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Support Lorraine’s Leap of Love!

On 12th May, brave Scottish mother Lorraine Mathers will be diving out of a plane at 10,000ft to help raise funds for HPTH UK. Spurring her on will be the thought of her one year old son Reece who has hypoparathyroidism. Joining Lorraine will be Reece’s aunts Michelle Roberts and Claire Clark, and his uncle Thomas Muir. Quite a family affair!

If you’re near Strathallan Airfield, do go along to give them your support. They hope to raise £400 each for HPTH UK through this and a family fun night they held at the beginning of May. Good luck everyone - we’re rooting for you!!

Please sponsor Lorraine and her family on their Bmycharity page, here - www.bmycharity.com/laineyshell

Support Lorraine’s Leap of Love!
Dear Members and friends,

Welcome to you all. I don’t know where the year has gone so far but it’s going much too fast. There never seems to be enough time to fit in everything that we want to do but we have been busy, as always, raising awareness about parathyroid conditions, fundraising, supporting our members and getting involved in research wherever we can. Here’s a round up of what we’ve been up to:

World Awareness Day

Once again we will be joining with HPTH groups around the world to raise awareness about hypoparathyroidism. We are also collecting your stories to highlight the difficulties of living with idiopathic, genetic, congenital and autoimmune forms of hypoparathyroidism. If you would like to help raise awareness and contribute your story, you can use the form inside this newsletter. Please do help as these case histories ARE seen by doctors, students and researchers who visit our website looking for information and who are interested to find out more about our condition. We will also soon be selling awareness pins, badges and bracelets in the new website shop, thanks to the help of Jayne Jackson, a member from Stoke on Trent. Thanks, Jayne!

New Patient Information Leaflet

Now available to order by phone or email as a ready printed leaflet, or to download online here http://www.endocrinology.org/policy/docs/11-10_Hypoparathyroidism.pdf, this is the first patient information leaflet on Hypoparathyroidism. Please contact claire@hpth.org.uk for orders of this and our leaflet on hypoparathyroidism as well.

BES Conference

HPTH UK exhibited at the British Endocrine Society conference again in March along with other endocrine groups such as British Thyroid Foundation, Amend, Addison’s Disease Self Help Group and the Turner Syndrome Support Society, amongst others. It is always a wonderful opportunity to talk to endocrinologists about HPTH, listen to new research being presented in the lecture halls, read posters and to maintain links with other organisations so we are very grateful to the Society for Endocrinology for our free stand and passes. This year, the dynamic duo Mandy and Judith did a brilliant job at the stand and I was very sorry not to be there with them. Each year we ask a local member to get involved and were delighted to be joined by Harrogate resident and YouTube star Sharon Lovatt (see her video here http://www.youtube.com/user/HPTHUK1?feature=mhee), whose presence was much appreciated. And in case anyone thinks this is a jolly, I can assure you that it is an exhausting week and all three deserve huge thanks, especially as no one was in any way jolly, I can assure you that it is an exhausting week and all three deserve huge thanks, especially as no one was in

Rare Disease Day

This year, the event was held at Royal Holloway College, University of London, where we had a stand. Judith Taylor was ably assisted by new member Emma Thomas, on her first outing for HPTH UK but hopefully not her last - she was brilliant. Read her report inside.

Fundraising

The family of little Reece McMillan, aged 1, who was diagnosed with HPTH, have really gone all out to raise funds for HPTH UK. As well as organizing a pub crawl and two Family Fun Nights (at which they have already raised £1800) they are planning a skydive! Please do support them either by turning up on the day to cheer them on, or donating by cheque or via their Bmycharity page at www.bmycharity.com/laineyshell - or both! Thank you so much to you all – you’re very kind and very brave!

Other Money Matters

Good news! We started the year off in style with an award from the Society for Endocrinology, for which we are hugely grateful. This grant will be put towards a new patient information leaflet, setting up regional groups and our computer maintenance fund. This was followed by the long awaited news from the Inland Revenue who have now declared HPTH UK a charity for tax purposes. This means that we are now eligible for Gift Aid, so please do bear us in mind when you are planning a sponsored event. The HRMA have also backdated it for us so that we can claim Gift Aid on the money raised for us by Liam Sale in the London Marathon 2011.

