INSIDE THIS ISSUE....

- News Update
- Awareness Event
- Out and About
- Benefit Advice
- Member’s Stories
- Fundraising

HPTH UK CHRISTMAS CARDS

Buy a special card for someone you love...

This year we bring you just one very beautiful Christmas card by award winning illustrator Sophie Burrows, who designed our butterfly logo.

‘Little Robin’ is a high quality original art card. An A6 watercolour design printed on lovely thick 350gsm card, it is supplied with a white envelope and cello-wrapped.

£2.50 each, including postage.

For further details, or to place an order, please visit our website http://hpth.org.uk/home.php?id=213 or see inside

All proceeds will go towards the work of HPTH UK - thank you.

New patient information leaflet out on Hyperparathyroidism

HPTH UK is delighted to endorse the new patient information leaflet for Hyperparathyroidism which has been produced by the Bone and Mineral Special Interest Group of the Society for Endocrinology.

This is an important publication for patients and their families and friends who will now be able to access reliable and accurate information on the diagnosis and treatment available for both Hypoparathyroidism (HPTH) and Hyperparathyroidism (PHPT).

The new leaflet is only available online at the moment but we hope to have printed copies available soon. You can download it from the Society for Endocrinology’s website here http://www.endocrinology.org/policy/docs/11-10_Hyperparathyroidism.pdf

HPTH UK would like to thank all those who were involved in producing this document. Read more inside.
Dear members and friends,

Welcome to you all. Getting the HPTH UK News out this winter has been a bit of a struggle. Mandy Mainland, our editor, has not only been very unwell these last few months but has also had to move house and put up with the freezing conditions that Scotland is now experiencing. She has done a fantastic job putting this edition together and I know you will join me in thanking her and wishing her well. Meanwhile in Sussex, where we have a drought, my dining room, AKA the HPTH office, had begun to slip rapidly downhill and we endured 5 months of subsidence work to rebuild it. I’m still surrounded by boxes so if I haven’t replied to you yet, please bear with me. But we’re here, with pages of interesting news to tell you about so read and enjoy – and please do let us know what you think. We’d love to hear from you!

Clinical Advisory Team

In August, our lead advisor, Professor Bill Fraser left Liverpool to head up a new bone and muscle research centre in Norwich and we wish him good luck in his new post. Fortunately HPTH members in East Anglia will now have an expert on their doorstep. We are delighted to welcome 2 new experts to our team: Dr Mark Cooper and Dr Neil Gittoes, both in Birmingham. You can read their research on the ‘Diagnosis and management of hypocalcaemia’ on the website. Like all our advisors, both consultants are willing to see members from HPTH UK in their area and we have already had a glowing report from a previously languishing member who is now feeling like a new person thanks to her now properly adjusted medication. We are also very grateful to Professor Simon Pearce, an expert in calcium metabolism, who begins his question and answer column in this edition of the newsletter. If you have any questions for him, please send them in.

Focus on Surgery

The British Association of Thyroid and Endocrine Surgeons (BAETS) audit in 2007 showed permanent damage to the parathyroids in 7.56% following thyroidectomy and not the 1-2% that had previously been thought and also that (according to Mr John Lynn at Endocrine Surgeon), in the UK only 17 surgeons performed more than 20 parathyroidectomies a year (in his view the minimum number to maintain surgical skills), 43% of BAETS members performed 10 or less parathyroidectomies, while a staggering 21% performed less than 5 cases a year, so our efforts to highlight the dangers of neck surgery and to promote safer techniques continue.

We have been approached for our support by two UK research projects investigating parathyroid surgery techniques. In June we attended the Multidisciplinary Thyroid and Parathyroid Meeting at the Royal College of Surgeons, a 2 day event in London supported by BAETS. Find out about the parathyroid presentations by reading Judith Taylor’s encouraging report inside. It’s good to be hearing a positive response and a rise in interest from surgeons about HPTH UK. If you have had a positive experience with your surgeon please visit http://www.iwantgreatcare.org/ and choose ‘Endocrinology’ to leave a comment to help others. We are still collecting stories from those of you with post surgical HPTH, as part of our ‘Living with Hyopoparathyroidism’ project so if you haven’t sent yours in yet, we’d love to hear from you. Your voice counts. Please use the form provided inside.

PHTH 1-84 Clinical Trial update

Professor Fraser writes: ‘The PTH(1-84) Trial has finished the treatment stage of the study and I was at a meeting in San Diego where the plans for the close out were finalised and the future analysis is being coordinated. It will be some time before the Trial results are available and then application to the various regulatory bodies will be required. At a rough estimate 2-3 years before it will be prescribed if the Trial turns out to be positive.’ In November, he sent us this good news: ‘NPS Pharmaceuticals announced positive top-line results from pivotal Phase 3 REPLACE Study of NPSP558 in Hypoparathyroidism. NPSP558 could become the first replacement therapy for hypoparathyroidism; the company is planning for U.S. marketing submission in 2012.’ See more here http://www.npsp.com/PressReleases/1626785 Fingers crossed...

Awareness

This has been a busy few months for raising awareness about Hypoparathyroidism and HPTH UK especially for Judith Taylor, our Public Affairs Officer and Bridget O'Connor, our Fundraising Officer who both ended up in Newark, although thousands of miles apart! In October, Judith flew to Newark, USA to attend the first AGM of the Thyroid Cancer Alliance (TCA), an international coalition of major, national advocacy organisations who represent thyroid cancer patients. It includes organisations from the USA, Canada, Argentina, France, Germany and the Netherlands as well as the UK. In November, closer to home, Bridget went to Newark, Nottinghamshire as well as to Kings Mill Hospital in Nottingham itself, where local consultants spoke to both audiences on thyroid and parathyroid issues. In December, Judith was out and about again in London, displaying our publicity materials and leaflets at two annual British Thyroid Association (BTA) meetings in London. Read their full reports inside this issue. The Society of Endocrinology has again offered us free exhibition space and delegate places at the British Endocrine Societies Meeting, in Harrogate in March 2012 and we are looking forward to raising awareness about HPTH at this major conference.

Hyperparathyroidism Patient Information Leaflet

In October, the Society for Endocrinology issued their position statement on Hyperparathyroidism (PHPT). HPTH UK was praised for our ‘helpful, insightful and interesting’ comments and we were subsequently invited to endorse the information leaflet which has just been released (see front page). We are delighted to be invited to work with doctors in this way and to help ensure that accurate and reliable patient information is produced. Thank you to Debbie Williss at the SfE, and the Bone and Mineral Special Interest Group, especially Dr Mark Cooper and Dr Neil Gittoes, for their involvement in this much needed publication.

Forum Moderators

We are very lucky with our moderators! Lisa Burke (dibdab) does a truly fantastic job and held the fort without complaint while Mandy and I were otherwise engaged. Thank you Lisa - you deserve a medal. She has recently been joined by Su Clifton (soops) who brings her special brand of humour and much needed support. Meet Su and Lisa inside this issue.

Benefits Advice

In these difficult times, we are delighted to announce our new quick guide to benefits and employment on the website explaining which benefits you may be entitled to and where to go to find out more. We hope this will be helpful. We are also now members of the ‘Benefits & Work’ publication which provides amazingly helpful step by step guides. These are now available to you, free, via Su who will also be moderating the Benefits Advice board on the forum. Thanks to Jean Clewes (jeanski) for kindly suggesting this publication to us, and to Su for kindly volunteering her services.

Local Groups

At last – you will be able to meet each other! Local groups are gradually being set up around the UK and Ireland. All the groups will be listed on the website in the Members Section under ‘Find a local group’ here http://hpth.org.uk/members.php?id=214. Please sign up in your area if you haven’t already done so. Postal members will receive a letter and further details will be sent out to everyone as soon as possible. Thank you so much to those of you who have offered to run these groups and well done to the Scottish group who have already arranged their first meeting – with 2 people even coming from the islands to meet fellow HPTH-ers for the very first time. What an emotional meeting that will be!

