Designated Safeguarding Lead is Pat McBride, Head of Support Services and supported by Ren Renwick, CEO, as deputy. Our named trustee dedicated to safeguarding issues is Debbie Cooper

They will be available to all staff, volunteers and service users to speak to when they have any concerns, issues or complaints regarding the safety, well-being or conduct of service users, volunteers and staff.

3.6.5 Health and Safety

In all our work we have a responsibility to ensure that places we meet and work in are safe. If you are working in our office, you will need to watch our Health and Safety presentation and to familiarise yourself with first aid and fire procedures.

If you are coordinating meetings in the community, you will need to ensure that spaces are safe and accessible for everyone. There is more information in the relevant handbooks about this.

3.6.6 Keeping Safe online

As a volunteer, you will have access to online data on your own computer or when in the office.

When given a Pituitary Foundation email address, you should use this email only when acting as volunteer and refrain from the use of sending personal emails with this address. Before sending out emails, please also ensure that you check all emails for accuracy and if they are being sent to the correct recipient.

Passwords

When logging into our computers or your email services, please make sure you are using strong passwords. The same applies to passwords protecting sensitive or confidential information, e.g., documents containing names of Local Support Group members. A strong password is three random words, numbers and symbols, for example TreeCowNews%3.

Never use any personal information like someone's name, birthday, or your favourite sports team. Once you decided on a password, make sure to keep it safe. Don't share your password with anyone else and change it immediately if you think someone else knows it.

Suspicious emails

If you receive an inappropriate message, you must delete it immediately and report it. Whilst we have antivirus software, this does not eliminate risk. Be careful when opening unknown emails and report them to a member of staff if the email is suspicious. If you don't know the sender, do not click on any links given in the email.

3.6.7 Social Media Policy

Social media is essential to the success of communicating The Pituitary Foundation's work. It may be important for some staff and volunteers to participate in social media to engage with our audience, participate in relevant conversations and increase awareness of The Pituitary Foundation's work.

You may use your own social media to share messages and posts from the Foundation, or you may have a dedicated Pituitary related account.

We have strict guidelines about the use of social media, as detailed below.

Point of contact for social media

Lottie Storey, Communications Officer, is responsible for the day-to-day publishing, monitoring and management of our social media channels. You can speak to her if you have specific questions about any aspect of these channels.

If you see any content on our platform that is controversial or misrepresented, please highlight this to Lottie Storey, Communications Officer, who will respond as appropriate.

Which social media channels do we use?



Facebook <https://www.facebook.com/pituitaryfoundation>



Twitter https://twitter.com/Pituitary_org



Instagram <https://www.instagram.com/pituitaryfoundation/?hl=en>



LinkedIn <https://www.linkedin.com/company/the-pituitary-foundation/>



YouTube <https://www.youtube.com/channel/UCnzncZctddYi10e9bxZd18Q>

General Guidelines

1. Volunteers must only set up Facebook groups or pages, Twitter accounts or any other social media channels linked to the charity with our express consent. Otherwise, this could confuse messaging and brand awareness.
2. When a volunteer has the consent to set up social media channels, please make sure the channel clearly communicates that it is not the official The Pituitary Foundation account who is posting but a volunteer of the charity. This can be done by using a different logo/profile picture than the official Pituitary Foundation ones and by explaining your volunteer role/ the support group in the channel's description.
3. Volunteers should ensure they reflect The Pituitary Foundation's values (welcoming, caring, empowering, trustworthy, collaborative, passionate) in what they post about The Pituitary Foundation. Social media content should be an ambassador for our brand and purpose.
4. Volunteers must not post disparaging or defamatory statements about The Pituitary Foundation, its staff, volunteers, members, supporters or service users, past and present on either their personal or Pituitary Foundation accounts.
5. If any media contacts you about social media posts that relate to The Pituitary Foundation, they should talk to Jay Sheppard, Head of Fundraising, or the CEO, Ren Renwick.
6. The Pituitary Foundation works with several high-profile people, including our celebrity ambassadors. Please don't approach high profile people from your personal social media accounts to ask them to support the charity, as this could hinder any potential relationships that are being managed by The Pituitary Foundation. This includes asking for retweets about the charity. If you have any information about high profile people that have a connection to our cause, or if there is someone who you would like to support the charity, please speak to a staff member to share the details.
7. Never use The Pituitary Foundation's logos or trademarks unless approved to do so. Permission to use logos should be requested from Lottie Storey.

