The Solent and IOW Pituitary Support Group

The Pituitary Foundation
Solent & Isle of Wight
Support Group

Newsletter No. 86, March 2024

Hello everyone,

Welcome to another edition of the Solent and IOW Pituitary Support Group Newsletter, for March 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. Now that coronavirus restrictions are behind us we are meeting again at Cosham Community Centre. The next meeting is on **Saturday 23 March at 10 am**. There will be tea, coffee, juice and biscuits. And a raffle. 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.

We are very pleased to confirm that we will be joined by Dr James Lawrence, Consultant Endocrinologist from Salisbury Hospital. Dr Lawrence often attends the Salisbury Pituitary Support group meetings and gives a very good talk. There will be lots of opportunity for our questions so come along and we can take advantage of having his undivided attention !

Then there is our Southampton meeting at Southampton General Hospital on Saturday 11 May. See page 3 for details.

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.

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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 ===================

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 23 March 2023 at 10 am – Our speaker is Dr James Lawrence, Consultant Endocrinologist from Salisbury Hospital.
- Southampton meeting Saturday 11 May 2024 at 10:30 am at Southampton General Hospital. See page 3
- Saturday 29 June 2024 at 10 am – No speaker; instead a patient-led meeting
- Isle of Wight meeting Saturday 20 July 2024 at Lake Community Centre with Dr Victor Lawrence – **Please note**: We have an amazing resource in our Consultant on the IoW, who gives up his time for us plus answers our questions in our newsletters too, of course. But, the turn out when we came over for you last year was quite frankly rubbish, so it has to be said that if you don't support us this year, we won't come again alas, which would be a great shame because we, your committee members, enjoy coming over. In other words … 'if you don't use it, you lose it' !! I would add that Dr Lawrence was concerned that the low turnout last year was down to him and it is upsetting to think he felt that way.
- Saturday 28 September 2024 at 10 am – Tai Chi plus arthritis exercises with Kathryn Pearce
- Saturday 7 December 2024 at 10 am – pre-Christmas meeting with quiz, festive food to bring and share, etc.

Possible speakers for future meetings include a radiographer, a pharmacist 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 May 2024.

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.

Southampton meeting

We are very pleased to let you know that we have organised a further meeting at Southampton General Hospital on Saturday 11th May this year for 10:30 am and we will be joined by several members of the Endocrine Team. The opportunity to ask questions with a refresher on steroid education and sick day rules. Refreshments plus biccies available plus a raffle too of course (please bring along a prize). The details are as follows.

Conference Room
Northwing F level
Heartbeat Education Centre
University Hospital Southampton
Tremona Road, Southampton
SO16 6YD

Gail here: I know I always have something to say about Dr Victor Lawrence in our newsletters, but I am yet again, blown away by just how fortunate our support group is in that he replies to our questions in such depth. As a patient, I do sometimes feel overawed by how complicated our particular pituitary conditions are and from my recent emails with Dr Lawrence, I know he feels that he can’t always do justice to our questions because of limited space in our newsletter. Mind you, any ‘quality publication’ has a limited word count of course!
Also, when you add in the complexity of our questions, the answers don’t take 5 minutes do they, so, are we LUCKY or what ??? ☺

Q1) Is it normal to have a personality change in behaviour / mood swings, etc, after pituitary tumour surgery, which I had 6 years ago? I am an acromegalic male taking Hydrocortisone & testosterone replacement by injection. - Chris Y