Thank you to everyone - patients, families, friends and professionals - who so kindly support us. Have a merry Christmas and may 2012 be a happy and healthy year for you all!

Liz Glenister
Director
liz@hpth.org.uk
In June I attended a Multidisciplinary Thyroid and Parathyroid Meeting on behalf of both HPTH UK and the British Thyroid Foundation. The Meeting was held at the Royal College of Surgeons in London on 16-17 June.

This was a course aimed at specialists and trainees in endocrinology and surgery who have an interest in thyroid and parathyroid disorders and was supported by the British Association of Thyroid and Endocrine Surgeons (BAETS).

It was organised by Mr Neil Tolley and Mr Fausto Palazzo who are both surgeons at Imperial College, London; and Dr James Ahlquist who is a clinical endocrinologist at Southend University Hospital. There was a fantastic range of speakers who included internationally recognised endocrinologists and surgeons from Australia, France and the USA as well as the UK.

I have picked out here some of the talks that have special relevance to hypoparathyroidism.

Day One was dedicated to thyroid cancer and thyroid nodules and included an update on differentiated thyroid cancer by Professor Graham Williams (Imperial College, London), discussions on the surgical management of thyroid cancer and current controversies about radioactive iodine treatment, and a session on medullary thyroid cancer. Thyroid cancer is increasing in the UK and cases have doubled between 1975 and 2007 although deaths from thyroid cancer have fallen, Professor Williams pointed out. Although it accounts for less than one per cent of all cancers it is now the 18th most common cancer in women. By implication therefore, rising surgery rates may involve rising complications rates.

A recurring theme throughout the day was how to manage thyroid cancer surgically with some clinicians and surgeons favouring doing just a lobectomy in very low risk patients, and others favouring a total thyroidectomy straight away (together with central compartment node dissection where the lymph nodes are involved). Surgeons have been debating this since my own first thyroid surgery 46 years ago. It is a complex subject, which I cannot begin to do justice to summarising as I am not medically trained. And as one speaker pointed out, doctors can advocate any operation and find support for it somewhere in the literature. What is clear is the huge amount of evidence-based data that are accumulating on the management of thyroid disorders and specifically thyroid cancer. According to one of the speakers, Professor Ashok Shaha (New York, USA) there is a new research paper on thyroid cancer published every eight hours!

Several speakers drew attention to the unacceptably high rates of permanent hypocalcaemia and hypoparathyroidism following thyroid surgery. Because not all thyroid and parathyroid operations are audited there is no clear picture of the number of patients throughout the country who go home with either temporary hypocalcaemia or permanent hypoparathyroidism. Where there was agreement, though, was that the rates are rising and that there is cause for concern.

On Day Two there were two parathyroid sessions and a thyroid forum about managing more complicated cases of thyroid surgery.

The conference chairman Mr Neil Tolley (London, UK) spoke about revision (i.e. repeat) thyroid surgery, and reported that the rate of permanent hypocalcaemia (i.e. hypoparathyroidism) after revision surgery is estimated at 16.5% in the UK and even higher in the USA if I understood correctly. In his own practice, Mr Tolley aims to identify at least two parathyroids when doing thyroid surgery and always autotransplants some parathyroid tissue, which is far from standard practice. He does a total thyroidectomy in the majority of cases and also uses a nerve monitor. He strongly advocates concentrating thyroid surgery in a few specialist hands as the highest volume of surgery leads to the lowest complications and the shortest length of stay, he says. The BAETS recommends that surgeons who perform thyroid cancer surgery do a minimum of 30 thyroid surgeries a year (although there are some endocrine surgeons who do many more).

Mr Fausto Palazzo (London, UK) gave the audience - and me! – a wake up call by presenting a slide of the HPTH UK website’s ‘World Hypoparathyroidism Awareness Day’ page - saying ‘this is a big enough problem to warrant its own awareness day!’ He pointed out that at present rates, there are at least 200 new patients each year with HPTH, mostly younger women who are dependent on medication for life and may develop other unwanted side-effects. His advice to those in the audience was to ‘treat every parathyroid gland as if it’s the last’. He provided the audience with some information about the recombinant PTH trial which he said would be reporting at the end of this year and which he said may be the answer for patients with permanent HPTH.

Mr David Scott Coombs (Cardiff, Wales) spoke about the issues that can arise with revision (i.e. repeat) parathyroid surgery where the risk of permanent hypoparathyroidism following revision surgery can be 2-20%, he said, as healthy glands may have been removed during the first operation. He added his voice to the ‘clarion call for centralisation’ of parathyroid surgeries, preferably for all, but definitely for revision surgery.

Mr Tolley put up a slide showing the main patient organisations and told the audience that patient pressure groups have an increasing role to play to challenge surgical practice and bring about change. This was echoed by several clinicians and surgeons that I spoke to.

I came away from the meeting persuaded that professional thyroid specialists are open to working together with patient support organisations and that in the interest of future patients we should support the argument for the concentration of surgical skills in fewer centres, encourage patients who come to us for advice to look for an experienced endocrine or ENT surgeon who does a high volume of thyroid/parathyroid surgeries and has a low complications rate, and highlight to patients facing surgery that they may need to be prepared to travel to get high quality care. This was an invaluable opportunity to meet with leading endocrinologists and surgeons as a patient support group representative, learn about current developments, and raise awareness for HPTH UK and the BTF. I am grateful to the organising committee for the opportunity to attend.

Judith Taylor - Public Affairs Officer HPTH UK and thyroid cancer survivor
OUT AND ABOUT - THYROID CANCER ALLIANCE AND BRITISH THYROID ASSOCIATION MEETINGS

Thyroid Cancer Alliance holds its first AGM in Newark, NJ

The Thyroid Cancer Alliance (TCA) held its first Annual General Meeting in October. The meeting was held in Newark, New Jersey.

The TCA is an international coalition of major, national advocacy organisations who represent thyroid cancer patients. It includes organisations from the USA, Canada, Argentina, France, Germany and the Netherlands as well as the UK.

I attended the meeting as the British Thyroid Foundation’s thyroid cancer project group lead and also represented HPTH UK at the meeting. There were ten people present, representing 11 organisations.

The organisation is set up under Canadian law. The representatives formally accepted the By-Laws, with certain amendments, and three officers were formally voted in: Kate Farnell (Butterfly Thyroid Cancer Trust, UK) President, Joan Shey (Light of Life, USA) Vice-President, and Rita Banach (Thyroid Cancer Canada) Treasurer.

After the formal part of the AGM each of the representatives gave a short presentation about their organisations and I presented a brief overview about HPTH UK as well as distributing copies of the patient leaflet on hypoparathyroidism.

There were also presentations of the awareness activities that some of the organisations had held during Thyroid Cancer Awareness Month (September). Our sister organisation Butterfly Thyroid Cancer Trust held a ‘neck check’ event in Newcastle where doctors checked nearly 1,000 necks.

The TCA plans to undertake regular patient surveys, in collaboration with clinicians, with the aim of publishing the results in a peer reviewed journal. The next survey is directly of interest to HPTH UK as it was decided to focus on surgery, which should contribute to a better understanding of the extent of parathyroid damage after thyroid surgery, and other post-surgical complications.

The TCA hopes to expand to include organisations from other parts of the world and plans to meet every year, wherever possible to coincide with a major professional meeting. The next meeting will be held during the European Thyroid Association meeting which will be taking place in Pisa, Italy, in September.

If you know of an existing support group in a country not listed here, please contact Rita at info@thyroidcancercanada.org

British Thyroid Association meeting

The annual British Thyroid Association meeting was held in London on Thursday 30 November and Friday 1 December in the elegant building of the Royal College of Pathologists, next to the Royal Society, in London.

The BTA is the organisation that represents clinicians and researchers.

