INSIDE THIS ISSUE....

- HPTH UK News Update
- Surgical Onset Survey Results
- PTH 1-84 Trial News
- Fundraising
- Meet Our Members
- Emergency Card

NHS REFORMS - A BETTER FUTURE?
In July the coalition government issued, along with many other consultation documents, a White Paper - ‘Equity and Excellence: Liberating the NHS’ which, if implemented, could bring about the biggest changes to healthcare, in England at least, since the NHS was set up over 60 years ago.

‘Liberating’ is government-speak for abolishing. What are to be abolished are the Primary Care Trusts and Strategic Health Authorities so that future responsibility for commissioning services will be handed over locally to GPs and, regionally and nationally, to a new National Commissioning Board.

How this will work remains to be seen. How the budget will get divided up and where cuts will be made is also unknown at present. What is certain is that there will be many changes and we can only hope they will be positive ones.

One of the new ‘domains’ in which NHS performance will be measured is ‘enhancing the quality of life for people with long term conditions’ which at first hearing sounds like a very positive move for people with permanent hypoparathyroidism. However, as our condition is rare and patients are few, it is possible that we and other rare conditions will be overlooked and we will have to fight to be heard. Nothing new there then, but how can we do this?

HPTH UK is a member of Rare Disease UK and the Genetic Alliance UK who are vigorously campaigning on behalf of all their member groups to influence legislation and future policy. We are very grateful to them for all their efforts on our behalf and would like to express our appreciation for all the work they do. We will keep you posted on their progress but meanwhile you can read their responses to the White Paper and to 4 other consultation papers here http://www.geneticalliance.org.uk/policycampaigns.htm and here http://www.raredisease.org.uk/documents/Strengthening_National_Commissioning_GIG_RDUK.pdf

Liz Glenister, Director
liz@hpth.org.uk

HPTH UK CHRISTMAS CARDS
We are delighted to offer you three high quality artist cards this year. The first is a witty new design, made exclusively for HPTH UK by graphic artist Alex Rout at Red Mist Designs. The greeting inside reads: ‘Goodness nose it’s Christmas’.

The other two are beautiful winter scenes from original paintings by Sussex artist William de Wilde. These are blank inside for your own seasonal message - or use them as greetings cards throughout the winter. All proceeds will go towards the work of HPTH UK.

Red Nose
Alex Rout
10x15cms
Smooth white card
£3.50 for 10 cards

Standen
(National Trust)
William de Wilde
Pastel 10x15cms
White silk finish card
£3.50 for 10 cards

View of Ellison’s Pond
(Ashdown Forest)
William de Wilde
Acrylic
15x15cms
Glossy white card
£4.00 for 10 cards

Payment is via cheque, made payable to HPTH UK. Please send your order, cheque and contact details for delivery to HPTH UK, 6 The Meads, East Grinstead, West Sussex, RH19 4DF. Don’t forget to include the P&P!

Postage and packing

1 pack  £1.75
2-5 packs  £3.25
6-10 packs  £4.45
11+ packs  £8.25
Dear members and friends,

The first half of our year was dominated by the considerable increase in membership and interested queries generated by our new website and by the launch, at the BES conference, of our first patient information leaflet, both of which were very well received by patients, doctors and clinics alike. Our leaflet is always available to order as a hard copy (individually or in bulk) or to download from the website.

Gradually, information is becoming more available. Recently, we were invited to comment on a draft of the new leaflet for Primary Hyperparathyroidism being developed by the Society for Endocrinology to be published next year (and on a new piece of research related to thyroid and parathyroid surgery at the University of Sheffield). The Society for Endocrinology is currently building a new website called ‘Welcome to You and Your Hormones’, a new web-based project that aims to give patients and the general public access to reliable online information on endocrine science. We will keep you informed about all these developments.

We were asked by NHS Direct to become one of 200 core resources in their health information service. Our website, online resources and leaflet were described as ‘very valuable and helpful additions’ to the publications currently stocked in the central library and are now being used in NHS Direct call-centres to provide information to the public and also to refer patients to us.

How forthcoming changes in the NHS will affect us is the subject that occupies much thought at the present time. Find out inside how our needs are being championed.

Awareness

During the second half of the year, we have been concentrating on awareness and fundraising events, getting the word ‘Hypoparathyroidism’ out into the world. Once people have got their tongue round it, they do tend to remember it! However, Hypoparathyroidism is regularly (and easily) confused with hypothyroidism and most people assume, quite naturally, that HPTH has something to do with the thyroid. For this reason, and because, as the only UK organisation dedicated to parathyroid issues, we now receive as many queries from people with hyperparathyroidism as with hypoparathyroidism, we may soon be changing our name to reflect this. We will keep you posted.

In September, one of our members, Ingrid, gave a presentation about hypoparathyroidism and HPTH UK in Winchester and in November, Bridget represented us, along with BTF, at the second Awareness Meeting at the Kings Mill Hospital in Nottingham. Once again, this event proved very popular with over 100 people in attendance. Read our reports inside.

Fundraising

Despite a slow start, we have been delighted to see donations starting to roll in. We have been very touched by the efforts to which our amazingly kind and generous supporters will go in order to help us reach our goal of £5000 per year. (This is the amount needed to become a charity – but also what we need to keep going.) Our own Christmas cards are now on sale so we do hope you will place an order very soon. You can now support us by setting up a standing order for HPTH UK – see how inside. Including the leaflet grant we received from the Society for Endocrinology in April for £2000, our bank balance currently stands at £4,750 which is the most it has ever been in 5 years and is a fantastic result. Thank you all. Please don’t stop!

