Hello everyone,


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

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 2nd December and it will be our pre-Christmas get-together. We will have festive food, a quiz and plenty of opportunity to speak to other people and find out how they are coping with their pituitary-related situation. It is always useful to learn from other people what has worked for them. And equally important, what has not worked so well.

We have welcomed several new patients and their partners, family or friends at the meetings recently 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 2017 and 2018

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

- Saturday 2nd December 2017 at 10am – Christmas get-together
- Saturday 18th March 2018 at 10am – our birthday meeting with speaker Dr Janine Domjan, a consultant neuro radiologist
- Saturday 21st April 2018 (time TBA) – Bournemouth meeting at Royal Bournemouth & Christchurch Hospital
- Saturday 30th June 2018 at 10am
- Saturday 7th July 2018 at 10.30am – Isle of Wight meeting at Lake Community Centre
- Saturday 6th October 2018 at 10 am (not the last Saturday in September as usual)
- Saturday 1st December 2018 at 10 am

Possible speakers for future meetings include Dr Partha Kar of Queen Alexandra hospital, Dr James Lawrence and Dr Smith from Salisbury. Also possible speakers on mindfulness, air ambulance, from the Bristol national office, 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.

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.

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 March 2018.

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.
Q1(i) - How can a pituitary disorder, specifically deficiency of ACTH replaced by low dose of hydrocortisone effect the systems and structures in the body? – Sharon G

A(i) - Sharon, this is a very complex question but I will do my best to shed some light on at least some aspects of it. Part of the difficulty is that when someone has ACTH deficiency they most likely have several other things too and it can be difficult to tell what might be causing a particular effect. Specifically, people with ACTH deficiency will usually have:

a) a condition that caused it in the first place (eg. pituitary tumour, brain radiotherapy, brain trauma, systemic illness also affecting the pituitary gland etc.). Although isolated ACTH deficiency is described in people with seemingly otherwise intact pituitary glands, this is rather rare. The cause of the ACTH deficiency and whether it is ‘partial’ (needing either very low dose hydrocortisone replacement or even replacement only at times of stress) or complete (needing full replacement, typically 15-17.5 mg per day of hydrocortisone) will have a large effect on how replacement affects the body and indeed on how the individual feels. For example, complete ACTH deficiency following surgical cure of Cushing's disease is a very different situation from isolated partial ACTH deficiency with no other pituitary disease and like comparing apples with pears.

b) People with ACTH deficiency may have had pituitary surgery or may well have problems with the rest of their pituitary function (ie. have pan-hypopituitarism rather than just isolated ACTH deficiency). This means that a person with ACTH, growth hormone and TSH deficiency with diabetes insipidus after complex surgery for a craniopharyngioma might have very different symptoms and bodily effects from somebody who has isolated ACTH deficiency without other pituitary dysfunction.

c) People may be over-replaced or under-replaced with hydrocortisone. This is probably very important and we can never make replacement exactly correct under all circumstances. Too little replacement and the individual will most likely have symptoms of cortisol deficiency which might include but not be limited to fatigue, dizziness, headaches, vulnerability to adrenal crises, low blood sodium levels and low blood glucose together with lack of appetite and weight loss. Too much steroid replacement may lead to symptoms of Cushing’s which might include weight gain, depression, fatigue, osteoporosis, diabetes, high blood pressure, raised cholesterol, muscle wasting and weakness, central fat accumulation and susceptibility to infection. Crucially, fatigue is common to both conditions and it is very important not to treat the fatigue of over-replacement with even more over-replacement! In general, it has become very clear in recent years that we have often tended to over-replace and this causes its own problems.

d) People with ACTH deficiency may or may not be affected by the effects of ACTH deficiency on androgen (male sex hormone) production. In men, the production of weak androgens by the adrenal gland under the direction of ACTH is dwarfed by testicular production of the stronger androgen, testosterone so it doesn’t usually matter if this is lost. In women, adrenal androgen production may be more important and there is some evidence for replacing DHEA (the weak adrenal androgen) in some women with ACTH deficiency. This is a subject we have discussed before in these columns and one that does have some ongoing debate around it.
As you might expect, all of these factors mean that any individual’s personal experience of ACTH deficiency may be rather different to another’s and it is difficult to be absolutely precise in my answer.

