The Solent and IOW Pituitary Support Group

The
Pituitary
Foundation
Solent & Isle of Wight
Support Group

Newsletter No. 88, September 2024

Hello everyone,

Welcome to another edition of the Solent and IOW Pituitary Support Group Newsletter, for September 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 28 September 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.

For this meeting we had hoped that Kathryn Pearce would lead us with some Tai Chi exercises, as well as a set of exercises to help to combat arthritis. However, unfortunately she is not available on 28 September. We hope to invite her for Tai Chi and arthritis exercises during next year. Instead Howard Pearce will be speaking about how to keep mentally and physically healthy, speaking about five ways to wellbeing.

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.

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

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 28 September 2024 at 10 am – a talk on five ways to well-being, with Howard Pearce
- Saturday 7 December 2024 at 10 am – pre-Christmas meeting with quiz, festive food to bring and share, etc.

Dates for 2025: Cosham meetings, all Saturdays 29 March, 28 June, 27 September, 6 December
Isle of Wight meeting, Saturday 19 July (to be confirmed)

Possible speakers for future meetings include Dr James Lawrence and Dr Smith from Salisbury, 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.

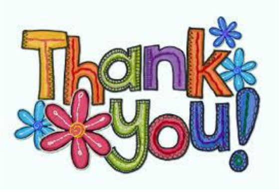
The cost of posting the newsletter – Printing and postage of the newsletter for those who do not get their copy by email is a major cost item, around £300 a year, and the price of stamps has gone up again. It would be very much appreciated if those receiving the newsletter by post would make some contribution 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 November 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.



Gail here: I know I always have something to say about Dr Victor Lawrence in our newsletters, and usually I am just blown away by just how fortunate our support group is in that he replies to our questions in such depth. We sent him three questions during August. However, in this edition of the newsletter, Dr Lawrence is not answering those questions, but he will deal with them in the next newsletter. He wrote that he has been extremely busy, and there would not be time for him to give them the attention that they require during a short timescale. As Dr Lawrence wrote:

Sorry, it's just that I haven't had any time off this year yet and I do need some.

Have a well-earned rest, doctor.

If it works, try it – from Eireen

I have resolved two health issues, which were impacting my life in a huge way, with surprisingly quick and easy treatments.

In January of this year, fatigue was reducing me to tears, my breathing on the least exertion was laboured, I lost my voice, and my feet and legs were so swollen, I couldn't get into my shoes.

A visit to the GP resulted in test after test, all coming back negative.

However, 6 months on, with no improvement, I mentioned my symptoms to Krishan, my NSA chiropractor, who some of you will remember from his talk at Cosham.

"I think you have Long Covid" he said. He suggested I wear nicotine patches, as nicotine has been found to stop the virus from attaching to the receptor cells. (I understand people with heart problems should not use nicotine).

Within two weeks my symptoms had disappeared! My breathing was normal, my voice has gradually grown stronger and I could wear my shoes again. I had been grateful, in a way, for the bad weather during spring and summer, as I had been able to wear my floppy canvas boots throughout the rainy season.

Of course, I still had a Pituitary Brain, that foggy brain feeling, when no matter how hard you try to figure something out, nothing happens and your head is a blank. You forget what you had for breakfast, can't recall facts, words or people's names. I also have a neurological condition which results in brain fog (double whammy) and impacts on my mobility.

Again, Krishan to the rescue. "I think you would benefit from taking Lion's Mane" he said. Lion's Mane is a mushroom. It strengthens the myelin sheath around the nerves and spinal cord. It is well known as a remedy for brain fog, strengthening all those nerves in your head. I have been taking it for 2 weeks and my head feels normal!! It feels clear. It has let the sunshine in! It's a very strange feeling, one I haven't had for a long time. It's wonderful. I'm keeping my fingers crossed it will help my mobility, too.

I asked Krishan if he thought it was the result of taking the Lion's Mane. It seemed too soon. He had to check a few things in my body's responses to his tests. Yes! My nervous system was already more relaxed, stronger and less resistant. I am overjoyed.

