

The Solent and IOW Pituitary Support Group

Chairman and Newsletter Editor

Howard Pearce,
18 Wyde Feld,
Bognor Regis,
West Sussex,
PO21 3DH

Tel: 01243 863627
Mobile: 07518 759778

howardpearce1@yahoo.com

Joint Area Co-ordinator

Gail Weingartner,
17 Whitfield Road
Haslemere, Surrey
GU27 1DX

Tel: 07525 041947
01428 651526

g.weingartner@btinternet.com

Joint Area Co-ordinator

Pam Weingartner,
17 Whitfield Road
Haslemere, Surrey
GU27 1DX

Tel: 01428 651526

Hon Treasurer

Melissa Reeds
80 Kimberley Road
Southsea, Portsmouth
PO4 9NS

Tel: 07894 531879

mel_reeds@yahoo.com

Minutes Secretary

Howard Coulson
21 Laburnum Close
North Baddesley
Southampton
SO52 9JT

green3sky@yahoo.co.uk

The ● Pituitary Foundation

Solent & Isle of Wight
Support Group



Newsletter No. 89, November 2024

Hello everyone,

Welcome to another edition of the Solent and IOW Pituitary Support Group Newsletter, for November 2024.

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 normally it is timed to be issued shortly before each of the main support group meetings at the Cosham Community Centre. The next meeting is on Saturday 7 December at 10 am. There will be tea, coffee, juice and biscuits. And a raffle. We will also have festive food, on a bring and share basis. You may bring your own sweet or savoury snacks if you wish. Please note that NO nuts or nut derivatives are allowed in the building.

As usual for the pre-Christmas meeting, we will not have a formal speaker. There will be a quiz, with some of the questions based on news items throughout the year. By special request, the quiz will also include some pituitary-related questions. There will also be time to chat, and to give and receive advice and information about pituitary conditions and related matters.

We have in the past, often welcomed 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 2024 and 2025 =====

Most meetings 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. Masks are no longer essential at the meeting, but you may wear one if you wish.

- Saturday 7 December 2024 at 10 am – pre-Christmas meeting with quiz, festive food to bring and share, etc.
- Saturday 29 March 2025 at 10 am – We hope to have Kathryn Pearce providing tai chi exercises, as well as exercises specifically designed to help those with arthritis
- Saturday 28 June 2025 at 10 am – No formal speaker; a patient-led meeting
- Saturday 27 September at 10 am – Speaker not yet confirmed
- Saturday 6 December 2025 – Our pre-Christmas meeting
- Isle of Wight meeting, Saturday 19 July at 10:30 am, probably at Lake Community Centre, although other venues are being considered

Possible speakers for future meetings include Dr James Lawrence and Dr Smith from Salisbury, the endocrine nurse Sirbrina, a radiographer, a pharmacist, tai chi and arthritis exercises, and blood bikers. Also possible speakers on mindfulness, laughing yoga, a life coach and others.

There is always a raffle at the main meetings in Cosham and Lake. 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 has gone up again. 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 your 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 2025.

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.



Gail here: I know I always have something to say about Dr Victor Lawrence in our newsletters, but I am as always, amazed by his so very in-depth answers to our questions. **THANKS big time Dr Lawrence.**



We as patients, do become 'experts' to a degree, in as much as we learn over time, how our bodies respond, how to best work with our endocrinology / pituitary team and the NHS, etc, etc. However, when we listen during talks and presentations and read the below plus articles in Pituitary Life, etc, I for one, realise even more just how intricate and complicated the whole pituitary subject matter is.

Q 1) Adrenal Insufficiency and Hydrocortisone replacement

Having looked at the graph and read the interesting article written by Dr Lawrence in the last newsletter, I would like to know if perhaps one should split the Hydrocortisone doses one takes (I am prescribed 10mg;5mg;5mg) Especially, if one should sometimes wake early ie take 5mg not long after about 5.00 am then another 5mg later, circa 07.30am and similarly, at separate times during the day and if so would the timing for these need to be totally regular day by day?