Q1(ii) Is there an effect on nerves and can it influence pain receptors or are they unrelated? – Sharon G

A- I am not aware of a clinically important general effect on pain receptors or neurons but certainly inadequately replaced ACTH deficiency can lead to headache and muscle pain and over-replacement can cause muscle wasting.

Q1(iii) Is there a link to no ACTH being replaced and migraine and/or cervicalgenic headaches?

A- I do not think there is clear evidence that ACTH deficiency as opposed to cortisol deficiency causes these headaches but cortisol deficiency can certainly cause headaches. All patients on high dose steroid treatment for inflammatory conditions eg. Some forms of arthritis/ asthma will have suppressed ACTH and I am not aware of clear evidence that this directly leads to these kind of headaches in these individuals. ACTH can be used to treat one or two very specific types of headache, particularly the one that occasionally develops after an epidural but that is a very specific situation and not really relevant to commoner types of headache.

Q1(iv) Can it cause the body to prematurely age and damage in the case of disc degeneration, small random bones becoming necrotic? – Sharon G

A- High dose steroid treatment (not hydrocortisone replacement) can cause a rare condition called ‘avascular necrosis’ of bone which is death of a piece of a bone or even whole bone caused by its blood supply blocking up. We don’t fully understand what causes this but it is not really a feature of replacement doses but of higher ‘treatment doses’ of steroids, usually with other risk factors eg. alcoholism, some cancers etc. There have been one or two case reports of avascular necrosis in pituitary patients on replacement but so few that it almost serves to show just how rare this is- I have never seen it in a pituitary patient but have seen it quite a few times in people on high doses of prednisolone or other steroids used to treat other conditions.

Q1(v) Stressful situations that others seem to handle well lead me to develop negative physical symptoms; could this relate to the ACTH deficiency? Other than minimise stressful triggers is there anything else I can do to cope better? – Sharon G

A -This is difficult - there are many factors that might be relevant alongside the ACTH deficiency. I think all I can say is get onto the dose that best manages your symptoms without over-replacement, consider a temporary small dose increase for major stress (eg. bereavement, other serious life events) and use all the other techniques that we all can use to try to deal as best we can with these issues. It is harder for pituitary patients because of your hormonal status and the condition that may have led to your pituitary problems and indeed all the worries you may have over treatment eg surgery, other medications. So many pituitary patients describe this symptom that I am sure there must be something in it although I’m afraid that it isn’t easy to separate from other factors (this can be a symptom of growth hormone deficiency for example which can accompany ACTH deficiency) and the tools we have to replace hydrocortisone, even the much publicised newer formulations, are sadly not as good as nature, as is so often the case in medicine. I’m sure everyone reading this would have sympathy for the symptoms you describe.
Q2 - If Diurnal’s Chronocort gets marketing approval at the end of this year and becomes available, what are your views on prescribing this for cortisol-deficient patients, given that it more closely follows the body’s natural rhythm as opposed to the current 10/5/5 or 3x daily doses? - Steve H

A - Dear Steve, Thank you for asking this very relevant question.

In people without hormonal imbalance, the production of cortisol usually follows a circadian rhythm, which means its pattern repeats on a daily basis. In other words, the cortisol usually peaks in the morning, just after waking up, then, decreases over the day, producing other peaks, but usually lower than the morning one, and gradually its concentration becomes very low during the night. And every day the cycle repeats again and again.

On hydrocortisone replacement, we try to mimic this daily pattern. We currently have two kinds of hydrocortisone tablets available. The immediate release hydrocortisone tablet is the one the vast majority of people with adrenal insufficiency use. As the absorption of hydrocortisone is fast, the level of cortisol peaks just after taking the tablet. Therefore, to mimic the above described levels, the morning dose is higher leading to a higher peak, and the lunch time and afternoon doses are lower leading to lower peaks. During the night, the cortisol levels are low and flat.