Clinical trials and surveys

The PTH 1-84 study continues in Liverpool and is still recruiting new patients. Read about their progress inside. Sadly, the Oxford centre was forced to close due to lack of patients in the area who met the necessary criteria but we would like to extend our thanks to Dr Brian Shine for his commitment and support. Our editor Mandy Mainland gives us an update and explains what to expect if you enrol on the study.

Also published inside are the results of the survey by Dr Norman on post surgical HPTH patients in which many of you participated earlier this year. They make shocking reading but we hope the results will inform patients and professionals about future treatment and care.

The results of the International Thyroid Cancer patient survey was presented in Paris in September by Kate Farnell of the Butterfly Thyroid Cancer Trust alongside the top thyroid cancer experts in the world. She will also present it in Newcastle this month at the NCRI and TCF-UK conference. We would like to extend our love and thanks to Kate who lost both her parents this year but has carried on representing the patient voice and making sure it is heard where it matters.

Committee News

This year we were very sad to say goodbye to Caina Cuthbertson who gave us so much valuable time and support, especially on the forum, before moving on to spend time on other passions. We all miss her and wish her well. Taking her place as Admin Officer (now a wider role to include distribution and sales) we welcome Claire Sale who was married in June and whose husband Liam will be running a marathon for us next year. What a team! Bridget O’Connor officially became our new Fundraising Officer this month, a role she has already been doing very well for some time.

Welcome to all our new members - do get in touch if you have any queries and/or comments or would like to get involved. I hope you find this newsletter interesting and I wish you all a healthy and happy 2011,

Liz Glenister, Director
liz@hpth.org.uk
ANOTHER SUCCESSFUL AWARENESS MEETING!

Following the resounding success of our first Awareness Meeting in April, another one was held in Nottingham this month. It was a great success, attracting 112 people! It was attended by The British Thyroid Foundation as well as HPTH UK, and discussed thyroid and parathyroid conditions.

Two consultants gave presentations on the night -

Professor Devaka Fernando (Consultant Endocrinologist) spoke about the thyroid gland (what it is, what it does and what can go wrong). He described the different types of thyroid disorder, and explained the various treatment options regarding medication and surgery. The presentation was extremely informative and easily understood. This was followed by a very interesting question and answer session.

Mr Keshav Nigam (Consultant Surgeon) then gave a presentation on thyroid surgery. He spoke about the indications for surgery and described the investigation techniques used, including blood tests, biopsy and radioactive iodine scan. He discussed the different types of surgery, and the possible complications. He talked at length about the parathyroid glands (what they are, what they do and what can go wrong). He described the symptoms of low calcium and the treatments for HPTH, stressing the need for regular calcium monitoring. He also held a question and answer session following his presentation, and then both doctors took the time to talk to the guests on a one-to-one basis.

We would like to thank both doctors for generously giving their time, and also Professor George Thomson who unfortunately couldn’t be there on the night, but was very instrumental in organising the event. Our thanks also go to Sarah Elphick, who took care of all the bookings and organised the volunteers. She has been a great support during both these events. The King’s Mill hospital hopes to hold another meeting next year.

As ever, we couldn’t have done any of this without the hard work and dedication of Bridget O’Connor - thank you Bridget!

“A Never again!! Well…. Maybe.”

Hi, my name is Ingrid and I recently asked Liz to give a presentation on Hypoparathyroidism and the work of HPTH UK to my work colleagues. I had been asked to organise the agenda for our monthly meeting – an ideal opportunity for a brief introductory talk on the subject. All was going to plan but unfortunately, at the last minute, no one was available from HPTH UK due to illness. Thankfully Liz had sent me a slide deck so that I could deliver a shortened version of the presentation myself. Was this against my better judgement? Quite possibly!!

It wasn’t a large audience. On that day we were a group of about 15 people – with very varied backgrounds (sales, marketing, IT, nursing, project management, MBA students etc). Presenting to my colleagues is something I usually take in my stride. However, as soon as I started to explain why hypoparathyroidism was on the agenda, I felt my two worlds – work and private life – collide.

Self disclosure about my experience of thyroid cancer in my early twenties - and the ensuing damage to the parathyroid glands - was not a topic I had discussed publicly before. I choked up. I lost my place in the presentation and felt very, very uncomfortable. As one of my colleagues (an experienced nurse) in the team commented, “this is too close to home, isn’t it?” But they understood, and I was able to open their eyes to a condition that none of them knew much, if anything, about previously.

The condition, the cause, the range of reported symptoms, and the lack of real treatment in the form of a replacement parathyroid hormone, was new to everyone in the audience in spite of our line of work; our team specialises in providing healthcare options for people with long term conditions. And, although its not currently on our company’s road map (yes, I hate the jargon too!) to focus on the causes, treatment or management of hypoparathyroidism, it felt good to raise the awareness of this rare condition amongst this particularly sympathetic and highly interested group of professionals!

MAGNIFICENT MANCHESTER

The Summer issue of The Endocrinologist includes an article about HPTH UK and our experience of participating for the first time at the Society for Endocrinology’s British Endocrine Societies (BES) conference in Manchester this year. The newsletter can be downloaded free of charge. To download or read the article, go to: http://www.endocrinology.org/endocrinologist/issue.aspx?issue=96.

