FIRST UK CLINICAL STUDY ON PTH 1-84

There is currently no approved replacement therapy for Hypoparathyroidism...but we're working on it! HPTH UK are involved in the first UK clinical trial on the use of parathyroid hormone (PTH 1-84) for the treatment of Hypoparathyroidism, which is currently recruiting in Liverpool and Oxford as part of a global study sponsored by NPS Pharmaceutical Inc.

NPS Pharmaceuticals, a company which specialises in developing therapies for rare endocrine disorders, is currently running a Phase 3 registration study, known as REPLACE, to evaluate NPSP558 for the treatment of adults with hypoparathyroidism. NPSP558 is a proprietary recombinant full-length human parathyroid hormone (PTH 1-84), which mimics the action of natural parathyroid hormone.

The primary objective is to demonstrate, over a 24-week treatment period, that once-daily subcutaneous dosing with NPSP558 at doses of 50mcg, 75mcg or 100mcg is a safe and effective hormone replacement therapy for the treatment of patients with hypoparathyroidism. For more information on REPLACE, please contact NPS Pharmaceuticals, Inc. www.npsp.com

WE STILL NEED PATIENTS TO TAKE PART

The news from patients currently on the trial is very positive. Would you like to join these pioneers? Be one of the lucky ones to try PTH for yourself and help future HPTH patients to have a better life.

INTERESTED?

To take part you must be a UK member aged 18-65, have had HPTH for at least 18 months and be on Vitamin D and calcium treatment. Check other criteria here to make sure you are eligible. Changes to these criteria have recently been made. If you do not live within 40 miles of Liverpool or Oxford, NPS are willing to pay reasonable travel and accommodation expenses. You may also now apply if you are of child-bearing age, on contraception and willing to have a pregnancy test.

HOW DO I APPLY?

Simple. If you have checked all the other criteria, please download this form, complete it and return it to us as soon as possible. We will forward it to the appropriate research team who will then contact you. You will be able to discuss the study in detail with the doctor before choosing whether to participate and you may withdraw at any point. There will be a screening period to check you are suitable. If you have any questions about your eligibility, please contact us.

Thank you.

FIRST UK PATIENT INFORMATION LEAFLET - OUT NOW!

The first Patient Information Leaflet on Hypoparathyroidism has now been produced by HPTH UK and the HPTH UK Clinical Advisory Team working in conjunction with the Society for Endocrinology. It is essential reading to all patients learning to live with Hypoparathyroidism and we hope you will find it helpful. The leaflet was launched at the British Endocrine Society conference in March and attracted much interest - doctors took away 500 copies and we have taken many orders. We would be very pleased if you could help publicise it by printing a copy to give to your GP and endocrinologist at your next appointments. Please let them know that hospitals and surgeries may now place orders for printed copies with Sarah on sarah@hpth.org.uk or Liz on 01342 316315. Patients can Download the Patient Information Leaflet to read online or print off and keep. Download the printable, foldable version.

We would like to thank all those who have been involved in producing the leaflet, particularly Dr Mo Aye and Professor Bill Fraser, Dr Steve Orme, Dr Brian Shine and Dr Abhi Vora. Our grateful thanks also go to the Society for Endocrinology who, last month, awarded us a grant to help with the leaflet printing and distribution costs.
Dear Members,

Since the new website was launched in January, membership has increased considerably and we were delighted to receive your many positive messages. But now we need your help. The trial continues to recruit but only for another couple of months so I urge you all to consider taking part if you fit the bill. This is so important to the future of HPTH treatment. The leaflets have met with a very good response from patients and doctors alike. Please help us to circulate them further by printing off a copy to take with you to your appointments. Let your doctors know they can place orders now! Thank you for all your continuing support.

BES Conference 2010

In March, we were honoured to be offered a stand at the British Endocrine Society conference, held in Manchester, where we were able to launch the new leaflet. Many thanks to Judith Taylor and Mandy Mainland, who represented us and worked so hard over the 4 days. You can read their report inside.

Money Matters

In April, we were awarded a grant by the Society for Endocrinology, to be used towards printing and distributing the Patient Information Leaflet for which we are most grateful. I am always moved by the letters and donations we receive from members and which keep us going – thank you all.

Surveys

Thank you to the many members who participated in the Boston ‘Quality of Life’ survey comparing the perceptions of HPTH patients with those of surgeons and pre-op patients. Dr Dan Ruan recently told HPTH UK that ‘we found that doctors and pre-op patients given a standardized pre-op talk about the risks of surgery consistently underestimate the severity and impact of Hypoparathyroidism on patient quality of life.’ This matches our own findings and highlights a crucial area for awareness raising which we hope to commence this year.

Thank you also to our thyroid cancer patients who took part in the first International Thyroid Cancer Audit held in March. We supported the Butterfly Thyroid Cancer trust, members of the Thyroid Cancer Alliance, who hope to present the results at 14th International Thyroid Congress in Paris in September. We’ll keep you posted.