Nationwide, government plans to cap tax relief on charitable donations led UK medical charities to warn that this could hinder their research activities by deterring wealthy individual donors from providing funding. While HPTH UK still awaits its wealthy donor (hello, anyone?), we are in agreement with other medical charities who oppose these plans, particularly in these difficult times when the impact would be compounded.

Benefits Update

We have started to write letters of support to the DWP about those members who are facing the ordeal of benefit reassessments, and this appears to be a helpful measure. We can back up the member’s claim by explaining what it is like to live with HPTH, how symptoms may be misunderstood, provide relevant research and, as we have often known the person for some time and supported them online, we can also submit evidence of their ongoing difficulties. With a rare condition, you need all the help you can get!

Facebook Moderator

Our private Facebook group is growing fast. Set up for UK members only, it attracts those who prefer the instant access of Facebook and helps people get to know each other. It’s also a good place to ask about local resources – hospitals, endocrinologists etc. It’s a lovely, friendly and supportive group and, between them, members have a lot of knowledge to offer. It’s a great place to post instant photos of fundraising events too – not to mention pictures of each other! I am very pleased to announce that I have now been able to put this group into the competent hands of member Gillian, who not only moderates the group very efficiently, but also keeps an eye on our information leaflet on Hyperparathyroidism. Please contact claire@hpth.org.uk for orders of this and our leaflet on hypoparathyroidism as well.

Committee News

The HPTH UK committee are delighted to welcome Emma Thomas on board this year. Emma has post surgical HPTH following an operation for Graves Disease in 1993. She is a nurse and has two children aged 10 and 12. Welcome, Emma, we look forward to working with you.

Thank you to everyone who so kindly supports us. I wish you all a very happy summer soaking up your vitamin D!

Liz Glenister
Director
liz@hpth.org.uk
Royal Holloway, University of London hosted a Rare Disease Day event this year, with a very varied programme of events and activities. The afternoon’s presentations were also streamed live online. Speakers included Prof George Dickson from Royal Holloway’s School of Biological Sciences presenting research into treatments for Muscular Dystrophy, and Diana Ribeiro from Action Duchenne, discussing patient and families perspectives on living with Duchenne. The keynote speaker was the inspirational Paralympic athlete Helene Raynsford, who suffers from a rare disease herself, Ehlers-Danlos Syndrome.

HPTH UK was lucky enough to exhibit at the event, and member Emma Thomas attended with Judith Taylor. Here is Emma’s experience of the day -

“Royal Holloway College is part of the University of London and is situated in Surrey. I live nearby, have had HPTH for 19 years following a thyroidectomy for Graves’ Disease, and I have a ‘medical background’ (I was studying nursing at UCH when I had my operation, but I left shortly after qualifying to convalesce), so that made me an ideal candidate to go along to the event and talk about what it’s like to live with HPTH.

Now, anyone close to me knows I LIKE TO TALK, but the prospect of this event almost made me mute! I didn’t know what to expect, and how would I feel discussing what I have learned to live with privately for all these years? Challenges frighten me - but challenges are what make me keep going...and so I went.

The Bio Science Department at the Royal Holloway College hosted the event, which not only included HPTH UK but about 10 other rare disease charities. The aim of the event was to provide information and raise awareness of rare diseases to students – both under and post graduate as well as other attendees. So, as I stood in the HPTH UK allocated area, it dawned on me that I felt a bit like a fraud standing there looking ‘very well and healthy’! You see, its my personal anchor to look ‘healthy’ – my mantra is if I look well, I convince myself I feel well. Actually, if my levels are good then I am good. However, there is also the other side of the coin - the days I can’t function well mentally or physically because my levels aren’t good, and I realised there and then that any one of these bioscience students may be the researchers of the future that provide HPTH patients the hope of a normal and healthy life. So, to work I went, using one of my best talents – the ability to TALK.

