Pituitary Awareness Month: Living Well - Ways to Get Involved

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<u>Intro</u>

This coming October is Pituitary Awareness Month and the theme will be 'Living Well'! We are asking the pituitary community to share your story. This will help to raise awareness of pituitary conditions throughout the month, and this pack contains some practical ways to share your story and reach different audiences. You don't have to do everything in this pack, but doing just one thing can help to raise essential awareness and could help other pituitary patients.

We are also sharing some graphics and social media assets available for you use on social media if are able to.

<u>Graphics</u> – available on website. If you would like these emailed to you instead then please contact lottie@pituitary.org.uk.

Contacting your local press

Having your story displayed in a local newspaper is a great way to reach a large audience and raise awareness of pituitary conditions during Pituitary Awareness Month.

How to do this:

- 1. Contact your local newspaper, most prefer email contact these days, not if you are unable to do that then a phone call would also work. You'll be able to find the contact details on a copy of the paper, or on their website.
- 2. Explain to them about Pituitary Awareness Month, tell them about your story, and what The Pituitary Foundation are and how they can help. There's a template for this below and remember to include some high-quality photos as well.
- 3. If they don't get back to you straight away then you can chase them after a couple of weeks.

Template email

"Dear...

October is Pituitary Awareness Month, a month to raise awareness of rare pituitary conditions. The pituitary is a small gland near the brain and it controls many of the hormones in the body. If this goes wrong then it can cause significant health problems. I have a pituitary condition called... [Outline what the condition is]. This impacts...

For Pituitary Awareness Month I want to share my story to raise awareness of pituitary conditions. As a rare condition, it can often be challenging for people to get a diagnosis, and if more awareness is raised then it will help people to recognise the symptoms and improve diagnosis times. [Could share your diagnosis story].

You can find a press release from The Pituitary Foundation, who are running the campaign here: https://www.pituitary.org.uk/news/2022/07/pituitary-awareness-month-press-release/

Thank you for taking the time to read my email and I look forward to hearing from you and sharing my story further.

Kind Regards

...'

GP awareness

Your GP is often the first person you go to when you are experiencing unusual symptoms, and we want to ensure that they are aware of pituitary conditions so they know what to look for. We also want to make sure that GPs are aware of The Pituitary Foundation so they can signpost their patients to our services.

There are two ways that you could raise awareness amongst GPs.

Firstly, we have awareness posters and documents that you could send your Doctors surgery to display in the surgery.

How to do this:

- 1. Contact your doctor's surgery. You may already have a good relationship with your GP or have another contact at the surgery. If not, then you can contact the community care coordinator or practice manager. Usually this information is available on the website.
- 2. Ask if they have electronic notice boards or notice boards where they can share posters, and find out the email address or postal address to send this information to.
- 3. If you are sharing a graphic on an electronic notice board then you can download this from our website and email it to them direct.
- 4. If you are sharing physical posters then you can contact The Pituitary Foundation (enquiries@pituitary.org.uk) with the address and name of your liaison where the posters can be sent and we can post these on your behalf.

Another way to engage with your GP surgery would be to host an education event. This could just be 5 minutes and often can be done at the beginning of a meeting where all the GPs and senior staff will already be.

- 1. Contact your doctor's surgery. Again, you may already have a good relationship with your GP or have another contact at the surgery. If not, then you can contact the community care coordinator or practice manager. Usually this information is available on the website.
- 2. Ask them if you are able to give a short presentation about your experience as a pituitary patient at the beginning of their staff meeting as part of Pituitary Awareness Month.
- 3. Remember to let us know and we can send you any resources that may be useful, for example our GP handbook.

Some example content for your presentation:

- Introduce yourself and what your condition is
- Summarise what the pituitary gland are, and what it does [can we provide this?] and conditions it can include such as cushing's, acromegaly, and diabetes insipidus
- Explain that pituitary conditions are uncommon, and the diagnosis often incredibly stressful for patients
- Remind GPs that they may want to do XX tests when patients present with symptoms like yours
- Summarise the ongoing relationship with your GP and the endocrine unit and how it works best
- Take any questions
- 4. Remember to thank the GP surgery afterwards for their time.

