Hello everyone,

Welcome to another edition of the Solent Pituitary Support Group Newsletter, for September 2016.

Thank you to everyone who has contributed, both by sending material for the newsletter and by giving their encouragement. The newsletter includes several articles with information about hydrocortisone.

We aim to produce a newsletter four times a year, timed to be issued shortly before each of the main Solent Pituitary Support Group meetings at the Cosham Community Centre. This time the meeting is on Saturday 24th September and our speaker will be Dr James Lawrence from Salisbury Hospital. Not to be confused with Dr Victor Lawrence who is at St Mary’s Hospital in Newport on the Isle of Wight and who has answers to questions in this newsletter.

We have welcomed several new patients and their partners, family or friends at the recent meetings in Cosham, Lake and Southampton, so if you have recently found out you are a pituitary patient or just found out that we as a support group exist, come along and join us for a get-together and you’ll be made very welcome. There is no charge to attend; just come along and find out what other people with pituitary conditions have learned. Give us the benefit of your experience. Or just enjoy yourself.

Find us on Facebook

Chloe has created an Isle of Wight Facebook group and Melissa has updated the Solent page 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 groups. They are listed as the following:
- Pituitary support Isle of Wight
- The Solent Pituitary patient support group.
Meeting dates for your diary for 2016 and 2017

The meetings are at Cosham Community Centre, Wootton Street, Cosham, PO6 3AP unless otherwise stated.

- Saturday 24th September 2016 at 10 am – Dr James Lawrence from Salisbury Hospital for an informal discussion with a question and answer session
- Saturday 3rd December 2016 at 10 am – our pre-Christmas meeting
- Saturday 25th March 2017 at 10 am - Speaker to be announced
- Saturday 24th June 2017 at 10 am - Speaker to be announced
- July 2017 - IOW and Southampton Meetings (dates to be announced)
- Saturday 30th September 2017 at 10 am - Speaker to be announced
- Saturday 2nd December 2017 at 10 am - Christmas get-together

Possible speakers for future meetings include Dr Partha Kar of Queen Alexandra hospital and Shaun, a Tai Chi practitioner. Also possible speakers from the Carers’ Association, the National Osteoporosis Society and a Biochemist, and others.

There is always a raffle at the main meetings. 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 and let him know. Or let Gail or Howard know if you wish to come off the mailing list altogether.

About half of the newsletters are now sent out by email. Unfortunately, there are always 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.

Gail and Pam Weingartner are always happy to receive a book of stamps from anyone who receives the newsletter by post. Pam sends 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 2016.

Donations

Our thanks to our fundraisers for their kind donations / 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.

A special thank you to all who contributed to this newsletter.
Answers to your questions from Dr Victor Lawrence (questions 3 and 4) and Dr Lorena Arnez (1 and 2)

Dr Arnez has recently joined Dr Lawrence at St Mary’s Hospital on the Isle of Wight and she’s signed up to answering your questions already! We are so very lucky to have this support, so please keep submitting your questions.

Q1 - I've got a question! Every endo seems baffled. So Dr Lawrence’s input would help. I've always had high IGF-1. But failed on the ITT test. My IGF-1 is still really high. What causes high IGF-1? And how can they check my growth hormone replacement is adequate? Without using IGF-1? And will I end up with acromegaly symptoms if it stays high? They said I'll get bone cancers etc.... – Jodie

Hi Jodie,

It is difficult to provide an accurate answer to your question without understanding your specific medical history. Adult growth hormone deficiency (GHD) diagnosis, GH replacement indication and GH replacement monitoring requires taking many clinical details into consideration.

I am not certain how your GHD diagnosis was made. Although the ITT (insulin tolerance test) is the gold standard to diagnose it, false positives can occur, in as many as 5% of the cases, or even higher in certain situations, such as, overweight or obesity. This means some people can have an “abnormal” response to ITT without having GHD.