Clarify that your opinions are your own

1. Personal accounts from volunteers should be clearly labelled as private and state that their posts do not reflect the official views of The Pituitary Foundation. Personal opinions may be shared by commenting, or indirectly by 'liking', 'sharing' or 'retweeting'. Please do not copy our posts and post them as your own as this might be confusing for audiences.
2. The Pituitary Foundation is not a political organisation and does not hold a view on party politics or have any affiliation with or links to political parties. We have every right to express views on policy, including the policies of parties, but we can't tell

people how to vote. Please be aware of this and make sure any political views expressed are clearly your own and not on behalf of The Pituitary Foundation.

3. Volunteers should not post content or photos about supporters or service users without their express permission. If volunteers are sharing information about supporters, service users or third-party organisations, this content should be clearly labelled so our audiences know it has not come directly from The Pituitary Foundation.

Follow the law, follow the code of conduct

1. Volunteers are personally responsible for everything they post online. It should be remembered that all online posts will be available to read by everyone for many years in the future. When in doubt, do not post.
2. Do not share confidential, internal or unconfirmed information regarding the charity.
3. Never engage in a one-to-one conversation online with minors (under 18's). If using interviews, videos or photos that clearly identify a child or young person, volunteers must ensure they have the consent of a parent or guardian before using them on social media.
4. Volunteers should not encourage people to break the law to supply material for social media, such as using unauthorised video footage. All relevant rights for usage must be obtained before publishing material.
5. Volunteers cannot use offensive language towards someone else.
6. If you see something being shared related to The Foundation online that violates any laws or uses harmful language, please tell Lottie Storey immediately.
7. If you come across complaints made to The Pituitary Foundation on social media and think they have not been dealt with, report it to Lottie Storey.

Additional Guidelines for great content

1. Take care with the presentation of social media content. Make sure that there are no typos, misspellings or grammatical errors.
2. Check the quality and diversity of images used. Before using images, it is helpful to think about questions such as: do these images portray our values; are they inclusive and diverse, do they reflect the lived experience of our patient community?
3. Always check facts. Volunteers should not automatically assume that material is accurate and should take reasonable steps where necessary to seek verification, for example, by checking data/statistics and being wary of photo manipulation.

3.6.8 Using The Pituitary Foundation brand

Below you can find our brand guidelines. You can use these for communications when acting as volunteer for The Foundation or asked to speak in public. If applicable, please

use the logos dedicated to your role, e.g., support group logos before using the official logo. Please don't use our logo, colours or description for your personal profile or in private settings. When unsure about when to use our branding, please contact the Volunteer Coordinator or Communications Officer.

Templates for newsletter, banners etc can be requested from Lottie Storey, Communications Officer.

Short text description

We're The Pituitary Foundation. We're a dedicated team offering practical, emotional and peer support to everyone living with or impacted by a pituitary condition, to feel empowered and live with a greater sense of wellbeing.

Medium text description

We're The Pituitary Foundation. We're a dedicated team offering practical, emotional and peer support to everyone living with or impacted by a pituitary condition, to feel empowered and live with a greater sense of wellbeing.

For over 25 years, we've been amplifying voices and striving towards positive developments for the pituitary community. We work alongside healthcare professionals, clinical research teams and specialist organisations to raise the profile of pituitary conditions, finding better solutions for everyone affected by these life changing illnesses now and in the future.

Long text description

We're The Pituitary Foundation. We're a dedicated team offering practical, emotional and peer support to everyone living with or impacted by a pituitary condition, so they feel empowered and live with a greater sense of wellbeing.

For over 25 years, we've been amplifying voices and striving towards positive developments for the pituitary community. We work alongside healthcare professionals, clinical research teams and specialist organisations to raise the profile of pituitary conditions, finding better solutions for everyone affected by these lifechanging illnesses now and in the future.

We believe that empowerment is crucial to living well with pituitary conditions. So, we give guidance directly via our Support and Information Helpline and specialist Endocrine Nurse Helpline, as well as offering expert, up-to-date, online resources. This helps people navigate the UK healthcare system and gain the best clinical outcome possible.

