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 30th September and our speaker will be Sirbrina Ramharack, the endocrine nurse from Southampton General Hospital who will answer our questions and also give us a demonstration on how to administer an emergency steroid injection in the event of an adrenal crisis. Sirbrina had to cancel coming to our June meeting at the last minute and has been very insistent that she come along for our September get-together.

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 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 30th September 2017 at 10am – Our speaker, also answering your questions and demonstrating emergency hydrocortisone injections, will be Sirbrina Ramharack an endocrine nurse from Southampton General Hospital
- Saturday 2nd December 2017 at 10am – Christmas get-together
- Saturday 18th March 2018 at 10am
- Saturday 30th June 2018 at 10am
- July 2018 – Isle of Wight meeting at Lake Community Centre
- Summer 2018 – Possible Southampton meeting
- Saturday 29th September 2018 at 10am
- Saturday 1st December 2018 at 10am

Possible speakers for future meetings include Dr Partha Kar of Queen Alexandra hospital, Dr James Lawrence from Salisbury and Dr Smith and the radiologist Dr Janine Domjan. Also possible speakers from the Carers’ Association, the National Osteoporosis Society, Air Ambulance 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.

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 November 2017.

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.
Dr Victor Lawrence answers your questions below (Dr Arnez is enjoying a holiday). Unfortunately, we don’t have room for all the questions submitted for this issue of the newsletter, but they will be answered in our next edition.

Q1 – I was operated on in 2013 for a Craniopharangyoma. I know that, amongst other tests, I am regularly blood tested for adult growth hormone levels, which have never apparently shown abnormality. I am unaware though what symptoms I need to be aware of in case levels change in between endocrinologist appointments. Could you please advise. – Mike S

Growth Hormone deficiency (GHD) is the most subtle of all the pituitary hormone deficiencies that can occur as a consequence of pituitary disease or its treatment. It wasn’t thought that GHD existed as a real clinical condition until the 1990’s- before then it was assumed that the role of GH ended when growth completes in late adolescence. We now know that after linear growth (getting taller) is complete there is a period of somatic development (acquisition of peak bone and muscle mass) that lasts well into the 20’s that is supported by growth hormone and we now often extend GH treatment in children to cover this. In adults, GH continues to support bone health and muscle mass (otherwise known as ‘body composition’- the ratio of lean tissue such as muscle to body fat and the relative distribution of fat in different places in the body) but GHD also presents with a collection of other symptoms that may sometimes be hard to differentiate from symptoms that many or most people feel from time to time at least. These include a sense of restricted overall quality of life, lack of social confidence, a tendency to depression or anxiety, being easily emotionally upset and feeling abnormally tired. Cholesterol levels may be raised and there are complex effects on other metabolic and hormonal parameters such as blood glucose levels and diabetes risk. The Pituitary Foundation has a very useful pamphlet on GHD which can be obtained at https://www.pituitary.org.uk/media/312424/Fact-sheet_Grth_Hor_16-10-15.pdf. GHD may present with all or none of these features- mostly the effects and response to treatment are fairly subtle although there are some individuals whose life is unquestionably transformed by adult Growth Hormone Replacement. Almost always it takes some time (months to years) for the symptoms to develop so it is very unlikely indeed that you would develop them suddenly in between appointments and the most important thing is for you and your endocrinologist to periodically review your symptoms and blood tests to see whether or not you may potentially benefit from further tests to confirm whether or not you have GHD. If you do have GHD and meet the criteria specified by NICE, then you may consider a trial of GH replacement to see whether or not your symptoms improve sufficiently for you to want to continue treatment. I hope this answers your question.

Q2 – Can prolactinomas (a tumour of 1.5cm) cause deep bone pain/aches? And is this something that can go gradually once operation has removed it? I suffer so badly all over and it's so debilitating. – Lisa D

Dear Lisa, the tumour itself is unlikely to cause these symptoms although some patients with pituitary tumours can develop headaches, which respond to treatment of their tumour (the vast majority of people with pituitary problems do not have pituitary headaches although they can and do get headaches like anybody else). Prolactin itself does not cause these symptoms either, otherwise breastfeeding women would probably ache all over too, as would people whose Prolactin is elevated by taking mental health or anti-nausea medications. I am assuming your pituitary function is otherwise either normal or replaced appropriately? Did your pain increase or reduce with treatment for your Prolactinoma (I assume you were treated with Cabergoline or a similar drug)? I guess if the pain did not improve when you started a drug that should have
shrunk your tumour and reduced your prolactin, then it is unlikely to be caused by the tumour or prolactin. Very occasionally, Cabergoline itself may cause myalgia (widespread muscle aches) and I guess if the pains started after starting this, then one could explore this possibility with a change in drug although in general, Cabergoline is the best drug for this condition and certainly shouldn’t be stopped without close consultation with your endocrinologist. Pains all over the body may occur for another reason altogether and it might be worth exploring some of these – vitamin D deficiency, some forms of arthritis, some medications, fibromyalgia etc. for example. I think I would look at these other causes first as it is unlikely that your prolactinoma would be the sole explanation. I hope that at least gives you a few ideas to work through.