And even if the diagnosis is confirmed, the indication to treat GHD is often debatable and depends on symptoms and their response to GH replacement. GH replacement is usually adjusted aiming to reach an IGF-1 in the upper half of the normal range without side effects. The main concern is in regards to the potential cancer risk or tumour re-growth. Thus, GH replacement should be avoided if there is active malignancy. However, the most common side effects in adults are: leg swelling, joint pain, carpal tunnel syndrome and glucose intolerance (something that can predispose to developing type 2 diabetes). Side-effects are more common in overweight and older people and those with higher than ideal IGF-1.

IGF-1 is mainly regulated by GH, but there are many factors that can influence IGF-1 levels too, such as nutritional status and thyroid hormones. IGF-1 level is the single best way to monitor the appropriateness of GH replacement. More clinical information is needed to understand why your IGF-1 is persistently above the normal range and how your GH replacement is being monitored.

Q2 - I have Secondary Hypogonadism, due to the removal of a pituitary tumour. In the UK this is treated by giving Testosterone either as an injection or as gel on the skin. In the US some people are given human chorionic gonadotropin or HCG, which replaces the missing hormones LH/FSH so the patient can make their own Testosterone. My question is what are the differences between these two treatments and is one beneficial over the other. Also, Is HCG even available in the UK? - Carl

A - Hi Carl, As you know, hypogonadism in man is related to the impaired ability of the testes to produce testosterone or sperm. In your case, hypogonadism resulted from a disease of the pituitary or hypothalamus as you state you have secondary hypogonadism.
Secondary hypogonadism can be treated with testosterone replacement therapy (TRT) if you aim to maintain sexual characteristics, increase in libido, muscle strength and muscle mass. However, TRT usually decreases the sperm count. Consequently, infertility is one of TRT possible adverse effects. Occasionally, TRT reduces testes size, especially if the testosterone dose is higher than ideal.

Therefore, if your goal is to improve fertility, TRT should not be used. Human chorionic gonadotropin (HCG), mimics the LH (a pituitary hormone that is low in secondary hypogonadism), and thus stimulates the testes to produce both testosterone and sperm. It is given by subcutaneous or intramuscular injections, 2 to 3 times weekly. HCG increases testosterone levels in a variable way, the increase is higher in younger than older men. The long term efficacy and safety for HCG for treating secondary hypogonadal men without fertility desire is not well established.

Both in the US and UK, TRT is by far the first choice treatment for secondary hypogonadism if fertility is not an issue. This is because TRT has a much more solid scientific evidence for efficacy and safety. In addition, TRT is less complex (usually requires 4 injections a year only instead of 100 injections annually needed for HCG) and is easier to reach the optimal dose. And, if fertility becomes an issue, the response to HCG would not be affected by the previous TRT use.

In the UK and the US, experts from respected institutions advocate against HCG treatment for hypogonadal men without fertility desire. The off-label use of HCG in these patients is occasionally (but increasingly) prescribed to “treat” significant testes shrinkage or to maintain sperm and testosterone production on patients on TRT or as a sole medication. This unlicensed use is more common in the US, as you indicate, but the drug is also available in the UK. At this stage, I would definitely choose TRT if the main goal is to improve sexual health, mood and muscle strength and would wait for more evidence in benefits and risks related to HCG.

**Q3 - Pregnant women who have premature babies quite often have a steroid injection to mature the unborn baby’s lungs. This steroid injection has been linked to ADHD in later childhood. Has there been any research into women who have carried babies whilst having Cushing’s Disease and the affect the high cortisol level could have on their unborn baby? - Charlotte**

**A -** If you had Cushing’s during a pregnancy I can see why you could have been worried about the possibility that your baby might have been affected by the high levels of steroids during pregnancy, particularly as you say with the concerns that have been raised about medical steroid administration during pregnancy. You may also have seen some research suggesting that there can be subtle long lasting psychological effects on some people who have had Cushing’s syndrome and wondered whether this might apply to unborn babies exposed to high steroid levels during pregnancy too.