We won't stop until everyone with a pituitary disorder is getting fair, timely, effective treatment and everyone in the pituitary community has their voice heard.

Font

We use Tommy Soft for headings, Karla for body copy and Caveat Brush for call-outs, quotes and other decorative elements.

You can request these fonts from Kim Wegner, Volunteer Coordinator as they have to be downloaded to your device. Alternatively, you can use Arial.

Charity Number

When using The Pituitary Foundation's logo, the publication must always carry the wording: Registered Charity Number 1058968.

Logo

Please only use this logo when speaking on behalf of us, e.g., at public presentations



Colour Palette

As volunteers, we encourage you to use the navy and teal colours in your communication as this is also reflected in support group logos.



Wording

As part of our rebranding, we spent a long time thinking about how we want to communicate with members of the pituitary community. These are a few guidelines we settled on to ensure all our communication represents our values (welcoming, caring, empowering, trustworthy, collaborative, passionate)

- When talking about our organisation, clinicians and everyone affected by pituitary conditions as a whole, we say *'the pituitary community'*
- When talking about anyone affected by a pituitary condition, we don't say *'suffering'*, *'sufferers'* or *'victims'* – this can be seen as negative or patronising
- When referring to individuals and their conditions, we say *'Amanda has Cushing's'* rather than *'Amanda suffers with Cushing's'* or *'Amanda is a Cushing's patient'*

- We aren't only here to help anyone with a pituitary condition, but also their support network, so we prefer to use the term '*anyone affected by a pituitary condition*'

3.7 If you're asked to speak in public

We are often approached by different organisations, including the pharmaceutical industry, who are looking for a patient speaker for an event. This can sometimes result in a payment for the speaker and thus The Pituitary Foundation has to be careful to distinguish between a volunteer attending to represent The Foundation, or that they are attending in their own right as a patient. It is of course illegal to pay a volunteer as it contradicts current employment law.

The Foundation will ensure each volunteer is clear on which of the following two scenarios applies to them for the event they are to attend:

1. A patient speaker is attending in their own right and is required to talk about the patient journey with no official reference to The Foundation. This means that the main payment agreement has to be between the company and the individual, and payment will be sent directly to the individual. The patient would be in personal contact with the company, rather than The Foundation arranging this and dealing with any correspondence or payments issues.
2. A patient is going to an event as a representative of The Foundation. This is as an official Pituitary Foundation volunteer and thus cannot be paid apart from their expenses reimbursed. If any funds are given by the pharmaceutical in respect of the talk (e.g. honorarium) these will be donated to The Pituitary Foundation directly and we will then reimburse any expenses you have incurred. The Foundation will arrange the volunteer's attendance, dealing with any logistical arrangements and supply the resources required.

The Foundation will ensure the organisation/pharmaceutical company and the patient volunteer understand which of these two scenarios applies.

If there is a scenario where the company legally cannot pay an individual directly, or The Foundation absolutely has to get involved, then The Foundation will charge the company an administration fee to cover our time spent on invoicing work, and payment and reimbursement issues.

3.8 Holidays/Illness

If you are intending to be away on holiday or are ill and therefore will not be able to volunteer at the agreed time, please let Kim Wegner, Volunteer Coordinator know as soon as you can that you will be away and when you are likely to return. England wide Bank holidays are seen as automatic holiday for staff and volunteers.

3.9 Conflict of Interest

The Foundation requires that employees and volunteers do not undertake any employment or engagement which might interfere with the performance of your duties for The Foundation.

In your role as volunteer, you must not make use of or exploit The Foundation, connections with it or any information obtained during your time volunteering with us for

your own private interest. Volunteers must not act in a manner likely to bring The Pituitary Foundation or its Trustees into disrepute or to affect its reputation for integrity.

4 Appendix

4.1 Code of Conduct Policy

At The Pituitary Foundation we believe that our members, community, and every person who works or volunteers with us, should be treated with dignity and respect, and feel that they are in a safe and supportive environment.

The Pituitary Foundation recognises its responsibility to create an inclusive culture that does not tolerate inappropriate, discriminatory, offensive or harmful behaviour towards any person.

We strive to make The Pituitary Foundation, both in terms of its office, meetings, events, online platforms and all other services, a place where people's wellbeing and emotional health are valued and promoted.

