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Awareness Day

This year we will be launching our new website to mark the HPTH World Awareness Day on January 5th 2010.

Our new URL will be www.hpth.org.uk - quicker and very much easier to spell!

Please visit us to have a look around. Show your support by leaving a message on the Visitor’s Page and if you haven’t yet joined the forum, now is your chance. Do remember to keep us updated with any change of addresses.

This year’s eye-catching World Awareness Day poster has been designed for us by Bristol art student Sophie Burrows. If you would like to display it in your surgery or elsewhere, please contact us.

Last year, our Awareness Day got noticed by the media for the first time. Liz Glenister, Director, was interviewed in a BBC West Midlands radio show along with Dr Nick Shaw from Birmingham, member Sonia Williams, and our very own Caina Cuthbertson (aka Tusi, forum queen) getting in the final word. We were also invited to appear in the Woman’s Own magazine where member Sue Baskett bravely stepped up to be interviewed about her own HPTH experiences. We had a great deal of positive feedback from these events and would like to thank everyone who took part.

HPTH UK Christmas cards now on sale. See back page or visit our website to order.
At last - another HPTH UK newsletter!
Like Hypoparathyroidism itself, the HPTH UK newsletter is a rarely seen phenomenon, but once you read about the work we have been doing during these last two years to bring about positive change for us all, I hope you will forgive the delay. Look out for more regular news from now on! We are proud to announce that the first steps have been taken towards achieving two of our main goals; to get PTH licensed for use in the treatment of HPTH and to develop national treatment guidelines.

PTH 1-84 Clinical Trial
By now, most of you will know about the international NPS clinical trial in which we are participating and in which some of you are already involved. This will be the first study on the use of parathyroid hormone (PTH 1-84) in the treatment of Hypoparathyroidism patients in the UK and will be an important step towards finding an appropriate treatment. Replacing our missing hormone must be the way forward. The study has now begun in Liverpool under Professor Bill Fraser, where we have 8 members involved so far, and Dr Brian Shine has just begun recruiting in Oxford. If you would like to take part please let me know. To find out more please see full article inside.

Patient Information Leaflets
We have been working with the Bone and Mineral Special Interest group of the Society for Endocrinology to develop patient information leaflets on Hypoparathyroidism. In September, these were presented and approved at the Society of Bone and Mineral Research meeting in Denver, Colorado and are currently being redrafted. Our grateful thanks go to Dr Abhi Vora of SfE and Dr Brian Shine for getting the ball rolling, Dr Mo Aye in Birmingham for all his hard work writing and drafting, Dr Steve Orme in Leeds for his contribution and to Professor Bill Fraser in Liverpool who will be doing the final editing. Next on our agenda - treatment guidelines for doctors and eventually our aim is to see national guidelines on the treatment of HPTH to be issued by NICE.

HPTH UK Goes To Conference
HPTH UK made its presence known at its very first Society for Endocrinology conference in Harrogate in March this year. Judith Taylor, who went as our Patient Group Representative there, reports. She has also attended the BAETS Annual meeting in London this month. Thanks to Janis Hickey for kindly displaying our leaflets and poster on the BTF stand. We will have our own exhibition stand at the 2010 Society for Endocrinology BES meeting for the first time so doctors, look out for us, please!

Money Matters
We need to raise funds to keep going, to get the patient leaflets printed and distributed and to achieve our goals. We also need to raise £5000 annually to be a registered charity. To this end we have so far taken part in 3 marathons - see more on the fundraising page where you can also read about our star fundraisers. In June 08, we won a grant from the Society for Endocrinology - £2000 for start up costs and we have been invited to re-apply next year. Your kind donations have also helped us enormously to keep on keeping on - thank you all.

Telephone Helpline
In Aug 08, we were awarded a further small grant from the SfE to send a volunteer to telephone helpline training. Bridget O’Connor bravely took on that role despite her own struggles with HPTH this year and our deepest thanks go out to her. You can read her report in this issue.

Helpline numbers are 01342 316315 (South) and 01623 750330 (North).