First HPTH Awareness Meeting

HPTH UK and the British Thyroid Foundation participated in an awareness meeting which was part of a monthly series of awareness raising events held by the Kings Mill Hospital in Nottingham. Our speaker was the ubiquitous Judith Taylor. This was a first for us and our presence there was thanks solely to HPTH UK committee member, Bridget O’Connor. You can read her report inside and if you would like to hold a patient information event in your area too, please get in touch.

Fundraising Events

Our goal is to raise £5000 annually to become a registered charity. The new website seems to have brought us a much needed surge in fundraising opportunities which are all very exciting. Read more about our star fundraisers and activities on the Fundraising page and do get involved too.

Committee News

This summer we welcome two new officers onto the team. Claire Butchers will take on the role of Fundraising Officer after her wedding in June. All our best wishes, Claire! Long standing member Sarah Bradbury has taken on the task of Distribution and is also our first patient contact for Pseudohypoparathyroidism. Thank you both.

Member News

Now that we have an online forum and a telephone helpline running successfully, our next aim is to help you to meet up face to face. Many of you have asked about this, so this year we will be setting up regional groups so that you can find, phone and meet other local members. You could even organise local events if you wanted to! It is intended to be quite informal and entirely up to each group what they do. We need a person in each area to head up the group and act as a liaison so if you are interested, please get in touch.

Don’t forget our growing Facebook groups too. Welcome to all our new members – we are always happy to hear your comments and improve our service so do get in touch. I hope you find this newsletter interesting and I wish you all a very happy and healthy summer boosting your D3 levels!

Liz Glenister, Director
liz@hpth.org.uk
This was the 3rd annual Rare Disease Day and the focus of this year’s events was to highlight the importance of research to patients. There are no cures or treatments available for the vast majority of rare diseases and without research this situation cannot improve. As a result research is fundamental to improving the lives of people with rare diseases and their families.

The reception was also an opportunity to celebrate the work of many patient organisations for initiating and supporting research projects. Many of GIG’s member organisations raise funds for research, act as an important source of practical knowledge and recruit the cohorts needed for clinical trials. Patient organisations have also acted as catalysts for collaboration between researchers, clinicians, industry and patients.

Christine Grahame MSP, convener of the Health and Sports Committee, hosted the event and delivered an engaging opening speech. Ms Grahame commented on the large turnout to support Rare Disease Day and highlighted the considerable wealth of academic, clinical and industry research ongoing in Scotland and its strength as an international centre for excellence in life science research.

The second speaker, Alastair Kent, chair of Rare Disease UK, outlined how the Rare Disease Day campaign came about and gave an overview of the issues facing people with rare conditions. He argued that we need to see rare diseases as a public health issue because collectively they affect around 300,000 people in Scotland – equivalent to the combined population of Inverness and Aberdeen. Mr Kent highlighted Scotland’s world class reputation for research including work into several rare conditions. However, as one of the founding principles of the NHS is equity of care, rare disease patients have the same right to high quality, integrated service delivery from the NHS as other service users. Delivery of such a service to a population of people with rare complex needs across Scotland’s vast geography is logistically difficult. Mr Kent asked the Scottish government to act strategically by creating links within the UK, as well as within Europe and further abroad so that best practice can be shared between health care professionals.

Professor Sir Ian Wilmut then spoke from the perspective of a researcher. He started his speech by giving a realistic idea of the time lines involved in taking a scientific discovery from its initial elucidation to a practical application in the form of therapeutic intervention. Professor Wilmut was keen to emphasise what we can learn from history: “Over the past two centuries research has developed the first effective treatments for diseases that are the result of infections.” “In the coming decades, the new research will provide new treatments for diseases that reflect the loss of normal function from cells.”

The final speaker was Susan Green from the Niemann-Pick Disease Group UK. Susan gave a moving and fascinating talk reflecting on her life as a parent of two children with Niemann-Pick Disease (NPD), an extremely rare life-limiting metabolic condition. She described how families who receive a diagnosis of a rare condition often have their hopes and dreams for the future destroyed in a single moment and struggle to come to terms with the fear, anxiety and isolation this provokes. Susan then described how the first NPD clinic was set up in Manchester and how the charity worked with scientists at the National Institutes of Health in Bethesda, USA to provide samples to help identify the gene that causes NPD. The group’s dedication to furthering (and funding) research ultimately led to many fruitful collaborations and the first treatment for NPD type C, Zavesca.

The key message from Rare Disease Day 2010 is that research and development for rare diseases are restricted by a lack of mechanisms for bringing together patients and recording their data; a lack of opportunity/cost perception by the pharmaceutical industry; and difficulties in finding sustainable sources of funding. As a result, research into rare diseases requires collaboration between countries across Europe, and beyond, as well as long-lasting infrastructure and sustainable sources of funding.