The Pituitary Foundation stands against abuse of trust and power including bullying, intimidation, harassment, discrimination or victimisation in all its activities. We work to ensure anyone is able to be supported if they experience unacceptable behaviour and we encourage the reporting and resolution of allegations, suspicions or concerns about abuse of any kind or inappropriate behaviour.

We ensure that anyone working or volunteering for the charity understands the expectations placed upon them, undertakes any necessary safety checks and has the relevant training and support to enable them in meeting their responsibilities.

Behaviours we expect from everyone

The Pituitary Foundation's staff, volunteers and stakeholders who access our services are requested to:

- Communicate and respect boundaries, bearing in mind that they are different for everyone.
- Keep any physical or online contact safe and socially appropriate.
- Speak up if something makes you uncomfortable, or if you notice another participant may be uncomfortable
- Listen with an open mind if somebody else speaks up.
- Behave with integrity.
- Uphold and adhere to our charity's values which are to be welcoming, caring, empowering, trustworthy, collaborative and passionate.
- To follow our Safeguarding Policy at all times.

We will never tolerate rudeness, brusqueness or off-hand behaviour.

All employees and volunteers are expected:

- to discharge their responsibilities honestly, effectively and efficiently;
- to show respect for each other and for Foundation property.
- to communicate openly, sensitively and honestly with other staff, volunteers, and customers;
- to devote their full attention and abilities during your working/volunteering hours;
- to act in the best interests of The Foundation at all times.

Please always remember that at social events you are representing The Foundation and must always behave in a way which demonstrates our professionalism.

4.2 Confidentiality and Disclosure Policy

The Principle

Information considered confidential by The Pituitary Foundation is as follows:

- all information about its individual members, supporters, service users, volunteers and staff;
- information regarding donors, benefactors and sponsors (unless expressly excluded by the organisation/individual concerned);
- some aspects of The Foundation's internal affairs such as finances, staffing details, organisational matters, etc.

Practical Aspects of this Policy

All staff and volunteers should be made aware of The Foundation's Confidentiality Policy:

- The confidentiality of the enquirer should be respected at all times.
- Electronic and paper records held at the Office, in home offices of Foundation staff and by Local Support Groups or other volunteers must be kept secure at all times.
- Prior consent should always be obtained from an enquirer if it is necessary to contact a third party on their behalf.
- No person's details should be shared without their express consent. If an enquirer wants to get in touch with someone their details should be taken and passed on.
- Information about an enquirer, sufficient to enable identification, should not be disclosed to a third party without the prior consent of the enquirer.
- Discussion about the content of an enquiry should take place only between appropriate personnel and should always be purposeful.
- If a supporter is asked to participate in a media story, then the full implications of so doing should be stressed to the participant before any personal details are given to the journalist in question. If there is any concern the supporter does not fully appreciate the implications of being part of a story, their details should not be shared.

Third Party Disclosure

The principle of confidentiality is fundamental to The Pituitary Foundation. Breaking confidentiality is a serious matter and not be taken lightly. The Chief Executive Officer must be prepared to account for such actions.

The only circumstances in which a breach of confidentiality may be justified is where there is a danger to the enquirer or others, this includes the threat of suicide, safeguarding concern or terrorist action or if it is required by law, or there are concerns a serious crime is being committed.

The Foundation must be made aware of any breach of confidentiality at the earliest possible time. A detailed written or electronic record relating to any breach of confidentiality must be kept by the Chief Executive Officer.

Agreement

I understand that during the course of my engagement with The Pituitary Foundation, I may have access to, gain knowledge of or be entrusted with personnel information, medical information, financial information and any other details concerning individual

members and/or groups of staff and/or service users of this or a partner company. This information may contain matters of a highly sensitive and/or personal or organisational nature.

I understand that access to this data, whether digital or manual records, is made available only to those who have an absolute right and need to know.

I agree not to disclose to any person or make use of such confidential information as described above at any time, whether during the temporary engagement starting on with The Pituitary Foundation or after the end of the engagement.

This duty includes keeping the names and other details relating to individuals or groups of staff and/or service users of this or a partner company strictly confidential.

I understand that I must keep data, whether confidential or not, secure and ensure, in line with GDPR policies.

Any wrongful disclosure or misuse of such information will be considered by The Pituitary Foundation to be a serious matter and advice sought on any appropriate action to be taken.

