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The Solent and IOW Pituitary Support Group

The Pituitary Foundation
Solent & Isle of Wight Support Group

Newsletter No. 93, November 2025

Hello everyone,

Welcome to another edition of the Solent and IOW Pituitary Support Group Newsletter, for November 2025.

Thank you to everyone who has contributed, by sending material for the newsletter and giving their encouragement.

We aim to produce a newsletter four times a year, and it is timed to be issued shortly before each of the main support group meetings at the Cosham Community Centre. The meeting at Cosham is on Saturday 6 December at 10 am. Our pre-Christmas get-together.

When we meet in December there will be tea, coffee, juice and biscuits. Plus festive food. The meeting will not have a designated speaker this time, but there will be a quiz and a raffle. Please note that NO nuts or nut derivatives are allowed in the Cosham building. There will also be time to chat generally, and to give and receive advice and information about pituitary conditions and related matters.

Note that this will be our last meeting in Cosham. For meetings in 2026 we will have a new venue, Portchester Parish Hall. See page 2 for the address.

We often welcome new patients and their partners, family or friends at meetings, so if you have recently found out you are a pituitary patient or just found out that we as a support group exist, please get in touch and join us for future meetings and you'll be made very welcome.

Find us on Facebook - The Solent and IOW page is in the form of a group. Together we'll be updating and posting relevant information on there. Anyone that uses Facebook can search and join the group. It is listed as the following: - The Solent & IOW Pituitary Patient Support Group. This is in addition to the main Pituitary Foundation page and other pituitary Facebook groups.

========== Meeting dates for your diary for 2025 ==========

The December meeting will be our last one at Cosham Community Centre, Wootton Street, Cosham, PO6 3AP

At the Cosham meetings we will have tea, coffee, juice and biscuits available. You may bring your own snacks if you wish, but please note: NO nuts or nut derivatives are allowed in the building.

- Saturday 6 December 2025 at 10am – Our pre-Christmas meeting, with festive food and a quiz

========== Meeting dates for your diary for 2026 – Change of venue ==========

Note that in 2026 we will no longer be meeting in Cosham. Instead we will be at Portchester Parish Hall, 1 Assheton Court, Portchester PO16 9PS at the new time of 1030am so enjoy an extra half hour in bed 😁. As usual, we will have tea, coffee, juice and biscuits available. You may bring your own snacks if you wish.

- 2026 dates (all Saturdays): 28 March, 27 June, 18 July (IoW venue TBA), 26 September, 5 December. We will welcome Emma Cooper CEO of the Pituitary Foundation for our March meeting and we will have Specialist Endocrine nurse Sirbrina Ramharack at our September 2026 meeting. Dr Victor Lawrence will join us for our Isle of Wight meeting.

Possible speakers for future meetings include Dr James Lawrence and Dr Smith from Salisbury, a radiographer, a pharmacist, and blood bikers, and on mindfulness, laughing yoga, a life coach etc.

There is always a raffle at the main meetings in Cosham, Portchester and on the Isle of Wight. Prizes gratefully received on the day please.

Receiving your newsletter - If you would rather receive your newsletter by email, please email Howard at: howardpearce1@yahoo.com or Gail at g.weingartner@btinternet.com and let them know. Or let Gail or Howard know if you wish to come off the mailing list altogether.

More than half of the newsletters are now sent out by email. Unfortunately, there are often a few people who have changed their email address, and they do not get their electronic copy. We usually manage to send them a copy by post, but inevitably it is a few days late. If you have changed your email address, please let us know.

The cost of posting the newsletter – Printing and postage of the newsletter for those who do not get their copy by email is a major cost item, around £300 a year, and the price of stamps keeps going up. It would be very much appreciated if those receiving the newsletter by post would make some contribution towards the cost of printing and postage, either by stamps or money, or change to email delivery. Gail and Pam Weingartner and Melissa Reeds are always happy to receive a book of stamps from anyone who receives the newsletter by post. They send a special thank you to everyone who has given stamps or money for this.