Judith Taylor, Public Affairs Officer judith@hpth.org.uk
Many thanks to all the surgical HPTH patients who kindly took part in the study by Dr Norman and the Parathyroid Centre, USA, earlier this year. It was the largest study of surgical hypoparathyroidism patients in the world to date and the results make very interesting reading. We would like to thank Dr Norman for carrying out this much needed survey which we hope will inform both patients and professionals about future treatment.

Surgical Hypoparathyroidism

Norman, J (2010)

Introduction

Hypoparathyroidism is a medical condition caused by a surgeon removing all four of a patient’s parathyroid glands. This is a terrible complication of surgery performed on the thyroid or parathyroid glands, and its occurrence should be near zero. It can cause very significant medical problems and can be so severe as to make a person’s life quite miserable.

Surgery of the thyroid and parathyroid glands can be quite tricky. The parathyroid glands have the most variable anatomy in the body. Because of this, even the most experienced thyroid surgeons in the world could, on occasion, make the mistake of destroying or removing all of a patient’s parathyroid glands. Unfortunately, as will be discussed throughout this paper, the chance of this life-changing complication occurring can be over 1000 times higher when the operation is performed by an inexperienced surgeon.

The ‘acceptable’ rate of a surgeon causing hypoparathyroidism during an operation on the thyroid or parathyroid glands is about 1% or less, as reported in the medical literature. The reality, however, is much different - and very dependent upon the skill and experience of the surgeon. To publish a scientific paper in the medical literature, a physician must have enough experience in the field that allows him/her to accumulate sufficient data that is worthy of publication. Accordingly, only surgeons that have done a lot of thyroid or parathyroid surgery have enough patients that they have something to write about. It follows that a surgeon that performs a couple of thyroid or parathyroid operations per year will never accumulate sufficient data to allow him/her to publish. Thus, the ‘acceptable’ rate of hypoparathyroidism following thyroid/parathyroid surgery of 1% is the rate of very experienced surgeons. Those surgeons who are inexperienced and have bad complications clearly do not write journal articles telling the world about their poor outcomes.

This is the largest study of surgical hypoparathyroid patients in the world. We worked with the Hypoparathyroidism Association and Hypoparathyroidism UK to collect data on over 200 patients who were made hypopara because of surgery on their thyroid or parathyroid glands. As we will show here, almost every patient with this complication was operated on by a surgeon that does NOT perform parathyroid or thyroid surgery more than once per month. These are very inexperienced surgeons and their inexperience is directly related to the occurrence of this problem.

Patient Demographics

In this study of 215 patients with surgeon-induced hypoparathyroidism, the average age was 42 years and 90% were female. 80% were operated on for thyroid disease while 20% were operated on for parathyroid disease. This makes sense, since thyroid surgery is much more common than parathyroid surgery and both thyroid and parathyroid disease are 3 times more common in females.

Surgeon Experience

We contacted each surgeon or their office manager and established the number of parathyroid or thyroid operations performed by that surgeon in the past 2 years. Every patient who developed hypoparathyroidism had a surgeon that performed thyroid/parathyroid surgery less than twice per week. Ninety five percent (95%) of the surgeons who caused this performed less than one thyroid/parathyroid operation per week. 85% of the surgeons performed this operation less than once every two weeks, 65% performed this operation less than once per month. There were no patients with hypoparathyroidism that had a surgeon who performed more than 150 of these operations per year.

Surgeons that performed between zero and five thyroid/parathyroid operations per year had a 9% chance of making their patient hypoparathyroid. The chance of this happening decreased to 5% when the surgeon performed 25 of these operations per year. Ninety five percent (95%) of the surgeons who caused this performed less than one thyroid/parathyroid operation per week. 85% of the surgeons performed this operation less than once every two weeks, 65% performed this operation less than once per month. There were no patients with hypoparathyroidism that had a surgeon who performed more than 150 of these operations per year.

Surgeons that performed between zero and five thyroid/parathyroid operations per year had a 9% chance of making their patient hypoparathyroid. The chance of this happening decreased to 5% when the surgeon performed 25 of these operations per year. It was not until the surgeon performed 150 or more thyroid/parathyroid operations annually that the rate of hypoparathyroidism decreased to the ‘acceptable’ rate of 1% or less.

The experience of the surgeon can also be seen when the duration of the operation is examined. Surgeons that perform a particular operation frequently will usually become much faster and efficient. Over 85% of patients who developed hypoparathyroidism following their operation had an operation that lasted 3.5 hours or more, with 65% having an operation that lasted 4.5 hours or
more. As a comparison, it typically takes the author of this study (Dr Norman) an average of 55 minutes to perform a total thyroid removal and an average of 17.8 minutes to perform a parathyroid operation (he has performed nearly 8,000). Clearly the most inexperienced surgeons take much longer to perform the operation, and in doing so, have a much higher incidence of killing (or inadvertently removing) all of the parathyroids.

**Associated Complications**

The second major complication associated with surgery of the thyroid or parathyroid glands is injury to the voice box nerve. This nerve is called the recurrent laryngeal nerve and there is one nerve on each side of the neck, just behind the thyroid and immediately adjacent to the upper parathyroid glands. If this nerve is damaged, the patient cannot talk except in a very slight whisper. If BOTH of the nerves are injured, the patient must have a tracheostomy in order to breathe. The ‘acceptable’ rate of injuring this nerve is 1%; however, as stated above, the rate of this complication is directly related to the experience of the surgeon. In this study, 54% of patients who were made hypoparathyroid ALSO had an injury to the voice box nerve. In 11% the injury was permanent (they can’t talk well for the rest of their lives), and in 4% the injury was on both sides so the patient had to get a tracheostomy. As a comparison, the author of this study (Dr Norman) performs approximately 1800 of these operations annually, and has never had a permanent injury. Surgeons who don’t do an operation very often have a MUCH higher rate of complications, and often have SEVERAL complications. These complications are often life-changing.