However what has prompted me to query this now is that for the last 6-8 weeks I have been told to double my doses – sick day rules – due to consistent diarrhoea & constipation – a problem which currently isn't easily being resolved; no fever, pain nor infection. I have therefore been taking 10mg x2 in the morning – separated by time as above; 5gm x2 at lunchtime & 5gm x2 at about 6pm. I feel it might be better if these doses were spread out better during the day?

Also how long should one keep doubling up the dose? Would that be until the problem is over and done with? As it is, I worry that so much doubling up, may not be very good for one. Many thanks – Caroline

Thanks for your question Caroline. I do not know your medical history and it is always difficult to give you personal specific advice given that, but my immediate feeling is to agree with you that this is a very long time to be doubling up on your hydrocortisone. The idea of doubling is really to mimic the body's natural response to an acute illness rather than to keep on doing this open-endedly. If a person suddenly develops diarrhoea out of the blue, this may be because of an infection (usually viral but other infective types e.g. salmonella, amoeba etc exist), which requires more hydrocortisone to deal with. As you suggest, it could also be that the diarrhoea may be a sign that you are developing an adrenal crisis for some other reason. However, if this were the case, to be honest, diarrhoea would rarely if ever be the only sign of being under-replaced or going into crisis, this would usually be together with other more obvious signs (hitting the buffers, dizzy, vomiting etc). For the usual infectious type of diarrhoea, you would need 'stress doses' (double) hydrocortisone for a short period of time, usually no more than a few days, until you are feeling better, any temperature has resolved, and the diarrhoea is settling. If it really was thought that diarrhoea was a sign of a usual hydrocortisone dose that was too low for your needs, then the dose might be increased a little, but I would stress that diarrhoea alone with no other symptoms would rarely, if ever, signify this. If you have developed more 'chronic' (meaning long lasting) diarrhoea, then this would seem much less likely to be due to a simple infection and if it didn't get better with doubling your hydrocortisone, then it seems most unlikely to be a sign that your steroid replacement doses are too low. This would suggest to me that you may need some tests to find out why you have had what would probably better be called a 'change in bowel habit'. There are many simple causes of this from stress, change in diet,

new medication etc. but a few more serious causes do exist that need a diagnosis and specific treatment. In general, if there is no obvious cause and a change in bowel habit goes on for more than a couple of weeks, most people would be offered some tests that might include any or all of a stool sample (to test for inflammation and possibly for some parasites and other infections), some blood tests and possibly a colonoscopy (examination of the colon using a fibre-optic tube or 'telescope'). It sounds to me that the time may have come for you to discuss more extensive investigations and to move on from the idea of just doubling your hydrocortisone and living with it but again I have to stress that I do not know your full medical history and whether or not you may have had tests like this done already or whether there are any other factors to consider. I would be concerned that fixation with your steroids could delay appropriate testing for you and also share your concerns that this is not a long-term strategy. Although there are some inflammatory causes of diarrhoea that can be treated with steroids (in anyone, regardless of whether or not they have a pituitary condition), these require a specific diagnosis and then more targeted treatment. I hope this is helpful and has answered your second question which I agree may be the more pressing of the two.

In terms of your first question, I agree that it is theoretically possible that taking small doses of hydrocortisone more often could mimic natural secretion better than the normal three times a day dosing that we generally use. To some extent, the concept of a hydrocortisone infusion is trying to do exactly this by infusing hydrocortisone continuously. My only concerns would be that we don't really have good scientific data to show that it is actually better, that one would have to be really careful to avoid a situation where levels are high into the evening and night where they could be most harmful and that you could miss out on ever achieving a peak level which may be important for at least some aspects of steroid action. I think what I am saying is that I see where you are coming from and there are reasons to think that this makes sense but I would just have a concern that the history of medicine is littered with good ideas that made sense but ended up being worse than existing treatments for reasons that were difficult to foresee at the time. It is hard to know, for example, what taking a 5 am dose of hydrocortisone might do to your circadian sleep rhythms (would you get back to good quality sleep for example or could it make you wake up and stay awake every day at 5 am?) and how it may interact with the circadian rhythm of cortisol binding globulin, the protein that binds most of the cortisol in the blood and affects how cortisol is either cleared by the kidneys or made available to receptors over time. Probably no harm to try it for a short time if you feel strongly minded to but I think I would suggest discussing it with your endocrinologist before doing something like this over the longer term. Of course, if it didn't make a noticeable difference, you would probably just continue taking it in the traditional way. This is just my opinion, I don't think there is any strong scientific evidence either way and it's probably important if you are considering going 'off-piste' so to speak, to do it with the agreement of your endocrinologist. I hope that's helpful.