HPTH UK Committee News
With only Caina (secretary & forum) and I running the show during 2007 we had our hands very full indeed. Caina has been very ill this year and I know you will join me in wishing her a good recovery. Joined early the following year by Mandy (editor) and Bridget (helpline), we made good progress. Judith (a medical publisher, just retired) and Ray (a discovery scientist) brought their valuable experience to the team. This year we were delighted to welcome Raj on board whom many of you may know from his famous HPTH yahoo list. Raj is our Pharmaceutical Advisor. Huge thanks to you all.

Vacancies As you can see, this is a small committee and we are an ever growing community. If you have some time to spare and would like to get involved please do let us know. We are particularly keen to find people who have experience in health, fundraising, IT, education - or are just willing to have a go.

Members
Membership has just hit the 500 mark! Perhaps we’re not as rare as we thought. Thank you all for your continuing support and to those of you who sent me cards and messages of support when my mother died suddenly in March this year. I was very touched.

Welcome to all our new members too - we are always happy to hear your comments and improve our service so do get in touch. I wish you all a very happy and healthy 2010 - and don’t forget to visit the new website in January!
Liz Glenister, Director
liz@hpth.org.uk
The UK’s first clinical study into the use of parathyroid hormone PTH 1-84 for the treatment of Hypoparathyroidism, sponsored by NPS pharmaceuticals, is now open in Liverpool and Oxford and is recruiting UK patients.

A press release from Stockwatch last December stated ‘NPS Pharmaceuticals, a specialty pharmaceutical company focused on developing therapeutics for rare gastrointestinal and endocrine disorders, today announced it has begun patient enrolment in a Phase 3 registration study, known as REPLACE, evaluating NPSP558 for the treatment of adults with hypoparathyroidism. NPSP558 is the company’s proprietary recombinant full-length human parathyroid hormone (PTH 1-84), which mimics the action of natural parathyroid hormone. Hypoparathyroidism is a rare condition in which the body produces insufficient levels of parathyroid hormone causing lower than normal levels of calcium in the blood, known as hypocalcemia. There is currently no approved replacement therapy for hypoparathyroidism. NPS believes positive results from REPLACE will enable it to seek U.S. marketing approval for NPSP558 for the treatment of hypoparathyroidism.’

Should this be successful, we hope that
• PTH 1-84 will, in due course, be licensed in the UK for the use of Hypoparathyroidism patients for the first time.
• It will lead to a safer, more reliable means of treating HPTH patients.
• It will lead to a significant decrease in the severe renal outcomes that are currently being experienced by patients on vitamin D and calcium therapy (how it will affect bone turnover remains to be seen).
• The trial will help to further knowledge and understanding of Hypoparathyroidism.

If you would like to talk to patients already undergoing treatment on the US trials, please visit the HPTH UK Forum, or the HPTH UK Facebook group.

Disclaimer: Please note that patients choose to enter this trial at their own risk. HPTH UK is not responsible for any part of this trial, nor for any patient outcome and cannot endorse PTH 1-84 as a treatment for Hypoparathyroidism until satisfactory trial results are published.

INTERESTED?
If you would like to be considered for the trial please note that you must
a) Live within 40 miles of Oxford or Liverpool
b) Meet the inclusion criteria given here.

If you still fit the bill, please send the following details to liz@hpth.org.uk -

1. Your name, address, tel, email, DoB
2. Name and address of your doctors
3. What type of HPTH you have, if known.
4. How long you have had HPTH
5. Your current HPTH medication and dosage.

THANK YOU

HOW PARATHYROID HORMONE WORKS
Calcium levels are normally monitored 24 hours a day by four tiny parathyroid glands. These glands produce a hormone called parathyroid hormone (PTH).

Vitamin D3 is converted in the liver and again in the kidneys where PTH helps to make calcitriol, the active form of vitamin D3 (really a hormone).

Both these hormones work to restore normal calcium levels in three ways –

• Taking calcium from our bones and putting it back into our blood
• Increasing the amount of calcium we absorb from our diet
• Reducing the calcium and increasing the phosphate we excrete through our urine.