The conference included a half-day session on thyroid cancer culminating in the ‘George Murray Lecture’ which was given by Professor Martin Schlumberger (Paris, France) who is a very highly regarded international expert on thyroid cancer. His talk fell into two parts: routine follow-up and management, and management of patients with recurrent or persistent differentiated thyroid cancer. He also spoke about a network of clinical research centres in France called TUTHYREF which exists to share knowledge about ‘refractory’ thyroid tumours, including those that do not respond to radioactive iodine treatment.

I was attending the meeting on behalf of the British Thyroid Foundation, but we also displayed the HPTH UK patient leaflet on hypoparathyroidism and several people came over to the display table expressly to ask about HPTH UK and our activities. One endocrine nurse took a bundle of leaflets to display in her clinic and several clinical endocrinologists took information away with them. This was a very helpful meeting for raising awareness and making contacts.

Judith Taylor
Public Affairs Officer
judith@hpth.org.uk
OUT AND ABOUT
Focus group meeting at the MHRA

The MHRA are the Government Agency responsible for ensuring that medicines and medical products work and are acceptably safe. A central tenet of the 2010 White Paper Equality and Excellence: Liberating the NHS and the Quality, Innovation, Productivity and Prevention (QIPP) framework is the need for public health organizations to focus effort on delivering high quality outcomes. In response to this, in October 2011, HPTH UK were invited by the MHRA to participate in a focus group meeting designed to help MHRA understand what a successful medicines and medical devices regulator looks like from a patient’s point of view and what outcomes we would like them to work towards.

Accompanied by Bill (husband, HPTH UK treasurer and trained doctor), I met with representatives of other patient organisations and MHRA personnel in the impressive glass offices of the MHRA building in Victoria, London. (Yes, the views were spectacular.) The meeting was opened by Rachel Bosworth, MHRA Director of communications and led by the delightful Susan Frade, MHRA Patient and Public Engagement Manager.

One of the most interesting questions raised, and one that is central to the work of the MHRA, was about risk versus benefit. Do the benefits to patients and the public justify the risks? The discussion was wide ranging and touched on several issues of relevance to HPTH UK; regulating the sale of internet drugs eg vitamin D3; speeding both the clinical trials and orphan drugs approval processes; getting off label drugs that had already been trialled (eg PTH 1-84); the need to invite people onto committees who have understanding of the medical conditions under discussion. The ‘Yellow Card’ medicine reporting system was considered by all to be successful. A link to this can be found on our website.

We also discussed ways of raising the MHRA profile and brand recognition which, unlike at NICE, were very low; in a public survey only 2% were aware of the MHRA and what they do. Apart from the new ‘Patients and Public’ section on the website, how could public perception be improved? Various useful ideas were put forward and it was also agreed that a regular, mutual exchange of information between MHRA and patient organisations would be helpful.

Afterwards, Susan Frade asked me to explain more about Hypoparathyroidism and the issues that concerned us most, such as vitamin D analogues, PTH and especially blood testing. I was able to pass on Professor Fraser’s view that a testing device like the i-stat would become obligatory once PTH was in use and that a decent trial of these devices was required, although a simpler, cheaper hand held device for calcium measurement needs to be produced.

Although aware that this was largely a fact finding mission we nevertheless came away feeling that there was actually a human face to this massive, anonymous organisation, and that they were interested in our concerns. I allowed myself to feel a little more hopeful that one day we might get home testers, after all…..

To find out more about the MHRA visit their website at www.mhra.gov.uk

Liz Glenister
Director

DON’T FORGET YOUR MEDIC ALERT DISCOUNT!

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

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

KEEP IN TOUCH....

Already a Facebook fan?

Why not get Tweeting too?

Chat and find friendly support as always on our Forums

HAVEN’T JOINED OUR FORUM YET?

Go on, give it a go! It’s a safe, friendly place to chat about HPTH and other parathyroid disorders. You can benefit from other people’s experience and pick up lots of tips on how to cope with the day to day problems of living with a parathyroid condition. We can’t offer medical advice, but there is a wealth of caring, support and knowledge to be found. We’ve all been there, and we know how you feel, so even if you’ve just had a bad day and need someone to listen - we’re here for you to chat to.
A further two Awareness meetings were held this year in Nottingham hospitals to highlight thyroid and parathyroid issues. Attended by over 200 patients, as well as medical staff, student doctors and nurses, this is a great way to raise awareness about Hypoparathyroidism. If you (patients or doctors) would like to hold a similar event at your own hospital, please contact us. The meetings are organized by BTF, and HPTH UK has a stand run by local member and HPTH UK fundraising officer, Bridget O’Connor. Huge thanks to Bridget for all her unflagging support at a time when she herself was not well. Here is her report:

Newark Community Centre - November 10th 2011

A very successful evening! 50 people attended this year and we were fortunate enough to be joined by two consultant endocrinologists, Professor Thomson and Professor Fernando, one consultant surgeon Mr Nigam and Luckni Sellahewa a specialist registrar.

Specialist registrar, Dr Luckni Sellahewa, presented an overview of the thyroid gland - what it is, what it does, what can go wrong, the different types of thyroid disease and the symptoms, treatments and the side effects. She also talked about the possible eye problems which can arise due to an over active thyroid. She stressed the importance of the support groups in helping patients to live with a thyroid disorder.

Of most interest to HPTH patients was the talk by consultant surgeon Mr Keshav Nigam who asked ‘When do I need surgery?’ He described the different types of lumps that may be found in the thyroid (goitre, cancer etc), red flag symptoms, hyperthyroidism and the different investigations and indications for surgery for thyroid nodules. He then went on to talk about the different types of surgery available, about preoperative prep and complications of surgery. Mr Nigam spoke in depth about the parathyroid glands and the complications that may arise during surgery. He explained the difficulties for the surgeon - that the glands are only as big as a pin head, they sometimes look like fat, that they may be within in the thyroid itself – and the risk of Hypoparathyroidism leading to the need for treatment with calcium and vitamin d. He explained that Hypoparathyroidism may be temporary - some parathyroids could recover. However, others do not and treatment for permanent Hypoparathyroidism is life long, affecting around 5% to 10% of patients. Mr Nigam then talked about thyroid cancer, the risk factors, treatment and prognosis of the different types. We were shocked to discover that there are now around 1,800 new thyroid cancer cases per year.

All four doctors then held a question and answer session which was very interesting. Many questions were asked and many useful pointers given by the doctors. Professor Thomson closed by saying how useful it is to be able to access support and information on the internet but warned us to be cautious about making sure it was from a reliable source such as The British Thyroid Foundation and HPTH UK.

Patient feedback: this event was held near to Lincolnshire and quite a few members who had rung the helplines or emailed me for support came along to the event and we met in person for the first time which was nice. Very positive feedback was given afterwards by everyone who said how much they enjoyed the event and found the information very useful.

Kings Mill Hospital
November 15th 2011

This was another very successful evening with around 150 people attending to hear Professor Thomson and Professor Fernando and Mr Nigam speak. This time, Professor Fernando presented the overview of the thyroid gland as before. He then talked about the support available and invited the audience to visit the BTF and HPTH UK information stands, which they did. Mr Nigam repeated his presentation about surgery, stressing the caution needed to avoid injury to the parathyroids during surgery. There followed a question and answer session with all three doctors taking part which, as always, was very popular.

A number of student doctors and medical staff, including nurses, also attended this meeting which gave us the opportunity to raise awareness about Hypoparathyroidism to a wider audience. They were keen to ask questions and they visited the stands afterwards taking away information and leaflets. I was very pleased with the response.

Special thanks go, of course, to the doctors, to BTF, and to Sarah Elphick, the hospital Communications & Membership manager, who organised the event. Also, to the lovely ladies of the local BTF support group and friends of HPTH UK who have worked so hard at both events. I hope we long continue, my friends! Thanks also go to Mr Barry Wade, who gave up his time to take photographs for us. A Christmas hamper was raffled, contents kindly provided by the group members, and a soft toy ‘guess the name’ competition was also held, raising £100 to be divided between the BTF, HPTH UK and the Nottinghamshire local BTF support group. I was delighted to fly the flag for HPTH UK, to raise awareness of the seriousness of the condition and of what it is like living with HPTH on a daily basis.’