I buy Lion's Mane from British Supplements. It is produced without fillers and additives.

I also use mushroom tea, Myracle, containing Lion's Mane and other beneficial mushrooms.

Krishan recommended a coffee, London Nootropics Lion's Mane, but I try to avoid caffeine, so I looked for an alternative.

Give it a try. What have you to lose but a few pennies, erm……pounds!

The Southampton meeting

Our meeting at Southampton General Hospital in May was very good and was well supported, Mr Philip Newland-Jones was very interesting and it was good to get the chance to practice the emergency injection with specialist Endo Nurses Nemia and Alicja.

A BIG thank you to Pauline Swindells who made the following notes for us:

People mentioned issues with certain brands of Hydrocortisone and although Philip said they shouldn't be that different, however that's not the case from the forums. As it is an essential drug, we should be able to get the brand that suits us best regardless of the cost. Most people find Accord to be the best brand even if it is more expensive.

The following brands have the same PL number PL 20075/1249 meaning they are the same formulation as the Accord brand. The brands are Northstar Accord (brown box) and Almus Accord (greyish box).

If people want a lactose free brand of Hydrocortisone then Resolution is the brand to ask for.

DHEA was also mentioned and our very own Dr Victor Lawrence answered a DHEA question in great length in our November 2023 Newsletter no. 85. If you do not have access to that edition of our newsletter email Gail g.weingartner@btinternet.com or telephone 07525 041947 and she can let you have a copy. DHEA is rarely prescribed here in the UK but you can buy it from Biovea.com. You should of course, ask for your levels to be checked before you take it.

Plenadren was also mentioned, which is a modified release tablet for cortisol replacement that is supposed to be taken once a day. However, research has found that you don't get the full amount of the drug in one dose. So if prescribed 20mgs you may only get 16-18mgs of the drug so you will be short for the 24 hours. Whether there is any benefit to taking Plenadren is questionable.

If you would like more information about Plenadren, Pauline is happy to provide this. It is more expensive than other drugs. Pauline tried it for several months but didn't find it any better than HC, although she is now taking Prednisolone for her cortisol replacement.

Prednisolone is prescribed as a once a day drug; however, many people, including Pauline, split the dose. Some will split it in two doses while others will split 3 or 4 times.

The other thing Pauline wanted to share was that the Hydrocortisone injection can be drawn up and kept in the fridge in a light proof box for up to 80 days and can still be used (from the Addison’s Self Help Charity website). This would help those who may go into crisis frequently or who are unwell so can make it up in case they go into crisis.

More information from
https://www.addisonsdisease.org.uk/news/drug-shortage-alert-injectable-hydrocortisone

The other take home message was that our drugs are our property so if you are admitted to hospital, hydrocortisone / cortisol replacement should not be taken from us. We can sign a form to say that we will self-administer if the dose or medicine hasn't changed (SAM form). Our steroids should never be taken from us ! – Thanks Pauline

New NICE guidelines on adrenal insufficiency, from the Addison’s disease website.

On 28 August, the National Institute for Health and Care Excellence (NICE) has published its first-ever national guidance for the identification and management of adrenal insufficiency.

The guidance aims to improve patient safety and treatment for those with adrenal insufficiency. Put together by a committee of experts made up of healthcare professionals and people with lived experience, it is used to inform healthcare professionals when treating someone with adrenal insufficiency. It is also useful for people with the condition themselves and those who support them, such as families and carers.

It reflects evidence from research, clinical studies and clinical practice. The Addison's Disease Self-Help Group were part of the consultation process for developing the guidance alongside the medical community and other health organisations.