As calcium levels then begin to rise in the blood, PTH falls. This also works the other way around and is called a feedback mechanism. In HPTH, this mechanism cannot work because we lack PTH and calcitriol and so cannot regulate our calcium levels. We need Alfacalcidol and calcium to do this for us which is not always good news for our kidneys. PTH 1-84 treatment maintains stable PTH and calcitriol levels. It treats the root of the problem (lack of PTH), instead of the secondary effects of the problem (low calcitriol and calcium).

We will look at this in more detail in the next newsletter on the Medical Matters page. Our clinical advisors will be kindly contributing to this section so if there is an area you would like to see explained please contact me.

Mandy Mainland, Editor
mandy@hpth.org.uk
A STRATEGY FOR RARE DISEASES

Rare diseases are collectively not rare! There are over 6000 rare conditions identified, and they affect over 3.5 million people in the UK and over 30 million in the EU at some point in their life.

A European survey of patients with rare diseases published this year shows:
• 40% of respondents to a recent survey of patients said they received the incorrect diagnosis
• 25% of patients waited between 5 – 30 years for a correct diagnosis.
• 50% of respondents seeking social services reported that their expectations were only met “somewhat” or even “not at all”

The report can be downloaded at the following URL: http://www.eurordis.org/article.php3?id_article=1912

Feb 2009: Government campaign group launched to make NHS plan for rare diseases a priority. HPTH UK was again represented in 09 at the Parliamentary receptions in London by Liz and Judith Taylor and in Edinburgh by Mandy Mainland. We met some wonderful people, in particular Dr Abhi Vora of the Society for Endocrinology who has since been so very helpful to us in developing information leaflets. It is always heartening to see different groups coming together to support a common cause and this day was a very important one for patients with rare diseases like Hypoparathyroidism - a day of promise and hope for the future.

Alastair Kent, Chair of Rare Disease UK, said: “It is a national disgrace that the NHS does not have a coordinated plan to treat the many thousands of people who are every year affected by rare diseases. Currently patients, families and individuals affected by rare diseases are denied their right to high quality care and support, due to a lack of coordination and information provision to both health professionals and patients. Finding expert help is too often a matter of chance rather than planning by the NHS. A national plan would help to bring together expertise and skill to ensure that patients with rare conditions are not denied high quality care”. He added: “The paradox of rare diseases is that they collectively affect over 3.5 million people in the UK but that all too often patients go undiagnosed and misdiagnosed with appalling consequences. Ministers can do more and must do more to make the NHS fit for the purpose of treating rare conditions.”

Dr Peter Corry, a leading Paediatrician at St Luke’s Hospital, Bradford, said: “Many rare diseases are severe, or even life-threatening. Diagnosis is often difficult and the complex treatments required may involve several specialists. Frontline medical staff need good sources of up-to-date information, clear pathways and access to the appropriate experts.”

June 09: EU Health Ministers adopted a Council Recommendation that called on Member States to develop & implement plans or strategies for the treatment of rare diseases. An important step. HPTH UK would like to thank Rare Disease UK for the important work it is doing on our behalf. We will keep you updated on progress and you can read more at www.raredisease.org.uk and www.gig.org.uk

Liz Glenister, Director
liz@hpth.org.uk
Representatives of eight patient support groups for various endocrine disorders met together with executive staff from the Society for Endocrinology in Harrogate on Tuesday 17 March during the Society for Endocrinology BES 2009 conference. The Society for Endocrinology (SfE) is the major British society representing medical professionals (scientists, clinicians and nurses) who work with hormones. See: http://www.endocrinology.org/. Many of the patient groups had a stand at the meeting to display literature and raise awareness for their organisation amongst the conference attendees.

I attended the patient groups meeting on behalf of both the British Thyroid Foundation and HPTH UK. The other groups represented were the Addison’s Disease Self Help Group, the Association for Multiple Endocrine Neoplasia Disorders (AMEND), the Klinefelter’s Syndrome Association, the Pituitary Foundation, the Thyroid Eye Disease Charitable Trust, and the Turner Syndrome Support Society. The meeting was chaired by Jennie Evans, Public & Media Relations Officer for the SfE.