HPTH UK is a member of Rare Disease UK
www.raredisease.org.uk

As I was unable to attend this year’s Rare Disease Day reception, this article has been adapted from the report kindly sent to me by Claire Cotterill, Genetic Interest Group Scotland - Ed.
In March, Judith Taylor and Mandy Mainland manned a stand at the Society for Endocrinology’s annual British Endocrine Societies (BES) conference in Manchester. The Society for Endocrinology is the professional body for endocrinologists in the UK and its membership includes clinicians, researchers and nurses, so it was an excellent opportunity to introduce the organisation and to ‘launch’ the new hypoparathyroidism patient information leaflet which was developed in conjunction with the SfE’s Bone and Mineral Special Interest Group.

There were over 1,000 participants at the conference and it was great to meet some of them personally and hear at first-hand about their experiences in managing HPTH. It was also a chance for us to meet representatives from other patient support groups (PSGs) who have many years experience and were all too happy to share.

During the conference, the Society for Endocrinology hosted a meeting of patient support group representatives where we exchanged ideas about some of the common issues facing us. Some of us were also able to attend a talk by Ellen Raphael of Sense About Science who introduced the organisation’s work, explaining how they help people distinguish between sense and nonsense, the importance of peer review, and some tips for dealing with the media.

Very many thanks to the SfE for inviting us to participate at the BES and we hope that, space allowing, we will be asked back to future conferences.

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

Mandy writes - ‘Judith and I represented HPTH UK at BES 2010, which was held at the Manchester Central Convention Complex. I really didn’t know what to expect, and was quite nervous, but Judith quickly put me at ease. It was lovely to finally meet her after chatting online for so long.

Despite my nerves it was very exciting, and once I’d spoken to a couple of people I felt much more relaxed. We had a lot of visitors to the stand, and they were all very interested in what HPTH UK does, and it was an excellent opportunity to raise awareness as many of them hadn’t heard of us. It was also great that I could tell them first hand what HPTH can be like. The new leaflet also attracted a lot of interest. While I was there, I went to a couple of fantastic lectures about calcium, Vitamin D and magnesium too. It was a great experience all round, and definitely worth the trip down from Scotland! It was a little odd too though - I’m not used to being told how beautiful my scar is!!’

The next issue of ‘The Endocrinologist’ will also feature an article by Judith about her experience of attending the BES conference - Ed.

UPCOMING SfE EVENTS FOR THE PUBLIC

The Society is organising a number of public events in 2010. ‘Sex on the brain: can hormones change your mind’ which will take place at the Cheltenham Science Festival, 9-13 June, will explore the science of attraction and the unconscious influences that hormones can have on the decisions we make.
‘The obesity epidemic: whose fault is it anyway?’ takes place at 10.00 on Wednesday 15 September at the British Science Festival in Birmingham. Further details can be found at www.endocrinology.org/public.

THYROID CANCER - FOR PATIENTS, BY PATIENTS

The British Thyroid Foundation has now released the second edition of their booklet “Thyroid Cancer - For Patients, By Patients”. It has been edited by Judith Taylor, who is a BTF Trustee as well as being part of our team. The enlarged, updated version has a lot of valuable information designed to help patients facing a diagnosis of thyroid cancer - from a diet plan and recipes, to information about the possible side effects of different treatment options.

The booklet is priced at £6.50 (£3.50 for BTF members)

Copies can be obtained from: The British Thyroid Foundation, 2nd Floor, 3 Devonshire Place, Harrogate, North Yorkshire, HG1 4AA. Tel/Fax: +44 (0)1423 709707 or 709448, or by email books@btf-thyroid.org.
ENDOCRINE PATIENT SUPPORT GROUPS MEET IN MANCHESTER

During the British Endocrine Societies (BES) conference in Manchester in March, the Society for Endocrinology hosted a meeting of patient support group (PSG) representatives which was attended by Judith and Mandy on behalf of HPTH UK.

Other groups represented at the meeting were the Addison’s Disease Self Help Group (ADSHG), the Association for Multiple Endocrine Neoplasia Disorders (AMEND), the British Thyroid Foundation (BTF), the Pituitary Foundation, the Prader-Willi Syndrome Association, the Thyroid Eye Disease Charitable Trust, and the Turner Syndrome Support Society. The meeting was chaired by Jennie Evans, Public and Media Relations Officer of the Society for Endocrinology, and was also attended by Sue Thorn, the Society’s Chief Executive.

The aim of the meeting was for the Society to share some of its own plans and to enable representatives of the different groups to discuss some of the issues they face.

One issue facing many of us is the reluctance of many physicians to prescribe medicines for chronic, stable conditions for longer than 28 days. The BTF has been campaigning for attention for this issue for more than a year: Janis Hickey of the BTF co-authored a research study into prescription length which was published in *BMC Public Health* (2009) which found that more than half of BTF members could not obtain prescriptions for longer than 28 days, and BTF has lobbied the Department of Health both directly and through its local MP but with no effect so far; and Katherine White of the ADSHG has written a paper which has been accepted for publication in the *International Journal of Pharmacy Practice*. Both of these studies demonstrate the savings that could be made by issuing longer prescriptions for chronic, stable conditions as well as the convenience for patients.