It's <u>your</u> newsletter – We would love you to write something for the newsletter. If you have something to share – your experience as a patient, something you have done, some wise words, something to make us laugh, or something that we all ought to know – please send it for the next newsletter, which we are aiming to produce in March 2026.

Donations

Our thanks to our fundraisers for their kind donations and fundraising on our behalf. It is because of the continued support of this kind that we are able to have our quarterly meetings and fund the newsletter. But, **we DO NEED** some proactive fundraising to keep our bank balance in the black, so please give thought to and let one of us know your ideas.

A special thank you to all who contributed to this newsletter.

Stop press – moving from Cosham to Portchester

As you all know, we have been using the Cosham venue for our meetings for many years but recently the service they provide has not been as we would expect. As a result, we have been looking into a change of venue and have visited two possible venues in Portchester, both of which are good, with kitchen access, parking etc.

Following our discussion at the committee meeting recently, and taking into account your valuable feedback, we have decided to change our venue from Cosham to Portchester Parish Hall (the smaller hall). The address is 1 Assheton Court, Portchester PO16 9PS. We are impressed with the facilities, the disabled spaces/access/kitchen and adjacent free parking. The change will take place for our meeting on 28 March next year and the start time will change from 10 am to 10.30 am. We think this time will be better for everyone. We have been developing plans to make it a great meeting! Full details to follow later.

It you have any questions or concerns please email: jenny.gatland@googlemail.com

News of upcoming on line events by the Pituitary Foundation

There are exciting online events coming up during November:

- Sick Day Rules reminder, with an endocrine specialist nurse Aldons Chua, 24 November 7-8 pm
- AVP deficiency talk, with consultant endocrinologist Prof Miles Levy, 28 November 6-7 pm

If you'd like to sign-up to attend any of these events for free, please click the link below.
https://www.pituitary.org.uk/join-our-community/all-events/?event-category=online-events&current_page=1

A poem from Jenny

Hello everyone, I thought you might like this little poem for November, although it may not quite be the reality. November is a month of darker evenings, rain and wind. misty mornings, spider webs, jobs to do which I didn't do in the summer, soggy leaves, leftover pumpkins, Black Friday, runny noses...

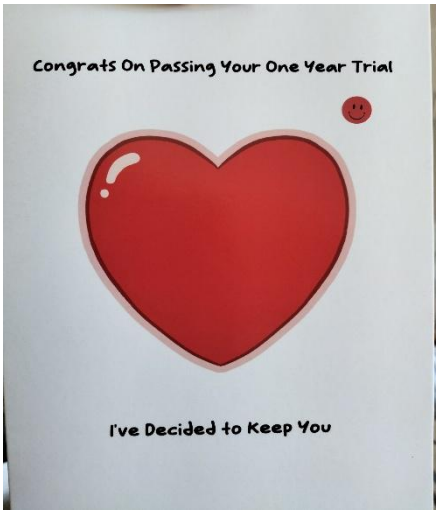
So, perhaps we could use November to start planning for Christmas and get ahead of the game. Take some time to indulge ourselves, think of holidays, put our feet up with a good book, eat nice food.

I look forward to seeing you all at our meeting on 6th December - Jenny

A Lesson Learned ('til the next time !)

Hi all, Gail here with a recent pituitary experience to tell you about.

I am not always the best at practising what I preach and although I am fully aware of the likelihood of having an adrenal crisis, I have been very lucky and only experienced these a couple of times. Until recently that is …….



Rod and I married a little over a year ago and celebrated our first anniversary on 5th October but we don't actually live together because I'm still at my Mum's (Pam) who has now reached the grand old age of 97 and needs a little support.

I do however, stop over at Rod's quite regularly and a couple of weeks ago we had been to the 100th Birthday party held for Rod's Mum Jean. That generation really are stalwarts !