Q3 – When anaemic, could the long use of steroids such as Hydrocortisone be responsible for suppressing the bone marrow from producing red blood corpuscles? My Haematologist advised that my blood count had risen from 84 to 89 after a second infusion of iron. My bone marrow is not producing enough red blood corpuscles. I have been given another appointment four weeks away in the expectations of an increase from all the iron running around inside of me. Normal count should be 120 or more. Low blood count also reduces platelets – Charles (Mike) H

Dear Charles, I don’t think this is likely. The hydrocortisone is just at levels that would replace what would have been present if you didn’t have a pituitary problem rather than at the very large doses used in some other situations which may have effects on the bone marrow. Hydrocortisone becomes the natural steroid hormone, cortisol, by the time it reaches the blood stream. I would be considering another cause as it is rare for platelet levels to fall in iron deficiency anaemia (usually the platelets actually rise). Have you had further investigations done? A cause of iron deficiency needs to be identified in all cases of iron deficiency (with the possible exception of women with heavy periods although that is only because the cause there is obvious).

Q4 – I am interested to learn more about the interaction of soya on thyroxine levels in the body. I have been using soya milk and yogurt in my diet for over 20 years and so far my thyroxine levels are acceptable. Does the problem only occur when replacement tablets are being taken? – Mary W

Dear Mary, you are absolutely right, soya is only relevant to those who obtain their thyroxine by eating it where it may meet soya in the stomach and have its absorption into the blood stream reduced. If your thyroid is working and is under the control of a functional pituitary gland (ie. a gland that can release enough TSH to keep your thyroxine levels normal), you release thyroxine directly into the blood stream and so whether you have soya products in your stomach or not, is irrelevant.

Q5 – Has thought been given to recommendations to be given to patients taking medicine as to how to manage their medication as they age and gradually become less able to manage the administration and advance re-ordering? Tim G

This is a very good question and one that I don’t think I have been asked before in this forum so thank you! There are a number of changes with ageing that need to be considered with prescribing any medication or planning treatment, which include interactions with other medications that may be taken (polypharmacy- the tendency for many older people to be on very many different medications), alterations in the way that drugs are handled (kidney and liver function tends to reduce with age so drugs may linger longer in the body), changing requirements (men in their 80’s for example may not always need testosterone for all the same reasons that they might have done in their more youthful days and have greater vulnerability to side effects eg. on the prostate gland and heart) and as you point out, simpler dosing regimens may be easier for individuals to remember and to take as they age. Finally, optimal dose ranges may shift with advancing age - we now know that replacement of thyroid hormones in later life to
the same levels as in younger individuals can increase the risk of a number of very significant side effects/adverse events and should be reviewed in many cases beyond the age of 65. These decisions are always very individual and depend on many factors but it is good to consider the effects of aging on previously stable replacement and treatment regimens and I would probably suggest doing this at least every 5 years after the age of 65 and then probably every year or two after the age of 75 with this specifically in mind alongside any prescription reviews that your GP or pharmacist may already be doing. I think these concepts are appropriately being taken very seriously now with regular medication reviews as we know that adverse effects of medications are a very common cause of falls, hospital admissions and other adverse effects in the aging population.

Reflections from a medical student who attended a pituitary support group

According to Steve Jobs, what makes a company great is its values. He illustrates in a video that what makes certain brands like Nike stand out from many others in the industry is their values. Those companies never advertise how great they are or describe what makes their products better... Instead, instead they honour great athletes and great athletics. Although the video is about business and marketing, I think the principle could be applied on an individual basis. What would make me a great doctor in the future, I think, is the values I will have then; the ability to honour and respect each patient as individuals taking into account their culture, religion and background. And individuals, such as those I met at the support group are great guides because they have a lot of experience with many healthcare staff. One of the things they say makes a great doctor is ability to listen. ‘Listen, truly listen to your patient. It shows respect and makes all the difference in their experience with you as their healthcare provider.’ At the end of the day we are not treating just an illness, but a whole being.