One development is the Society’s new Public Engagement Committee which has been set up to oversee and advise on all the activities the SfE Public and Media Relations department carry out. There are two representatives on the committee who will specifically advise the SfE on working with patient groups - Professor Stephen Shalet (Manchester) and Dr Philip Harris (Ipsen). This Committee has made a number of suggestions already: inviting patient groups to support relevant sessions at the Society’s meetings; providing case studies to talk with the media; and providing members to visit medical schools and talk to medical students about their condition. All groups confirmed they would welcome the opportunity to work with the SfE on these initiatives.

One of the key issues we discussed at the meeting was the length of prescriptions for endocrine patients. Many doctors are limiting prescriptions for long-term medication to 28 days in direct contradiction to the guidance issued by the National Prescribing Centre which states that ‘...prescriptions for longer periods may be more suitable, and more convenient’ for patients who have stable chronic conditions and can manage their stocks of medicine. A press release by the British Thyroid Foundation, which has surveyed its members and found that nearly 40% of the respondents were unable to obtain prescriptions for more than 28 days, was picked up by the BBC News website, BBC Radio York, and The Yorkshire Post. The MP for Harrogate and Knaresborough, Phil Willis, visited the conference to show his support for the campaign. (The findings of the BTF survey have since been published in a peer-reviewed journal BMC Public Health. The article ‘Trends in thyroid hormone prescribing and consumption in the UK’ by Anna L Mitchell, Bryan Hickey, Janis L Hickey and Simon HS Pearce, can be downloaded here.) The Public Engagement Committee plans to develop a position statement on the length of prescriptions for long-term medications such as levothyroxine, hydrocortisone and calcium to target the Primary Care Trusts. All agreed this would be very welcome.

This was the first time that HPTH UK has been represented in any way at the SfE conference and it was a welcome opportunity to make contacts, to hear about the SfE’s plans, to exchange ideas about collaboration between patient groups and medical professionals, and to discuss common issues with other patient groups.

Judith Taylor, Public Affairs Officer judith@hpth.org.uk

BES 2010 will be held in Manchester, 15-18 March and we will be having exhibition space there, also for the first time - Ed.
UK patients with ANY form of Hypoparathyroidism are invited to participate in this new study on Hypoparathyroidism currently taking place in the USA. This will be a very useful study for us, and we do hope that as many of you as possible will take part.

‘An Endocrine Oncology research group from Harvard Medical School of Public Health is conducting a study to Compare the perceptions of Hypoparathyroidism held by surgeons and pre-operative patients with those held by people who actually live with Hypoparathyroidism’.

The survey asks for your views about your health as an individual with permanent Hypoparathyroidism. Your responses will indicate how you feel and how well you are able to do your usual activities.

There are 25 questions that should take around 10 minutes to complete, including a series of demographic questions at the end. The information you provide is completely private and completely anonymous. There are no questions that involve identification.

Some of the questions are not phrased perfectly, some are specifically for American patients and some are for post-surgical patients only but please help by marking the one box that best describes your answer, where possible.

To take the survey, please click here.

Thank you for your participation.

Dan Ruan, MD.
Harvard Medical School’

Thanks to Dr Ruan for this invitation - and also to Matt LeClair, research assistant at the Brigham and Women’s Hospital in Boston and James Sanders of the Hypoparathyroidism Association, USA.

For more than 40 years, MedicAlert has been providing a life-saving identification system for people with hidden medical conditions.

This takes the form of body-worn bracelets or necklets (known as Emblems) which carry the MedicAlert symbol as well as an Individual ID number and 24 hour emergency number. The emergency number is accessible in more than 100 languages and enables emergency personnel to access Medical records in an emergency.

Chris Lunn from MedicAlert says ‘There are now more than 280,000 members of MedicAlert in the UK who benefit from this service. We are very pleased to say that along with the traditional identification jewellery you can now purchase sportsbands, designer bracelets, necklets and also the MedicAlert watch.

