

# Hypoparathyroidism UK

The UK's first HPTH website & forum

Registered members 136

Forum members: 138

Newsletter no.1

September 2006

**This newsletter aims to keep you informed about the work of HPTH UK and its campaign to raise awareness about Hypoparathyroidism , to bring you updates on any news, medication, research, relevant articles and case histories that may help you manage your own Hypoparathyroidism.**

## HPTH UK TEAM

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## MEDICAL ADVISORS

**Dr Denise Adams**, GP  
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**Dr Simon Pearce**, Senior Lecturer in Endocrinology/ Honorary Consultant physician

## Message from Liz



**Welcome to our first newsletter!** We're a bit late but we've been waiting to bring you some truly wonderful news that has just been released today! Thanks to the tireless work of Gudrun Ruth Vidarsdottir of Iceland, a new, full parathyroid hormone (hPTH 1-84) is soon to be produced and developed for the use of HPTH patients. This extraordinary news means that HPTH patients will no longer have to juggle vitamin D analogues and calcium supplements – like diabetics, we will have a full replacement for our own missing hormone. This is something we have long dreamed of but had never thought could happen so soon. Read more about this, and about Gudrun, in our Update.

At moments like this, it is an honour to be able to share such news with so many friends and to thank you all for your support. Many of you have helped to shape the identity of HPTH UK, to bring it to life and to make it to its first birthday – in particular, our 100 founder members whose support got us off the ground and our 135 forum members whose honesty and guts have built a whole new community. You are what HPTH UK is all about.

We wouldn't be here at all without the backing of the HPTH Association and the support of a small number of special people who donate their time and expertise: our team of doctors, especially Denise, my own GP Stephen Bellamy, our webmaster Ivor at Good Imprint Designs, Ian Yeeles at Abbott ,and many others who have taken an interest in our plight. To other HPTH groups, whose leaders also work tirelessly on your behalf, especially Gudrun, Helle and Raj and to all those who have helped HPTH UK take its first teetering steps in to the world I extend my heartfelt thanks.

The daily grind, however, is down to just three fantastic people, Judith, Tusti and Jan, who keep the forum - and me – going and work their socks off for the cause while coping with HPTH themselves. Huge thanks to them!

But, now that HPTH UK has grown so fast, we URGENTLY need help! Please read the 'How you can help' section and if you would like to contribute in some way, however small, we'd love to hear from you!

**If you have any comments please contact us on our new,shorter address.**

**Email:** [info@hpth.org.uk](mailto:info@hpth.org.uk) **Website:** [www.hpth.org.uk](http://www.hpth.org.uk)

# HPTH UK UPDATE

## A growing concern

If you have been a regular visitor to the forum you will, by now, have some idea of how fast we have grown. Total membership is now around 250 and we are Google UK's top listing for Hypoparathyroidism – not that there are many! As a sizable group we now have some visibility and this means that we have a greater potential to further understanding of our needs and to effect change.

## Publicity

Alongside establishing an online community in the UK, my aim this year has been to begin raising awareness about Hypoparathyroidism and related parathyroid conditions. As HPTH didn't then exist on any UK health sites ( except as definitions in netdoctor etc) or was frequently mistaken for Hypothyroidism when I enquired, we set about getting our name known in the medical world and creating mutual links to our website. Although this is a slow and ongoing process we are now recognized by the British Thyroid Foundation (Judith is currently editing their new leaflets which now includes a mention on HPTH ), the Endocrine Society ( from whom we may get a small grant) and Orphanet ( rare diseases) and other health sites and organizations, as a viable patient group which is representative of HPTH patients in the UK. Dr Adams has also approached the professional based British Thyroid Association on our behalf.