**Patient / Surgeon Interaction**

Over ½ of patients who were made permanently hypoparathyroid by their surgeon never asked their surgeon about their experience in performing this operation. Just over 55% said it never occurred to them to ask the surgeon - do you do this type of surgery very often? …. and thus had no idea that their surgeon did NOT do this operation often… or ever! Within two weeks of the operation, 61% of patients found out that their surgeon was not experienced in this type of surgery and that their surgeon did very few of these operations. Another 26% found out a few months later when they went to a new doctor to get treated that their doctor was the best choice… even in their home town!

Another interesting finding was that when we asked surgeons about their experience performing thyroid/parathyroid operations, nearly every surgeon overestimated the number of these operations that they performed on an annual basis. When the surgeon’s estimate of his experience in the past two years was compared to the actual number as reported by his office to the insurance companies for payment (the real number of these operations they actually performed), we found that the surgeon OVER ESTIMATED the number of thyroid/parathyroid operations by two fold or more in nearly 55% of all cases. In other words, most surgeons would tell us how many operations they performed, only to find out that his office records showed he/she performed less than half that many.

Sixty percent of patients said that the possibility of getting hypoparathyroid was never discussed prior to their operation… their surgeon never mentioned it. The bottom line: patients never asked their surgeon if he/she was experienced in performing the operation and they paid a very dear price. If a patient did ask the surgeon, in over half of the cases the surgeon exaggerated the number of these operations they perform by two-fold or more.

Patients in this study were asked to tell us how their surgeon explained to them that they had zero parathyroid glands left, and that they have a complication called hypoparathyroidism. 61% said that their surgeon NEVER told them what was going on and never told them that the problem was due to the mistaken removal of all of the parathyroid glands - some other doctor had to explain what was going on and why they were so sick. 27% said that the surgeon did some explaining, but not much, and the final 11% said their surgeon was very good at explaining what happened and why. When these patients were asked if they were pleased with how their surgeon communicated with them, 65% said ‘not at all’, while only 8% said ‘yes, he/she has been a great communicator’. Finally, when asked about their feelings toward the surgeon that caused their hypoparathyroidism, 58% said they were very angry with the surgeon, 30% said they were indifferent, and less than 10% said they still liked their surgeon a lot.

**How Hypoparathyroidism Affects Patient’s Lives**

**Calcium and Vitamin D Requirements**

Patients who have had all of their parathyroid glands removed or destroyed will require high doses of calcium and Vitamin D every day for the rest of their lives. Almost all patients in our study are required to take 4 or more calcium pills per day. Two-thirds (67%) have to take 5 or more calcium pills per day, and 25% have to take 8 or more calcium pills per day. Almost all patients take at least 2 Vitamin D pills per day, with 1/3 taking 3 or more per day. Thus, most patients who have hypoparathyroidism must take 8 or more pills per day in order to carry on the daily functions of life. Despite taking these pills, 45% of patients say they still get symptoms of low calcium at least once per day. The most common symptoms reported by these patients are:
fatigue (77%), hand cramps (68%), mental confusion (43%), and anxiety/fear (36%). One third of patients state that they get these symptoms once or twice per week, while only 5% say they rarely or never get these symptoms.

**Work and Employment**

Having hypoparathyroidism often makes people feel bad frequently enough that nearly 25% say they cannot work and have become unemployed. Of those still working, 72% said they had to change jobs because of concentration abilities or other issues related to symptoms (can’t teach school, can’t drive a truck, etc). 65% of patients say they miss 2 weeks or more of work per year more than they ever did before. One third stated that their employer doesn’t understand their issues and why they are sick on a frequent basis.

**Personal Interactions**

A minority of patients say their family ‘understands’ how they feel and their family has been great. However, 78% say their family and/or friends ‘simply don’t get it’. Just over 40% have been put on antidepressants. Two thirds say that hypoparathyroidism and the symptoms it causes have put significant stress on their relationship, with 8% saying this ailment is directly responsible for the breakup of their marriage. Clearly, patients with hypoparathyroidism feel poorly and this puts significant stress on their interactions with others.

**Seeing Doctors for Ongoing Care**

Less than 10% of all patients with hypoparathyroidism say their disease is managed well enough that they never have to go to the emergency room to receive IV calcium. Almost half of patients make one ER visit per year, while 25% make 3 or more ER visits per year.

Having hypoparathyroidism is associated with a dramatic increase in the number of doctor visits per year. Only 20% said they were not referred to a new doctor to help manage the problem, while 30% said they have 3 or more NEW doctors that they have seen to help manage this problem. Importantly, 61% said that even their endocrinologist doesn’t understand their symptoms fully, and state that their doctor is often more interested in their lab (calcium) values instead of how they actually feel. One third of patients with hypoparathyroidism are now required to see an endocrinologist every 1-2 months, one third see their doctor every 3-5 months, and one third see their doctor every 6-12 months. Two thirds of patients have to get their blood calcium checked every 4 months or less; one third gets their blood tested every month.