MedicAlert also works extremely hard to ensure that emergency personnel recognise the Emblem and are able to react accordingly in an emergency situation.’

As an HPTH UK member, you will be given a 5% discount on your purchase. Just give the code HPTH.

To find out more about MedicAlert and to join, please contact Tel. 0800 581 420 or visit www.medicalert.org.uk

WHY NOT JOIN IN?

Feeling low? Confused about things? Maybe you’ve been recently diagnosed?

Why not come along and join in on our FORUM?

It’s a safe, friendly place to chat about HPTH and other parathyroid disorders. You can ask questions and benefit from the experience of others. While we’re not a substitute for medical advice, we can offer general advice, support, and practical tips on how to deal with the day to day trials of living with a parathyroid condition. Even if we don’t have an answer for you, often just knowing that there are others out there who know how you feel and are there to listen can be the biggest help of all.

Having a rare condition like HPTH can feel like a very lonely place to be, but you’re not alone....we’re here.
PATIENT PERSPECTIVES - YOUR VOICES HEARD

LIFE CHANGING EVENT

I am soon to be 70 years of age but until August of 2008 felt more like a 50 year old; very active, able to enjoy regular walks of 8/10 miles and even did a back packing adventure off the beaten track in India. Met a lovely widower (I was widowed) making a super new life for ourselves with lots of travel and bags of energy to give to our large extended family.

THEN!!! On registering with a wonderful new surgery and having a health check I mentioned casually, abdominal discomfort, frequent urination and irritability. The clever doctor discovered primary hyperparathyroidism. Calcium levels of 2.82 and 2.91, parathormone level 35.1. Endocrinologist confirmed diagnosis but after examination stated "a fit lady with no stigmata of underlying illness" and recommended a Sestamibi scan which showed “prominent focus of high activity below the lower pole of the right thyroid" He made the whole thing sound like "a breeze" and I was very confident that all would be well. Visit to surgeon who said "operation fun as could make people feel better" Further ultrasound of which I was not told results. I questioned the surgeon about risks and was told that I could possibly have a hoarse voice. Again I felt confident that all would be well.

Operation August 2008 as an overnight patient; coming round from operation I felt terrible and knew that something was very wrong with my body; during the night ECG but nothing was found. Next morning surgeon acknowledged that I was unwell but said likely that I “had hungry bones” and gave me a 4 day supply of calcium and pain killers and I was discharged. Letter to GP stated that operation had gone well but that was certainly not how I felt. Calcium levels dropped to 1.5 and I felt awful. GP concerned and monitored me after contact with surgeon. Put on Sandocal and Alfalcacidol. After three weeks further letter from surgeon to GP stated that histology showed all 4 parathyroids had been removed. Since that time in August I feel that I am not the person I was - often grumpy, tearful, emotional, very tired to the point of exhaustion, dry skin and hair. Frequent headaches on waking, pins and needles and terrible cramps at times.

At my request, I now have a different endocrinologist who acknowledges my symptoms, will continue to monitor me and my lifelong medication but has also said "that I must grieve for the loss of my former self". With hindsight how I wish I had researched the consequences of the operation and would advise anyone else to do so very thoroughly.

Have also realised that the medical profession in general know very little of this condition (not their fault as they rarely come across it). We must also be proactive in keeping records of our symptoms, medications and medical visits in order to remain positive. The Hypoparathyroidism UK web site has been my salvation in knowing that my symptoms are not all in my mind as perhaps some people think because I look so well!!!!!!