Prescription length is an issue for patients on long-term medication for different endocrine conditions, and it was encouraging therefore that the Society for Endocrinology plans to take up this matter and to issue a statement which it will circulate to members of the PSG group for feedback before finalising.

The group also shared their views about the Information Standard, a new scheme launched by the Department of Health to accredit organisations. Opinions of those present were mixed. Only one group has applied for accreditation and it is unclear how much it costs and whether this is a one-off or recurring fee, but it is something we need to be aware of as it may in the future affect our chances of getting grants from public or government bodies.

Rare Disease UK was recommended as a good resource for the patient groups present (HPTH UK is already a member).

This was a great opportunity to exchange ideas about some of the common issues facing us and to learn from other groups, many of which have a great deal of experience. Many thanks to Jennie and colleagues at the Society for Endocrinology for making this possible!

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

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HPTH UK IN THE GENETIC INTEREST GROUP NEWSLETTER

The Winter 2009-2010 issue of the GIG Newsletter – a publication of the Genetic Interest Group (GIG) – features an article about Hypoparathyroidism UK called Hypo-splutter-what?? The article sets out to explain what hypoparathyroidism is and describes how Liz came to set up the group, and our present activities.

The Genetic Interest Group has a membership of over 130 patient support organisations including HPTH UK. Its mission is to promote awareness and understanding of genetic conditions through a wide range of activities including campaigning on issues of policy and practice, providing support and information to families, educating policy-makers, health professionals, patients and their families and the general public, supporting the development of high quality services and information and ensuring they are available to all, and providing a common platform to unite the voices of patients and families affected by genetic conditions.

To read the article, download the newsletter at: [http://www.gig.org.uk/docs/gigwinternewsletter_final2010.pdf](http://www.gig.org.uk/docs/gigwinternewsletter_final2010.pdf).

On 1 June GIG is changing its name to Genetic Alliance UK. For more information, see: [http://www.gig.org.uk/](http://www.gig.org.uk/).
**PATIENTS WITH LONG TERM CONDITIONS NEED GREATER SUPPORT TO RETURN TO WORK**

Society for Endocrinology Media Release

A new study has identified a significant shortfall in patients with life-long but treatable conditions re-entering employment. The research is being presented at the annual Society for Endocrinology BES meeting in Manchester. Led by Prof John Wass of the Churchill Hospital, Oxford, the group found that under half of patients with chronic endocrine conditions returned to work.

This study is the first to show the effect of long-term endocrine conditions on employment status, and highlights the need for increased medical and social support for patients to return to work.

Endocrine conditions result in life-long imbalances in the body’s hormones, however, symptoms can be stabilised with medication and patients can enjoy a healthy, normal life. However, patients suffering from chronic conditions may be at increased risk of long term unemployment, a known contributor to poorer health and increased health inequality. Improving return to work among this group of patients may contribute to improvements in their health and quality of life.

Prof John Wass, Dr Barbara Alberts and Dr Emily Parker examined unemployment and return to work rates amongst people with a variety of long-term endocrine conditions; Addison’s disease, Cushing’s disease, craniopharyngioma and Klinefelter’s syndrome. In a group of 130 patients, the study found a high rate of unemployment (40.8% vs. 27.5% for the UK population). 60.8% reported a period of unemployment which was related to their disease, and only 40% of 130 patients had entered or re-entered work following a period of unemployment.

Researcher Prof John Wass, Consultant Endocrinologist, Oxford Radcliffe Hospitals NHS Trust said: “Long term unemployment is a significant problem for people with chronic diseases. More people should consider returning to work following diagnosis and more doctors need to encourage and support their patients in this. Whilst a return to work may not be suitable for all patients, it can significantly improve their wellbeing and quality of life. As a country, we need to provide more support services to allow people with long-term conditions to re-enter the workplace, at a rate that is feasible for them.”

Full Media Release here -
www.endocrinology.org/press/pressreleases/2010-03-17_Return%20to%20work%20support.pdf
On 27th April 2010, HPTH UK and The British Thyroid Foundation participated in an awareness meeting which was part of a monthly series of awareness raising events held by the King’s Mill Hospital in Nottingham. There was a great deal of interest and the event was attended by 130 people. As others sadly had to be turned away at the door, the hospital is hoping to organise a further meeting later in the year.

We would like to thank all those who took part and helped to make the event such a success:

- **Consultants** Professor George Thomson and Professor Devaka Fernando, and surgeon Mr Keshav Nigam kindly gave up their time to speak to us about thyroid and parathyroid matters.
- Judith Taylor, HPTH UK Public Affairs Officer and also Trustee of BTF, spoke about the work of both organisations.
- Sarah Elphick, Communications and Membership Manager at King’s Mill Hospital organised and co-ordinated the meeting.
- Bridget O’Connor, HPTH UK Committee member and telephone helpline person for both organisations, had the idea and got the ball rolling.