This all turned out to be quite timely as patient - led information has become an important part of current initiatives. Prodigy <http://www.prodigy.nhs.uk> is a new NHS resource of 'clinical knowledge that being created to help healthcare professionals and patients in managing the common conditions generally seen in primary and first-contact care'. Dipex <http://www.dipex.org> is an award winning resource which collects patient experiences and information for use by doctors and patients. While neither have immediate plans at present to include HPTH due to it's rarity they do now know that it exists and that we wish it to be included in the future. However, the new NHS Medicines Guide Project <http://www.medguides.medicines.org.uk> will shortly be reviewing all thyroid medicines and we are hoping to contribute to this in some way.

We are slowly writing our own **information leaflets\*** with the approval of our resident doctors and these will be posted on the site for you to download as they become available. We have also produced a **poster** for you to put up in your surgery or local endocrinology clinic to publicise the website for new patients (and doctors).

## Hypoparathyroidism Awareness Day

In conjunction with the Hypoparathyroidism Association and other groups around the world we have been working to establish January 5<sup>th</sup> ( the day that Halla Ruth Vidarsdottir in Iceland became the first child to be injected with Forteo, a synthetic parathyroid hormone replacement) as a worldwide Hypoparathyroidism Awareness Day. Hassan Fadhul has set up a website about this on <http://www.hassanfadhul.com/awareness/> I am happy to tell you that in the UK this day will shortly be on the Department of Health Events Calender for 2007 and we hope that you will do your bit for HPTH. **Please check the HPTH UK website nearer the time to see what you can to do help.**

## Campaigns

We are working on two main campaigns: treatment and treatment guidelines,

### **1) Treatment**

Regular blood testing is a necessity for many people with HPTH in order to manage their condition, but this need is not widely recognized and regular testing is not readily available. We want to get calcium home testers for those who need them. A home tester does exist but is expensive (£5000) and is only licensed for use by health care professionals. Tusti has been approaching laboratories to find out whether a simpler version could be made for us. However, because of the nature of calcium this is quite challenging - a diabetic type thumb prick is not workable and a strip test would be too inaccurate - but we haven't given up hope and nor have the labs.

Parathyroid hormone (PTH) which we are largely missing is now available in synthetic form (1-24) and is given by injection. (An oral PTH is apparently in the pipeline though that may yet be some way off.) It is known as Forteo. However, in the UK it is only licensed for use by patients with Osteoporosis and not HPTH. We have been campaigning along with our sister European groups for these drugs to be made rightfully available to HPTH patients. We are the only patients with a missing hormone who do not have hormone replacement therapy - even though it exists!

BUT - this week, as you have read, a complete version of the hormone (1-84) went on sale and is called Preotact. It is made by a company called NPS in America and is now awaiting approval by the FDA, which I understand is soon to happen. Then it's up to us to make sure that it becomes available here and is licensed for use in the UK *by HPTH patients*. HPTH UK will be working on that on your behalf.

This fantastic news has been made possible by the efforts of Gudrun Ruth Vidarsdottir, mother of Halla Ruth mentioned earlier, who was the first child to receive PTH in the world and whose website you may visit on <http://www.hallaruth.com/> If you would like a copy of the CD showing the moving story Gudrun's fight for her daughter's health please let us know.

### **2) Treatment Guidelines**

HPTH UK have been working in collaboration with Abbott Diagnostics who make the i-STAT calcium home tester to try and achieve, in the long term, both of these goals. We hope to set up a professional body to develop treatment guidelines for HPTH and through these to get recognition of the need for home testing as part of the management of the condition. Although this is a long term goal it could have far reaching results and is a wonderful opportunity for us to be actively involved in improving life for HPTH Patients.

Finally, to tie in with this, we will be having our first HPTH conference in the UK in 2008. Watch this space.

## Meet our Moderators

**Judith, Tusti and Jan** moderate the forum on a daily basis and do a truly brilliant job. Here they tell you their HPTH stories. I would also like to thank Alice here for all the work she did before she left.