The other available tablet is a modified release one, commercial name is Plenadren. This tablet has an outer coating layer that provides very fast absorption, which leads to a peak, as the tablet described above. But also, has an inner core that provides very slow released hydrocortisone, resulting in a gradual fall in cortisol levels over the day. This allows patients to take once daily, instead of twice or thrice daily.

As you rightly mention, there is a new formulation for hydrocortisone, marketed as Chronocort, this tablet has different layers and is supposed to better mimic the natural cortisol pattern, especially in terms of the very slow and subtle increase level of cortisol during the night just before the waking time peak. This is more important in people with congenital adrenal hyperplasia than in those with pituitary-related problems. It is required to be taken twice a day.

At the moment, the modified release once daily hydrocortisone has not shown to be better than the usual immediate release hydrocortisone. I can see that once daily tablets can be an advantage for those with serious problems to remember taking their tablets. But there is no evidence of benefits in terms of diurnal rhythm levels, as it was promised.

And for now, Chronocort, is still not licenced, and we don’t have any experience with it to be able to judge it. However, the investigations so far have shown it could be advantageous for those with congenital adrenal hyperplasia, but I am not too convinced that it would be much better than the usual hydrocortisone for those with lack of cortisol due to a pituitary problem.

Q3 – Approximately 3 weeks ago I went out for a meal with a friend and the next day, my stomach was unusual in as much as I had several ‘poos’ the following day and my tummy was very noisy, ie, gurgly and growly. My stomach continued in this way and I kept thinking I would perhaps make an appointment to see my GP, which I did but it couldn’t be for over 2 weeks time! Last Friday, I awoke feeling tired but OK and managed to carry out the weekly shop and several other chores but then my stomach starting griping, which became so severe I was doubled up with really quite violent pains and I had a very high temperature of 38.1c = 100.4f. My family were trying to persuade me to go to A&E, which, on a Friday evening, I didn’t consider to be a brilliant option, if I could avoid it. They also wanted to call an ambulance. Anyway, I did fight my way through it (ain’t I brave, lol) with the help of paracetamol but my stomach took 3 days to feel anywhere like normal and I felt totally washed out and pretty vile for a couple of days. Strangely, I wasn’t sick and only had one slightly loose motion with no diarrhoea as such. I decided to double my hydrocortisone dose for 2 days and then slowly decrease this. Was I right to do this or should I have gone to A&E or even called an ambulance? – Gail W
Dear Gail, I am sorry to hear you had such a bad time with severe abdominal pain and fever and it sounds like you are really brave. I think you are right to think that A&E is not a great place to spend your weekend, if you can avoid it. It is difficult for me to judge what you should have done only with the limited information I have from you. If you are an elderly person and frail, for example, I would think you should have gone to A&E with the symptoms you describe. If instead, you are young, strong and very fit, deferring A&E was the best decision. If you are somewhere between frail and very fit you could have considered consulting your GP. Apart from your age and physical situation, I would need to assess you clinically to be able to give you proper advice. I am happy you increased your hydrocortisone dose, perhaps you could have increased all those days you had fever and required being in bed.

Living with Hypopituitarism
and other things that happened to come along

Marilyn Harvey has written about her pituitary experience

My story starts way back in 1972 when I awoke one morning with a headache to end all headaches. Three days later I was rushed into hospital with suspected meningitis but doctors decided it must have been meningism instead, a diagnosis which wasn’t revised until 1982 as a pituitary apoplexy.

I spent those ten ‘lost’ years struggling to understand why I never felt in the best of health until a diagnosis of hypopituitarism was finally made. Once I began taking hormone replacement my health gradually improved although not without set-backs, including getting my dose of hydrocortisone right and the terrifying experience of having an adrenal crisis.

Then in the early 1990’s other things started to happen, possibly or probably as a result of those ten years when my body had not been receiving adequate amounts of vital hormones. From that time to the present day I describe not only the difficulties that living with hypopituitarism presents, but my complex experiences in dealing with my bone health.