Bridget’s account of the evening -

‘What can I say? I am bowled over by the response and the support given by my local hospital.

Professor Thomson was very informative. He explained how the thyroid works, how to recognise the signs and symptoms of thyroid disease and the treatments which are available. Mr Nigam talked about aspects of surgery, which was fascinating. He described the lumps and bumps and their treatments - surgery and radioactive iodine. He also explained what the parathyroid glands do, and the possible risks of surgery to the parathyroids and the voice. Our dear Judith spoke next, and showed slides, about the work of the BTF and HPTH UK and she was brilliant. All the speakers were very informative and interesting.

The doctors (including Professor Fernando who had been detained on the wards) then participated in a question and answer session which the audience appreciated. I was impressed that the doctors even talked to people one to one after that, and all stayed until everyone had been seen. They were all so friendly and approachable, and made the evening a great success.

I was especially pleased that medical students had also been invited along as this gave us the opportunity to help raise their awareness about Hypoparathyroidism and the seriousness of post-operative Hypocalcaemia.

Leaflets were given out for the proposed BTF and HPTH UK support groups in my area, inviting anyone along who might be interested in getting the groups established. My local CVS recorded some of the speakers on video, which you will hopefully be able to see on our website (www.hpth.org.uk) soon. The new BTF and HPTH UK banners also made their first public appearance!

At the end of the evening, I thanked everyone for attending. I gave magnolia trees to the doctors as a token of our appreciation, and I just could not let Judith return home without a piece of Nottingham lace, for which we are famous. Thank you all.’

Very many thanks to Bridget for her part in this. If your consultant is interested in raising awareness about Hypoparathyroidism and if you would like to organise a similar event at your local hospital, please contact us - Liz.
In April 2010 we were very fortunate to receive our second grant from the Society for Endocrinology for which we are hugely grateful. Our first grant had been a set up grant which provided us with much needed basic equipment and helped to cover running costs. The award this year is specifically to be used towards the cost of printing and distributing our patient information leaflet, produced in conjunction with the SfE. Writing in the Spring edition of the SFE newsletter, ‘The Endocrinologist’, Philip Harris, Chair of the Patient Support Grants Panel, explains what is involved. Patient support group spending reports for 2008 were also published including ours, by Liz Glenister.

Supporting Patient Support

Patient support groups serve to help people with a wide variety of disorders, as well as their carers and families. While some groups are small, others are larger and better established. The Society for Endocrinology is pleased to award grants to these groups periodically, to provide support for specific projects.

For instance, grants may be provided to support logistics, such as running helplines, to obtain computing facilities for specific tasks, to train support workers, to provide patient information documents, and to stage meetings where expert speakers are invited. Starting in 2000, there have been four rounds of awards, on a 2-yearly basis. The first three rounds were supported jointly by the Society and the Clinical Endocrinology Trust. The last round was supported solely by the Society. Approximately half the applications have been successful, leading to 34 grants totaling £54 500. In 2008, grants worth £20 000 were divided among nine support groups.

The rigorous review process for applications means that groups must have a written constitution, with minuted board meetings. They should have charitable status and be supported by appropriately experienced external experts. Support workers must have appropriate training. The application must include a clear rationale and realistic costings. The group must provide a written report on completion of the project.

The Society takes a broad view of the proposals that should be supported. The main criteria are that the support group should have an endocrine focus and that the request is for a real unmet need. The grants are an important component in strengthening links between the Society and patient support groups. The groups clearly value the help they have been given, as is evident from the comments below, made by recipients of the 2008 grant round.

PHILIP HARRIS
CHAIR, PATIENT SUPPORT GRANTS PANEL

We were delighted to receive our first grant from the Society for Endocrinology last year and found the advice coupled with the freedom of choice that you gave us most helpful. Thanks to your grant, HPTH UK has been able to move up to another level in terms of provision and recognition, and we have had a very successful year. We have been instrumental in getting the UK included in a global trial of parathyroid hormone in the treatment of HPTH, which is now recruiting in Oxford and Liverpool. We hope that building an HPTH community of patients, professionals, researchers and donors with different perspectives, yet common goals, will form a fruitful alliance. We have learnt a lot from this monetary experience and look forward to further progress.’

Liz Glenister
Chair and Founder, Hypoparathyroidism UK (HPTH UK)

DONATIONS

1/11/09 – 30/04/10

Our very grateful thanks to the following for their kindness and generosity -

Edward Davies £25.00
Anna Cole and Colm Cahill £60.00
Richard Severino £60.00
Stuart Hirst £25.00
Derek Steele £450.00
Peter Goodwin £20.00
Bridget O’Connor £100.00
Mrs SW Frohlick £15.00
Robert Davis £10.00

We rely on your donations. Please help us make a difference.

We have decided to keep membership free.

However, we will now ask for a voluntary donation on joining. If you joined without a donation, please do consider sending us one to help us keep going.

If you would like to set up a direct debit we would be very grateful. If 100 members gave just £2 a month, we would receive £2,400 a year - a very helpful income! Details will be on the website soon.