### JUDITH



Liz has asked me to tell you a little about me. First, let me explain that I don't have hypoparathyroidism, although I have run the gauntlet several times. I was diagnosed with thyroid cancer and had two operations on my thyroid, one in 1965 (no that isn't a typo - I was 15 years old) and one in 1982. I was warned about the possibility of damage to my parathyroids, especially as both operations involved removing some of the surrounding lymph nodes as well, but although one parathyroid was removed and found at post-op biopsy, my blood calcium quickly returned to normal after each operation. Scroll forward another...18 years.

After months of misery I was diagnosed with Primary Hyperparathyroidism (PHPT). The main symptoms were fatigue, bone and joint pain, tendonitis, confusion, depression, memory loss, going to the loo excessively, and probably some other things I've forgotten right now. It turned out that I had osteoporosis and high blood pressure, both probably related. PHPT is caused by one or more enlarged parathyroid glands and I was recommended to have surgery to have it, or them, removed. My surgeon said he could make no guarantees about preserving my good parathyroids, because the scar tissue from the previous thyroid surgeries meant there was a high risk of damaging them permanently, but fortunately he managed to localise and remove the one "bad" one without any disruption. My memory, depression and concentration problems disappeared just like that, the blood pressure improved overnight, and within a year my bone density was back to normal for my age.

I am here because I have been very fortunate with my doctors, and would like to help the cause in getting high quality treatment for all; to help Liz, for whom I have a great respect for getting this forum and the website off the ground; and to help people with high calcium issues or with PHPT when this subject comes up - there is really no support group like this for people with PHPT, and although it is usually treatable, people going through it can still use support - I know I felt very lonely going through it and could have done with some buddies.

I was born in London but moved to Holland with my husband "for two years" over 30 years ago. We have two children. I work for a scientific and medical publishing company and have been involved at various times in publishing journals and books on bone biology and metabolism, so I know my way around the main scientific literature databases.

## TUSTI



Dear All HPTH Friends

This is Tusti, one of the HPTH UK forum moderators.

I'd just like to share a few words with you all about how I developed HPTH.

I became a vegan about 9 years ago but failed to research the vegan diet thoroughly and developed iodine deficiency goitres. This means my thyroids swelled up. I did not have a thyroid condition as such – just the fact that the outer casing of the thyroids were swollen.

My doctors at the time knew I had the goitres but did not put 2 and 2 together and suggest I ingest iodine even though, I have since learnt, that there is a proven link between iodine deficiency, goiters and veganism.

I was eventually referred to a Consultant General Surgeon once the swelling became obstructive to my breathing and I had a 5 minute appointment with him where he took a “let’s whip ‘em out” (meaning my thyroids) approach to the whole thing telling me that I would just have to take a little pill for the rest of my life and would be back to work within 6-8 weeks. He made it sound as if it was no more trouble than having tonsils out.

Within days of surgery I knew something was terribly wrong with me. Bottom line is (without boring you all with the ins and outs of the whole sorry saga!) the Surgeon killed all 4 parathyroids during that surgery and I now have 0.00 something parathyroid function. He did not tell me this though as from his side, only 1 parathyroid was damaged and retransplanted during surgery. It took 3 and a half years after that to get the diagnosis and proper treatment during which time I lost my job, home and was sent to every debt collector in the book.

Tough times but thanks to Liz and you all at HPTH UK, I know there *IS* life after HPTH and am beginning to get a handle on how to actually have a life. Until I found out what was actually wrong with me and also found our wonderful website 11 months ago, I was lost in an abyss of helplessness and hopelessness. But no more. I urge anyone who is struggling to cope with this debilitating condition to keep close to the HPTH UK Forum and share how you feel – often. We may not always be able to give you immediate help (as often we are too ill to come on-line) and definitely no quick fixes (!! ) but when and where we can help, we will do our utmost to.

Hoping to meet present day and newcomers to the Forum soon!!