The theme for Pituitary Awareness Month is 'Living Well' and a great way to not only live well and be active whilst raising vital funds for The Pituitary Foundation would be to organise a 'Walk for Awareness'. This is something that can be done alone or it is also a great way to get together with friends, family and/or colleagues. Getting involved is simple:

- Choose a date, time and location for your awareness walk. You could walk a specific distance on a specific day, or you could try to complete a certain distance or number of steps across October.
- 2. Invite as many of your friends, family and colleagues as possible to get involved. Don't forget that the more people getting involved equals more awareness.
- 3. Set up a fundraising page via www.justgiving.com and start asking people to sponsor you, encourage everyone who is joining in with the walk to do the same. Don't forget to ask if anyone getting involved has an employer who operates a matched funding scheme, many companies offer this and it's a fantastic way to add to your fundraising.
- 4. Email jay@pituitary.org.uk to let him know about your walk and to request t-shirts.
- 5. Contact the local newspaper to ask if a journalist could come along and take a photo of your walk for awareness (we also have a template for approaching your local newspaper in this pack).
- 6. Please tag us in any photos of your walk for awareness so that we can share via our social media channels.
- 7. Enjoy your 'Walk for Awareness' and please email any photographs of the event to Jay.

Raising Awareness in Schools/Colleges/Universities

Going into schools is a great way to raise awareness of pituitary conditions to a large group at a time. If you are a parent, grandparent, auntie or uncle, then you could go into your child's school and hold a short talk in an assembly to help raise awareness. As a benefit the school might even decide to do some fundraising. This could also be done with other community groups such as the WI, youth clubs or

How to do this:

- 1. Contact your school, it's probably best to go through your child's teacher or form tutor.
- 2. Ask to host a short talk about pituitary conditions for Pituitary Awareness Month.
- 3. Remember to let us know and we can send you any resources that may be useful, for example t-shirts or stickers. We also have an example presentation with some images that you can use.

Some example content:

- Do you know where your pituitary gland is? It is about the size of a pea (about 1.25 cm) and is situated in a little hollow, just behind the bridge of your nose. (show hand on top head & bridge of nose to where these meet)
- The pituitary gland is often called the master gland because it controls several other hormone glands in your body. It automatically and constantly checks glands and organs in your body to find out when to send or to stop the chemical messengers (hormones) that control their functions - these include helping you grow, balance your body temperature, balance your stress hormones etc (the thyroid and adrenals)
- Talk about some of the different conditions, this is where sharing your story may come in useful.
- A tumour in the gland or surgery to a tumour might disrupt the usual working of hormones, so these will have to be replaced with medication.
- 4. Don't forget to thank the school afterwards for allowing you to give a talk and for their time.

We know that many people aren't aware of The Pituitary Foundation and the support services that we offer, and there are also many people who aren't aware of pituitary conditions. Providing a talk to a group in your community is a great way to engage with these groups. There are many groups or business networking clubs all over the UK and we are sure that they would love to hear from you.

- 1. Contact your local groups such as Rotary, Lions, Women's Institute, Soroptimist International, BNI, etc to see if you can give a talk to the group during awareness month. They will usually have a website where you can find the email address of the secretary.
- 2. Contact The Pituitary Foundation (admin@pituitary.org.uk) with date of your talk and any materials, posters etc you want to use on the day. We will also provide you with a pituitary foundation t-shirt.
- 3. Contact the local newspaper to ask if a journalist could come along and take a photo of your awareness month talk (we also have a template for approaching your local newspaper in this pack). The group may also produce a newsletter and could add details about your talk or share it on their website.
- 4. Provide your talk

Some example content:

- Do you know where your pituitary gland is? It is about the size of a pea (about 1.25 cm) and is situated in a little hollow, just behind the bridge of your nose. (show hand on top head & bridge of nose to where these meet)
- The pituitary gland is often called the master gland because it controls several other hormone glands in your body. It automatically and constantly checks glands and organs in your body to find out when to send or to stop the chemical messengers (hormones) that control their functions - these include helping you grow, balance your body temperature, balance your stress hormones etc (the thyroid and adrenals)
- Talk about some of the different conditions, <u>this is where sharing your story may come</u> in useful.
- A tumour in the gland or surgery to a tumour might disrupt the usual working of hormones, so these will have to be replaced with medication

Tea Party Fundraising and Awareness

A great way to raise awareness whilst raising some money for The Pituitary Foundation is hosting a tea party or coffee morning. You could invite friends, family or colleagues, and we have lots of materials available to help you to host your own.