The food was lovely, great photos on a loop plus lots of bonhomie and a good time was had by all. We got back to Rod's about 8pm, ate a fish finger sarnie and were in bed by 11pm. At approximately midnight, I started feeling stomach cramps, which progressively got worse and I thought I'd grab a couple of paracetamol. It got so bad that I must've been groaning as I perched at the top of the stairs and it woke Rod up, which takes a lot believe you me 😉.

I suddenly realised that I had better get to the loo quickly as an 'eruption' came forth, quickly followed by a second bout. I stood up to wash my hands, went very dizzy and promptly collapsed in the bathroom against the door, which opens inwards. Apparently nowadays, housing regulations mean that bathroom doors must open outwards.

I had sent Rod out of the bathroom whilst the eruptions were occurring but then he couldn't get back in, which we can laugh about now. Thankfully though, I was 'compos mentis' enough to slide over a little so's Rod could get in to help me and also again very thankfully, there were no more bouts of diarrhoea. I was shaking, extremely cold and very out of sorts so Rod fetched my dear old Hydrocortisone and I immediately took 2x 10mg tablets.

I've said thankfully several times but I'm going to say this one more time because 'thankfully' the Hydrocortisone magic worked; I slept well and actually felt brilliant the next day. It wasn't needed on this occasion but we didn't have an emergency injection to hand even if it had been required. Had my diarrhoea continued, it would probably have been another story altogether.

I am very naughty and rarely think about carrying my emergency injection with me but Rod and I definitely learnt a lesson that night. There is now an emergency injection kit ready for action at Rod's but let's hope there isn't a next time. Also, Rod has added the words 'Adrenal Crisis' and 'Addisons' into his mobile so this can prompt him with what to say if calling for an ambulance.

For goodness sake you various drug companies, HURRY UP and provide us with an Epipen type device to use if experiencing an adrenal crisis. This is looking more promising but not exactly just around the corner alas.

Regular reviews of lifelong medication needs please!

I was diagnosed with Addison's disease/ primary adrenal insufficiency almost twenty five years ago. Since then I have been on a daily regime of replacement therapy of hydrocortisone and fludrocortisone. As I've moved location several times since then I have also needed to switch Endocrinology departments for my yearly outpatient appointments. While my medical records have moved with me from one location to another, one aspect that concerns me about NHS monitoring of my condition over the last couple of decades is that never once has an endocrinologist suggested carrying out a review of my medication doses and management plan. This, despite the fact that since diagnosis at the age of 46 I have changed lifestyle from that of a busy working professional to a more measured life as a retiree, and I have aged nearly a quarter of a century in that time! Over these years I have noticed significant changes in my energy levels and my body's ability to manage the internal and external stresses of everyday life. No doubt some if this is due to the impact of ageing itself but I suspect that my medication needs have also changed.

While I've been proactive in regulating my own medication, where necessary topping up by small amounts as well as actively taking part in research to try out alternative medications, always in search of a better quality of life on medication, this has been at my own initiative and not instigated by any endocrinologist that I have seen. To return to my original point, what bothers me about this passive attitude is that so long as nothing amiss shows up in the results of blood tests prior to the annual outpatients appointment, no endocrinologist has ever suggested reviewing the overall management of my lifelong medical condition. In my opinion, it would be surprising if my body required the same medication doses at 69 as it did at 46, yet this seems to be the underlying assumption at work. I am aware that most endocrinologists now doubt the usefulness of reliance on day curve tests to establish correct doses but I would have hoped that a review of medication management plans could be done from time to time to take into account the inevitable changes that occur over a lifetime - Julie Watson

We would be very interested in any of you own experiences or feedback after you have read Julie's account. Please contact Gail if you'd like to contribute

Adrenal insufficiency, from Pauline S

"Many patients with adrenal Insufficiency have issues when attending A&E in adrenal crisis or possible adrenal crisis. We can show them the red steroid card with details of how to treat a crisis but they don't always pay heed to them.