However, the placenta is very used to inactivating the mother’s hormones so that only the right amounts of the right hormones get through to the baby. Imagine the effect of all the oestrogen circulating in a mother on her unborn baby, male or female, if this mechanism did not exist! For cortisol, the placenta expresses an enzyme called 11-β hydroxysteroid dehydrogenase type 2 which converts the mother’s active natural cortisol to inactive cortisone and therefore protects the foetus from the high maternal cortisol levels. This barrier means that when doctors want to give steroids that get across the placenta to help a baby, we have to use synthetic steroids that won’t be inactivated before they get there. We therefore use potent synthetic fluorinated steroids such as betamethasone or
Dexamethasone and not hydrocortisone that appears in the blood as cortisol. So, to answer your question, I am not aware of any long term data to raise concerns over ADHD in babies born to women with Cushing’s and I would not expect any problems for the reasons given above.

There was a good article in the European Journal of Endocrinology which you should be able to access using this link http://m.eje-online.org/content/173/2/R85.long?view=long&pmid=25872515 which gives a lot of detail about the difficult subject of Cushing’s Syndrome during pregnancy.

Q4 - During my teenage years I dreaded physical education lessons, particularly when they involved a lot of running...
Between my temples and at the back of the eyes would thump like mad, to the point I felt my head would burst.

Outside of school I was a keen cyclist and covered quite an area of Tunbridge Wells. I was able to do this because I managed my energy, and took frequent rests as I recognised the pattern, BEFORE my head began to hurt. By my mid-twenties my pituitary tumour was diagnosed.

Occasionally, when I'm physically active or if I get too hot, I reach the, 'my head hurts' stage. What's the likelihood these occurrences may cause an ischemic attack? I have witnessed these in my family and it fills me with dread.

This can also happen if someone tickles me! I get cross with them because with immediate effect, my head feels as if it is about to explode - no laughing matter.

I wonder too, IF, I ever manage to overcome my fear of water and start swimming again (in September, I hope) if there's a link with: the most unpleasant feeling when I tried (pre-teens) a few times to put my face under water and only made it up to my ears: the overwhelming sensation was 'my head's being squashed in a vice'. It was awful each time so I gave up. At present I'm challenged to get as far as even putting my face IN the water, a prerequisite to swimming!

I'd be very interested to hear your thoughts on these subjects (and maybe any ideas on how to overcome the latter!). Many Thanks - Christine

A - How difficult for you! I guess the first thing is to try to work out whether this might be anything to do with your pituitary tumour. Unless this was very large indeed, so large that it was able to interfere with the circulation of the fluid (cerebrospinal fluid) that bathes the brain and spinal cord, or was affecting the nerves in the cavernous sinus (again, very unusual in 'normal' pituitary tumours and I'm not convinced that the symptoms would be related even so) then I guess it is probably unlikely to have been due to your pituitary problem and your symptoms and the tumour you had would most likely have been unconnected. If your pituitary tumour was treated by surgery or by tablets to shrink it (e.g. cabergoline if it was a prolactinoma), did the symptoms improve or not?

Transient ischaemic attacks (TIA's, sometimes called 'mini-strokes') are caused by blockages of small blood vessels in the brain which usually happen to people who are predisposed to arterial disease (e.g. people who smoke, have high blood pressure, high cholesterol etc.) and are painless, cause transient paralysis or speech disturbance or a drooping mouth on one side and recover within 24 hours. Is this what some people in your family have had or was it different in which case TIA is unlikely to be the diagnosis. Assuming you are otherwise fit and well, your pituitary tumour has been well treated and
you have been having these symptoms for many years, and nobody in your family has been told they have a hereditary problem like an aneurysm or conditions associated with excessive adrenaline release, it seems unlikely that there is anything too serious going on and perhaps you are very highly sensitive to the changes in blood flow through the head and brain that happens naturally when we exercise largely as a result of releasing adrenaline and other similar hormones (the heart rate and its force of contraction increase and some people feel this more than others). The same changes in blood flow and therefore pressure in the head can be caused by a ‘Valsalva Manoeuvre’ which is when you try to breathe out against a closed mouth and nose. This may possibly be what you are experiencing when you are tickled. Your symptoms certainly do not sound at all like TIA's and I can confidently reassure you on that point. Do you suffer from other headaches such as migraines or tension headaches?