Thank you
**WHAT SHOULD I DO IF I HAVE A HYPO?**

**Hypo is short for a hypocalcaemic crisis or, in other words, when your calcium falls too low, too fast.**

Mostly, you manage your calcium levels very well. You eat regularly, drink water through the day and take your meds properly. You have regular blood tests to monitor the situation and your doctor tweaks your medication when necessary. You understand that levels fluctuate and different factors can make a difference. For example, if you go out for a run or it’s a very hot day, or you had a bug or your period, you know what to watch for and how to compensate for a small dip in your levels. You know that most symptoms will pass. But occasionally they don’t. Levels can sometimes fall without you being aware until suddenly you realise that things aren’t quite right. You feel a bit irritable, then a bit dizzy. Before you know it you are shaky and cold and the tetany is kicking in quite fast. You are having a hypo. What should you do?

First of all, don’t panic. Make an effort to stay calm and breathe slowly. Panic can make your calcium fall faster and make things worse.

Get some extra calcium in you, with some vitamin C to aid absorption. Orange juice is good. Often a hypo can happen if you haven’t eaten - so have some calcium rich food.

While you wait for this to kick in, keep still – you don’t want to use up more calcium or aggravate the muscles – and keep warm as your temperature may drop rapidly. Try to distract yourself - sounds mad but it does help. In 20 minutes or so you should notice a difference. In an hour you should be feeling better.

If not, and symptoms are worsening, take another calcium tablet and call your GP (or endocrinologist if he has given you his number) or get someone to take you to A&E. (We will be printing an emergency card shortly to take with you in this event.)

You will find out for yourself over time what you need to do - whether 2 extra tablets will do the trick for you or whether you need to go to a hospital for a blood test.

Whatever happens, please go to your GP as soon as possible and ask them to monitor your levels for a while so you can get a clear picture of what is happening.

The most important thing to understand is that if this happens to you, and you have been taking your meds properly and eating well, it is almost always a signal that your vitamin D medication needs adjusting. Your requirement does change from time to time which is why regular blood tests are so important.

Many of the people who visit us on the forum with ongoing low calcium symptoms are usually fine once their Alfacalcidol dose has been increased. Many people are started off on 1mcg which, over time, may not prove to be enough to meet your individual needs. If Alfacalcidol doses are too low for you, you will keep having low calcium symptoms. So avoid a big hypo, take control, get a test and get it sorted. You don’t have to put up with it!

**HAVE YOU HEARD OF ICE?**

This was the idea of East Anglian Ambulance Service paramedic Bob Brotchie and was launched in 2005. **It’s simple and effective - store your personal details and doctor’s contact number on your mobile phone under the heading of ICE – In Case of Emergency.** Paramedics or police are then able to use it to contact a relative or doctor. A good idea and one that could help patients with severe Hypoparathyroidism feel reassured.

**MEDIC ALERT**

Alternatively – and we do recommend this at HPTH UK – a MedicAlert bracelet does the same thing. Important medical details are recorded on your bracelet or neck chain as well as a number which links the paramedic to a full history and your doctor’s contact number.

**DON’T FORGET YOUR MEDIC ALERT DISCOUNT!**

Please remember that as a member of HPTH UK, you are entitled to a 5% discount when you purchase any MedicAlert Emblem, 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

**TELEPHONE HELPLINES**

01342 316315 or 01623 750330
**A WALK ON ‘THE WIRRAL SIDE’**

Hannah Mullen (who has HPTH) and Hannah Knott have generously offered to do The Wirral Coastal Walk on behalf of HPTH UK. On the 23rd of May, they will be taking on a 15 mile walk from Seacombe Ferry on the River Mersey to Thurstaston Country Park on the River Dee.

You can support the girls by donating online - https://www.bmycharity.com/V2/2hannahs

This was a last minute decision by the girls, and they don’t have much time to get their donations in, so let’s give them all the help we can!

We’re rooting for you!

‘The Two Hannahs’

**FANCY CLIMBING BEN LOMOND?**

One of our Scottish members, Natalie Love, has come up with the fabulous idea of climbing Ben Lomond to raise money for HPTH UK. It’s quite a challenge for someone with HPTH, so we really do appreciate Natalie’s effort. Natalie is now training in preparation for her climb, which is due to take place (weather permitting) on Saturday, June 12th. Good luck!

If anyone else would like to take on this challenge, please get in touch and we will forward your contact information to Natalie.

We’ll put details of how to donate and support Natalie on our homepage as soon as we can - keep checking!

**THE SHORT WAY ROUND**

Two cyclists, Grant Strong and Lewis Carter are planning to cycle approximately 2000 miles around Britain next year to raise money for their two favourite charities - one of which is us!! These two brave lads will cycle from Kent to John O’Groats, then on to Land’s End and finally back to Kent!

Keep an eye on our homepage for further information...

**MEET OUR NEW FUNDRAISER!**

Having developed HPTH following two thyroid operations, Claire Butchers found HPTH UK, and a wealth of knowledge, experience and much needed support on our Forum.