HPTH UK would like to thank all the doctors who gave their time and support to further education and raise awareness about Hypoparathyroidism. We are very grateful.

Bridget O’Connor
Fundraising Officer
bridget@hpth.org.uk
Do I have a disability?

Disabled people are protected against discrimination by the Disability Discrimination Act, 1995.

A person is considered disabled under the Act if they have:

“...a physical or mental impairment that has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities.”

A condition is classed as a disability if it has a substantial and long-term adverse effect on your ability to carry out normal daily activities. This impairment must:

- have lasted for 12 months
- be likely to last 12 months or
- be of a recurring nature where a recurrence is likely in a 12 month period

Hypoparathyroidism is a long term condition with both physical and mental effects. Some people have few symptoms and may not experience any difficulties. Others may have severe and unpredictable long term symptoms which may be considered to a disability. Depending on the severity of your Hypoparathyroidism, you may be able to claim a number of different benefits and tax credits. Some patients with Hypoparathyroidism do receive Disability Living Allowance.


What help is available to me?

If you are sick or disabled, there are a number of different benefits and tax credits you may be able to claim.

If you have care or mobility needs, you may be able to claim Disability Living Allowance or Attendance Allowance.

If you are unable to work, you may be able to claim Statutory Sick Pay or Employment and Support Allowance.

If you work, you may be entitled to Working Tax Credit.

If you are a student you may be eligible for the Disabled Student Allowance.

If you care for someone who is disabled, you may be able to claim Carer’s Allowance.

Remember that you may be able to get other benefits as well, depending on your circumstances.

You may be able to get benefits for being on a low income like Housing Benefit and Council Tax Benefit, or Child Tax benefits if you have children. Even if you cannot claim any benefits, you may be able to claim National Insurance credits if you are unable to work or you are a carer.

Also, if you are disabled, you may be entitled to other help apart from benefits and tax credits. For example, you might get cheaper public transport, parking concessions and practical help with care from your local council. You also have the right not to be discriminated against at work or when you receive goods or services.

November 2011: The above information was adapted from the CAB website and while its use has been approved by CAB they are unable to check for accuracy all the information that appears here.

BENEFITS INFORMATION AND ADVICE

Do you need advice about benefits or work? Are you worrying about how to answer the questions on your claim form?

Some of our members are now receiving letters about their Incapacity Benefit or Disability Living Allowances. Others are contacting us for information about HPTH and employment rights. As this can all be a very distressing business, HPTH UK have taken action to provide some help.

On the website we have compiled a new section called Benefits and Work Advice (see Members on the menu). Once there, help is just two clicks away and our new Benefits Advisor, Su, will be on hand to help you.

1. A ‘Benefits Advice Guide’, a quick guide to help you find out which benefits you may be eligible for and where to go for further advice.

2. A step by step guide to helping you tackle those forms:
   - Learn how to complete every box on the DLA form.
   - Prepare for a medical visit.
   - Learn how to complete your ESA questionnaire
   - Find out what questions will be asked at your medical

To see the page and to find out more please go to [http://hpth.org.uk/members.php?id=210](http://hpth.org.uk/members.php?id=210)

REMEMBER TO MAKE SURE YOU HAVE ENOUGH MEDICATION TO SEE YOU THROUGH THE HOLIDAYS. HPTH UK WISHES YOU ALL A HAPPY AND HEALTHY FESTIVE SEASON.

Season’s Greetings
WE NEED YOUR STORIES!

You may remember that we launched our Awareness project called ‘Living with Hypoparathyroidism’ last summer. This is a collection of your stories that are being published to raise awareness about HPTH.

These stories help doctors, researchers and medical students as well as patients and their families and friends to understand what it feels like to live with this condition and is a unique resource.

We hope to build on this collection to include all types of HPTH and we need you to send in your stories. Please help.

Just write down how it started for you, how you were diagnosed, what happened next and how you are now. Keep it fairly brief – it’s quite hard to stop once you get started! Or just write about one incident, if you prefer.

Also, if you are willing to raise awareness of (any type of) Hypoparathyroidism by allowing your story to be published on our website or newsletter please fill out the form below or email the details and return it, with your story, to judith@hpth.org.uk or post it to HPTH UK, 6 The Meads, East Grinstead, West Sussex, RH19 4DF.

HPTH Case Study

Information and contact details

Name:
Age:
Address:    Street:
            Town/City:
            County:
            Postcode:
Telephone:    Mobile:
Email:

Type of Hypoparathyroidism (please circle): Iatrogenic - post surgical (thyroid, parathyroid or other)
                Idiopathic - genetic, congenital, autoimmune or other

Year diagnosed:

Had you been ill for long before diagnosis?

Occasionally we receive requests from the media for case histories. If we feel the story will genuinely help to raise awareness, and approve the request, would you be willing for us to keep your information on record so that we can contact you in this event? (All information will be treated confidentially):

Yes    No

If you agree for your story to be used by a magazine/paper would you be willing to have a photo taken by their photographer?

Yes    No

Would you be willing for your story to be used anonymously for research purposes?

Yes    No

Any comments or requests?

I look forward to hearing from you.

Thank you for your support,

Liz
WHO IS FIGHTING YOUR CORNER?

A short time ago, very little was heard about rare conditions. ‘So what’s changed?’ you may be thinking. Actually, more than you probably know. Take us. A member wrote to me the other day and said that finding our group had felt like ‘stepping off a desert island’. She was no longer alone with her rare condition. Similarly, we are no longer simply a little group shouting for help into the darkness. Rare disease groups have been brought together and now have a louder and more effective voice. We are part of a wider community. People are joining together all over the world to make a difference, for you. Campaigns and projects and policies have sprung up that aim to bring us equal access to the services we need. We have a way to go yet, but all our voices count from yours and mine, to the larger organizations, all the way up to the European Commission. I thought I would introduce you to some of those organisations, and to the important work they are doing, fighting your corner.

Genetic Alliance UK is the national charity of patient organisations with a membership of over 140 charities supporting all those affected by genetic disorders. They were instrumental in helping HPT/H UK get off the ground. They set up Rare Disease Day and the many important initiatives that followed. Amongst the hugely varied work they do, they are currently working closely with some patient organizations to develop two projects designed to help patients with rare conditions: Route Maps for Rare Conditions will help patient groups improve information, access and coordination of health and social care services for individuals and families with a wide range of rare conditions. Patient Information Pathways, being developed in conjunction with the National Specialised Commissioning Team, will help patient groups to find ways to deliver accessible and useful information for patients at the appropriate points in their journey. For more information visit Genetic Alliance UK http://www.geneticalliance.org.uk/index.html

Rare Disease UK is the national alliance for people with rare diseases and all who support them. They believe that ‘everyone living with a rare disease should be able to receive high quality services, treatment and support’. Here they explain what they are fighting for: ‘RD UK are campaigning for the Health Departments across the UK to develop a strategy for rare diseases to ensure that patients and families living with these conditions have equitable access to effective services. A cohesive, well-implemented strategy for rare diseases would improve the health and quality of life of those living with a rare condition, as well as ensuring the most effective use of NHS resources. For further information or to join the campaign for a strategy for rare diseases please click here.

- 1 in 17 people will be affected by a rare disease at some point in their life.
- This amounts to approximately 3.5 million people in the UK.
- 75% of rare diseases affect children and 30% of rare disease patients will die before their 5th birthday.
- There are over 6,000 recognised rare diseases.
- Collectively rare diseases are not rare.

For more information visit Rare Disease UK www.raredisease.org.uk

EURORDIS is a non-governmental patient-driven alliance of patient organisations representing more than 492 rare diseases patient organisations in over 46 countries. EURORDIS promotes the implementation of services adapted to the situation and special needs of people living with rare diseases.

‘A disease or disorder is defined as rare in Europe when it affects less than 1 in 2000. One rare disease may affect only a handful of patients in the EU, and another touch as many as 245,000. There are between 6000 and 8000 rare diseases. On the whole, rare diseases may affect 30 million European Union citizens. 80% of rare diseases are of genetic origin, and are often chronic and life-threatening.’