In terms of the feeling in water, I wonder what happens when you are in the bath or shower? Can you wet or submerge your face in this situation? What about a wet flannel on your face? If some of these are ok, perhaps it might be worth trying to progress slowly from wet flannel to partial and then full immersion in the bath to immersion in the swimming pool? Just a thought, I'm not sure there is a definite medical answer to this but it seems that it might help. I hope that helps and good luck with your exercise!

Please submit your questions for our next newsletter to Gail either by email g.weingartner@btinternet.com or post to 17 Whitfield Rd, Haslemere, Surrey GU27 1DX

A TRANSFORMATION by BRIAN AVERY

In the 90’s my failing sight resulted in a series of Pituitary operations. Afterwards I needed to take hormone replacement medication, some worked, some didn’t. The one thing that pleased me apart from my improved sight was that I still produced my own ACTH hormone and had no need to take Hydrocortisone replacement.

My various visits to the Endocrinology clinics over the years made changes and updates to my medication but avoided the need for Hydrocortisone.

Over the past year I have felt my health weakening, various aches and pains, lack of appetite, tiredness, increasing frailty and loss of weight became very noticeable.

After a blood test for my next Endocrinology visit it was noticed that things weren’t right so I was summoned for a Short Synacthen Test with the promise of results in a week or so. Two days later a call from the hospital told me there was a prescription request at my GP and to start taking then asap.

After the first tablet I felt transformed, all the aches and pains were gone, appetite had returned and I had energy and desire to get things done. Hydrocortisone had finally become a need and welcomed with open arms despite the implications.

I am happy but none more so than Ann who looked after me during the past year.
Gail also writes about hydrocortisone

Hi All, Gail here.

Those of you who are members of the Pituitary Foundation may have read my article in the autumn 2015 edition of Pituitary Life. This was about how my quality of life has improved beyond recognition because in March 2015 I attended a presentation day in London entitled Getting Steroid Replacement Right and Minimising the Side Effects, which was held by Professor Peter Hindmarsh and Kathy Geertsma. I am so very thankful that I went along that day.

It is because of my now very different Hydrocortisone replacement regimen, that my health is so improved and I now don’t experience many of my ‘blip’ days, which you have heard me go on about over the years. And interestingly, on the days when I do, I can often still function and work my way through them, albeit with a bit of a struggle. WOW!

Anyway, the Salisbury Pituitary Patient Support Group have asked me to give a talk about the above at 2pm on Saturday 22nd October in the Fisherton Mill Meeting Room of St Paul’s Church Centre, Fisherton Street, Salisbury SP2 7QW. So, I’m flagging this in case any of you would like to come along to listen to my Hydrocortisone story and then have the opportunity to consider your own replacement regimen before discussing with your Endo. Perhaps you can also improve your quality of life!

- Gail

But sometimes we still struggle …

If there is anyone who is having a hard time of it at the moment, we wish you well.

In particular we wish Sue Cooper on the IOW all the best from us all because she hasn't been well.

Dealing with Fatigue

In July Sammy Harbut from the Pituitary Foundation gave a presentation on the management of fatigue. We have sent a copy of this to everyone who receives their newsletter by email. It is seven pages long, which is too much to include in the printed version of the newsletter. However if you would like to be sent a printed copy, please let Gail or Pam Weingartner know and we will send it to you.
Hydrocortisone phone app

If you take Hydrocortisone, or are caring for someone who does, and you own an iPhone, iPod Touch or iPad you can now download a brand new app all about hydrocortisone!

If you take Hydrocortisone, or are caring for someone who does, and you own an iPhone, iPod Touch or iPad you can now download an app all about hydrocortisone! iCortisol is an app created by The Pituitary Foundation, in collaboration with a basement software company, Existential Ltd, for anyone who takes replacement hydrocortisone.