**Summary of Surgeon-Induced Hypoparathyroidism**

Surgeon-induced hypoparathyroidism is a serious medical condition that is life-long. Patients with hypoparathyroidism are required to take lots of medication, yet most of them continue to get symptoms of low calcium daily or weekly.

Hypoparathyroidism takes a serious toll on the interpersonal lives of these patients at home and at work, and has significant costs associated with multiple doctor visits and lab tests.

Surgeons who perform more than 150 thyroid/parathyroid operations per year are extremely unlikely to cause hypoparathyroidism, while those that perform fewer than 20 of these operations annually have a 10% chance of causing this or another serious complication. Surgeons who perform less than one thyroid/parathyroid operation per month have a risk of causing permanent hypoparathyroidism nearly 1000 times higher than the few elite surgeons who perform over 500 of these operations per year. Patients usually do not ask their surgeon about his/her experience, and when asked, surgeons almost always exaggerate their expertise, with half of the surgeons exaggerating the number of these operations they perform by more than two fold.

Reducing the incidence of hypoparathyroidism lies in the hands of the patients. Few surgeons will refuse to perform an operation that is referred to them because they feel that they lack the experience to do a good job. Patients must be educated about hypoparathyroidism as a life-changing complication PRIOR to undergoing surgery on their thyroid or parathyroid glands. Going to the ‘local surgeon’ that your doctor sent you to is often not the best choice. Patients must check on the qualifications and experience of their surgeons if they expect the lowest possible complication rates. Having a nice diploma on the wall isn't enough! Patients must be informed and must take charge. Patients must ask hard questions of their surgeons or the consequences could be life-changing.

This article is reproduced here by kind permission of The Parathyroid Education Foundation and Parathyroid.com

http://www.parathyroid.com/
http://parathyroidfoundation.org/
**PTH 1-84 TRIAL UPDATE**

With the PTH 1-84 trial now underway, we are all getting excited at the prospect of better treatment in the future. A few of our members have taken part in the trial, and those of you who use our Forum will no doubt have been keeping up with their progress. It’s been quite a journey so far, with some dramatic results – both positive and negative. As it’s a double blind trial, we don’t actually know who is receiving the PTH 1-84 and who is receiving the placebo. However, having spoken to most of our members who are participating, the effect the medication is having on some of them is very encouraging indeed. The need for supplementation has been greatly reduced in most cases, and some people report that they are feeling very well indeed. One of the participants told me that she actually has to force herself to rest! She’s now able to get her ironing done before doing a full day’s work, and still has enough energy left to do things after she gets home at night!

However, with the good comes the bad, and it’s a far different story for others. Some people are really struggling, and have to take even more supplements than before. Of course, these may be the people who are receiving the placebo injection. One of the participants was very sensitive to the study medication and had to end the trial early. Some people have needed more of the study medication than others, and different levels of supplementation are required too, so everyone’s journey is a little different. No change there then!

This is all purely speculation for the moment of course, as the trial is still ongoing and we don’t know how things are progressing at the other centres. We’ll have to wait until the trial is finished and the results are published before we can really get excited about it. This will take some time, and it will take a while to go through the licensing process too, before it can become widely available. We’ve still got some waiting to do, but there is light at the end of the tunnel!

**DETERMINED SCOT MAKES IT TO LIVERPOOL IN A LORRY!!**

We finally have photographic evidence that some people will do just about anything to get hold of that elusive PTH!

As soon as the trial criteria was changed to allow anyone in the country to apply, our newsletter editor was first in the queue! Undeterred by the 600 mile round trip for every appointment, Mandy was eager to take part. Many hours were spent online, searching for cheap first class train tickets to help ease the strain of travelling, but it wasn’t always that easy! Being “financially challenged” meant that when she got a last minute call to the hospital, she had to show some initiative - and ended up getting a lift all the way from Scotland in her brother’s lorry!!!

Determined…or desperate? You decide...

**WHAT TO EXPECT…**

For those of you out there who are still considering taking part in this trial, or are just beginning the process, I thought I’d write a few words about what to expect in the months ahead. You will have an appointment where you undergo various tests. These include blood tests, an ECG, a full physical exam, a bone density scan and 24hr urine collection. You will also have an in-depth review of your medical history. This will determine whether or not you can be accepted onto the trial.

That done, you are then transferred onto the oral calcium and vitamin D supplements used for the trial, and these are adjusted over the next few weeks until your calcium is stable and within the study range. You are also given an electronic diary to fill out every day. Then you are given the study drug (random PTH 1-84 or placebo) as a daily injection. It’s a small needle, which I don’t find painful at all. You are carefully monitored and adjusted over the coming months to determine the right doses of study drug and oral supplements that you need to keep your calcium stable. You will have blood tests at every visit, submit a 24hr urine at most visits and have regular ECGs. That’s it basically - it can be difficult at times whilst adjusting, but I really do believe the possible long term benefits are worth it.

**EXCERPTS FROM THE NOVEMBER 2010 NPS PRESS RELEASE**

We look forward to a number of near-term milestones including randomization of the last patient in our Phase 3 REPLACE study of NPSP558 in hypoparathyroidism.

Our market research continues to confirm the high patient and physician support for and commercial promise of NPSP558. And as a result of another successful financing, we further strengthened our cash position and we expect to deliver full-year cash burn at the lower end of our prior guidance.