Two years on, Claire is still symptomatic, but knows she has somewhere to go to find people who know what she’s going through. Feeling that she’d like to give something back, Claire answered Liz’s plea for volunteers...and here she is - our new Fundraising Officer! Claire will be taking on her post following her wedding next month. Good luck Claire!

**HOEDOWN FOR HPTH UK!**

Once again, our star fundraiser Bridget O’Connor managed to come up with an innovative way to raise money for HPTH UK!

On the 17th April, Bridget organised a fantastic hoedown at her local community centre - what a brilliant idea! She invited family, friends and colleagues and had a great mix of adults and children. She served fun, country style food - bangers and burgers, mushy peas and baked beans, and muffins and flapjack to top it all off! Bridget’s nephew organised the music, and her sister called out the dances. Bridget also organised a raffle, a quiz and a colouring competition for the kids. It looks like a fun night was had by all, and the evening raised around £300!

Well done Bridget!

**RAISE MONEY BY SHOPPING ONLINE**

You can raise money every time you shop online, simply by visiting www.easyfundraising.org.uk first. Once you’ve registered and chosen 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!
Bridget O’Connor, a member of HPTH UK since Jan 2008 following her thyroid surgery, has written a children’s book called 'Hisham's Envelope'. It follows a small boy on the first steps of his journey from local GP to hospital, where he has to have his blood taken for diagnosis. Accompanied by his friend, the envelope, Hisham meets new people and learns the routine that will soon become familiar to him as someone with a long term condition. With notes for parents and carers as well as a list of useful websites, this book will positively reassure parents and provide the opportunity for lots of questions and discussion. Illustrated in cheerful colours, 'Hisham's Envelope' is a positive approach towards learning to accept the blood test procedure that children with Hypoparathyroidism have to endure. It also helps them to understand what will happen when they have an appointment. And as we all know, understanding is half the battle!

Bridget says ‘The book came to be as a result of having to have lots of blood tests for my own condition. As I work with children on a daily basis this started me thinking about what it must be like for the little children that have to have blood tests, especially for the first time - hence Hisham’s Envelope.

I have not said that children will get better but that they will feel a bit better and will have to keep coming back to the clinic where they meet other children like themselves. They are not alone.

Bridget works for Sure Start with children and families in Nottinghamshire where her book was first tested and it has been very well received. Sales have already reached £450 and proceeds (minus printing costs) are to be shared between HPTH UK and BTF. There are two versions of the book - an everyday one at £3 or a special occasion one at £5, both plus £1 postage and packing. There are also note pads with illustrations taken from the book available at £1.

HOW TO ORDER

Send your order details (including your name and address for shipping), along with a cheque made payable to B. R. O’Connor to the following address -

B. R. O’Connor (Hisham’s Envelope)
Ashfield Links Forum
Council Offices
Fox Street
Sutton-in-Ashfield
Notts
NG17 1BD
My name is Mary Stack. I was diagnosed with Pseudohypoparathyroidism in 1982 when I was 8 years old after going to what I can remember as lots and lots of doctors. I have a short stature, am very overweight and have short fingers and toes and balance problems. I have had all my teeth removed due to extreme dental problems, I fatigue pretty easily and have multiple learning disabilities and I get around using a walker and power wheelchair. Although I have all these things going on, I have had many incredible experiences in my life so far, and I am sure many more to come!

When I was in school, when it came to physical fitness and physical education classes, they didn’t know what to do with me and I just kind of hung out in the corner and bounced a ball. But in high school I assigned to the adaptive physical education class to attempt to get my P.E. Credit. My teacher said that I had the right build to be a bench presser. I was like yeah right, I don’t do sports, I can’t keep up with anyone and I am not even close to being built like an athlete. But he got me into it. In high school he got me into my first competition and I took first after just a few months of training. I pretty much got hooked after that. I got involved with wheelchair sports and did everything after a few years - Track and Field, Swimming, Table Tennis and more. But Powerlifting was my sport. I finally felt like I was doing something that I could achieve in. Something that I was good at!

In 1998, I was asked to represent the country at the 1998 World Championships in Dubia, U.A.E. I took 18th place and lifted 175lbs. But I came home seeing that there were people with all sorts of challenges and they were doing this, and so could I! I came home from Dubia with a new sense of ability! I trained for Powerlifting 5-6 days a week and ate, slept and lived Powerlifting. But what it meant to me was that I wasn’t unable to do things - I was going to be ok!

Since then I have been to 3 Paralympic Games, 2 Pan American Games (intercontinental games), and 3 World Championships and just this weekend I made the team for my 4th World Championships. I bench 135kg (295lbs) and am in the top 10 best women lifters in the world and hold countless lifting records for nondisabled federations.