For more information visit EURORDIS http://www.eurordis.org/

Orphanet is the portal for rare diseases and orphan drugs and is led by a European consortium of around 40 countries, coordinated by the French team. National teams are responsible for the collection of information on specialised clinics, medical laboratories, ongoing research and patient organisations in their country. All Orphanet teams respect the same quality charter. Orphanet offers a range of freely accessible services such as inventories of rare diseases and orphan drugs, Directories of services, clinics, research projects, patient groups etc, a diagnosis tool and emergency guidelines, and a newsletter Orphanews.

There is no disease so rare that it does not deserve attention. Rare diseases are rare, but rare disease patients are numerous.

For more information please visit Orphanet http://www.orpha.net/

The European Commission is one of the institutions involved in EU decision making. There is currently one commissioner from each EU country. They work to protect the interests of consumers, cut red tape, make better laws and make Europe a healthier, safer place. The Commission has a policy on Rare Diseases and a committee of rare disease experts. The EU encourages the development of orphan drugs and helps patients and professionals share expertise and information across borders. They work to improve recognition and visibility of rare diseases, support national plans for rare diseases in EU member countries, encourage research and link centres of expertise.

In EU countries, any disease affecting fewer than 5 people in 10,000 is considered rare. That number may seem small, but it translates into approximately 246,000 people throughout the EU’s 27 member countries. Most patients suffer from even rarer diseases affecting 1 person in 100,000 or more. It is estimated that today in the EU, 5-8000 distinct rare diseases affect 6-8% of the population – between 27 and 36 million people.

For more information about the European Commission visit http://ec.europa.eu/health/rare_diseases/policy/index_en.htm

Organisations working together

Watch a video on ‘European Actions to Improve the Life of Patients Living with Rare Diseases’

A good example of how such different organizations can work together to a common purpose can be seen here.
In October, Jo Grey, Director of the patient organization Amendment (Amend), and her mother Janet French were selected by Rare Disease UK to participate in a film they were making to provide an insight on what is done at European level in the domain of rare disease and the impact of the EU action on the daily life of concerned patients and families.

Watch the video here on the European Commission website http://ec.europa.eu/health/rare_diseases/videos/

As well as the patients, it featured European Commissioner for Health and Consumers, Mr J.Dalli. The video was screened at a conference entitled ‘European Actions to Improve the Life of Patients Living with Rare Diseases’. The meeting was hosted by the Executive Agency for Health and Consumers and included presentations by other support groups as well as ORPHANET and EURORDIS.

For more information about Amend please visit www.amend.org.uk

WANT TO FIGHT YOUR OWN CORNER? HELP US TO HELP YOU!

HPTH UK is run entirely by volunteers. We have no paid staff at all, and most of us are coping with HPTH too. If you can help out in any way, or would like to find out more about volunteering, then please get in touch with Liz.

liz@hpth.org.uk

MEET OUR NEW MODERATORS!

As some of you already know, we are delighted to introduce two new moderators to our forum - Lisa and Su. They’re doing an amazing job offering advice and support (and some much needed humour!) to our members. Thanks girls!

Lisa - ‘dibdbab’

In August 2009 I went for my straightforward thyroid surgery, I had been suffering with re-occurring Graves for over 10 years but had begun to form a reaction to the medication. After surgery all seemed well but I mentioned in passing to the Registrar that my top lip felt tingly. I spent 10 days in hospital, hooked on and off to IV calcium, suffering several episodes of tetany and wondering what the hell was happening to me and when I would get home to my 1 and 4 year old children. In the past two years I have been on a bit of a rollercoaster ride, initial elation when all PTH tests came back within normal range to feeling real desperation when I received my diagnosis of ‘functional HPTH’, I have struggled like many with trying to obtain stability but am hoping things in the future will improve. The one constant light for me throughout this has been the HPTH UK site and the wonderful people it attracts, I have felt as if someone has been there to hold my hand and help me through the dark times. I now feel honoured to help take part in the forum as a moderator and if I can give back just a small part of the help I received I will feel like I have done a good job!

Su - ‘soops’

I was diagnosed with Grave’s Disease back in the summer of 1999. After eight years of swinging between hyperthyroid and hypothyroid, and with a goitre that made me look like I’d swallowed a golf ball, I decided that enough was enough. Following my total thyroidectomy, in November 2007, I developed Hypoparathyroidism. Being a member of the HPTH forum for the past few years has been fantastic. When I’ve asked pointless questions, needed help or just needed to let off steam there has always been someone there to offer guidance and support. People don’t always know the answers but they understand what you’re going through. I have, very recently, become a moderator on the forum and a point of contact for benefit information. I may not always know what to say and my sense of humour leaves a lot to be desired but I will try to be as supportive as I can and if I can raise a smile along the way then that’s great :)!

I was diagnosed with Graves disease when I was 25, The doctor said “here take these pills, they’ll make you feel alive”

I took my pills as I was told and boy they made me sick,

And as my mind fell on that guy I thought, boy what a …..wally!

Days and months and years went by and still I was no better,

So off I trudged to my GP and asked her for a letter,

A surgeon was to read this note and offer me a meeting,

And as my mind fell on that guy I thought, boy what a …..wally!

They wheeled me in and whipped it out and soon I was awake,

I took my pills as I was told and boy they made me sick,

He drew a diagram for me, I then felt bright and breezy,

I asked if I could have some tea and a Cadbury’s chocolate flake,

So off I trudged to my GP and asked her for a letter,

A surgeon was to read this note and offer me a meeting,

A day went by I felt a twitch, some numbness in my hands,

Then very soon your fears and pain will soon be all forgot”

As our community continues to grow, we are currently trying to set up regional HPTH groups to give our members a chance to get to know others in their area, and benefit from some local support.

You could just keep in touch with each other, or meet up if you like - maybe even get together to raise some money for HPTH UK!

If you’d be interested in being part of a regional group, or possibly running one in your area, then please go to the forum and sign up. We can’t wait to hear from you!

HPTH UK REGIONAL GROUPS

As our community continues to grow, we are currently trying to set up regional HPTH groups to give our members a chance to get to know others in their area, and benefit from some local support.

You could just keep in touch with each other, or meet up if you like - maybe even get together to raise some money for HPTH UK!

If you’d be interested in being part of a regional group, or possibly running one in your area, then please go to the forum and sign up. We can’t wait to hear from you!
Professor Simon Pearce answers your questions

Professor of endocrinology, Newcastle University, and Consultant Endocrinologist at the Royal Victoria Infirmary, Newcastle, Professor Pearce is a specialist in calcium disorders and thyroid disease. His research interests are in the molecular genetics of autoimmune endocrine disorders (eg. Graves’ disease, Addison’s disease & autoimmune polyendocrinopathies), parathyroid and calcium sensing disorders, and the outcome of subclinical thyroid diseases.

I had my thyroid out for Graves disease in 1984. Lots of numbness as surgeon accidently removed 2 of my parathyroids. Went on Calcium for about a year, then nothing but thyroxine for 30 years. Then numbness etc back, after blood tests my calcium low and specialist said “your 2 remaining parathyroid glands have WORN OUT” thus I have HPTH. Have you heard of getting HPTH this way after so many years past my surgery??

“This seems possible but relatively unlikely given you have been feeling OK without calcium supplements for 30 years. It would be a good idea to make sure that your blood vitamin D levels are OK, as the gradual development of vitamin D insufficiency could have precipitated your symptoms of what was an otherwise balanced situation with regards your calcium levels. It is also possible that medications may also have precipitated the symptoms, so its worth thinking about whether you started any new tablets before the symptoms came back.”

I wanted to know if it is okay to have Botox if you have HPTH? I have been to a professional Clinic and they were unable to advise me as the condition is so rare. Concern is that the Botox relaxes the muscles...just wanted some thoughts before I bombard my Doctor with questions about it!