NPS believes that a sufficient number of patients are currently enrolled, scheduled or identified to achieve the 110-patient randomization target for REPLACE, an international, double-blind, placebo-controlled Phase 3 registration study evaluating NPSP558 for the treatment of hypoparathyroidism in adults. Assuming a continuation of the current percentage of patients who have discontinued between enrolment and randomization, NPS expects to randomize the last patient in REPLACE in the second quarter of 2011.

NPS believes positive results from REPLACE will enable it to seek U.S. marketing approval for NPSP558 in hypoparathyroidism. ([Full report here - http://www.npsp.com/PressReleases/1490278](http://www.npsp.com/PressReleases/1490278))
FUNDRAISING

YEE-HAW! IS IT A ‘STAG DO’?

Bridget’s friend Annette Terry from Edwinstowe held a Western themed night for her family and friends in June, raising £375 for HPTH UK!
Annette works for LEO (Local Enterprise Organisation) and she also helped to organise the Mansfield Town Football Club event where Bridget O’Connor was selling her book on behalf of HPTH UK. Thanks Annette!

Bridget was at the Mansfield Town Football Club event, where she had managed to get space to set up an HPTH UK stall, raising awareness and selling the children’s book she has written about coping with a long term illness, ‘Hisham’s Envelope’. All proceeds of Bridget’s book are being split between HPTH UK and The British Thyroid Foundation, and can be purchased via our website www.hpth.org.uk.

Unfortunately the event was rained off, but Bridget still raised £52.50 for HPTH UK, and made some useful contacts for the future. She even managed to have her picture taken with the club mascot, Sammy the Stag! What a way to fly the flag for us Bridget - keep up the great work!

GIVE HPTH UK A PRESENT THIS CHRISTMAS - FREE!!!

You can raise money every time you shop online, simply by visiting www.easyfundraising.org.uk first. Once you’ve registered and selected Hypoparathyroidism (HPTH) UK as your chosen charity, then every time you shop via their site up to 15% of your shopping total is donated to HPTH UK - without it costing you a penny!

HPTH UK, 6 The Meads, East Grinstead, West Sussex, RH19 4DF, UK
liz@hpth.org.uk

2011 VIRGIN LONDON MARATHON 17th April 2011

Liam Sale (husband to member Claire Sale) has managed to get a place in the 2011 Virgin London Marathon, and will be raising funds for HPTH UK and The Willow Foundation!

Liam has chosen to run for The Willow Foundation after his brother Adam sadly passed away shortly after being diagnosed with a rare form of cancer. He is very grateful to them for helping to make Adam smile during such a difficult time, and he would like to help them continue to bring light, happiness and hope into the lives of others in need.

HPTH UK is also close to Liam’s heart. His wife Claire was diagnosed with thyroid cancer in 2009 and had to undergo two operations to remove the tumour. Unfortunately, Claire’s parathyroids were damaged during the second operation and she now has Hypoparathyroidism. Claire struggled to find information about HPTH, and felt isolated having such a rare condition. Thankfully she found HPTH UK, and a wealth of information and support on our website and forum. This was invaluable to both Claire and Liam, and has helped them to understand and come to terms with her condition. They got married in Crete on the 18th of June this year. Congratulations!

You can support Liam by donating online - https://www.bmycharity.com/V2/marathonliam

Please give what you can to help Liam help us!

Thank you Liam - good luck!
DONATIONS
April - November 2010

Thank you so very much to all these kind and generous people:

Bridget O’Connor, who set up a stall at the Mansfield Town Football Club event to sell her book ‘Hisham’s Envelope’. She raised £52.50 on the day.

Mary Jane Malherbe Jensen donated £100.

Annette Terry, who held a Western themed night for her family and friends, raising a fantastic £375!

Caroline Fletcher donated £10.

John and Annette McKellar, who climbed Ben Lomond in June with our member Natalie Love. They raised £260 for HPTH UK.

Isobel Cooper donated £5.25.

Lawrie Marshall, husband of member Gillian, cooked an Indian dinner for members of the Nailsworth Rotary Club (twice!), raising a whopping £468!! Lawrie plans to continue annually, and this year hopes to cook for 28 people. Thanks to Lawrie and the club members!

Mrs S. A. Ewin donated £15.

Hannah Knott and Hannah Mullen (a member), raised £180 by tackling The Wirral Coast Walk - well done girls!

Pamela Deeprose donated £30.

Thank you everyone! Thanks to you, our donation total is an amazing £1595.75!!

THE SHORT WAY ROUND - UPDATE

As we mentioned in our last newsletter, we have another exciting charity event coming up next year!

Grant Strong (whose girlfriend Vicky Tippett has HPTH) and his friend Lewis Carter plan to tackle a mammoth sponsored cycle on behalf of HPTH UK and St Dunstan’s. The lads plan to take ‘The Short Way Round’ and cycle approximately 2000 miles around Britain next year - from Kent to John O’Groats’s, onto Land’s End and then all the way back to Kent!

Grant and Lewis had hoped to do this earlier, but it takes quite a bit of organising! They’ve begun training and bike building (and going to the gym I’d imagine!) in preparation for next year’s event. They are both in the navy, so spend a lot of time away from home, which has made organising such a major event quite difficult. Grant is currently in the Falklands, but will be home in the New Year and will finalise all the details then. We’ll keep you posted!

CAN YOU SPARE £2 A MONTH?

If you would like to set up a standing order we would be very grateful. If 100 members gave just £2 a month, we would receive £2,400 a year!