Q2) When you are vomiting and you use the emergency cortisol injection, if this then stops you vomiting, does that mean the vomiting was low cortisol? Or is it that a huge injection of steroids would make everyone feel better?

My Doctor originally told me that steroids would make superman feel better, which is why I questioned it - Jodie

Hi Jodie, thanks for your question. It is a good one and gives me a chance to clear up something I think many patients and even non-endocrine doctors may become confused about. The answer in some ways is a little similar to some of my answer to Caroline's question above and I think there is no harm at all in me trying to give the same answer in a

slightly different way. We can vomit for all sorts of reasons and most of these are just seasonal (e.g. norovirus) or food related (food poisoning) infections unless there is some other obvious cause e.g. medicines such as chemotherapy or some types of morphine-like painkiller, severe anxiety etc. When it is an infectious cause like this, there are 2 things to consider for someone taking hydrocortisone (or other forms of steroid replacement). Firstly, an infection severe enough to make us vomit requires a stress (double) dose of hydrocortisone until it has cleared and all our readers on steroid replacement will be familiar with this. However, the second problem with vomiting is that it interferes with our ability to take that stress dose as we may bring that up. The advice is therefore after vomiting to take a stress dose and if that is vomited too, then to consider an emergency injection and either way come to hospital for steroid treatment before an adrenal crisis occurs. We would much rather treat someone for a while to prevent them getting too ill than for them to wait for a full-blown crisis and come to hospital potentially very unwell indeed.

However, vomiting can be a sign that someone is going into an adrenal crisis and can therefore be caused by insufficient cortisol levels. This would typically happen if someone who is unwell (e.g. because of some other infection) is not able to take stress dose steroids and stay well hydrated. Typically, there would be other potential signs of a crisis such as a temperature, dizziness, extreme fatigue etc. as well as the vomiting. In this case, a steroid injection may stop the vomiting. However, most people stop vomiting after they come to hospital anyway as they are given a hydrating drip and medication to stop vomiting so it may be difficult to know what actually worked. With adrenal insufficiency, it is always best to give steroids if there is any doubt at all and try and work out the finer details later on if possible (and it isn't always possible to be certain).

Finally, your point as to whether a huge dose of steroids will stop anyone vomiting and make anyone feel like superman is also a very good one. Many chemotherapy regimes that are expected to make people feel very sick are actually given with a very large dose of a steroid called dexamethasone (10 mg daily which is equivalent to about 300-500mg of hydrocortisone!) to reduce the vomiting and yes, some people feel great on steroids even if they don't need them at all, they get a real buzz. These are just some of the reasons that make getting the dose right for people very difficult indeed- we all want people to feel as well as possible but on the other hand, we don't want to give them an artificial steroid buzz that in the medium to longer term causes very severe steroid related side effects. This is a really delicate balance for many people and their doctors. I hope this slightly complicated explanation helps to make sense of what can definitely be quite a confusing issue.