Jeannette Jones

LOCKED IN MY SILENT HELL

Locked in my silent hell
A place where nobody can tell
What’s beneath this facade
Hiding in the shade
Locked in my silent hell
Oh, but you look so well
Locked in your silent hell

But inside this shell
The calcium is not behaving as it should
As it could
If only someone would look past my well-looking shell
They would realise all is not so well
Oh, it’s too complicated to understand
All that calcium business

“There’s nothing wrong with your body, it’s your mind”
Say the educated doctors, who don’t want to educate themselves any further
It’s easier for you to leave me locked in my silent hell
Easier for you to blame my mental health
The doctors don’t even believe me
They cannot and do not want to see what it is like locked in my silent hell
Because everything else looks so well

So here I stay locked in my silent hell
Waiting to be believed and rescued
But it’s incredibly lonely in here
I’d love to leave, but the calcium won’t let me
For I am forever held in its captivity
My only hope is parathyroid hormone
It may hold the key for me and set me free from my silent hell

Janette Langdell
**MY STORY**

"Your scar looks good….”

These were the first words that my surgeon said to me once I was awake after surgery. At that moment I felt somewhat relieved. My thyroid was gone and I wouldn’t have a scar that made me look like Frankenstein’s Monster - although on a bad day the similarity is frightening! Of course things are never that simple. Two days after surgery I got ‘the tingles’ and my parathyroid journey was just beginning. Being the optimist that I am, or maybe that should be used to be, I assumed that this would just be a temporary blip. After all, my surgeon had told me, with great confidence, that he had performed hundreds of total thyroidectomies and never damaged any parathyroids! How could I not trust him? He drew pretty diagrams and wore a nice pink tie. Three months after surgery I was still being told that it was just temporary and they would soon kick back into life. Six months passed and still no sign of improvement. At my last appointment, twelve months after surgery, they finally admitted defeat and said my parathyroids would probably never work again. That was the moment of realisation, that I was doomed to be a grumpy, tingly, tired and emotional wreck for the rest of my life! Which to be fair, isn’t much of a change from my normal self but at least now I have an excuse.

However, on my journey I came across a website all about Hypoparathyroidism, HPTH UK. A wonderful website with lots of useful information and a wonderful forum with helpful and compassionate people who, if they can’t offer advice, can let you know that you’re not alone. That I think is the hardest part, thinking that no one else knows what you’re going through. The paranoia that although you look ok you feel pretty poorly and people might think you’re making it all up.

Fourteen months post-op, I am now trying to find the right dose of Alfacalcidol to take and I have good days and bad days. The battles with the GP and Endocrinologist will continue. Eight years of unsuccessful Graves Disease treatment and the hope of a great new life after surgery didn’t materialise for me. However, knowing that there is help and support available makes the journey bearable.

I consider myself to be a “newbie”, I am the queen of asking pointless or stupid questions on the forum, yet no one has ever mocked me. So don’t be shy, join in, ask questions. The more questions we ask the more support we can get. Ride out the bad days, enjoy the good and remember there is always chocolate!

Su Clifton

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**ODE TO HYPOCALCAEMIA**

Is my calcium high, is my calcium low?  
Without a blood test there’s no way I’ll know.  
Am I feeling happy or feeling sad?  
Most doctors have the impression  
that I’m stark raving mad.  
With tingling in my feet, fingers and toes,  
The pins and needles that tickle my nose,  
The numbness, then I lose my hands and feet  
Makes me look like Charlie Chaplin walking down the street.

If I’m not being sick, I’ve got kidney stones,  
I get muscle cramps and creaking bones.  
So my calcium’s on the level but I still feel unwell  
It’s all in the mind, my consultants will yell.  
Hospital visits with whoever draws the short straw,  
Most make excuses, don’t want to see me anymore.  
As a patient I’m a pain, all full of moans  
‘Oh not him again’, my consultant groans.

So my chronic illness gets pushed to one side  
and if I put the doctor right, I’ve then hurt his pride.  
Just get lots of calcium, eat lots and lots of cheese.  
I should be turning cartwheels, instead I’m on my knees.  
Help is here for patients like me in a tizz,  
Click onto to Hypo UK and there find lovely Liz  
At last someone who understands,  
who really knows the score.  
What a relief, at long last, I’m not alone anymore!

Janice Hirst

(Oct 2008)

**SMILE!**

Smiling is infectious; you catch it like the flu,  
When someone smiled at me today,  
I started smiling too.