Here are the details you need to give to your bank to set this up:

<table>
<thead>
<tr>
<th>Bank</th>
<th>Santander</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sort code</td>
<td>09 – 06 – 66</td>
</tr>
<tr>
<td>Account number</td>
<td>42582811</td>
</tr>
</tbody>
</table>

HORMONE SPRAY MAKES PEOPLE DONATE MORE TO CHARITY!

A dose of Oxytocin via a nasal spray caused more people to give money to charity, and to give more on average, than controls given a dose of saline via the same method in a study presented at the Neuroscience 2010 meeting in San Diego. (New Scientist, 17 November 2010)

TELEPHONE HELPLINES - 01342 316315 OR 01623 750330
MEET OUR MEMBERS!

In this issue we are meeting some of our youngest members. They have their own forum on the website, and chat on our Facebook pages too.

Hannah - Wirral, Merseyside

My name is Hannah, I am 17 years old. It was a shock to find I had Hypoparathyroidism as it doesn't run in my family and I haven't had neck surgery. I got diagnosed with epilepsy, long QT when I was 14 and they had no idea why my calcium levels were so low until I was 16, when they discovered I had hypoparathyroidism. I am also on the 1-84 injection, Preotact, which has helped an awful lot. After a year and a half I have finally been able to attend sixth form. When I went back to school, HPTH UK provided me with an Emergency Card so people know what to do when my calcium levels go low or I black out. I would advise everyone with hypoparathyroidism to get one! It was a real struggle to cope with at the start but with all the support I now have, my HPTH is becoming easier to live with.

Vicky - Newham, London

Hypoparathyroidism has affected my life significantly. I was diagnosed in February this year after having my thyroid removed, and as a result of this, I suffer with Hypocalcaemia. As many of you would know it can be difficult to carry on as normal. At the moment I often worry about what the future will bring and feel I’m often misinformed by the NHS and have not been given a realistic view of what is actually happening. I find it most difficult that, because of my age, I often find it hard to cope and think it would be easier if you had someone of a similar age to compare your thoughts with. I feel these health issues can sometimes leave you isolated within your own age group because you can’t drink or be more reckless with your health. Also, because of the rarity of the disease, it’s often difficult even for your family to completely understand that it isn’t always easy to cope. But this organisation is something that gives me more of an understanding and a support network for any queries I may have.

Ariana - Atlanta, Georgia, USA

My name is Ariana Feiner, and I am 18 years old. When I was almost 17 years old, I had a complete thyroidectomy for Graves Disease, and due to a surgical error, all four of my parathyroids were removed as well. It has been a daily struggle learning to cope with this debilitating disease, and I am still learning. I have just recently gotten strong enough to earn my high school credit, and I will graduate this May. I have had to alter my lifestyle a lot to handle living with Hypoparathyroidism, but I am still determined to achieve my goal of being a writer and English professor. In the meantime, I would like to start an advice column for teens to encourage them to make good life choices.

KEEP IN TOUCH....

Already a Facebook fan?

Why not get Tweeting too?

Chat and find friendly support as always on our Forums

LIFE INSURANCE FOR HPTH PATIENTS

Many of our members have asked us whether we know of companies who deal with life insurance for long term conditions. Thanks to the Genetic Alliance UK who have been working with AllClear Life, we can offer a solution. AllClear Life is a fast online service which can find an indication of the cost that might be involved for you and then introduce you to an insurance specialist. Hypoparathyroidism will be included on their list of medical conditions shortly and more information will be available on our website in the next few weeks. To visit the AllClear Life website, please go to www.allclearlife.co.uk
My name is Natalie Wood - I was born in 1985 and I was diagnosed with Hypoparathyroidism when I was just 6 years old. It started off when I was about one, and my Mum noticed me acting strangely. I would stare into space for ages and topple over more than was normal. As I got older the staring into space carried on and I was also ignoring everyone when they spoke to me, like I just couldn't hear them. My hands would go into spasm and I would drag my leg when I was walking. My Mum initially gave me a row as she thought I was copying someone I’d seen. She knew something wasn’t right though, so she took me to the doctor. My ears were tested as she thought I was going deaf, but the results said I was fine.

When I started school, my Mum would receive reports saying I was daydreaming in class, ignoring the teachers and that I was falling behind. The next couple of years are a blur to be honest, as I started having seizures all the time and no one knew what was wrong. There were many tests done, but no diagnosis. Until one night I remember very well, when I was about 6 years old. I remember being in my Mum and Dad’s bed, sweating with a very high temperature, and I had a grand mal seizure. I went straight to Yorkhill Hospital for Sick Kids, and stayed there for quite a long time. They tested me for everything, and they eventually came to the conclusion that I must have adult epilepsy. Luckily for me, a Professor was in the hospital at the time who knew all about HPTH, and he came to see me. What did he do? He walked in, tapped my face and said “she has Hypoparathyroidism”!!!

I was treated straight away, given medication and everything fell into place. Further tests suggested I might have had HPTH from birth, which would explain the staring and toppling over. They said it would have been “mini-seizures” and that my brain would just shut down for a couple of minutes. Because of that I’d missed a lot of school, so I had a lot of catching up to do. My memories of my “mini-seizures” are that I always knew I was “different”. I couldn’t run or do many normal kid things. I remember having to crouch down and pretend I was tying my lace or rubbing my ankle so no-one would notice me going into a trance. Then I would be fine, I’d just get up and carry on with what I was doing. Then it settled down for a few years. I was taking 11 Sandocal tablets a day plus AT-10, and I was getting tested weekly at the hospital. The doctor eventually became concerned because of the amount of Sandocal I was on, so he scanned my brain and my kidneys and discovered calcium deposits in both. I was taken off the Sandocal and AT-10 and started on Alfalcacidol. I only took Sandocal if I needed it, which was great for me as I genuinely dreaded taking it! My Mum and Dad tried everything - mixing it with juice, bribery, they explained how important it was... But no, I hated the stuff and I still do. If you have had the pleasure of taking it you know exactly what I mean!