Dear Chris- The short answer to your question is definitely ‘yes’ but as always, things can be quite complicated. There are several things that could contribute: acromegaly itself, whether the acromegaly was cured or not, any treatment for acromegaly (surgery, medication, radiotherapy) and any unwanted effects of any of these, having the shock of a pituitary diagnosis/treatment, any other hormone disturbances and any lasting effects of the acromegaly that remain even after cure such as joint problems or change in appearance. Although there are quite a few studies showing that people who have, or have had, acromegaly are more likely than others to have changes in their mental wellbeing, very few have been able to tease out what the driving factors for this are. I suspect this may be because it would be quite difficult to gather large numbers of people with similar experience together in a trial as there are different presentations in different people with different baseline mental health and they all have different treatments with different success in controlling or curing acromegaly and different unwanted effects e.g. deficiencies of other hormones. You can probably see that designing studies to really untangle this is very difficult. What we do know is that there does appear to be an increased rate of depression (perhaps up to a third of people) in people diagnosed with acromegaly regardless of how they are treated and what the treatment outcomes are. In addition, there are reports in the medical literature suggesting that mood swings, a feeling of burden, reduced overall quality of life, impairments in body-self-perception, disruption in interpersonal relations, decrease in sleep quality, and social withdrawal anxiety may all be more common in people who have, or who have had, acromegaly. I don't know whether this helps to at least help you to understand that your symptoms are recognized as being possibly linked to your condition? Of course, all these are feelings that can be experienced by people who have not had acromegaly too but there is certainly an association.

In terms of treatment, it goes without saying that your acromegaly should be cured if possible or controlled as well as possible, any drugs you are taking for it checked in case they themselves can cause psychological issues and replacement of other hormones (you mention hydrocortisone and testosterone) should be as good as possible. Occasionally, people with treated acromegaly actually become growth hormone deficient and, for some with severe deficiency, treating this may be helpful for overall quality of life, mood and social confidence. Beyond that, treatment may involve either talking or drug treatments as recommended by a mental health professional if the symptoms you are experiencing are intrusive and affecting your life and quality of life. I hope this is helpful and hope it may help at least to know that there are others in a similar situation.

Q2) For the last 10 years since my pituitary macro-adenoma removal I have received the 12 weekly Testosterone injections and I am now 62 years of age. From what I've read, testosterone would naturally decrease as a man ages. Does this mean that my dose of Testo should also decrease (i.e. a frequency longer than 12 weeks) as I get older? Or would the dose remain the same, or is it simply decided by Testo levels in my blood, which is monitored annually? - Carl H

Dear Carl- Thank you for your question and it is a good one. As always, this is rather complicated but you may have known I'd say that! Testosterone is measured pretty accurately in blood tests and we certainly do get a number back when we measure it. However, that number is not the whole story. What we really want to know when we measure testosterone is 'how much is this man transcribing his androgen responsive genes'. What I mean by that is that testosterone is a steroid hormone that acts to change the way we make proteins using the recipe stored in our DNA (genes). Some may be increased in response to testosterone (an androgen, male type hormone but not the only one) and some reduced. We can't really measure this or at least not in any way that is useful in clinical practice, so we try to use the measured testosterone number as a guide to what we really want to know. The problem is that there are many steps between the testosterone number we can measure and this thing that we really want to know. Firstly, testosterone is mostly (98-99%) bound or 'mopped up like a sponge' by a protein in the blood stream that stops it being free to act on receptors. We measure all of the testosterone in the lab test but we don't know if a man is binding 98% or 99% so already there may be a large difference in the free testosterone which is the small but active amount (is it 1% or 2% of the number we measured, it might make a big difference!). Next, testosterone is converted to other hormones (e.g. DHT) which are more potent in many ways but we can't measure these routinely. Then men have a pretty individual receptor for testosterone that may vary enormously in how well it responds to testosterone or other androgens (so they may actually need different levels for the same effects in theory). Finally, there are a number of factors that can affect all the processes between testosterone binding its receptor and the reading of genes in that cell changing. What I am trying to give you an idea of is that it is much more complicated than the number we get from the lab. It is certainly true that testosterone does on average fall as we age and it is also true that the amount of that testosterone that is bound by the protein in the blood also rises meaning that even less of it is available to the receptors. We do not absolutely know whether there is a good reason for this (although I do sometimes think there may be a good reason that older men do not behave in testosterone driven ways quite like younger men on average most of the time!) or the precise extent that reading DNA is, or indeed should be, changed with aging. We also I think, have to bear in mind that people are often aging better these days and many are sexually active much later in their lives than perhaps may have been the case years ago so they won't necessarily want low levels to interfere with this just because the average falls with age. The bottom line is that testosterone safety is monitored with various blood tests and I'm sure this and any symptoms (or lack of symptoms) is reviewed by your endocrinologist. We do not tend to deliberately or systematically decrease the dose with aging although perhaps we might not be so keen to increase the dose for borderline levels in the absence of symptoms and we might be less tolerant of borderline high levels than we would be in a younger man. Beyond that, we don't really have any very scientific way yet to get this fully individualized. This is going to be a theme in some of the other questions in this issue relating to other hormones I'm afraid too!