Big Hug,  
Tusti XXX



I moved to Portugal in March 2004. My UK GP agreed to keep me supplied with my medicines from the UK. It has always been impressed on me how problematic it is swapping drugs. Over the years I have been given different drugs in economy drives by the pharmacy-----the results were always chaotic. This system worked well for a while, I returned to the UK every three months. I still have a house in the UK and my GP continued to support me.

However, the winter of 2006 became quite a challenge. I ran consistent very low calcium levels, I felt desperately ill for the whole of the winter. This, in turn, prevented me from travelling to the UK to collect more drugs. My Mum managed to get one repeat prescription and sent me some meds out. But, the situation was becoming difficult. I felt so ill, I had not seen an endocrinologist since November 2003, I had been told there were none in the Algarve. I had also been told by various pharmacies that it was impossible to buy my AlphaCalcidol and AdCal in Portugal as they were not used here. No one could give me an answer and I was getting very tired and worried by it all.

I have a GP here in Portugal who works in the Algarve for six months and then returns to his home in South Africa for the winter months. He returned here in April----I went for my weekly blood test with him and on reading my results since he had seen me last he was horrified. He could not work out how I had coped for the six months since he left. I told him the story of no endocrinologists in the area----his comment was to leave it with him as something HAD to be done. Amazingly, within 24 hours he had found me an Endocrinologist in Lisbon who was willing to travel to the Algarve for an appointment with me within a couple of days. The appointment was made at the main private hospital. The appointment cost me £60, which amazed me as Lisbon is 3 hours away!!!

The Endocrinologist was very helpful, spoke English very well. He advised me to change to the meds used here and advised how to change over, ie monitoring with blood tests. The meds recommended were Calcitab D and Rocaltrol.

I have to admit it took me until June to pluck up the courage to change. I cleared my calendar, had a blood test and took a deep breathe. My Husband had already checked out the drugs in depth on line and had discovered that the Rocaltrol worked in a different way to the Alpha Calcidol---it works on two organs not three so would work quicker. The first month was very difficult. I swung from very high to very low, very quickly, then back again to high it was a rollercoaster. I was glad I was not doing anything as I couldn't. I spent my time on the sun bed with a book feeling very sorry for myself. I slowly managed to balance the drugs out. At the end of the month people were telling me I looked better than I had for months, I did, indeed feel better than during the winter.

Now in September 2006 I am only taking 3 x Rocaltrol and 4 x Calcitab per day. That is half the amount I was taking of the old tablets. I cannot say I feel wonderful because I don't, but I do feel better than I did. I manage to do more now than I could six months ago which must have some bearing on the changed meds. We all know there is no answer to this 'condition', we just have to find a way of living with it and making the most of each morning that we wake up. I have the reassurance that I can get these drugs at the pharmacy here BUT the down point being I am paying for them. In the UK I had an exemption from paying for drugs, here in Portugal I do not. I am entitled to any benefits a Portuguese person with HPTH would get-----they do not get free drugs, so I do not. I take a large number of drugs per day and I have to pay for them all, I have to pay for my blood tests. We do not have an income as we retired out here so this does concern me.

I was very frightened of the medical side of our move down here, I am still paranoid about being sent to a state Hospital even though I am constantly reassured they are fine. I wear a Medic Alert which is reassuring. I have found that by using the International Medical Centre out here I have coped very well. I get instant treatment, yes I pay but they are very good to me and I only pay for a blood test, not a consultation, the blood test is €5 which is about £3. Here you pay for a blood test if you are a 'normal' person in the state system, about €5 so no different really.

Generally my health has been better since moving here, main reason being we see that sun more, extra VitD. In the UK I took 50 pills a day to keep a 2.1 calcium reading. Here I m taking 7 pills for the same reading. That makes life a little easier. As I have said previously, I am living within the condition. I would love to be fit but I am grateful to be alive!!

Love and cyberhugs to everyone. Please email me if you need any help at all.