I've spoken to Prof Wass about the issues that patients are having and he told me that there is a move to get a brief half pager on patients with adrenal insufficiency and steroid dependency to show in A&E. Hopefully this will help us.

The Addison's Disease Charity have just produced an updated steroid card which can be personalised with your name and other details, I ordered a couple of them and found that the QR code at the bottom of the card is supposed to take you to the NICE guidelines, however it doesn't and takes you to the press release about the updated NICE guidelines. I did contact the Addisons Disease self-help Group (ADSHG) to inform them of this but haven't heard back from them.

I've just looked again to see that they have published a correction to both the Adrenal Crisis Guidelines and the ADSHG steroid emergency card! What a huge mistake to make! They are printing a new version and say that as soon as they have them they will alert their members and post on social media how you can get the new one if you have, like me, already bought one for free.

https://www.addisonsdisease.org.uk/News/correction-to-adrenal-crisis-guidelines-and-adshg-steroid-emergency-card-content

News from the Southampton meeting on 27 September

"I just wanted to share my experience at the Pituitary Foundation get together in Southampton which some of us attended a few weeks ago.

The venue, The Leonardo Royal Hotel Southampton, was superb and the room was just the right size for the number of attendees, refreshments and lunch were fantastic. It was great to hear the talk by Professor John Wass and I had the opportunity to talk with him privately and ask a couple of questions outside of the function room which was extremely valuable to me.

My daughter Jen kindly took me and accompanied me throughout the day and encouraged me to chat to people with the same condition as myself (adrenal insufficiency). I had the opportunity to meet several other people with adrenal insufficiency and it was quite emotional hearing other people's life stories and how they cope with their condition.

Staff from the Pituitary Foundation were on hand and were very helpful, friendly and informative.

The whole day was a huge success and I look forward to next year's get together. Thank you Gail for sharing the invitation."

Mel H

Agreed. It was a great day, and it was good to see so many of our Solent group people there in Southampton. Like Mel, I also had the opportunity to speak with someone whose pituitary journey echoed my own – Editor

Here are two of us at Southampton. They wanted a photograph of pituitary volunteers, and here are Gail and Howard in this group of six volunteers.

Questions to the doctor - Please note that there are no questions to the doctor this time. We have given Dr Lawrence a break and hope to have more questions and his excellent answers in the next newsletter.

From a report of a meeting of the London group (LAPPS)

Professor Karim Meeran gave an amazing talk on 'Steroids and Prednisolone'

Glucocorticoid hormone, better known as cortisol, is replaced with either hydrocortisone or Prednisolone in Adrenal Insufficiency. Prednisolone as an alternative to hydrocortisone.

Oral Hydrocortisone has a short half-life: too short for one daily administration. We need to have a longer lasting version. Prednisolone is suitable for once daily administration.

If you do not have a Pituitary Gland or one that has been damaged (e.g. by a tumour) you do not have any ACTH which tells the adrenal glands to produce cortisol. So, it is essential to take a steroid. You should take as little as necessary but increase in stress situations or illness to avoid an Adrenal Crisis. An injection may be needed, but if you are not being sick or have diarrhoea you can try doubling the dose of your steroids.

Pituitary patients take Steroids as a replacement for the lack of cortisol, but steroids are also used for medication to cure/control conditions such as asthma. Taking steroids, you must avoid calcium and milk as they slow down their absorption. Ideally, take levothyroxine and steroids first thing in the morning and wait at least 30 minutes before eating breakfast. However, if your routine suits you, there is no need to change!!

Prednisolone

Professor Meeran believes Prednisolone has many advantages over the traditional hydrocortisone tablets. He has been involved with several research projects on Prednisolone, including a test with 214 pituitary patients which showed no medical evidence between Hydrocortisone and Prednisolone. The usual level is 3mg although some may need more, everyone is different. 3mg prednisolone is roughly equivalent to 20mg of Hydrocortisone.