Positively the new guidelines recommend and highlight:

- Clarity over the need for steroid emergency cards and emergency injection kits to be issued to all patients.
- Noted that a minimum of two emergency injection kits should be prescribed, so spares available for travel or in case a vial shatters and becomes unusual in an adrenal crisis.
- Stated hydrocortisone for intramuscular injection can be given *by anyone* when adrenal crisis is suspected – helping to remove worry from carers or first-aiders for example.
- The importance of glucocorticoid as a life-essential hormone replacement and life-saving treatment for adrenal crisis.
- In diagnosis, a patient being on oral oestrogens should not delay testing (risking adrenal crisis) but instead taken into account when interpreting serum cortisol responses.
- The safety and importance of continuing all steroid replacement during pregnancy emphasised. Increased doses of hydrocortisone, such as stress doses or injections, will not harm the baby because hydrocortisone is broken down and inactivated in the placenta.
- The psychological stress definition now includes examples such as bereavement, exams, and getting married or divorced, to help illustrate and provide real-life examples to improve understanding.

The full text, all 62 pages of it, is available on line at
https://www.nice.org.uk/guidance/ng243/resources/adrenal-insufficiency-identification-and-management-pdf-66143954919877

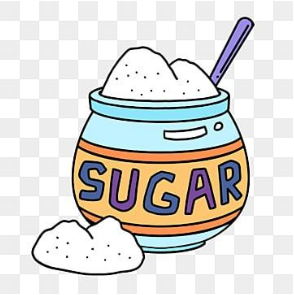
What happens next?

People may be understandably keen to implement and access recommendations in these new guidelines and we suggest that you speak to your Endocrinology team about this at your next appointment. It’s important to note that these guidelines have only been published very recently, meaning local areas will need some time to put them into practice.

We will of course be working to ensure this happens, so we can make sure we’re helping you to navigate changes to treatment, whilst supporting our incredible NHS.

There is still work to do, Addison’s disease and adrenal insufficiency are rare conditions so medical understanding and treatment is fraught with challenges. But the people at Addison’s Disease Self Help Group are celebrating a clear step towards many more people living with all types of adrenal insufficiency having access to support to help them live happier and healthier lives with the condition. Pituitary patients with adrenal insufficiency should also celebrate.

Ultimately, guidelines must be effective; the NICE document drives real change and rises to the challenge of improving outcomes for those with adrenal insufficiency. These new NICE Guidelines are vital to timely diagnosis and effective treatment, saving and improving lives, alongside reducing hospital admissions and lengths of stay, lowering costs to the NHS.



A Very Interesting contribution from Carl Hall – Thanks Carl

"Back in around May 2024, I decided to control my sugar intake, not go on a diet exactly, just cut down sugar. I am no dietician or expert in this field, this is purely my experience, but I thought the story may help you.
I have always had a sweet tooth my whole life, but I've never been overweight, yes I'm one of those annoying people! I was diagnosed with hypopituitarism in 2013, had the pituitary macro-adenoma removed in 2013 and have been on hydrocortisone and testosterone ever since, as my body no longer makes its own cortisol/testosterone.

So what led me to think about sugar intake? Energy crashes! On and off since I've started taking hydrocortisone, I have mid morning energy crashes, which I blamed on low cortisol and solved by taking an early hydrocortisone tablet dose. But this has always been quite random and annoying and if anything, was getting worse.

I had been reading about sugar online, which is obviously not always the best place to look, because sugar is somewhat demonised by many. However, it had occurred to me that despite me not being overweight (I'm 5 foot 6" and 63kg/10 stone) I do take in a lot of sugar. I was drinking around 5 cups of tea/coffee each day, each with 2 good teaspoons of sugar. I like orange squash…..so another couple of glasses of that each day. My breakfast was typical of many people; crunchy nut cornflakes or honey nut hoops etc. (i.e. sugary). So I began my journey to a change of diet.

According to the NHS the recommended intake of sugar each day for an adult is 30 grams. A teaspoon is about 4 grams, therefore at 8 grams of sugar per cup of coffee (2 teaspoons-full) and 5 cups per day, I was exceeding my daily allowance on hot beverages alone! So since May I started to reduce my sugar, less than 2 teaspoonfuls, one and a half etc. I am down to about a third of a teaspoon now and mix that with a Stevia sweetener. If I have a coffee out, then I don't need any sugar in that. For me it took over 2 months for my drinks to stop tasting absolutely horrible. Even now, I still prefer the taste of sugar, but I suppose having sugar in tea and coffee is a pretty hard habit to break after 60 years !.