Q3) It would seem that when testing for thyroid, sometimes it is only the TSH and FT4 levels which are checked. Is the FT3 level also automatically checked? If not, what symptoms might present when this would be deemed appropriate and what are the criteria to then be prescribed T3 replacement, ie Liothyronine? Thank you – Maggie

Dear Maggie, many thanks for your question- this can be quite a controversial area! When it comes to thyroid hormones, free thyroxine (fT4) comprises the majority of the thyroid hormones produced by the thyroid gland (usually about 85%) but a smaller amount (about 15%) of free tri-iodothyronine (fT3) is also produced. Thyroid hormone action is mostly driven by fT3, and fT4 is generally considered to be a less active precursor that needs to be converted into fT3 to have the majority of its effect. Thyroid hormones are mostly bound to carrier proteins in the circulation and only around 0.2% of the total is 'free' and therefore able to act on receptors, which is why we always measure this so-called 'free' level. As well as the small amount of fT3 produced in the thyroid, free T4 is converted to fT3 (mostly in the liver but also elsewhere) where it contributes to what we can measure in the circulation when we do a blood test. However, and crucially, this conversion also takes place as fT4

gets taken up into cells and moves to the cell nucleus where it binds to the DNA and has its action. This local conversion of fT4 to fT3 happens particularly in the brain (also in fat and in muscles) and is a way that the brain can control its own exposure to thyroid hormones. Several organs, including the brain, are also able to de-activate fT3 that has been taken up which is another way that they keep their exposure to thyroid hormones fairly constant over time. Because of all this, measuring fT3 in the blood does not help us to understand very much about how much fT3 is available inside important organs like the brain and muscle. In addition, for complicated chemical reasons, fT3 is difficult to measure accurately and blood levels taken from the same person may give quite variable results in different labs or even when repeated in the same lab.

In some ways vitamin D is organized a bit like this and if you think about why that would be, it makes perfect sense. Vitamin D is a hormone, so should we allow our very different levels of sunlight exposure (from Alaska to the Bahamas for example) to determine how this hormone acts in our blood? Of course not, that would be a disaster, our calcium levels would be determined by the sunshine and none of us would have any this year when we missed out on summer! What happens is that sunlight gives us a store of inactive 'ordinary' vitamin D which is then activated as required under very careful control by very specific processes in our kidney regulated by parathyroid hormone, so that the final action is precisely regulated. We do occasionally have to treat people with some forms of parathyroid disease with 'activated' vitamin D and I can tell you that this can be very difficult to control accurately. In the same way, giving thyroid hormone replacement in the form of fT3 runs exactly this risk- we would be bypassing the body's own controls.

So what does all this complicated physiology mean in practice?

- 1) The majority of fT3 comes from conversion from fT4 (thyroxine). Although we can measure fT3 in the circulation with a blood test, this does not tell us what the levels are in important organs such as the brain
- 2) Measurement of fT3 is not terribly accurate in terms of the number you get and even less accurate in terms of understanding how it is binding to DNA within our cells and having its effect.
- 3) In almost all individuals almost all of the time, having enough fT4 means that the body will be able to provide sufficient fT3 either in the blood or, more importantly, inside the brain where it is crucial.
- 4) Giving thyroid hormone replacement in the form of fT3 (liothyronine) rather than as fT4 (thyroxine) may bypass some of the body's own regulatory systems and that is potentially risky

So, one question may be whether it may be possible for a person not to be able to make this conversion from thyroxine to liothyronine and to have low levels of fT3? The answer is yes, but there have only been a handful of people in the whole world ever with this. So it is highly, highly unlikely.

Is it possible that people might feel better if given fT3 replacement (tablets called liothyronine)? This is what is really controversial. In scientifically designed trials where neither the researchers nor the patients knew what they were taking ('double blind placebo-controlled studies'), no particular benefit is generally detectable. However, there are a few people who say they feel great on fT3 (either alone or in combination with thyroxine) and less well on thyroxine alone. Whenever we measure fT3 in these individuals, we find that it is normal. There are risks of taking fT3 (liothyronine) - we bypass the body's controls,