Despite the challenges faced and the coping mechanisms I needed to use, I consider myself so fortunate to have received excellent care from both medical and holistic professionals and for the love and support of family and friends, which meant that none of my problems have been insurmountable.

I wanted to write this book for those who have hypopituitarism or any other pituitary condition - or indeed anyone who would be interested in my story. I hope it will provide encouragement and enable those who read it to remain positive! I am happy to say that all proceeds from the sale of my book will go to the Pituitary Foundation as a thank you for all the work they do.

Please go to the Amazon website to purchase either a hard copy or a Kindle version.
Pituitary tumours turned mum into prolific painter

A mum-of-two who says she could barely draw a stickman before she was struck down with two pituitary tumours has unexpectedly developed a talent for painting.

Abigail Barry, from Herne Bay, had never painted before or had any interest, but one day got an urge to put brush to canvas, with astonishing results.

Eighteen months previously, she had been diagnosed with a second tumour on her pituitary and believes the phenomenon is linked.

“I seriously had never painted,” she said. “It bored me, I thought it was far too monotonous. Let’s just say, whenever I played Pictionary at Christmas, no one ever got my answers right. I could draw a stickman, just. Then, about six months ago, I had the urge all of a sudden and now I’m totally obsessed with it. I zone out and can paint for six hours at a time, it’s all very odd.”

One of Abigail Barry’s paintings of animals

The 43-year-old, of Ravensbourne Avenue, was diagnosed with one pituitary tumour five years ago and more recently doctors found another mass on the stalk of the pituitary gland. She says the tumours are not cancerous but cause extreme fatigue, headaches and memory loss, and her speech and sight have been affected, forcing her to give up work and her volunteering role at the RSPCA. Now, however, due to her new-found love of painting, she spends her time creating colourful pieces, which she gives as presents to friends and family.

Ms Barry says her skill could be down to a rare medical phenomenon in which tumours or traumas are linked to creative ability.

“My neuropsychiatrist is actually looking into it right now,” she said. “He said it’s very rare.”

Ms Barry admits she is the biggest critic of her work. “I am utterly amazed whenever I paint something that I think is good,” she said. “I see a lot of perspective issues with my work and other problems but others have said they find it charming with almost childlike fun.”

Ms Barry says painting helps her remain calm and believes it has been her lifesaver. “It really makes me happy, it makes me feel useful, and as others seem to like my work, I love making them happy,” she said.

Ms Barry displays her art on her Abigail Barry Facebook page.
Message in a bottle

The Lions Club have produced a container which holds medical information for people who have medications in the home. It may be particularly useful for those of us who are dependent on regular hydrocortisone doses.

What is it?
It is a simple idea designed to encourage people to keep their basic personal and medical details on a standard form and in a common location – the fridge.

What does it do?
It saves the Emergency Services valuable time if they need to enter a property in an emergency situation. Not only does it help to identify who you are it also identifies if you have special medication or allergies. It is not only a potential lifesaver, but also it provides peace of mind to you, your friends and family by knowing that prompt medical treatment is provided and that the next of kin and emergency contacts are notified.

Who’s it for?
Anyone. Whilst it is focused on the more vulnerable people in a community, anyone can have an accident in the home, so this scheme can benefit anyone.

What does it cost?
When ordering one bottle the scheme is free to the public and is funded usually by your local Lions Club. Please see their website for more details of this.

Where can I get one?
You may find the bottles displayed in your local GP’s surgery, Local Pharmacy, Local Lions Club. If you have any difficulty locating a bottle please contact Lions Clubs Headquarters 0845 833 9502.

Who knows about it?
All Emergency Services are aware of the Message in a Bottle scheme. By displaying the green stickers in your home, the emergency services will locate the bottle in the fridge and use the forms inside to ensure you are treated quickly which can save time and save lives.

What’s in the bottle?
A form for you to fill in with your name, medicines, any allergies you may have. Also, relatives contact details. Two green stickers are also in the container.

What do I have to do?
Fill in the form, and put it in the bottle. Put the bottle in your fridge. Put one green sticker on your fridge door and the other green sticker on the INSIDE of your house door. This is so the emergency services know where to look.