I swapped my squash for plain water, obvious really. However, I have always hated the taste of water and somehow as time progressed, that has slowly tasted better as my sugar intake has lowered. I don't understand that one. I do still drink squash but nowhere near as much. The squash is very low in sugar, but it does have the sweetener Sucralose which means it still tastes very sweet.

I swapped my breakfast for the very popular breakfast of 'overnight oats'. Just plain porridge oats, but with various things added like almonds, walnuts, sultanas, fruit, dates etc. Supposedly oats release energy more steadily throughout the day rather than sugar-spiking you like sugary breakfasts do.

But, has this torture done me any good? I am over 3 months into the new regime and I do believe that it has, for me at least.

Reading online about the effects of taking in too much sugar and then having an energy crash, it very much mirrors what I was experiencing but blaming on lack of Cortisol. I have had FAR fewer mid morning energy crashes. I have had a couple of late afternoon low sugar events, which are quite different - I'm not diabetic. These low sugar events are quite different, shaking, sweating, brain fog…..but I've had my blood sugars checked and all is well. These are very rare, and stop as soon as I scoff a couple of biscuits.

There, that's it. That is my sugar journey so far. I'm hoping to continue with a lower sugar diet and hope that it continues to benefit me. I do fall off the wagon every now and then with sweet treats, but overall things are looking better.

Meant to say… an addendum to the story, I did check with my Endocrinology dept about the sugar thing before I started and they said there should be no issues with me cutting down on sugar and having adrenal insufficiency. There is no link, but they did say there is anecdotal evidence of too much sugar and then cutting back giving symptoms of brain fog and concentration issues." Cheers – Carl

From Pauline Swindells about storing ready made up hydrocortisone solution

There has been a discussion over making up the Hydrocortisone injection and keeping it in a light proof box for 80 days. The Addison's Disease Self Help Group had information on their website that states this is possible (if searched from Google)

Anyway I asked Philip Newland-Jones to research this to see if it was possible or if it was misinformation. This is a summary of what he came back with.

Making up Hydrocortisone injection & keeping it in the fridge for up to 80 days.

There's always been discussions around how long you can keep a Hydrocortisone injection made up in the fridge. The guidance we've gone by was published by the Addison's disease Society, stating that it can be kept in a light proof box in the fridge for up to 80 days. This is based on a research paper from 2005. However, in this study, doses were made aseptically and the data was intended for bulk manufacture in appropriately licensed facilities. This is very different from doing it yourself at home.

Hydrocortisone sodium succinate (i.e., Solu-Cortef)

This is supplied as a freeze dried powder and requires reconstitution with sterile water for injection before administration.

One manufacturer, Pfizer, states that after reconstitution this product should be immediately used. They cannot guarantee the stability or recommend its use outside of these conditions.

Another manufacturer of hydrocortisone sodium succinate (Panpharma) state that if made up and then not used immediately, the solution can be stored in the fridge for 24 hours.

American resources state that reconstituted hydrocortisone sodium succinate is stable at room temperature (protected from light) for 3 days. However it is unclear whether this relates to the same formulation available in the UK.

Someone contacted the manufacturers who said that it shouldn't be kept made up in the fridge.

There is also the ready-made solution, supplied as an aqueous solution, which can be drawn up without manipulation and administered in an emergency. I have not found any data to suggest that it can be drawn up and kept as a pre-prepared syringe.

I would be concerned about the stability and sterility of an injection kept in the fridge for 80 days. It is safer not to do it.

For fun, try these tongue twisters

Larry sent the latter a letter later.

Pass the big black blank bank book back. If you won't pass the big black blank bank book back, then pass the small brown blank bank book back.

Sooty Sukey shook some soot from sister Susie's sooty shoes.

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