osteoporosis appears more likely, it is easier to overdose, it has a short duration of action which means that even if it is taken three times a day, you get massive peaks in the blood levels followed by periods of time where the levels drop very low which may be far from ideal for example due to the way that the heart is driven during the peaks. One way to make sense of this is that liothyronine is a stimulant and like all stimulants (large amounts of coffee, even drugs like amphetamines), people feel good during the 'high' at first but over time the body can start to need the regular 'hit' just to feel normal and eventually the risks can become apparent. On the other hand, it is always difficult when some patients clearly experience beneficial effects from something that science tells us should not be needed and may even be harmful. I think the general consensus is probably that for most people most of the time, thyroxine is better and safer than liothyronine. For some people some of the time, who feel very strongly that something definitely changed for the worse in their lives on thyroxine we may give a trial of a small amount of liothyronine on top of thyroxine warning of the potential risks. If this is transformative (which I have only seen a couple of times to be honest and even then it is impossible to know whether it is just a 'placebo' effect), then we may continue. If it is not transformative, which is much more often the case, then it is safer and better to discontinue. Some endocrinologists are more 'purist' than others on this and don't use it at all and this view is the one that is really supported by evidence. Others do take a more flexible approach even if this is less supported by evidence. On a personal level, whilst I do occasionally give people a trial of liothyronine under specific circumstances, I am pretty certain that if I needed thyroid hormone replacement myself, I would just take thyroxine and would be confident that this would replace my thyroid hormones perfectly well. If I didn't feel perfect, just as now, I would look for other causes (diet, exercise, work-life balance, stress management, relaxation, hobbies etc.) and address those things that we know are essential to our wellbeing rather than take a drug with little or no evidence of benefit and real risks of harm.

Q4) Is it OK /advisable to have the Covid and flu jabs at the same time with Addisons or should there be a gap? If there is to be a gap, how long should this be? - Melanie

Dear Melanie, vaccination against both Covid-19 and flu is strongly advised for people with either primary (Addison's disease) or secondary (pituitary cause) adrenal insufficiency. Both can potentially lead to an adrenal crisis as well as make you generally very unwell (or worse) so any steps that can be taken to reduce these risks must be a good thing for most people. Taking steroid replacement does not mean that a person suffers from impaired or reduced natural immunity as steroid *replacement* is just replacement of what should be there which is different from steroid *treatment*, which is usually at much higher doses and can very much affect natural immunity. I am not aware of any current advice about separating these vaccinations in time other than based on a particular individual's personal experience of double vaccination being 'too much' for them. In other words, unless you have struggled having both before and I don't think there is any particular reason to predict that a particular individual will (other than by having two mildly sore arms and possibly feeling a bit below par and needing to take some paracetamol for a day or two) then both together is fine. They are usually given into different arms of course. I hope this has answered your question and I hope your vaccinations prevent you getting both flu and covid over the winter or at the very least, mean that you only get them mildly.

Comment from editor: I recently had a flu jab one day and a covid jab the next day. The covid nurse said that was fine, and she gave me the covid jab in the same arm as the flu jab, on the grounds that I would only have one sore arm, not two.

A Pituitary ditty ... from Jackie Stuart

We all belong to The Pituitary Foundation
Whom we all thank with gratification

Hints and tips to help each other out
If we don't know the answer we will put out a shout

Friendships are made from far and wide
Support is at hand from each and every side

As committee members we do our best
To give information with all the rest

We keep updated with what we have heard
Anything you want to tell us we will spread the word

Always remember there is someone to talk to
As each and every one of us are important and so are you

On the lighter side:

John: Have you heard about Dave? I've been told he was taken into hospital last night.

Bill: Really? I only saw him yesterday evening, dancing with an attractive blonde. They seemed to be getting on very well together.

John: Yes. But his wife saw him too.

Dave's brother didn't fare much better either. When he staggered back home drunk at two in the morning, he was met in the hall by his wife, holding a rolling pin.

"Oh hello darling," he said. "What are you doing making pastry at this time of night?"

And then there was the man who was on his way back from a heavy session at the pub when a policeman stopped him.

Policemen: Where are you going sir?

Man: Officer, I am on my way to a lecture.

Policemen: A lecture? Who'll be giving a lecture this late in the evening?

Man: my wife.

But their friend was much better behaved when he visited a pacific island without his wife. He was met by a beautiful native woman. The first day she showed him around the island. The second day she introduced him to some of the important people on the island. The third day she prepared him a wonderful meal made from local exotic ingredients. On the fourth day she gave him her most seductive smile and asked him if he fancied a bit of fun.

"Oh, do you play cricket here then?" he asked.

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