Q3) Blood tests – It used to be standard practice for us in our Pituitary clinic, and I believe for others across the country too, that we used to be able to go and have blood tests around 3 weeks before our endocrine appointment, so they would have the current status of our hormone levels when we see our consultant and therefore, be able to discuss /optimise during the appointment. This obviously can save time waiting (sometimes months) for our copy of the letter to our GP with blood test results from the actual appointment. Is this not now considered best practice ? - Patrick M

Dear Patrick - Thanks for your question. I don't know where you are treated and whether there has been a specific local change to your service. I still give patients a blood form during their consultation that they have in advance of their next one for exactly the reasons you give but without knowing more specifics, I can't really comment on other hospitals or departments. For most tests, a couple of days in advance is generally enough but there are some hormones (IGF-1, ACTH, metanephrines etc.) that can take up to a month depending on where the blood is taken and where it is sent for analysis. Most patients will be aware whether or not their condition needs any of these tests that take longer to process. I hope that helps but I realise that I may not have been able to address your specific concern.

Q4) Like many taking replacement corticosteroids to compensate for primary & secondary adrenal insufficiency, I suffer from poor energy levels from mid-to-late afternoon onwards. In common with many others, I also take the standard three doses of hydrocortisone daily (and fludrocortisone with my first dose). My degree of end of day debilitation has worsened since diagnosis with Addison's more than 20 years ago, and as I have got older (now 67), I do occasionally top up although I tend to avoid doing extra evening activity since, despite taking a top up, it invariably impacts my circadian rhythm and results in poor sleep. I have been proactive in joining various trials to explore what might improve my current regime. A trial of low dose prednisolone didn't help and I could draw few conclusions from my personal data from participating in the Ultradian trial. I don't have much faith in day curve tests from past experience.

My question is this - should current clinical practice be moving away from prescribing 2 or 3 fixed replacement daily doses towards a method that more closely mimics the natural production of cortisol within the circadian rhythm; secondly, could you comment on the approach developed by Prof Peter Hindmarsh in this area, and until such time as a wearable device is available to deliver a more personalised level of cortisol infusion, how can I, as a patient, firstly best determine, and then manage, my own replacement needs using hydrocortisone tablets? - Julie W

Dear Julie, this is such a good and ultimately difficult question and I suspect you probably know that I will not have a definitive answer because the greatest minds in the field do not have one yet either. It sounds like you have both pituitary and adrenal dysfunction and I am guessing either you had Addison's disease and then went on to develop a pituitary condition or alternatively you had to have both adrenals removed as a treatment for Cushing's disease after probably first having pituitary surgery that did not cure you permanently. You have clearly become extremely well informed about all of this and have joined trials in the hope of finding answers both for yourself and others. Firstly I agree with you about day curves. I think they can tell us if there is a big dip in cortisol at a time that fits with regular symptoms and they can tell us if someone is just not properly absorbing their hydrocortisone or if their hydrocortisone seems to have a particularly long or short length of time in the circulation before is excreted or broken down (this is actually rather variable between different people) but overall, they tend not to be particularly helpful a lot of the time although some (e.g. Hindmarsh who I briefly trained under once upon a time) do very much think they have a place. The 'standard' day curve (with cortisol levels measured from blood every 1-2 hours between 0800-1700 on a single day) is less than perfect for 3 main reasons (and there are probably others):