I think for me, knowing this from early on is important as it is essentially a skill, and just like any other skills, the earlier I start working and building on, the better.

I also used to assume that all patients were treated with dignity and respect, especially by doctors caring for them. I was shocked and surprised when I learnt this was not always the case from a day visit to a centre for people with learning difficulties in Toxteth during a training placement. What stood out for me was that it was not a one-time thing, but something common to many people. It is honestly sad! I am only in my third year, but I already appreciate the sort of hard work a person has to do to qualify as a doctor. To go through all that and then fail to treat patients in ways that they do appreciate is a shame.

Some of the themes that stood out during this and past sessions I attended were being talked down by healthcare staff, not seeming interested in patients’ presenting problems, saying the wrong things at the wrong places and time, inability to manage patients’ expectations and so on. I hope this means I have learnt from mistakes others have made as to not repeat them myself in the future.

I once read a quote, which made such an impression on me- “Words of comfort, skilfully administered, are the oldest therapy known to man.” I have known this to be true.
Pituitary Hormones and Bone Health

In June Dr Anand Velusamy, Consultant Endocrinologist at Guy’s and St Thomas’ Hospitals spoke to the London group about Pituitary Hormones and Bone Health.

Dr Velusamy started his presentation by saying “it’s all about hormones!” Hormones affect the cardiovascular system, cholesterol levels, mood, general health, body mass, bones and various other aspects of human functioning and evolution. Biosimilar and illicit Growth Hormone preparations and synthetic anabolic steroid abuse (amongst other performance enhancing drugs) are prevalent due to easy availability and is an ongoing challenge to uncover for specialists in Sports medicine.

He then gave an overview of Pituitary anatomy, Pituitary hormones and therapy and basic anatomy of Bones. The human body has 305 bones at birth however following fusion of smaller bones, we are currently left with 206 to look after. Bones can be broadly classified into two types – Cortical bone, the long strong bone e.g. Femur (thigh bone), humerus (arm bone) and Cancellous (spongy) bone which is found at the epiphyseal end of long bones and predominantly in skull, ribs, sternum, clavicle and vertebrae. These bones have more red bone marrow and in osteoporosis, spongy bones take the initial brunt due to their composition and increased metabolic activity.

Bones constitute 4 different types of cells - Osteoblasts (bone forming cells, derived from Osteogenic stem cells), Osteocytes (mature Osteoblasts trapped within the bone matrix laid by young Osteoblasts that play a vital role in maintaining bone structure), Osteogenic cells (stem cell) that give birth to Osteoblasts and Osteoclasts (Scavenger cells that are derived from white blood cells which aid in bone resorption and remodelling).

In clinical practice, total bone density is measured by a tool called DEXA bone densitometry. It is often evaluated using T-score that compares the subject’s measured bone density to that of a 30 year old adult who has attained his/her peak bone mass. Normal T-score values are higher than -1; between -1 to -2.5 indicates Osteopaenia (precursor to full-blown osteoporosis) while scores below -2.5 indicates osteoporosis. FRAX score is a tool designed by a specialist team in Sheffield to aid the treating Physician to analyse the overall risk of osteoporosis related fractures and make appropriate treatment decisions. It is vital to replenish Calcium and Vitamin D stores prior to embarking on specific therapies for bone protection.

Dr Velusamy then continued his presentation describing each Pituitary hormone and their role in bone health:

**Growth hormone:**
- GH and IGF-1 are fundamental in achieving a normal longitudinal bone growth and mass and in association with sex steroids, play a major role in bone growth and development.
- GH deficiency in childhood decreases bone mineral density (BMD), while GH treatment increases bone growth and strength and helps attain peak bone mass.
- GH stimulates Osteoblast proliferation and Osteoclast production. The net effect is increased bone remodelling and improved bone density.
- IGF-1 is considered essential for longitudinal bone growth, skeletal maturation, and bone mass acquisition not only during growth but also in the maintenance of bone density in adult life.
- Low serum IGF-1 levels are associated with increased risk of hip and vertebral fractures by 45% and 40%, respectively.
- Recent Swedish study suggested reduced incidence of osteoporotic fractures in post-menopausal women treated with GH therapy for 3 years during 10 years of follow up.
Cortisol and Thyroid hormones

- Cortisol increases Osteoclast activity (increased resorption) and reduces Osteoblast activity (decreased bone formation) - net-effect is reduced bone density and Osteoporosis.
- Thyroid hormones are necessary for normal development and function of human skeleton.
- Both untreated Hyper and over-treated Hypothyroidism can lead to increased fracture risk especially in post-menopausal women.