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**Note re forum fraud:** We have been pestered these last few months by a forum fraud who was banned because of her aggressiveness towards other members. This person has now persisted in visiting the forum (and all the other HPTH forums) under 6 different incarnations so we have now changed the membership registration as a result. From now on, the forum will only be accessible as a service to full members of HPTH UK. Only when registration has been approved will forum accounts be activated. If you have been put off entering the forum for this reason I do apologise and would like to reassure you that the forum is now a safe haven again.

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## Letter from James Sanders for HPTH UK

(President of the Hypoparathyroidism Association, our parent organization.)

This is part of a speech given by James at the recent HPTH conference in Maryland, USA

A little over twelve years ago I had a dream of an organization of Hypoparathyroidism patients. After bouncing the dream around in my head for a few months, I put together a list of all the medical colleges in the United States, held my family members captive, added a few fellow patients I had met through Dr. Karen Winer's protocol at NIH and published a four-page newsletter. It was the first issue of a newsletter which has been published every quarter since August 1994. Since that humble beginning, we have published 47 issues of the Hypoparathyroidism Newsletter, which is the official voice of the Hypoparathyroidism Association, Inc. In 1998, we organized as a non-profit corporation in the State of Idaho and at the end of that year we were officially recognized as a tax-exempt corporation by the Internal Revenue Service as tax-exempt under Title 501.3(c) of the IRS code.

Growth in the early years was slow, and we eventually grew to 1000 members, then 2000 members, and finally the 2161 members in 59 countries as of March 31, 2006. We have, I am told, the largest association of patients diagnosed with Hypoparathyroidism in the world. Until a couple of years ago we were the only such Association in the world. At that time Frauke Sieger, from Germany, organized InSenSu as an association for Hypoparathyroidism patients in Germany. Our organization has expanded to include the Washington Chapter, which covers the Pacific Northwest; the Idaho Chapter, which covers the Intermountain West; and the Indiana Chapter, which covers the Midwest. The Indiana Chapter has its own web site. Internationally, we have a branch for our 252 members in the United Kingdom and one for our 6 members in Norway. Both of these chapters have their own web site. A Google Search came up with 333,000 references to Hypoparathyroidism. Among the top five listings in Google were our web site and the web site for the United Kingdom branch.

What do these numbers mean? I believe it essentially means that patients who have been diagnosed with Hypoparathyroidism no longer need to feel they are all alone. More importantly, it also means that physicians have what I feel is a reliable source of credible information about Hypoparathyroidism. They can find a myriad of reference material on our web sites about how their patients can be managed. Our goal has always been described in our Mission Statement, which states: "The Hypoparathyroidism Association, Inc. is a voluntary, non-profit organization, dedicated to improving the lives of people with all forms of Hypoparathyroidism, a rare medical disorder, by maintaining a worldwide network of family support, and promoting public, as well as professional, awareness of this disorder through a quarterly newsletter and our Web Site." In retrospect, I feel we have met the goal and mission of our Association. In view of our growth, and what we have accomplished up to now, the Board of Directors may have to reconsider our Mission Statement, as we look ahead to the next twelve years, what we will be involved in, and the challenges we are sure to face.

When I look back on the past twelve years I realize while I may have been the driving force behind this Association there are 2199 (as of May 6, 2006) members who make up the Association. They are the ones who have made everything possible; they are

the ones who are truly important and the ones who have made a difference. Hassan Fadhul a young engineering student from the country of Bahrain in the Middle East. He had to put his studies on hold because it became necessary for him to spend several hours in the hospital every day in order to receive calcium supplements by IV. On January 2, 2006, he became the first person in Bahrain, and the Middle East to receive FORTEO, as a treatment for the Hypoparathyroidism. After several days on FORTEO he commented; "I love FORTEO. I feel great and I have gained weight!" Roger Evans is a few years older than Hassan is, is from Denver. He too was a medical mystery until he found out he had an extremely rare diagnosis of Adult DiGeorge Syndrome. Incidentally he was apparently born with Hypoparathyroidism but was not diagnosed until he was an adult. He is waiting for a transplantation of parathyroid glands, which, is hoped, will allow him to recover from the medical problems he has had to deal with all of his adult life. This will be a radical departure from conventional treatment, even beyond the use of FORTEO. Each of the patients I have described has exhibited an intelligence and wisdom I personally envy. Roger and Hassan are very knowledgeable about their medical condition and are able to converse with their physicians on their level, and work closely with them in managing their medical care.