“There should be no specific problem at all having Botox injections if you have hypoparathyroidism. The one thing to look out for is a general problem, that some people breathe more quickly (hyperventilate) if they are nervous or worried about something (like a needle heading towards your face). This fast breathing can precipitate the symptoms of a low calcium in some people with hypoparathyroidism. This fast breathing can precipitate the symptoms of what was an otherwise balanced situation with regards your calcium levels. Even a small overdose of these medications has the capacity to create problems for you, in terms of making the blood calcium too high, reducing kidney function, producing kidney calcium deposition or even kidney stones. The first sign of such an overdose is often thirst, and this reflects that your kidneys lose the capacity to concentrate the urine, so you go for a pee more often and become dehydrated and thirsty. Preventing accidental overdose of alfacalcidol and calcitriol is one of the main reasons endocrinologists would advise even people with stable HPTH to have regular monitoring with once or twice yearly blood tests.

This is a big difference to calcium supplements. While calcium supplements do contribute to the calcium in the blood, they aren't really a strong medication in the same way, as healthy people are recommended to eat about one gram of calcium daily, mainly from dairy products. An overdose of calcium tablets will leave you feeling bloated and constipated, but as long as you haven't taken anything else, you should have no long-term problems from the calcium alone.”

Many of us have been advised that a higher dose of Alfacalcidol is safer for our kidneys as we can then reduce calcium supplements, and opinion amongst our Endocrinologists does seem to differ on this subject, so we contacted Professor Pearce again to comment on this and to ask him to clarify the situation for us -

We have been totally misled about the calcium then. We have all been advised that calcium is really bad for the kidneys and it is better to take more Alfa and little or no calcium so that urinary calcium levels stay low. You don’t agree with that then?

“No that's totally not true, as the studies show that a small dose of calcium along with the alfa actually reduces the renal calcium excretion, as less alfa is then necessary. The alfa predominantly works on the gut to increase calcium absorption, but most UK people have reasonable dairy intake, so the calcium tablets just boost that.”
‘Welcome to the first day of the rest of your life’. That’s what my surgeon should have said when he briefly visited me after completing my total thyroidectomy nearly 4 years ago for a retrosternal goitre.

Pre-op, I did everything ‘by the book’ - I researched my choice of surgeon, and finally chose an eminent endocrine surgeon.

At the initial consult, the surgeon reported that he does approximately 2000 thyroidectomies a year. He ran through all the ‘Risk Factors’, such as scar, possible laryngeal nerve palsy, bleeding...and he briefly touched on the possibility of low calcium post op which may need calcium replacement **BUT did not indicate that I could possibly need it for life or why the need for calcium replacement**. On reflection, the consultation was all rather rushed. I didn’t ask too many questions - after all, HE was the expert, and I was confident I was in good hands. However, he failed to tell me how radically my life could change if any of those post op complications should befall me. Then again, how could he possibly know if he had never had any personal experience?

I developed surgically induced Hypoparathyroidism within 12 hrs of surgery (corrected calcium 1.7), following the ‘inadvertent’ (quote Surgeon) loss of 3 out of my 4 parathyroid glands. The remaining gland has insufficient function. My symptoms were tingling around the mouth and in my hands. I was given intravenous calcium; however had a ‘reaction’ to it. My blood pressure and heart rate went rapidly high within minutes of starting the infusion. They called a ‘Code Blue’ - a resuscitative situation, but once they stopped the infusion my vital signs went back to normal. They said that I must have had a reaction to some preservative in the infusion, yet now I realise it was because I cannot tolerate any rapid shift in my ionised calcium, and that is what the infusion was causing in an effort to correct my levels. I was not kept in hospital until my calcium levels were stable. I was discharged on the 4th day post op (a Friday), with a corrected calcium level of 2.02, and given Caltrate - 3 tabs, 3 times a day PLUS Rocaltrol - 3 tabs, 3 times a day in an effort to raise my serum calcium levels, and told to see my GP on Monday.

I was totally ignorant of the ramifications of this high dose of calcium supplementation, and ended up in Emergency Department 2 days later with a corrected calcium of 3.5! I had slurred speech, jerking movements, impaired walking, decreased conscious level and palpitations. Again, it was a resuscitative situation, and I was very afraid. They finally got my levels down to 2.59 with 5 litres of intravenous fluid and an intravenous medication.

The surgeon reported to the Emergency Department specialist that my symptoms had nothing to do with him or the surgery, and maybe they should consult a neurologist as he said I could have had a stroke!! I was eventually admitted under the care of a local Endocrinologist, albeit with limited knowledge of HPTH, but with Endocrine colleagues who specialised in ‘calcium disorders’.

I changed from the local Endo, and now have an awesome Endocrinologist, who actually diagnosed me with post-operative Hypoparathyroidism.

The major symptoms of MY Hypoparathyroidism are frequent episodes of fatigue, brain fog, leg cramps, tetany, and seizures. I require PTH, however it is not available on PBS here, and we cannot get it off label...so I am hoping for a clinical trial to come around in my country.

The other disabilities I have are, that at 55 I am unable to find a consistent well being physically, emotionally and mentally to achieve being a functional wife, mother, grandmother, homemaker, friend, working class citizen and reclaim the ‘quality of life’ I enjoyed pre hypopara. It seems like I’ve aged 20 years since surgery!

The effects of my hypoparathyroidism primarily touch every aspect of every relationship I have - whether it be at home, socially or in my work environment. I may not be able to sustain my vocation of 35 years, a vocation I was ‘born’ to do, and the very core of who I am.....Nursing....as a result.

The secondary effects go deeper! It is sad to say that it is these secondary effects that only a minority of General Practitioners and Endocrinologists ‘get’....

I experience a constant pendulum of physical and neurological symptoms, simply because I have lost the exquisite ability to control a delicate and dynamic bodily function - my blood calcium levels. Without my parathyroid hormone actively adjusting my calcium levels every few minutes, I am vulnerable to unpredictable calcium ‘crashes’, resulting in tetany or seizures. However, I am also susceptible to symptoms that occur as a result of even a mild shift in my ionised calcium.

From a neurological perspective, the ‘brain fog’ is a real challenge and very embarrassing to me personally – someone whom is considered ‘an expert’ in my field of nursing, and normally a very articulate person. I now find tasks that require my concentration for any length of time (4hrs), can deplete my calcium levels, as can physical demands and stressors. Not being able to anticipate when my brain will cooperate makes me feel helpless and out of control!

Over 4 years, I have had to endure consultations with 10 specialists....4 neurologists, 3 endocrinologists, 3 cardiologists, oh...and 1 psychiatrist. The psychiatrist was called in as the endocrinologists (except for 1) could find no organic reason for my symptoms (despite my corrected calcium levels dropping at the time of my symptoms.....!)

They pre- diagnosed me with ‘Conversion Syndrome’; however, it was the psychiatrist who was the only professional to actually see a correlation between my hypocalcaemic episodes, the pathology results and my tetany episodes!! Thus....he deemed me SANE!!

Cont’d >>
Now, nearly 4 years ‘down the track’, having a nursing background has helped enormously in my journey of discovery regarding MY hypoparathyroidism.

I believe that ‘knowledge is POWER’!

The things I have learned are:

- It is a lonely road...VERY few healthcare professionals FULLY understand the disease.
- Very few people know about the disease.
- Because we can look well, people do not relate us to ILLNESS.
- Research....read....
- Find and link into a support group - even if they are thousands of miles away!!
- Find your asymptomatic range of corrected calcium....not necessarily the ‘normal values’!!
- It’s about balance.....
- Try to keep ‘between those flags’ with meds, rest, planning your activity, using your calcium medication prophylactically if you know you are going to overdo it.
- Balance your life - accept your limitations, work within them, and enjoy feeling well, because as sure as eggs are eggs you will be hypo again soon!
- You are an individual, and your treatment should reflect this....INSIST on it.

I have adopted the analogy that I have $10 worth of Calcium to spend per day. If I overspend, I will be in deficit the next day. Again, it’s all about balance.