My calcium was under control for a while, but then there were my damaged teeth to deal with! I was about 8 when I had to have 11 teeth removed in hospital. My adult teeth grew in quickly, but that wasn’t the end of it. After much drilling and many crowns, my teeth were still horrible. I was bullied in school and you can imagine the cruel comments I got! To this day I’m still having lots of work done on my teeth, but I’m still traumatized from the terrible experiences I’ve had. The dentist I have now is good and is going to repair all the damage to my teeth, so then maybe I can finally be confident about them.

My calcium didn’t stay stable for long though. By 18, I was in denial and hated having HPTH. I thought it was all in my head and I started rebelling. I partied all the time, and wouldn’t take my medication regularly. I just wanted to be normal and I felt far from it. I found out that my ovaries had failed and I couldn’t have my own children. There’s nothing worse than being told that, when it had always been my dream to have a big family. So, my way of dealing with the pain was to party. I was hardly sleeping either, and we all know what happens when we do that - our calcium crashes and we collapse, or have a seizure and end up in hospital on drips. That happened often, but it didn’t stop me partying all night. This carried on for about a year, and I was in and out of hospital every couple of weeks until I just stopped and realised how dangerous it was. I still have fun now, but I take better care of myself. I eat well and party once a month at most. I’m not willing to give in to HPTH and stop having fun and being a normal young girl, but there is a line that I wouldn’t cross now. I wouldn’t ever miss my medication now, as I know how important it is, and I’ve learned to eat healthy meals. I’ve started cooking using fresh organic foods which I think helps me to control my calcium.

I feel in control of my Hypoparathyroidism now, and sometimes I know things the doctors don’t, which I love! I find HPTH a very interesting condition - it is a part of me and always will be. Who wants to be run of the mill and the same as everyone else anyway? I know I don’t! I tell everyone about HPTH, and try to raise awareness as much as I can. Right now I couldn’t be happier with my life; I’m in control and loving it! We all need to live our lives with HPTH and try to be proud of ourselves every day. Even if you wake up in hospital with drips, or you’re feeling depressed about having HPTH, just look in the mirror and say “IT COULD BE WORSE”. We are lucky! We all need to stick together, support one another and most of all BE HAPPY!!! You only get one life, so go out there and live it!!

Since writing this article, Natalie has climbed Ben Lomond to raise money for HPTH UK. She has also married and is celebrating her first anniversary this month.

Congratulations Mrs Love! - Ed
SELF MANAGEMENT PROJECTS

I am always banging on about self management and how it can help you to feel better, as forum goers know very well, so I was delighted to find out about these projects.

‘My Condition, My Terms, My Life’
The Long Term Conditions Alliance (LTCAS) launched their campaign ahead of Scotland’s first ever Self Management Week in October and it features real people living with long term conditions, telling their stories to encourage other people to get started with self management. The campaign received a great deal of coverage in the media and you can read some very helpful advice here www.myconditionmylife.org

‘Gaun Yersel!’
This is the Self Management Strategy for LTC’s in Scotland, launched by LTCAS and the Scottish Government in Sept 08. The Strategy calls for:

- People to have more access to high quality information about their condition and its impact on their life.
- People to have more access to support including peer support.
- Increased provision of emotional and mental health support for people with long term physical conditions.
- A change in culture so that people - those receiving and those delivering services - have the confidence and capacity to work together as partners.

- Better partnerships working by NHS, voluntary sector and local authorities.

‘Paving the Way to Self Management’
This is the Genetic Alliance UK’s new project which is being launched to find out how people living with rare conditions in Scotland self manage their day to day lives.

While these particular projects are based in Scotland, the resources they have produced are accessible and relevant to everyone, everywhere and I urge you to take a look.

‘How to manage your Hypoparathyroidism’
Also take a look at this page in our very own members’ section on the website where we are gradually collecting useful information to help you. Please take a look. If you have found any resources that may be useful, or any tips that you think will help others, please send them to us for this page. http://www.hpth.org.uk/memberlogin.php

Liz Glenister, Director
liz@hpth.org.uk

NEW FOR MEMBERS!!!
EMERGENCY MEDICAL CARDS

Have you ever
- been in A&E and not been able to explain the problem?
- been at your hospital appointment with a new doctor and can’t remember your medication or GP details?
- felt really ill while out alone and needed help?
- wanted a medical ID card for travelling?

Then you need our new Emergency Card.

This side explains your HPTH and hypocalcaemia (or unstable calcium levels), and any other serious conditions you may have, gives brief instructions for paramedics/others if required, and a list of your medications.

This side shows your photo and gives your name and date of birth, your personal contacts, your NHS number and the names and telephone numbers of your GP and consultant.

We are now producing bespoke emergency cards for our members at £5.

They are wallet sized and laminated. If you would like a card, please email all the necessary details to liz@hpth.org.uk, or post them, with a cheque made out to HPTH UK. Please be patient - you will get your card as soon as we can manage. Your details will be held in strictest confidence.