I educated those who had no idea what the condition was, and I addressed misconceptions - “but you look so well” being one of them! I am well, when my levels are good. I described what it is like to live with the condition, how it feels (hypers and hypos), the consequences, the frustrations and fears, and how it affects not only me and my life but also people who love and care about me. Don’t get me wrong, most of the time I am ok. Just ok that is - not fantastic. In fact, a lot of the time I struggle, and I don’t really want to acknowledge the number of enforced rests (duvet days) I have had to have, or the feeling that it’s held me back from achieving my full potential in life. And so I thought - maybe it was time I ditched the ‘front’ and came clean about just how hard it is at times to function and fulfil life’s commitments when you struggle with a long term, rare medical condition, which cannot be instantly corrected or controlled and depends on lifelong hospital based treatment.

I may have been a ‘drop in the ocean’ that day in our sea of change, but it made me realise that we aren’t alone, we have each other, and together we are strong. Like pillars we support each other, and together we make a voice which is heard and will make a change for the better of all those with HPTH and their families.

The saying goes “never judge a book by its cover”, and with rare medical conditions that are ‘hidden’ and not always apparent to the outside world this is so true. Education, awareness and research are the vital keys to improving treatment for those with HPTH and prevent future generations from having to live with this condition in the way that we have. With that in mind, I will always be happy to help Liz and HPTH UK spread the word and work for change.”

Emma Thomas
In March 2012, Judith Taylor, Sharon Lovatt and I (Mandy Mainland) had the pleasure of representing HPTH UK at The Society for Endocrinology British Endocrine Societies conference. This is the third time that we’ve exhibited, and this year it was held in Harrogate at the International Conference Centre.

Unfortunately Liz couldn’t attend this year due to ill health, and we missed her terribly, but it was wonderful to work with Judith again, and a great opportunity for Sharon and I to catch up, as we’d gotten to know each other well when we both participated in the PTH trial. Thank you both for all your time and hard work - and for keeping me going!

During the conference, we had an excellent opportunity to chat to endocrinologists from all over the world, and I had many interesting and enlightening discussions with them about the variance in prevalence and treatment in different countries. Several people took the time to have a long chat with us, and we really appreciated the interest they showed in HPTH UK. We were asked many questions regarding replacement PTH and when it may become widely available, and it was certainly a point of interest that I’d taken part in the trial. Many nurses came to see us at the stand too, and were very interested to learn more about what we do, and the help, information and support that we could offer their patients. It was very encouraging to be asked so many questions!

This year we were delighted to be able to offer the new Hyperparathyroidism leaflet which was recently produced by the Bone and Mineral Special Interest Group of the Society for Endocrinology, as well as the HPTH leaflet. You can download the Hyperparathyroidism leaflet from the SfE website - http://www.endocrinology.org/policy/docs/11-10_Hyperparathyroidism.pdf, and the Hypoparathyroidism leaflet from our website - http://hpth.org.uk/Files/File/hypoparathyroidism_leaflet_web.pdf

Thank you to our advisors who managed to make it round to the stand to see us, it was particularly lovely to finally meet Professor Thakker! A special thank you must also go to the lovely Dr Petros Perros, who took the time to chat to me on his way home on the train!

I’d like to thank the Society for Endocrinology for our place at the conference, and for looking after us wonderfully again. We’d love to see you all again next year.

Mandy Mainland
mandy@hpth.org.uk

Getting Disability Living Allowance as an HPTH patient should be straightforward for those who really need it but in fact it is no easy matter and is now set to become even harder.

The government’s own figures suggest that up to half a million people of the 3.2 million claimants could see their payments withdrawn altogether. And these are not huge payments. Many claims are unsuccessful, but the maximum benefit for someone on the highest level of care and mobility is £131.50 per week and the minimum is just over £20 per week. Many people use DLA to pay for mobility aids, travel costs or support that will enable them to work and DLA has one of the lowest fraudulent claim rates of any benefit.

DLA is being replaced with personal independence payment (PIP) assessments, to be managed by private companies set to make a small fortune from their disabled clients as 20% is slashed from the current rates. And who are the companies being shortlisted to deliver PIP’s? ATOS, currently responsible for the work capability assessments that many charities have called not ‘fit for purpose’ is one. SERCO, involved with nuclear arms and detention centres, is another along with G4S, security guards and Capita who run the Criminal Records Office for the Home Office.