I passed around the corner, and someone saw my grin,  
When he smiled I realised, I’d passed it onto him!  
I thought about that smile, then I realised its worth,  
A single smile, just like mine,  
could travel round the earth!

So, if you feel a smile begin, don’t leave it undetected,  
Let’s start an epidemic quick,  
and get the world infected!
FUNDRAISING

HPTH UK took part in the Royal Parks Half Marathon in October 08 and raised nearly £2000 thanks to the stalwart efforts of two great guys, Jack Gardener and Dan Lloyd, and your very generous sponsorship. Thank you to everyone who donated! It was a fantastic event made even more special by the members who turned up to the HPTH UK PICNIC we held afterwards. Imagine our surprise to see not only Jackie Spicer and son, but Jessy Clays and her husband Erik who had come all the way from Belgium and our own Judith Taylor from Holland! It was an emotional event, being the very first time that any HPTH UK members had ever met. Thank you to everyone who came and made it such a happy and successful day.

Jessy and Judith came all the way from Europe!

DONATE EVERY TIME YOU SHOP

You can donate money to HPTH UK every time you shop online - without having to pay any more than the price of your purchases!

Every time you make a purchase via one of the 2000+ well known retailers linked to www.easyfundraising.org.uk, they will donate up to 15% to us! It couldn’t be easier!

All you have to do is register and choose Hypoparathyroidism (HPTH) UK as your cause to support. Then every time you shop online, just go to the website, find the shop you want to go to, and click on “Visit Store”.

PLUS! Every time you make a purchase via the website, you will be entered into a fantastic competition prize draw! There is a different competition every month, with some excellent prizes to be won!

You also get an extra entry when you refer a friend to easyfundraising, so spread the word!

STAR FUNDRAISERS

Bridget O’Connor
Despite her own serious problems with HPTH, Bridget is unstoppable. An HPTH UK committee member, she not only raises funds through selling stocking fillers but has now written and published a children’s book about being diagnosed with a long term illness. Called ‘Hisham’s Envelope’, the book will be on sale on the new website but orders may also be placed with Bridget via the telephone helpline. Thank you Bridget!

Stuart Hirst
Stuart used our logo to print on T-shirts which he then sold as part of a Wakefield College mini enterprise project and raised £25 for HPTH UK. Stuart’s father has HPTH and his mother has a poem published in this newsletter, so a star family really. Thank you, Stuart!

If you have a marathon place in an upcoming event, and would like to run for us, please email liz@hpth.org.uk

“The greatest wealth is health” - Virgil
**HOW CAN YOU HELP?**

You can help us by donating your time, love or money. Here are a few ideas:

**VOLUNTEER** Got some time to spare? We need volunteers to help us run HPTH UK, to fundraise, offer professional advice or just muck in when needed.

**SEND A MESSAGE OF SUPPORT** Let us know what you think about our service and how we can improve it.

**FEELING FIT?** You could take up a CHALLENGE! http://www.bmycharity.com/challenges.aspx

**COME DINE WITH ME?** You can set up your own personal BMYCHARITY online fundraising page to collect funds for ANY event you care to hold - or just give out this link to collect donations https://www.bmycharity.com/hpthuk

**DONATE** Raising funds for a rare condition is not easy so any help, however small, is always welcome.

There are 3 ways to donate:

* go to the website home page at www.hypoparathyroidism.org.uk and click on the button to pay safely online via PayPal
* go to our BMYCHARITY page to donate at www.bmycharity.com/hpthuk
* post a cheque to HPTH UK, 6 The Meads, East Grinstead, West Sussex, RH19 4DF

**THANK YOU**

**STAY IN THE KNOW...**

 Already found us on Facebook?

You can now follow HPTH_UK on Twitter too!

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**TELEPHONE HELPLINE TRAINING**

Thanks to a grant from the Society for Endocrinology, we were able to send volunteer Bridget O'Connor on a telephone helpline training course last year. Here is her report –

Following my operation for a total thyroidectomy in November 07 and then developing Hypoparathyroidism, I decided to join HPTH UK. In June 08 while checking in on our Forum, I read a request from Liz asking for a volunteer to go on a telephone helpline training course. I decided to give it a go.