This disease is never going to go away. Understand that you will experience emotions very similar to grieving, eventually coming to acceptance. Then my friends, you will have some CONTROL and can reclaim some quality of life. Life is full of surprises, some good and some bad. In life we all have dreams and goals that change as we age, requiring us to re-evaluate. Hypoparathyroidism is just like life, it constantly needs to be re-evaluated.

My wish for the future is that ALL endocrinologists and surgeons will have a sound understanding of the clinical signs and symptoms, and also the ramifications of this ‘post operative complication’ called SURGICALLY INDUCED HYPOPARATHYROIDISM.

Earlier this year, on Rare Disease Day, Sharon set up HPTH Australia. ‘Keep on keeping on’ Sharon! - Ed

This sensitive drawing was made by 70 yr old postal member, Rosalind Marchant. It was the best way she could describe what happened to her on the 3rd/4th day post thyroidectomy and it clearly shows tetany in the upper body and arms and hands. Rosalind sent this to me to explain what had happened to her and was astonished to find that I recognized exactly how she had felt and that I had experienced the same sensations.

I think this is a brilliant way to express those sensations that are so hard to describe in words. If anyone else has any drawing or paintings that they have made, of any kind, about any aspect of living with HPTH, we’d love to see them!

To add to our HPTH gallery, please send copies to liz@hpth.org.uk or to 6 The Meads, East Grinstead, West Sussex, RH19 4DF.

If you’d like to share your story, then please get in touch!
Send any stories, poems or suggestions to mandy@hpth.org.uk
In the 2008 movie "The Bucket List", two men make a list of the things they want to do before they die, and they set out to do them. My mother wants to go skydiving. My father wants to hike the Appalachian Trail. My husband wants to build his own house. Me? I want to run a marathon. I set out this year to get halfway to my goal - run a half marathon (13.1 miles). No thyroid. No parathyroid function. Two ribs plus muscles surgically removed. Subclavian vein permanently clotted off.

Still running! I had no major surgeries this year. No complications or midnight ER visits. There were no episodes of tetany. I had no new diagnoses or specialists. There was nothing new under the sun for me this year, but it was by far my most challenging year as a patient with HPTH.

My training was going well until a small, seemingly innocent decision changed everything for me in a matter of days. My insurance company sent me a different brand of calcitriol. I wasn’t sure what to do. My husband gave me THE LOOK. He told me to change it immediately. I explained to him how they’re chemically identical, it’s the same stuff. And I started taking them. Within days, I was feeling horrible. For the first time ever, my calcium levels went into the high-normal range (9.9). I felt miserable. I was exhausted. I couldn’t train.

Instead of fun and relaxing, my runs were a push and hard work. I was no longer building distance. I was depressed. I slept a lot. I had no energy for life - for my children or husband. Even though I was taking anti-depressant medication, my calcium levels were in the driver’s seat of my emotions. When my meds ran out, I had my endocrinologist specify my usual brand for my next refill. The insurance company refused to fill them. I had to spend more to refill my prescriptions locally just so I could get the brand I needed. Within 48 hours, I felt "normal" again. I could run again, but I had lost ground. I had to start building mileage again.

Meanwhile, my calcium was still high, so my endocrinologist reduced my meds. At the lower dose, my running was much better. I had stamina and energy again. I was clear-headed. But my calcium levels were crashing during the recovery phase after my long runs. Each Saturday I would run 10+ miles to prepare for the race. On Monday night or Tuesday night, I was having issues with tetany. My hands would go numb. I would lose the ability to move fingers. Instead of going to the ER, I would take extra calcium, call my endo, and wait it out. I found it interesting that I only struggled with my levels when my body was recovering from the run, not during it.

I was able to train for and run my first half-marathon on November 13th. By alternating a higher dose of Calcitriol immediately before and after the race, I could stay out of tetany and low calcium as I recovered. However, three days after the race another problem erupted for me. My blocked subclavian vein caused my right arm to swell, discolour and cause pain. I went back to my vascular surgeon. He did a specialized ultrasound that showed him clearly the problems with blood flow. He started me on daily aspirin therapy. He advised me to use a compression sleeve for my running. In the weeks it would take to clear the swelling I was to rest the arm, keep it elevated, and apply heat. The best news of the day was to keep running. The more I run, the more my body will have to adapt by growing new blood vessels. The more I push, the better my collateral circulation will get. I could keep training.

I am still battling with Premenstrual Dysphoric Disorder (PMDD) secondary to HPTH. This is nothing new for me. For a normal, pre-menopausal woman, their calcium levels naturally fall when they ovulate. PTH kicks in to regulate their levels leading up to the start of their monthly periods. For myself, I was able to regulate this problem using Prometrium. Unfortunately, the Prometrium combined with Thoracic Outlet Syndrome caused blood clots in my right arm. I had to stop the treatment and have two ribs removed to correct it, leaving me back at square one, PMDD. Out of every 30 days, I have 14 days where I feel terrible and 16 days where I feel normal. As soon as I ovulate, I fight with my hormones. My appetite goes up, or I am nauseous. I get headaches, overwhelming fatigue, and emotional irritability. It is difficult to run because my stamina is just not there. I am out of balance. This was not a problem for me until I became HPTH.

As I reflect on my sixth year with HPTH, I am struck by my feelings of being frail. I felt vulnerable this year. A seemingly small decision that was out of my control left me feeling terrible for months. My emotional well-being depends on medication brands. It’s just not normal for your ability to experience happiness, joy and satisfaction to rest on what brand pills you take. I felt dependent on a medication. And I wondered how long that medication would leave my kidneys intact. Will it be next summer I find out my kidney function is failing? A routine blood test that would change my life even more? When is it coming? How much longer do I have in order to run a marathon? What if I can no longer get my chosen brand of calcitriol? I felt vulnerable. I felt frail. I felt beat up by life and the ordinary business of living. The hope that kept me going was my goal of running a marathon. It is still within reach. I can still do it. I can still try. I'm capable of getting there. I will never be an elite athlete. I will never "bring home the hardware". But I can and will finish, no matter what it takes to get me across that finish line, no matter how many hours it takes to get there.

I am dependent on the love and compassion of my family and friends to live with this disease. I depend on their willingness to see me through these tests of hope and faith. I count on them to bring me around when my calcium is in control of my emotions. I need people more than I ever have in my life. I need my endocrinologist, who is willing to support me as I train for this crazy goal. I need nurses who draw my blood. I need my husband to give me THE LOOK. I need my children to make me laugh. I need my friends to call or e-mail me to see how I am doing, and really care about the answer. I need my sisters to make me smile, no matter what is going on in my blood vessels. I need my pharmacist to ensure I get the right pills. I need my endocrinologist to reassure me that my blood vessels are intact. Will it be next summer I find out my kidney function is failing? A routine blood test that would change my life even more? When is it coming? How much longer do I have in order to run a marathon? What if I can no longer get my chosen brand of calcitriol? I felt vulnerable. I felt frail. I felt beat up by life and the ordinary business of living. The hope that kept me going was my goal of running a marathon. It is still within reach. I can still do it. I can still try. I'm capable of getting there. I will never be an elite athlete. I will never "bring home the hardware". But I can and will finish, no matter what it takes to get me across that finish line, no matter how many hours it takes to get there.

I am still battling with Premenstrual Dysphoric Disorder (PMDD) secondary to HPTH. This is nothing new for me. For a normal, pre-menopausal woman, their calcium levels naturally fall when they ovulate. PTH kicks in to regulate their levels leading up to the start of their monthly periods. For myself, I was able to regulate this problem using Prometrium. Unfortunately, the Prometrium combined with Thoracic Outlet Syndrome caused blood clots in my right arm. I had to stop the treatment and have two ribs removed to correct it, leaving me back at square one, PMDD. Out of every 30 days, I have 14 days where I feel terrible and 16 days where I feel normal. As soon as I ovulate, I fight with my hormones. My appetite goes up, or I am nauseous. I get headaches, overwhelming fatigue, and emotional irritability. It is difficult to run because my stamina is just not there. I am out of balance. This was not a problem for me until I became HPTH.