How to do this:

- 1. Set a date for your event and be sure to invite whoever you want to.
- 2. Bake or buy some cakes, and make sure you have a variety of drinks on offer. You could even ask if a bakery is able to donate some cakes.
- 3. Set prices for your cakes. You may want to do other activities to raise money such as selling tickets for The Pituitary Foundation's Christmas raffle!
- 4. Contact us (admin@pituitary.org.uk) and we can send you anything you need for your event, maybe t-shirts, leaflets, balloons, or raffle tickets.
- 5. Contact the local newspaper to ask if a journalist could come along and take a photo of your awareness month event (we also have a template for approaching your local newspaper in this pack).

Raising Awareness in your local hospital

We know that many people aren't aware of The Pituitary Foundation and the support services that we offer, and there are also many general hospital staff who aren't aware of pituitary conditions. Holding an awareness stand in your local hospital or endocrine unit is a great way to engage with these groups.

How to do this:

- 1. See if other pituitary patients could help volunteer to sit at a table with some resources on in an endocrine unit. You might do this through your local support group, or with friends or family who are aware of your condition.
- 2. Agree times and dates that could work for you. It is good to have a minimum of 2 people at any one time so you can take breaks.
- 3. Contact your local hospital or endocrine unit to see if it's possible for you to have a table with some resources on during awareness month.
- 4. Ask that they can provide a table (and some chairs) and where this could be sited, possible dates and what times would be convenient. Note down name and contact details for the person who authorises this.
- 5. Contact The Pituitary Foundation (admin@pituitary.org.uk) with date of your event and any materials, posters etc you want for the table, for example balloons, t shirts (and sizes).
- 6. Organise your stand accessories (tablecloth, posters, collecting tin, pens, paper) and how to get them to the hospital.
- 7. Contact the local newspaper to ask if a journalist could come along and take a photo of your awareness month event (we also have a template for approaching your local newspaper in this pack). The hospital may also produce a newsletter your event could be included in.

On the day:

- Meet up with volunteers at the confirmed site; set up table
- Take details of any patients or clinicians who visits the stand with an interest in your local group or wants more information about the Pituitary Foundation. You can encourage them to sign up to our newsletter or visit our website to find out more.
- Hopefully have a group photo taken by local newspaper and offer details about your group and what The Foundation does.

After the event, write a letter of thanks to the staff involved for allowing you to hold your awareness stand and remember to let us know how it went!

Raising Awareness in a Public Space

We know that many people aren't aware of pituitary conditions, so this Pituitary Awareness Month, holding a stand in a public space is a great way to raise awareness and some funds. Stands could be held in your local library, supermarket, or any community space.

How to do this:

- 1. See if other pituitary patients could help volunteer to sit at a table with some resources on in a community space. You might do this through your local support group, or with friends or family who are aware of your condition.
- 2. Agree times and dates that could work for you. It is good to have a minimum of 2 people at any one time so you can take breaks.
- 3. Contact the space where you want to host the stand, supermarkets normally have a community champion who would be the best person to contact.
- 4. Ask that they can provide a table (and some chairs) and where this could be sited, possible dates and what times would be convenient. Note down name and contact details for the person who authorises this.

- 5. Contact The Pituitary Foundation (admin@pituitary.org.uk) with date of your event and any materials, posters etc you want for the table, for example balloons, t shirts (and sizes).
- 6. Organise your stand accessories (tablecloth, posters, collecting tin, pens, paper) and how to get them to the hospital.
- 7. Contact the local newspaper to ask if a journalist could come along and take a photo of your awareness month event (we also have a template for approaching your local newspaper in this pack). If you are hosting a stand at an existing event then they may already have media coverage there.

On the day:

- Meet up with volunteers at the confirmed site; set up table
- Hopefully have a group photo taken by local newspaper and offer details about your group and what The Foundation does.

After the event, write a letter of thanks to the staff involved for allowing you to hold your awareness stand and remember to let us know how it went!