1. There is no 'one size fits all' level of cortisol at any given time of day that is ideal for everyone. The ranges are huge.
2. Even if we measure cortisol, we measure 'total cortisol' in blood tests and this contains a lot of inactive cortisol that is stuck to a binding protein which keeps it away from receptors. So we measure it, but it isn't really active. It doesn't much help even to measure the binding protein (which is difficult to do in routine practice) because this has its own circadian rhythm that is very different to that of cortisol. It was hoped that salivary cortisol might help with this as it is a form of 'free' cortisol but I don't think it has yet proved to be good enough to be able to transform our replacement strategy.
3. There is no single effect of cortisol that we can measure that tells us if the dose is right. Yes, we can rate an overall sense of wellbeing/energy and that is obviously important but it depends on much more than just cortisol and isn't an absolutely direct measure of cortisol action (we don't necessarily feel happiest in the morning when our cortisol levels are usually highest). Some hormones are different- if you inject adrenaline, you see an immediate and measurable increase in heart rate and blood pressure for example so you can measure the effect easily but there is nothing direct like this that we can measure for cortisol.

This brings us to the idea of using pumps (and possibly also cortisol sensors) to try to do better. There are some aspects of three times daily hydrocortisone that will never match perfect replacement. Normally cortisol starts to rise before we wake up but it's hard to take a pill whilst you are asleep. Normally, replacement will overshoot the natural target level of cortisol and then fall below it until the next dose is taken. Normally there will be a very low level of ongoing cortisol production at night never quite falling to zero but on tablet replacement, most people will have zero levels overnight. Finally, cortisol is produced in pulses rather than at a constant rate and tablets can not mimic this. There have been some promising trials of pump therapy which can try to mimic these cortisol pulses and very low but non-zero overnight levels and rise before waking. This is a body-worn pump that releases hydrocortisone continuously via a small tube inserted just under the skin (many people with type 1 diabetes are now using similar systems to deliver insulin). There is some early data from use over 6 weeks (the 'PULSES' trial available on-line at *Ultradian hydrocortisone replacement alters neuronal processing, emotional ambiguity, affect and fatigue in adrenal insufficiency: The PULSES trial (wiley.com)* that people on average may feel a little better (less fatigue in particular) but this is early data and not yet really proven in longer term studies and we do not yet know for example whether or not there could be longer term problems from this method of replacement. It is quite intrusive being connected to a pump all day and there are at least theoretical dangers from disconnection or pump failure although it did appear safe in the trial of 21 people over 6 weeks. At the moment, I think this is a space to watch but it does give some hope of future development in a field that hasn't really moved on at all over the past 30 years since I trained. At the moment, I can't give you a definitive answer about self-management because of all these difficulties and one of the reasons for this is of course that in the short term, people may sometimes just feel better the more hydrocortisone they have but this clearly stores up large problems in the longer term. But at least there is progress and I hope that is at least some consolation for a situation that many reading this will find very frustrating. This really is a big question and I am aware that space is limited and there is a lot more I could talk about. If there is wide interest in this whole subject, I would be happy to try to go into it in more depth in the next issue of the newsletter.

Gail says *- please let me know if you would like Dr Lawrence to go into this very interesting subject in more depth for our June Newsletter.*
Me, well I would definitely like more information.
Email: g.weingartner@btinternet.com or text / phone 07525 041947.