As I reflect on my sixth year with HPTH, I am struck by my feelings of being frail. I felt vulnerable this year. A seemingly small decision that was out of my control left me feeling terrible for months. My emotional well-being depends on medication brands. It’s just not normal for your ability to experience happiness, joy and satisfaction to rest on what brand pills you take. I felt dependent on a medication. And I wondered how long that medication would leave my kidneys intact. Will it be next summer I find out my kidney function is failing? A routine blood test that would change my life even more? When is it coming? How much longer do I have in order to run a marathon? What if I can no longer get my chosen brand of calcitriol? I felt vulnerable. I felt frail. I felt beat up by life and the ordinary business of living. The hope that kept me going was my goal of running a marathon. It is still within reach. I can still do it. I can still try. I'm capable of getting there. I will never be an elite athlete. I will never "bring home the hardware". But I can and will finish, no matter what it takes to get me across that finish line, no matter how many hours it takes to get there.

I am dependent on the love and compassion of my family and friends to live with this disease. I depend on their willingness to see me through these tests of hope and faith. I count on them to bring me around when my calcium is in control of my emotions. I need people more than I ever have in my life. I need my endocrinologist, who is willing to support me as I train for this crazy goal. I need nurses who draw my blood. I need my husband to give me THE LOOK. I need my children to make me laugh. I need my friends to call or e-mail me to see how I am doing, and really care about the answer. I need my sisters to make me smile, no matter what is going on in my blood vessels. I need my pharmacist to ensure I get the right pills. I need my endocrinologist to reassure me that my blood vessels are intact. Will it be next summer I find out my kidney function is failing? A routine blood test that would change my life even more? When is it coming? How much longer do I have in order to run a marathon? What if I can no longer get my chosen brand of calcitriol? I felt vulnerable. I felt frail. I felt beat up by life and the ordinary business of living. The hope that kept me going was my goal of running a marathon. It is still within reach. I can still do it. I can still try. I'm capable of getting there. I will never be an elite athlete. I will never "bring home the hardware". But I can and will finish, no matter what it takes to get me across that finish line, no matter how many hours it takes to get there.

I am dependent on the love and compassion of my family and friends to live with this disease. I depend on their willingness to see me through these tests of hope and faith. I count on them to bring me around when my calcium is in control of my emotions. I need people more than I ever have in my life. I need my endocrinologist, who is willing to support me as I train for this crazy goal. I need nurses who draw my blood. I need my husband to give me THE LOOK. I need my children to make me laugh. I need my friends to call or e-mail me to see how I am doing, and really care about the answer. I need my sisters to make me smile, no matter what is going on in my blood vessels. I need my pharmacist to ensure I get the right pills. I need my HPTH community to reassure me that my experience is shared.

It's uncomfortable to be needy. It's uncomfortable to feel frail. But it is important. It is a humbling experience. It is a very human experience. And I have decided that it is ok to need. It is ok to be frail. It is ok to be human. It is ok to say: "I am not well today." It is ok. I am ok. I am frail. I am needy. I am ok.

This was adapted from a forum post by Carem, who is one of our American members - Ed.
I tried to take legal action, 3 years of seeing a solicitor I was told that the claim couldn't proceed. During one meeting there was an Endocrinologist present. He was asked why I wasn't told of any parathyroid damage, and he said "The parathyroid will often recover following the operation. There were no indications at the time that it would be damaged and it did seem that it had recovered until the birth of her son in 1981 following which it does not appear to have recovered." The Endocrinologist could not really explain this. He said "It must be very rare, but the evidence is that it seems to have recovered and become damaged much later on."

I now see another Endocrinologist every 3 months. He's had to reduce my Alfacalcidol and put me on Bendroflumethiazide tablets to protect my kidneys. I still get tingling now and again, muscle weakness and fatigue; I still struggle at times with the mental health issues. In between visits to my Endo I see my GP who is very supportive, he lets me have a blood test whenever I want, and in my opinion, has gone above and beyond the call of duty to help me deal with my problems.

I can't emphasize enough the suffering I have endured.

The relationship with my parents was never the same, they couldn't understand what happened to their outgoing, carefree confident happy daughter. How could they when doctors didn't explain anything, even when they received a phone call the day of the operation and were advised to get to the hospital as soon as possible as they could not get me breathing. On their arrival they were met by a nurse who told them I was fine and was breathing on my own. Nothing was explained to them or if anything had gone wrong with the operation, and in those days you didn't ask such questions of doctors. As for my education I wasn't well enough to maintain the work levels demanded as well as doing the extra work to catch up so I never regained my academic position. The jobs I managed to get I was doing the extra work to catch up so I never regained my academic position. The jobs I managed to get I was either sacked or asked to leave due to my health problems.

Now I just take each day as it comes and thanks to HPTH UK and reading other people's stories, for the first time in 37 years I don't feel alone with this life changing condition. Maybe we can hope for a better quality of life if PTH becomes available to us, until then we have to cope with the Vitamin D treatment, although for many of us is not ideal.

My message to others would be: Never be afraid to speak up for yourself. If you think something is wrong talk to someone and get the treatment/support you deserve.
FUNDRAISING AND DONATIONS

DON’T FORGET!
HPTH UK
CHRISTMAS
CARDS NOW ON
SALE!

‘Little Robin’
£2.50 inc p&p

Additional postage -
2-5 cards £2.00
6-10 cards £3.50

How to order -
By email - claire@hpth.org.uk
By phone - 01342 316315
By post - HPTH UK, 6 The Meads, East Grinstead,
West Sussex, RH19 4DF

Payment is via cheque - send your contact details
and a cheque, including any postage costs, to the
above address. Your card(s) will be sent out to you
immediately, by 1st Class post.

REMEMBER TO USE EASYFUNDRAISING
THIS CHRISTMAS!

Donate money when you shop online, by visiting
www.easyfundraising.org.uk. Simply register and
select 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 - ‘simples’!

HPTH UK Income  May - Dec 2011

<table>
<thead>
<tr>
<th>Monthly bank transfers</th>
<th>101 00</th>
</tr>
</thead>
<tbody>
<tr>
<td>David Robinson</td>
<td>£5 40 00</td>
</tr>
<tr>
<td>Anna Potter</td>
<td>£2 10 00</td>
</tr>
<tr>
<td>Jenny Dixon</td>
<td>£2 16 00</td>
</tr>
<tr>
<td>Susanna Knight</td>
<td>£5 35 00</td>
</tr>
</tbody>
</table>

Thank you for your ongoing commitment

<table>
<thead>
<tr>
<th>Postal Donations</th>
<th>65 00</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sandra Minshull</td>
<td>20 00</td>
</tr>
<tr>
<td>Anna Potter</td>
<td>5 00</td>
</tr>
<tr>
<td>Nicola Colelough</td>
<td>30 00</td>
</tr>
<tr>
<td>Brenda Glencross</td>
<td>10 00</td>
</tr>
</tbody>
</table>

Thank you all as well!

<table>
<thead>
<tr>
<th>Fundraising</th>
<th>404 39</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bridget O’Connor</td>
<td>66 00</td>
</tr>
<tr>
<td>Bridget fundraised at 2 awareness events</td>
<td></td>
</tr>
<tr>
<td>Liam Sale</td>
<td>287 25</td>
</tr>
</tbody>
</table>
| Liam ran the London Marathon for us.
More funds to come.....
Easyfundraising | 51 14 |

Thank you to everyone who logged on to
this site before shopping online

Total | £570 39

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:

Our bank: Santander
Our sort code: 09 – 06 – 66
Our account number : 42582811

Our membership is free but we do ask for a voluntary donation on joining. If you joined without a donation, please do consider sending us one to help us keep going.

TELEPHONE HELPLINES - 01342 316315 OR 01623 750330
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
Telephone helpline
Newsletters
Free membership