The venue was in Birmingham and was facilitated by the Telephone Helpline Association. Everyone was lovely and very friendly and the course ran from 10:30 - 4:30. There were 15 other candidates there from all walks of life - from various charities to NHS workers. During a round robin of introductions, guess what? Not one person had heard of Hypoparathyroidism, so I immediately had the opportunity to raise some awareness. The course was very helpful and informative. There were many sections to the course including Introduction to Boundaries, Overcoming Barriers to Communication, Active Listening Skills, Effective Questioning Techniques, and Effective Call Management. Other things we learned were how to be friendly yet professional, how and when to ask the right sort of questions (open, closed, hypothetical or leading), how to deal with distressed and upset people - I could go on! The course had a good mix of study periods and active hands-on sessions. The day was very worthwhile attending and is proving very useful in connection with my voluntary role as helpline contact not only for us, but the British Thyroid Foundation as well.

The day concluded with a recap of what we had learned and we all left clutching our certificates - complete with shiny gold seal! The motto for the Telephone Helpline Association is QUALITY and CONFIDENCE for CALLERS to HELPLINES. That says it all really!

Bridget O'Connor, Telephone helpline
North area - 01623 750330

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“Volunteers don’t get paid, not because they’re worthless, but because they’re priceless”
- Sherry Anderson
Professor Bill Fraser, our lead advisor, and Dr Brian Shine who agreed to run the clinical trial for us, Gudrun Viddasdottir in Iceland who got the trial going; Dr Abhi Vora of the Society for Endocrinology who asked that simple but crucial question - how can I help? And then acted on it; Dr Mo Aye for writing the leaflets, Dr Nick Shaw for stepping up to a radio show at a moment’s notice; Professor Raj Thakker, Professor Simon Pearce and Dr Petros Perros for their continuing support; Dr Peter Swift, our PPHP advisor now retired, and our 2 GP’s Dr Stephen Bellamy and Dr. Denise Adams for telling it how it is. Helen Dahl-Hansen in Norway. All the team who have kept HPTH UK going despite their own HPTH difficulties. Ivor Humphreys, our webmaster (without whose generosity HPTH UK literally wouldn’t exist), for our new website and much laughter. Warmest thanks to you all.

Liz Glenister, Director
liz@hpth.org.uk

VERY SPECIAL PEOPLE...

View of Ellson's Pond
(Ashdown Forest)
Acrylic
15 x 15cms on glossy white card
£4.00 for 10 cards

Standen
(National Trust )
Pastel
10 x 15cms on white silk finish card
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1 pack £1.75
2-5 packs £3.25
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HOW TO PAY
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Please send your order with contact details to HPTH UK, 6 The Meads, East Grinstead, West Sussex RH19 4DF enclosing a cheque made payable to HPTH UK.

By PayPal
Please email liz@hpth.org.uk or call 01342 316315 to place your order and leave your contact details. Go to the website home page at www.hypoparathyroidism.org.uk and pay via the PayPal donation button.

Your order will be sent to you immediately by 1st class post when your payment arrives.

FROM THE EDITOR

This is your newsletter - so if you have any ideas about what you’d like to see in the next one, please contact me. This is the first newsletter I’ve edited, so if you have any comments or suggestions about how it can be improved, I’d love to hear from you. Please feel free to contribute - send me suggestions for articles or topics you’d like to know more about, and of course your own stories! Put pen to paper (well, fingers to keyboard probably!) and have your say!

Please send all contributions by 31st March.

Mandy Mainland, Editor
mandy@hpth.org.uk

HPTH UK CHRISTMAS CARDS

We are delighted to offer you two winter scenes from original paintings by Sussex artist William de Wilde.

They are blank inside for your own seasonal message - or buy them to send as greetings cards this winter.

All proceeds will go to HPTH UK.

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STANDEN (NATIONAL TRUST)
Pastel
10 x 15cms on white silk finish card
£3.00 for 10 cards

TELEPHONE HELPLINE
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NORTH - 01623 750330