Sex hormones

- Testosterone deficiency increases osteoclast activity and reduces bone density. Part of the action is by conversion of Testosterone to Oestrogen.
- Oestrogen deficiency causes profound increase in Osteoclastic activity (in Post-menopausal women). The spine is affected first.
- HRT is associated with 30% reduction in vertebral and non-vertebral fractures in women over 60yrs of age.

Gonadotrophins: Follicle Stimulating Hormone (FSH) and Luteinizing Hormone (LH) in post-menopausal women:

- FSH increases Osteoclast activity and elevated FSH in peri-menopausal women is associated with 2% bone loss per year until menopause (despite high to normal Oestrogen levels).

In conclusion, Growth hormone helps achieve peak bone mass and preservation of bone density in adulthood. Growth hormone therapy increases bone remodelling and may reduce incidence of fractures when used long term. Hydrocortisone over replacement can be harmful to bones due to increased bone resorption. Over replacement with Levothyroxine (or Lithyronine) can have a similar effect. Sex hormone replacement preserves bone density and reduces the incidence of fracture. The benefits of HRT in postmenopausal women are minimal after 60yrs of age and the risks may outweigh benefit.

Dr Velusamy answered many questions during and after his talk, too many to list but here are a few response:

- If you have a weak back especially with severe spinal osteoporosis, it may not be the best idea to use weights initially in the gym causing more strain to the vertebrae. Swimming, cross trainer, walking and spinal muscle strengthening exercises may be more suitable.
- A good diet is important with increased Calcium and Vitamin D supplements. However, the main source of Vitamin D is sunlight. In the summer it is good to get some sun on your skin but you may still require supplements to replenish the stores. He recommended a maintenance dose of 1000 international units per day.
- Low alcohol consumption is recommended as it is directly related to reduction in bone density. Along with IGF-1, Parathyroid glands contribute to bone development and remodelling. Although they are positioned closer to the thyroid gland, they are entirely different systems in terms of control and feedback.
- Pain in the joints is nothing to do with osteoporosis and one of the main symptoms of osteoporosis of the spine is loss of height.
- Patients with Acromegaly are more likely to suffer from arthritis. However, there are reported incidence of increased risk of vertebral fractures in untreated patients due to increased bone turnover.

Collecting tins

The Pituitary Foundation is a charity and relies on public support for its funding. If you would like a collecting tin at home, or at work, that can be filled with any spare change, please let us
know. Or if it is just to keep at home, you could use any suitable container. Then empty it from time to time and use it to make a donation.

Thanks to Pat & Bob Hobbs who collected £48.08 and Rowlands Chemist (Gill Oastler works there) in Southsea who collected £20.71.

David Hoad

Sadly David Hoad, who has attended our meetings for some time, has passed away. Our condolences to his wife Marilyn and family.

Sue Cooper

Our best wishes to long standing member Sue Cooper on the Isle of Wight. We called round to see her after our Isle of Wight meeting in July and although not well, she was her usual entertaining self.

National Pituitary Conference – Saturday 25 November 2017 Birmingham

This will be held at Birmingham Conference & Events Centre (BCEC), and will include talks and workshops run by specialists from across the UK. The venue is joined on to The Holiday Inn Birmingham City Centre which has accommodation available for you if you require this.

Registration is open from 9.30-10.30am. On arrival at the event, you will be given your name badge and delegate pack which will give you all the information you need about the day. There will also be tea, coffee and refreshments available. The conference finishes at 4:30 pm.

From 10.30am until lunch, the morning session will be ‘Your Pituitary Journey: Diagnosis and Treatment’ and will include presentations from specialist medical speakers from Queen Elizabeth Hospital Birmingham and others from across the UK.

In the afternoon, delegates will attend two workshops from a choice of: Adrenal Insufficiency and Steroid Regimes (inc. emergency injection); Paediatric and Transition Endocrinology; Diabetes Insipidus; Living with Hypopituitarism for Women; Living with Hypopituitarism for Men; Carers and families; Psychological Impact of Pituitary Conditions; Younger Patients and Parents.

There should also be an employment and benefits information stand available. Refreshments are provided throughout the day, including a two course lunch with hot and cold options. If you have any dietary requirements then you will need to let them know when booking.

Over & out until next time - Howard