It is with thanks to Existential Ltd that we are able to provide this app, as the company has undertaken the project to create the app free of charge in support of The Pituitary Foundation. One of the founders of Existential Ltd, Alenka Abraham, is a pituitary patient herself and originally Alenka and company co-founder, Adam Cubitt, had developed an app for Alenka to help log her Cortisol doses in an easy way:

Adam said: ‘We developed the app initially for Alenka, as she regularly logs when and how much Cortisol she is taking. She takes small doses of Cortisol frequently and sometimes cannot remember how long ago she took the last dose.’

Adam continued: ‘Waiting to see if she starts to feel 'low' isn't a good idea because it then takes a long time for the Cortisol to kick in and she feels lousy in the meantime. She can take an extra dose if in doubt but taking extra steroids is never ideal if it can be helped. Recording each dose through the app, as and when
she takes it, means she not only knows how long it has been since her last dose but also knows how much she has taken during the day. The other advantage is that she has a reliable record of exactly how much Cortisol she has been taking each day over a long period of time which is interesting to both her and her Endocrinologist. We have now also added additional features to the app to make it a comprehensive source of information which you can take with you anywhere about hydrocortisone.’

**Features**

The app is designed to be quick and simple to use and includes the following features:

- A smart reminder system so you don’t forget a dose of hydrocortisone. (Reminders are highly configurable allowing you to set simple alarms or reminders that only trigger if you have not taken enough hydrocortisone).

- A logging system which keeps a record of each dose you take and allows you to quickly review how much of each drug you have been taking. This log can be exported which can be sent by e-mail (to yourself or your endocrinologist) and opened using any standard spreadsheet programme.

- Quick reference information about how to take hydrocortisone and scenarios when you may need to take more hydrocortisone i.e. sick day rules (e.g. illness, medical investigations).

- Advice when travelling away from home.

- Hydrocortisone in an emergency, including information about how to give a hydrocortisone injection and instructions for ambulance and A&E clinicians.

**How to download the app**

Download the app for £1.99 today (70p will be donated to The Pituitary Foundation) Search for iCortisol in the App Store on your device. You can also visit the iTunes store

**Alternative versions and updates**

We have only developed the app for Apple at this stage. We will listen to all the reviews and feedback we receive about the app and hope to be able to develop and improve the app accordingly in future updates. If you have any feedback, please email enquiries@pituitary.org.uk

**Ratings and reviews**

When you’ve tried the app, please review and rate the app in the App store to help others find it.

With thanks to Existential Ltd
Rosa Watkin from Head Office writes about Pituitary Awareness Month

I wanted to let you know about Awareness Month which is going to be focusing on improving optician awareness of pituitary tumours.

We are delighted to announce the ways in which you can get involved during October! We hear of many pituitary tumours being diagnosed through routine eye tests; and making more opticians aware of tumours will help prompt earlier diagnosis for pituitary patients. Are you and your support group members able to take our awareness poster in to your local optician? Your involvement could mean that others do not have to go through the frustratingly long diagnosis. Email campaigns@pituitary.org.uk or ring 0117 370 1310 to tell us your address and request a poster.

There are lots of other exciting activities and ways to get involved including; giving an awareness talk, arranging your own ‘Great Pituitary Bake-off’, or running an awareness stand. To find out more and for further details visit our new Awareness Month webpage: http://www.pituitary.org.uk/get-involved/campaigns-and-raising-awareness/current-campaigns/pituitary-awareness-month-2016/

There will be more information in the September Volunteer News magazine and Pituitary Life for you to pass on to your group and encourage them to pick an activity and get involved.

Please do let me know if I can support your group in planning how to get involved ready for October. We really appreciated your help with making this awareness campaign have as much impact as we possibly can.

Best wishes

Rosa Watkin
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Finally here is something you shouldn’t say

I went with my wife to her school reunion. While we were there she kept staring at a man swigging a beer at a nearby table.

“Do you know him?” I asked her.

“Yes,” she sighed. “When we were at school he used to be my boyfriend. After we split up all those years ago he started drinking and I hear that he’s hardly ever been sober since then.”

“Wow,” I said. “Who would think that someone could go on celebrating for so long?”

That was when the fight started.