Too much of any steroid can increase weight, increase blood pressure and diabetes mellitus. Professor Meeran explained that you take one dose in the morning and it will last all day. It is easily available and CHEAPER for NHS, (but of course, a pituitary patient taking replacement steroids are free). Prednisolone is rapidly absorbed, long half-life, ideal for once daily admission. The profile is similar to the circadian levels of cortisol.

The BMJ stated in 2014 that there is no evidence of difference between prednisolone and Hydrocortisone in adrenal insufficiency.

Hydrocortisone

Hydrocortisone has been the drug of choice for treatment of adrenal insufficiency.

Hydrocortisone requires multiple daily dosing which can be an obstacle to patients. Consequently, this may have a negative impact on a patient's quality of life and may increase the likelihood of an adrenal crisis.

Professor Meeran set up a study across centres in UK: switch from Hydrocortisone to Prednisolone (4mg) daily and if OK decrease to 3mg and repeat measurements after 4 months. It started in 2018 but was affected by COVID.

Many Endocrinologists are reluctant to prescribe Prednisolone because their laboratories cannot measure Prednisolone in the blood. Professor Meeran said now any consultant can contact Charing Cross Hospital to arrange sending samples for testing.

He summarised by saying Prednisolone is more convenient, lowers blood pressure and some found a fall in waist measurement. Also, cardiometabolic risk is reduced as well as a reduced risk of osteoporosis.

Pituitary Christmas card

Hi my name is Claire Arnold and I'm lucky enough to be 63 soon !

I have a lot of medical conditions and have had many surgeries. I first came across The Pituitary Foundation in 2018 when I was diagnosed with a 20mm pituitary tumour pressing on my optic nerve. I had Transsphenoidal surgery to remove it. It was reduced to 9mm as was too risky to remove completely, too near the carotid artery. Seeing as in 2016 I suffered from a carotid artery dissection the opposite side… horrendous… I was happy with that bit being left behind. Unfortunately, I got meningitis with surgery so was in hospital a while. I have been left with Hypopituitarism, which includes Adrenal Insufficiency, AVP Deficiency, thyroid problems amongst others.

The Pituitary Foundation have been an invaluable service to me over the last seven years, with up to date information, care, and much needed support. As we know this is a very tough journey and only those that have it, truly know the daily or even hourly struggles we have on a day to day basis.

I was due for my eighth surgery last August. A triple ankle fusion and achilles lengthening. It was a big surgery which I had put off for four years for fear of hospital staff not being able to deal with my pituitary conditions. This had happened before, where I had to go on life support twice. So you can probably sympathise why I put up with my collapsed ankle for so long. The pain finally became too unbearable even for me. Both wrists got carpal tunnel using crutches so long….Plans were put in place for surgery. My endocrinologist had put a care plan together as the surgery was to be done at a different hospital. Without going into too much detail unfortunately the plan wasn't carried out to the letter and my fears came to fruition. I did have the emergency 100mg hydrocortisone injection pre general anaesthetic as requested …and initially woke up fine but that's where it ended. Almost literally for me! I deteriorated over the hours, sodium plummeted, had Hyponatremia which triggered my seventh Adrenal Crisis and ended in intensive care again…. As I write this, I'm actually waiting for op number nine tomorrow. So very apprehensive, updosing of steroids needed. Unfortunately one of my screws is sticking out and is being removed… let's hope the plan this time is successful and I'm in and out like a 'normal' person. They assure me they have learned. … Fingers crossed…Let's leave all that rubbish there as I like to refer to it.

Finally at home recovering and not being able to weight bear, six weeks in a cast then another six weeks in a boot. I actually fell after being home a week and badly broke my toe on the other foot.. . so a boot came sooner with the cast at the same time! I was basically stuck to my arm chair and I'm not one for sitting around. Although my cat who we adopted as a beaten up stray from Spain loved it.