Q5) For hypopituitary patients, how does our autonomic nervous system (sympathetic and parasympathetic) work /respond differently to the 'average' person? - Jessie N

Dear Jessie, this is a really interesting and complicated question and I think the short answer is probably that we don't really fully understand the inter-relationships between the autonomic nervous system and pituitary disease. For the benefit of other readers, the autonomic nervous system is an unconscious part of the nervous system that deals with many things that we don't have to think about. These are sometimes thought of as either 'fight of flight' referring to the sympathetic branch or 'rest and digest' referring to the (often) opposing parasympathetic branch of the autonomic nervous system. These effects include increasing heart rate, blood pressure, sweating and increasing blood flow to muscles at the expense of reduced blood flow to the gut and skin (which are mostly sympathetic nervous system effects mediated by adrenaline and noradrenaline) and also digestion, slowing heart rate, relaxing blood vessels, changing pupil size in the eye, urination and bowel control which are things we don't think too much about doing when running from a threat. There are plenty of publications reporting studies that show that, for example, sympathetic nerve firing rates measured in muscles may be affected by growth hormone deficiency and that CRH (the hormone that stimulates the pituitary to produce ACTH that in turn stimulates the adrenals to make cortisol) when injected directly into anaesthetized rat brains might modulate their autonomic nervous system activity but I don't think anyone really knows how these observations might usefully inform or relate to humans living with pituitary conditions. I think we can probably say that there are likely to be physiological links but that we don't understand how they all work in a fully integrated way. Certainly, cortisol is needed for a normal body response to adrenaline and when the sympathetic nervous system is activated, cortisol levels will usually begin to rise after around 15-30 minutes, and this will not happen when a person is on steroid replacement. To what extent this may cause symptoms is relatively unknown and also there is little that can practically be done to helpfully change the complex function of the autonomic nervous system in this situation other than to replace pituitary hormones as well as can be done and perhaps to be understanding of the fact that some things that people experience are not fully understood but nevertheless, real. I'm sorry I can't really give you a simple and authoritative answer to this very interesting question.

Q6) I am on prednisone 5 mg daily and it states within the information that this suppresses the immune system. When I was on Hydrocortisone I double dosed if sick. What should be done when on prednisone? - David G

Dear David- The package inserts assume that steroids (such as prednisolone or hydrocortisone) are being taken for inflammatory conditions at much higher doses than you will take for hormone replacement. This is just because the majority of people taking prednisolone take it at high doses (e.g. 40 mg daily or higher) for inflammatory conditions such as acute asthma, some forms of inflammatory arthritis or inflammatory bowel disease e.g. Ulcerative Colitis where the object is to slow the immune system down a little. Doses that are above the replacement dose (the replacement dose that you are taking is within the typical 3-5 mg per day range for replacement) of any steroid will depress the immune system but this is not really relevant to you because you are on a replacement dose. You should absolutely take sick day precautions (e.g. double-dose) when sick just as you were advised with hydrocortisone and please discuss the exact advice for your particular overall circumstances with your endocrinologist. Unfortunately this does cause quite a bit of confusion but just to be clear, I would not regard your immune system as being suppressed on this dose of prednisolone which is no more than what your body would make had you not had a pituitary condition.

Happy 30th Birthday to the Pituitary Foundation - Congratulations!

2024 marks 30 years since the Pituitary Foundation was founded and they have planned a year full of celebrations. So keep an eye out on their website www.pituitary.org.uk The website is full of information about all Pituitary conditions and their treatment. There are numerous patient stories describing their experiences before and after diagnosis. Throughout the year they host various online events, including top Consultant talks on specific pituitary conditions on zoom, with opportunities to ask questions. Some sessions are restricted to Pituitary Foundation members, but others are open to all. Details will be on the webpage, and if you're also a member of the Pituitary Foundation, you will receive emails and the three Pituitary Life Magazines a year.

So, it is well worth joining the Pituitary Foundation to learn, share and get support, as well as helping their vital work in raising awareness and providing support to those with pituitary conditions.

Be glad you're not a dog. Or a cat

I remember speaking to a woman who was telling me about her dog. Dogs can have pituitary problems as well, and this one had Cushing's, or whatever the canine equivalent is called.

"What did you do about it?" I asked.

"Oh, we had it put down."

Of course you have to find the animal first. My cat Logan likes to disappear under the bedclothes, like this. I call the first picture, *Has anyone seen the cat?*

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