Pituitary Foundation Confidentiality and Disclosure Policy

Creation Date Unknown

ver. 7 – reviewed February 2023

4.3 Formal Complaint Process

4.3.1 Complaints Procedures for service users who have been dissatisfied with any of our support services

If a caller/service user to any of the Pituitary Foundation's services is not satisfied with the service they have received, then they should be informed of the Complaints Procedure. Please refer them to a member of staff so they can go forward with the procedure.

4.3.2 Complaints Procedures for volunteers

Step by Step Procedure

Step 1

In the first instance, we ask the complainant to communicate, preferably in writing, their issue to Kim Wegner, Volunteer Coordinator or Pat McBride, Head of Support Services. We ask that the complainant do this within one month of the situation occurring.

They will attempt to come to a fair resolution with the complainant.

Step 2

If a resolution was not achieved in Step 1, the complainant can write to the Chief Executive Officer, Ren Renwick, who will acknowledge the complaint within seven days and will investigate the complaint. A written report will be compiled within one month and the complainant will be given the opportunity to explain the circumstances of your complaint. The Chief Executive Officer will consider the report and write to you with her conclusions and any proposed course of action.

Step 3

If the complainant does not wish to write to the Manager, and/or if the matter cannot be resolved by the Chief Executive Officer, then the complainant will be asked to put their complaint in writing and to address it to the Chairman of Trustees. The Chairman will acknowledge the complaint within seven days. If the Chairman is not available, the Honorary Secretary will acknowledge the complaint.

The Chairman will consider the complaint, reports and documentation and refer them, if necessary, to the Board of Trustees. Within one month, the Chairman will write to the complainant regarding his (and the Board of Trustees, where necessary) conclusions and any proposed course of action.

Records

A record of all complaints (verbal and written), reports and outcomes will be kept by the Chief Executive Officer.

Abusive, Harassing or Intimidating Behaviour

The Head of Support Services, Chief Executive Officer and Board of Trustees will do all in their power to protect staff and volunteers from abusive, harassing, threatening and intimidating behaviour. In the case of such abuse being experienced during the reporting of a complaint, whether verbally or in writing, The Pituitary Foundation will operate a Zero Tolerance Policy. The Foundation will endeavour to handle emotionally charged situations as sensitively as possible.

4.4 Reimbursement Form

VOLUNTEER EXPENSES CLAIM FORM

What is this claim for? (i.e. meeting, training course, etc.)		
What department, project, or area of work does this relate to? (E.g. fundraising, patient services, Conference etc.)		
Date of claim:		
	Account Code <i>office use only</i>	Amount
TRAVEL		
Train (standard class only)		£
Mileage, if by car (@35p per mile - please inc. details)		£
Air (standard class only)		£
Travel Sundries: (e.g., taxis, parking, etc. - please list details including dates)		£
TOTAL TRAVEL		£
SUBSISTENCE (Please itemise, including dates)		£
TOTAL SUBSISTENCE		£
ACCOMMODATION		

(Please detail, including dates)		£
TOTAL ACCOMMODATION		£
OTHER e.g. stamps, stationery etc (Please itemise, including dates)		£
TOTAL OTHER		£
GRAND TOTAL OF CLAIM:		£

Payee:	Sort Code:	Account number:
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Please note that receipts should support all claims. If you haven't provided your bank details previously or have changed them, please let us know here:

All expenses claims will be paid by BACS.

Name:	Approved by Name: Signature:
Signature:	
Date:	

4.5 Volunteer Checklist

I (print name) have read and understood the following documents (checked boxes below). I have been given the opportunity to ask any questions I have regarding their contents. Further signing this acknowledgment means that I understand my responsibilities and agree to the guidelines presented in this handbook.

.....
Volunteer Signature

.....
Date

.....
Staff Signature

.....
Date

Handbooks

- General Handbook for all Volunteers
- Office Volunteer Handbook
- Helpline and Buddy Handbook
- Volunteers Running LSGs Handbook
- Medical Committee Handbook
- Volunteer Campaigner Handbook

Policies and Guidelines

- Diversity Equality and Inclusion
- How we use your Data
- Keeping Safe
- Keeping Safe Online
- Social Media Policy
- Code of Conduct Policy
- Confidentiality and Disclosure Policy
- Health & Safety Presentation for Office Volunteers