In 2020 when Covid had us all indoors I taught myself to paint (sort of) …. By watching YouTube.. so whilst sat in my armchair surrounded by my paints, balancing water and card. Also my cat Vera who doesn't like to miss out on things (life is never easy!) I set about trying as best I could to give something back to the Pituitary Foundation in some way. I saw all the wonderful people in their magazines /website & Facebook doing all these fantastic challenges to raise much needed money for them, so courageous. I'm physically unable to run, climb etc … having metal in lower spine , neck and now ankle… I was browsing their website and being inspired by these incredible folk… and whilst browsing the Pituitary Foundations site some symbols caught my imagination. The membership symbol looked like a house, hormones in my mind could be snowballs, and even a symbol that would look great on top of a Christmas tree… I was getting carried away. I know, I'll

paint a snowman wearing a T shirt and incorporate as best I can wrist bands, pen etc... I can try and do a Christmas card.

I wasn't too sure my painting was that brilliant after all I'm just a novice painter but I enjoyed doing it and it took up quite a few hours to complete. It certainly cleared my mind and helped with my mental state just to concentrate on one thing.

I plucked up courage to send it to them (I have plenty of courage when it comes to illness & surgery but this was different) Eeeek! I wondered if they would be able to add it to their Christmas Cards they sell to make them some money . Guess what? they said YES!! I was thrilled, not too many things go my way normally .... So here it is.. I hope some of you like it and can appreciate the journey it took me to get here with it 😊 and some of you more importantly might buy it .. thanks for reading a bit of my journey .. oh and a very early Happy Christmas to you all x

A little humour from Paul Oastler

I am waiting for the Virgin Media guy to turn up and I thought what shall I do. So here we go; hope it's not too long or boring. Oh, by the way, the radio therapy mask worked a treat the other day for Halloween.

Hi how are we all? The quiet one here 😁. Hope everyone is taking their meds and most of all looking forward to Christmas. (I know it comes around so quick). I do hope Jill (the wife), is not reading this because I bought her an artificial leg for Christmas. Don't worry it's not her main present, just a stocking filler !

Anyway, what shall we talk about in this edition? How about your medical condition for a change I hear you cry. Well, this story has a funny side and a more serious side to it. I have water retention in my legs. Ok, before I carry on make sure you're not eating. The bottom of my legs and ankles get fairly fat at times. About 2-3 weeks ago I had a large blister about 50mm from at the bottom of my leg and it burst. So, what do I do? This is where the serious bit comes and being a typical bloke, I tried DIY. Finding a post operation plaster in the cupboard I thought that will do, how wrong I was. Removing it proved to be a painful challenge. So I thought let the air get to it and keep washing it. Wrong again. OK, I'll cut this down a bit and I still haven't told Jill at this point. Showed my mate at work who said you should go to the walk-in centre. So off we went. Got seen by a nurse and she had to put a very large thick bandage round it from toes to the knee. Can't get my work trousers or shoes on. So, the only thing they could find for me was a bright purple pair of PJ bottoms and a Velcro type sandal. Now at this point take yourself back to the bit of the story about me not telling Jill.

Well, you can imagine her delight when I walk through the door having left the house with dark blue work trousers and returning in bright purple PJs. So at our next pituitary meeting, if we are sat at opposite ends of the room you'll understand why .....

The moral of this little story is don't ignore things and get it sorted.

Before I forget though, there is one last thing, which is that the nurse at the walk-in centre had no idea what a Pituitary Gland was and she was going to google it that evening. which I really was quite surprised about !

On another note, I have just been offered a job working in a dry fruit company - I'm just waiting for them to get back to me with some dates (Paul, that is really TERRIBLE 🤣).

.

Actually I'm addicted to Hokey Pokey but I've managed to turn myself around.

Ok last one for Christmas. He's still going about with that old bag.

"Who?" I hear you say..... 'Father Christmas'.

Stay safe - Paul

If you're feeling lonely or just fancy a chat, then give Gail a call on either of the numbers shown on the first page. Stay safe and thanks soooo very much for your personal contributions folks.

Gail, Pam, Howard P, Melissa, Jodie, Jenny, Jackie, Eireen & Howard C