Remember we have links and advice to help you on the website. Please note, if you are having a DLA medical at a medical examination centre, you can now ask to have them recorded for free in the same way that ESA claimants can.
Professor Simon Pearce answers some of your questions

**MEDICAL MATTERS**

**Is there a link between HPTH and adrenal problems?**

“Great question! Hypoparathyroidism occurring for the first time in childhood (but not in babies who are born with hypopara) is commonly associated with adrenal failure. In this case the 2 conditions are autoimmune in nature and this forms the two major problems of the autoimmune polyendocrinopathy type 1 syndrome (aka APECED syndrome- autoimmune polyendocrinopathy, candidiasis and ectodermal dystrophy). A typical age for onset of hypopara in this condition is 5 to 8 yrs old, but it can occur before then. The adrenal failure is really important to recognise, as it can be fatal, and symptoms include severe lethargy, unintentional weight loss, poor appetite, low blood pressure and dizziness on standing up, craving for salty food, and increased skin pigmentation. Adrenal failure tends to occur a few years after the hypopara (9-12 years), but the order of problems isn't always the same. The other typical feature of this condition is a tendency to get thrush infection in the mouth or elsewhere, as the immune system is messed up in a specific way. Give-away manifestations that can lead to an early diagnosis in some kids are poor tooth development with a lack of enamel (teeth look dull and slightly chalky rather than shiny), and also opaque or crinkly finger or toe nails, which on close examination may have little dots missing from the top surface like they were excavated with a pin. If there is any hint of this problem, kids need to be seen by a paediatric endocrinologist ASAP.”

**Many thanks to Professor Pearce for taking the time to answer some questions for us, it’s greatly appreciated.**

**SOMETHING ON YOUR MIND?**

If you have a question you’d like to ask Professor Pearce in the next issue, please email it to me by October 1st - mandy@hpth.org.uk

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I have Thyroid eye disease. Will calcium supplements make my eyes even more dry, or make TED worse?

“There will be no effect of calcium supplementation on your eyes. They shouldn't change at all.”

With HPTH, are there any routine scans and tests that we should be having? Eg kidney x-rays, bone scans etc?

“Bone scans are not generally worthwhile as most people with hypopara have excellent bone mineral density and don't appear to be at risk of osteoporosis. For people taking 'activated' vitamin D analogues (that is alfalcaldiol or calcitriol) I would recommend a kidney ultrasound scan every 3 to 5 years to make sure there is not build up of calcium in the kidneys, either in the form of kidney stones, or within the tissue of the kidney, known as nephrocalcinosis.”

What is the best diet to have to optimise calcium and levothyroxine absorption?

“There is no best diet, but you should separate the levothyroxine tablet from the calcium tablets by at least an hour. As hypopara symptoms are often worse in the evening (I don't fully understand why this is) I would take my levothyroxine on waking 30mins before breakfast, then take my calcium tablets with lunch and at bedtime. If you know you don't have any stomach acid (or are taking a tablet to stop stomach acid - most commonly omeprazole or lansoprazole) then the levothyroxine absorption can be improved by taking it with something acidic, such as orange juice or a vitamin C (ascorbic acid) tablet.”

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.
June 1st is World Hypoparathyroidism Awareness Day, and HPTH groups around the world will be joining together once again to raise awareness of HPTH. Last year we focused our publicity on post-surgical HPTH, and this year we are looking at the rarer idiopathic, genetic, autoimmune and congenital cases. Read Ben Love’s story below, and you can find more patient stories on our website shortly.

Ben’s Story - Familial Hypoparathyroidism

“I was found to have low calcium levels during tests from a work medical at the age of 31 but have never had any symptoms of this. Calcium tablets alone did not have any impact and after further tests and no real understanding from my GP I requested to be referred for private treatment with a specialist for hypoparathyroidism who happened to be Professor David Russell Jones. I started on alfacalcidol which initially had no impact. Despite levels recorded at 1.49 I remained asymptomatic throughout.