Because of Powerlifting I was given a chance to do many things I would have otherwise thought impossible! I was given the chance to get a college education; I was recruited for a varsity Powerlifting team at Edinboro University in Pennsylvania. I graduated in 2005, and I received a Bachelors of Arts in Special Education. I was able to get the job of my dreams. I work at the Ann Arbor Center for Independent Living in Ann Arbor, Michigan. I am the sports and recreation coordinator - I help coordinate sports and recreation opportunities for people with disabilities that need help figuring out how to be active and I encourage them to enjoy life! I have worked at the Center for the past 5 years and truly enjoy what I do. I am even able to train for my sport at the gym we have there.

I also play and am a commissioner for a wheelchair floor hockey league in Michigan and I run the Michigan wheelchair sport organization and speak at numerous schools and conferences on my experiences, and life with a physical disability.

I am still in contact with the very special teacher who changed my life and he coaches me today, 20 years later. I hope that one day I can make that kind of impact on someone’s life!

**WANT TO TELL YOUR STORY?**

This is your newsletter, and we want you to get involved! If you’d like to contribute to the next newsletter, then send your personal HPTH stories, articles, poems or ‘funnies’ to the Editor (mandy@hpth.org.uk) by the 15th of October. We always want to know what you think, so if you have any comments or suggestions - get in touch!

**JOIN IN THE CHAT...**

Come along and join in the discussion on our Forum. It’s a safe, friendly place to chat about HPTH and other parathyroid disorders. There’s a wealth of practical knowledge and experience to be found, and invaluable support from others who know how you feel. You’re not alone...we’re here.
A LITTLE BIT CONFUSED....

If these symptoms are all in my head, Would I really imagine…

Tingling in my fingers, Cramp in my toes, With aching and shaking to add to my woes.

Although in my world of HP'TH gloom, Even I can daydream of…

Hot, sunny places, Bright, smiling faces, And winning some money at Newmarket races.

Maybe I really have myxomatosis, I know it’s for rabbits, But the symptoms fit closest, If you thought I was crazy before, it is true, I got the disease from eating a stew!

The World Wide Web is a great thing to see, Look up an illness then see your GP, She’ll tell you you’re crazy, And give you some pills, Consign you to the home at the top of the hill.

We know we’re not crazy, We know how we feel, The symptoms are endless and sadly they’re real, We’ll all keep on fighting until we are done, In the words of our leader “keep buggering on”!

Su Clifton

GOING ON HOLIDAY THIS SUMMER?

If you are going on holiday, particularly abroad, be sure to check out the travel advice on our website so that you can relax and have a happy, healthy holiday! http://www.hpth.org.uk/resources.php?id=184

TODAY’S LESSON...

One day a farmer's donkey fell down into a well. The animal cried piteously for hours as the farmer tried to figure out what to do.

Finally, he decided the animal was old, and the well needed to be covered up anyway; it just wasn't worth it to retrieve the donkey.

He invited all his neighbours to come over and help him. They all grabbed a shovel and began to shovel dirt into the well. At first, the donkey realized what was happening and cried horribly. Then, to everyone's amazement he quietened down.

A few shovel loads later, the farmer finally looked down the well. He was astonished at what he saw. With each shovel of dirt that hit his back, the donkey was doing something amazing. He would shake it off and take a step up.

As the farmer's neighbours continued to shovel dirt on top of the animal, he would shake it off and take a step up. Pretty soon, everyone was amazed as the donkey stepped up over the edge of the well, and happily trotted off!

Life is going to shovel dirt on you, all kinds of dirt. The trick to getting out of the well is to shake it off and take a step up. Each of our troubles is a stepping stone. We can get out of the deepest wells just by not stopping, never giving up! Shake it off and take a step up.

Remember the five simple rules to be happy:

Free your heart from hatred - Forgive. Free your mind from worries - Most never happen. Live simply and appreciate what you have. Give more. Expect less.

NOW.......... 

Enough of the gushy stuff..... The donkey later came back, and bit the farmer who had tried to bury him. The gash from the bite got infected and the farmer eventually died in agony from septic shock.

MORAL FROM TODAY’S LESSON;

When you do something wrong, and try to cover your ass, it always comes back to bite you!!!
Hypoparathyroidism (HPTH) is a rare endocrine condition caused by a lack of parathyroid hormone (PTH) in the blood.

Along with vitamin D, PTH helps to maintain calcium levels in the blood which affect nerve & muscle function, bones, kidneys & heart. Without PTH, lifelong medication is required and calcium levels must be regularly monitored to maintain stability.

HPTH may be due to a genetic disorder or may occur as the temporary or permanent result of thyroid, parathyroid or laryngeal surgery.

Telephone helplines 01342 316315 or 01623 750330

Contact us for more information, help or support at
HPTH UK, 6 The Meads, East Grinstead, W Sussex, RH19 4DF
Email liz@hpth.org.uk Phone 01342 316315

How can you help? Please call or visit our website for details

Website
Medical advisors
Online forum
TelephoneNumber helpline
Newsletters
Free membership

www.hpth.org.uk

HPTH UK is a small charity as defined by the Charity Commission and is a member of Rare Disease UK