Who co-ordinates the Scheme locally?
Your local Lions Club. Many Lions Clubs across the Country take part in this project.
They also on their website have a form like the message in a bottle form, which can be stored in a wallet. Please have a look on their website for more information, their website is www.lionsclub.co/

(from the recent Liverpool group newsletter)
**Cortisol replacement**

If you would like Gail to either email or post to you a very interesting article for those of us taking cortisol replacement, ie Hydrocortisone, let her know - g.weingartner@btinternet.com or phone 01428 651526. This is written by Professor Peter Hindmarsh who, through his work improved Gail’s quality of life to such an extent, she now leads a far fuller, interesting and exciting life. Before changing her hydrocortisone regime she had far too many of what she called her “blip days” when she felt dreadful. The actual article is entitled 'Getting Cortisol Replacement Optimal in Adrenal Insufficiency'. We as hypopituitary patients are usually AI type 2. This is an excellent 12 page article, written for the patient, makes sense and is easy to read.

**Red Flag / Treatment Plan / History Marking**

Depending on which ambulance trust you have in your area, these are some of the different names they have for registering that you are dependent on hydrocortisone or other steroids and they may need to inject you at home or in the ambulance before you reach hospital.

Whatever they call it in your area, you will need to re-register every year. Sorry.

**Remembering Maggie Morgan**

One of our most longstanding members Maggie Morgan recently passed away. She held various fundraising events, was a proactive committee member, always had a joke and a fag and will always be fondly remembered.

She also had stories about working in the East End of London at the time when the Kray twins were active.

I remember her comment about one of our speakers some years ago, “The talk was like the woman’s skirt. It was short enough to maintain the interest but long enough to cover the essentials.”

**Congratulations**

Congratulations to Mike Sizer, a member from the Isle of Wight, who recently obtained a Master of Science degree (MSc) in Leadership and Management. He studied volunteerism in education and its benefits for school children and staff.

This was how he shared the news:

“I got the news yesterday that I’ve achieved my MSc. Not quite four years since a touch of death, my hard work and determination has paid off.

I'm chuffed. Can you tell...?!”

*All members, please let us know of your achievements for future newsletters.*
New helpline service launched by Pituitary Foundation

The new Helpline Pituitary Text Service has been launched and you can now send your questions by text message to: 07786 202249.

This is in addition to the telephone and email Helpline Service, giving you another option for patient and family questions.

They aim to reply within 24 hours (except weekends and bank holidays), but as this is a popular service it may take up to five working days before you receive a response.

Your personal details will be used to provide you with information or services you have requested. Any data collected will be anonymised to help them in collecting statistics and evaluate their services.

Please note that the text service is not an emergency service. If you need to speak to someone or have longer, more complex questions they advise that you:

Call the Helpline on 0117 370 1320 (Mondays to Fridays 10am -4pm)
Or
Email: helpline@pituitary.org.uk

Some light relief to finish

The other night I was invited out for a night with the 'girls'. I told my husband that I would be home by midnight, 'I promise!'

Well, the hours passed and the margaritas went down way too easily. Around 3 am, a bit loaded, I headed for home.

Just as I got in the door, the cuckoo clock in the hallway started up and cuckooed 3 times.

Quickly, realizing my husband would probably wake up, I cuckooed another 9 times.

I was really proud of myself for coming up with such a quick-witted solution, in order to escape a possible conflict with him.

(Even when totally smashed.... 3 cuckoos plus 9 cuckoos total 12 cuckoos = MIDNIGHT!)

The next morning my husband asked me what time I got in? I told him 'MIDNIGHT'... He didn't seem pissed off in the least.

Whew, I got away with that one!

Then he said 'We need a new cuckoo clock!' 

When I asked him why, he said:

'Well, last night our clock cuckooed three times, then said 'oh shit' cuckooed 4 more times, cleared its throat, cuckooed another three times, giggled, cuckooed twice more, and then tripped over the coffee table and farted.'

That's all folks  - Howard