In the background our daughter had been unwell and had 12 seizures always with temperatures before the age of 2. After one such incident a calcium test was ordered and then we were able to make the link and Sophie was then also diagnosed with HPTH. She commenced calcitriol treatment which was successful and hence I also moved across to calcitriol. Levels for both us have remained unstable with Sophie having hypocalcaemic seizure type episodes and vomiting and loss of appetite when levels have gone to 3.3. I have only had symptoms on high calcium levels of itchiness, headache, loss of appetite and nausea. High levels for me have been 2.7 to 2.9. Treatment from Dr Mike Ryalls for Sophie and Prof Russell Jones has been excellent but we are often frustrated with the GP service and level of understanding in getting results.

During the time my calcium levels were low we were struggling to have a second child but saw no link at the time.

We were referred for IVF with the knowledge I had HPTH but consultants did not investigate my calcium levels. 3 failed cycles later we discovered some literature linking calcium with fertility and 3 months after my levels normalised we fell pregnant. We were not given any genetic counselling about the risks of another child having the condition and it now seems that Jessica has it too. She is on 2 drops of alfacalcidol and doing well though.

There is no prior family link of HPTH that has been discovered in either of my parents so it remains a mystery how I got it. We are waiting to see a geneticist to discuss. That’s pretty much our story!”

Ben, Heather, Sophie and Jessica

Ben Love

IF YOU’D LIKE TO HELP BY CONTRIBUTING YOUR STORY, YOU CAN USE THE FORM OVERLEAF TO HELP YOU GIVE US ALL THE RIGHT INFORMATION. THANKS!

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!
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
Gillian Adams is our new Facebook moderator. Welcome Gillian! Here is her story...

My Thyroid

In October of 2009, I was diagnosed as having Graves Disease. After about 2 years and a few conversations with my endocrinologist, we decided it was time to think about options other than Carbimazole. I reckoned that a thyroidectomy was the answer to my problems. Radioactive Iodine was not for me I had already decided, as having two teenagers, a seven year old, 2 dogs and a husband who works away for up to 3 months at a time on occasion, it was going to be too problematic trying to avoid having prolonged contact with them. Keeping one arm's length away from my seven year old would be almost impossible, as would not being able to sit in the same room as them for 11 days. Plus I already had mild Thyroid Eye Disease and radioactive iodine can make that worse. (I had already given up smoking because I was told that would make it worse, so I wasn't about to let something else affect it).

I was referred to the E.N.T surgeon at my hospital who, I was told, had performed a lot of thyroidectomies and that mine would be a nice easy one to remove. I had a meeting with him where we discussed why I wanted a thyroidectomy and hadn't opted for the radioactive iodine etc. He then started to tell me the risks involved in the surgery. He told me that there was a risk to my laryngeal nerve and that if it was damaged I may need a tracheotomy to breathe, but that he had only had to do this once in 11 years of performing this kind of surgery. He told me about my parathyroid glands attached to my thyroid and how they were very tiny and sometimes were damaged during surgery. That if they were, it would mean taking calcium tablets for the rest of my life. I listened to all this and said that, as I was going to have to take levothyroxine for the rest of my life anyway, another couple of tablets a day was no big deal. I just desperately wanted to feel normal again.

I was NOT told about tetany, muscle spasms, pins and needles, nausea, fatigue, leaden legs, chills, cotton wool brain, to name just a few of the problems that ARE associated with needing to take calcium. It was not explained to me that calcium does more than just make strong bones.

My surgery was performed in July 2011 and seemed to go quite well. My surgeon told me he had removed 1 of my parathyroids along with my thyroid, but that the other 3 appeared to be fine (That was the last I saw of my surgeon). All was going well, I had been told to let the nurses know if I started to feel any tingling in my hands, feet or mouth. I had no idea why, but when I started to feel it I let them know. The tingling eventually made its way to my face and I started to feel rather unwell and weird. This was during the night. They eventually gave me a drip of something, which made me shake uncontrollably and made me want to pee... A LOT!

I was discharged after 3 days and on leaving the hospital my calcium had gone from 2.00 to 2.17. All good. On the way home I felt pretty awful, but tried really hard to ignore it. I got home with my mum, made something to eat and all of a sudden the pins and needles were all over my face and my hands started cramping then my arms, feet and legs. I just collapsed onto a chair and told my mum to phone an ambulance. I was really concerned that if this was happening to my muscles it might start happening to my heart too! I didn't have a clue what to do. We got to A&E after the ambulance men pontificated about whether or not I was having a panic attack and hyperventilation was causing the cramping. Then in A&E I met the worst trainee Doctor, he was so arrogant and his bedside manner appalling. He kept asking me why I was holding my hands in a funny position and what was wrong with my mouth? Why was I talking like that? He got my bloods back and said they were a bit low (2.03) and he wanted to inject me with calcium. I didn't trust the guy at all so I refused until someone more senior could see me. I was admitted and ended up spending the best part of a week in hospital and I didn't get to see an endocrinologist until the day they were going to allow me to go home.

I am lucky that I haven't had as many severe symptoms as some people appear to have and I am very thankful for that! I'm getting used to the mild symptoms and learning to ignore them and just trying to live as normal a life as I can for my family. They know I get very tired and no one expects me to be happy and I refuse to let HPTH beat me.

MARY TO COMPETE AT LONDON OLYMPICS!

Many of you may remember reading about Mary Stack, the US powerlifter, in one of our earlier newsletters. Well, we’re delighted to let you know that Mary has just qualified for her 4th Paralympic Team and will be competing in London this August!

Congratulations from all of us at HPTH UK Mary, what an inspiration!

If you’d like to read Mary’s story, members can find all our previous newsletters on the HPTH UK website. Mary’s article was published in Issue 4 - Ed.
Well, I'm back to the real world!

My story starts back in October 2010 with really bad bone pain in my lower legs and I always felt very tired. I did think it was an age thing but only being 45 at that time how could it be?

So, off to the docs who took some blood and checked other medical things along the way. My test results came back with high levels of calcium - so what do you do? You Google ‘high calcium in blood’ and scare yourself! Bad move, but it's only human nature.

I was diagnosed with Hyperparathyroidism in the end, so off to hospital for more tests and scans which seemed to take ages, and I did think that different departments let themselves down by lack of communication. Bone scan was not a good result and I was told not to walk on uneven ground due to osteoporosis.

At this point I found HPTH UK, or should I say Mother Goose (Liz Glenister) found me on a Facebook site and pointed me in the right direction. More blood tests done, calcium level 3.15 PTH level 105. Ultrasound scan was booked and nuclear scan which I was not looking forward to but it was not that bad. Now on pain killers at this point Solpadol 30/500mg, which seemed to work at first but I ended up on Tramadol 50mg.

My quality of life had started to be compromised and all I wanted was my operation to remove the one parathyroid which had the benign tumour on. Wow, got the phone call and I'm in hospital on Friday 30th September 2011 - just get this thing out of my neck please! I was up, showered and dressed on Saturday morning with a dressing on my neck from the operation, wanting to go home.

It’s been 6 months since my op and I can now say that I'm feeling a lot better!

Thanks to my wife Cathy for putting up with me being very irritable and grouchy all the time while I was not well, and to Liz at HPTH UK who has been a big help in supporting me, and must not forget all my friends for being there when we needed you the most. What a journey it has been!

Love you all, Simon xxxxx
***RALLYING ROUND FOR REECE***

Well! What can I say?! I couldn’t even think about writing our Fundraising page without starting off by telling you about Lorraine Mathers and her amazing family, friends and her local community of Carluke in Scotland. What a busy few months they’ve had, raising so much money for HPTH UK. First things first, thank you all so much!

Lorraine’s 19month old son Reece was diagnosed with Hypoparathyroidism last November. She soon found HPTH UK on Facebook when she was searching for more information about his condition. Eager to help Reece in any way they could, Lorraine and her family set about finding ways to raise awareness and funds for HPTH UK, and what success (and fun!) they’ve had! They held a pyjama night in Glasgow, raising a fantastic £220. They wanted to do something even bigger though, and finally decided on a sponsored skydive!

The skydive will be taking place on Saturday 12th May at Strathallan Airfield, by Lorraine, Reece’s aunts Claire Clark and Michelle Roberts, and his uncle Thomas Muir. They are hoping to raise at least £400 each. While his other aunt, Lynn Mathers, will be keeping her feet firmly on the ground that day, she has also been incredibly busy helping to organise all these events. Their local newspaper ran an article about the skydive too, and shortly afterwards they received a £200 donation from a local slimming club who had read about their efforts! These lovely ladies invited Lorraine and Reece down to the church to receive the cheque in person.

This fabulous family have also recently held an amazing charity night in Carluke. They had a DJ, magic show and loads of great raffle prizes. Even Iggle Piggle and Upsy Daisy put in an appearance! It looked like a fantastic night was had by all, and they raised around £600 to boot!

HPTH UK would like to send you all our most heartfelt thanks for all the hard work you’ve put in, and dedication you’ve shown over the last few months. You’re absolute stars and we’re sending you all the luck in the world for your skydive - what a wonderful family, Reece is a very lucky boy!

**THREE CHEERS FOR TEAM REECE!!**

You can show your support for Team Reece by sponsoring them via their Bmycharity page - www.bmycharity.com/laineyshell

‘If you want happiness for an hour, take a nap. If you want happiness for a day, go fishing. If you want happiness for a year, inherit some money. If you want happiness for a lifetime, help somebody.’
- Chinese Proverb

HPTH UK has been registered as a charity for tax purposes, so please remember to claim Gift Aid whenever you can! You can also donate using PayPal via the button on our homepage.
**FUNDRAISING AND DONATIONS**

### HPTH UK Income Jan-April 2012

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<th>Monthly Bank Transfers</th>
<th>Amount</th>
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<tr>
<td>Susanna Knight</td>
<td>£20</td>
</tr>
<tr>
<td>MT Shaw</td>
<td>£20</td>
</tr>
<tr>
<td>JW</td>
<td>£20</td>
</tr>
<tr>
<td>Rosalind Marchant</td>
<td>£12</td>
</tr>
<tr>
<td>Bridget O’Connor</td>
<td>£8</td>
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<td><strong>Total</strong></td>
<td><strong>£116</strong></td>
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<table>
<thead>
<tr>
<th>Postal Donations</th>
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<tr>
<td>Ray Finlay</td>
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<tr>
<td>Chris Wray</td>
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<tr>
<td>Gillian Casson</td>
<td>£10</td>
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<tr>
<td>Ingrid Glenister</td>
<td>£14.50</td>
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<tr>
<td>Caroline Gould</td>
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<tr>
<td>L. McKettrick</td>
<td>£25</td>
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<tr>
<td>Peter Goodwin</td>
<td>£20</td>
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<tr>
<td>Mrs M Partridge</td>
<td>£10</td>
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<tr>
<td>Aileen Ander</td>
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<td><strong>Total</strong></td>
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<th>Fundraising</th>
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<td>Notts Thyroid Support Group</td>
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<td>Bmyhero</td>
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<td>City of London Corporation</td>
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<td><strong>Total</strong></td>
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<table>
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<th>Grants</th>
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<td>Society for Endocrinology</td>
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<td>Patient Support Grant</td>
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<td><strong>Total</strong></td>
<td><strong>£3652.36</strong></td>
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Our very grateful thanks go out to everyone for their generosity and kindness. We couldn’t do it without you.

**ploink!**

ploink! is a great new website, which offers you the chance to donate small amounts of money to charity, much like dropping your spare change into a collection tin in the street, or a piggy bank at home. It’s also our latest way for you to donate - why not give it a try?!

http://ploink.co.uk/charity/hypoparathyroidism-hpth-uk

Remember to raise money for HPTH UK every time you shop online by using www.easyfundraising.org.uk - simply go to the website and select Hypoparathyroidism (HPTH) UK as your chosen charity to earn up to 15% cashback from hundreds of major retailers!

**TELEPHONE HELPLINES**

01342 316315
OR
01623 750330

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.
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.

Website
Medical advisors
Online forum
Telephone helpline
Newsletters
Free membership

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

www.hpth.org.uk

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