Across the Atlantic Ocean, Raj Tiwary set up a separate Yahoo forum for Hypoparathyroidism and manages the day-to-day activity of this active group. Even though he is sick and not able to work because the problems he has experienced with Hypoparathyroidism, he still takes the time to provide intelligent insight and information to many of the questions which are brought up in the group.

Helle Jensen from Norway and Elizabeth Glenister in the UK took it upon themselves to organize branches in their respective countries. We support them, and applaud them for their concern and their hard work to provide a voice for Hypoparathyroidism to their countrymen. I should point out again that before the summer of 1994, there was no Hypoparathyroidism Newsletter, there was no Yahoo Group for Hypoparathyroidism, there was no Hypoparathyroidism Association, and there were no chapters in the United States, the United Kingdom, Norway or Germany. I may have had a small part in pushing the boulder to get it rolling, but it was Roger, Hassan, Elizabeth, Helle, and hundreds of others who kept it rolling down the hill gathering speed as it moved ahead. It is going to be the thousands of Hypoparathyroidism patients around the world we have not met yet who will maintain the momentum and carry us into the future.

What is our future? Several years ago I felt our future was with a belt-pack with a built-in computer which would constantly monitor our calcium level in the blood serum and deliver exactly the right amount of medication when it is needed. Today that dream still exists, and could become the best answer for many of us. For some the answer lies in the auto transplantation of parathyroid glands. Those patients will be the pioneers of modern medicine in the future just as heart transplant patients were the medical pioneers of the past. For others, the answer may be the use of synthetic human parathyroid, which was pioneered and proven by Dr. Karen Winer in her protocols at the National Institutes of Health in the 1990's, but was hijacked by Eli Lilly for the treatment of osteoporosis, a much more popular and profitable medical problem. For most of us, however, the answer will be with the traditional treatment of the past; Ergocalciferol, Calcitriol and other medications designed to make up for the lack of the vitamin-D we need in order to absorb calcium. The danger here is the increased risk of potential damage to our kidneys over a long period of treatment, which will last for the rest of our lives. Since there is no cure, and because it is little understood by the majority of the medical community called upon to take care of our

needs, it is imperative we work with the medical community to help educate the physicians who will be called upon to take care of our needs in the future.

As the largest association of patients diagnosed with Hypoparathyroidism in the world, we can and will work with the medical community in the future. We will support medical research designed to increase understanding of the effect the disorder has had on our lives and by working with the medical community to develop more effective methods of treating the disorder that do not have the risks associated with today's methods. Columbia University College of Physicians and Surgeons is a good example of a current research project supported by many of our members.

I would be amiss if I did not acknowledge everyone who has made this journey possible.

The J.W. and Ida Jameson Foundation of California stepped up to the plate in 2000 with a generous contribution to our work. Their continued financial support has made everything I have been talking about possible, and without that support our organization would number in the hundreds instead and we would not be having this meeting in Maryland this weekend.

Todd Clegg, our web site programmer, has spent many hours working on our web site, making it the professional looking site it is today. It has become and will remain our primary point of contact with the world of Hypoparathyroidism. It can be used by laypersons and professionals as a source of reliable and credible information about this little understood medical disorder.

Ruth Vidarsdottir and her daughters, Halla Ruth and Silja took it upon themselves to get the Rockville, Maryland conference on the road. Without their push the conference in April would never had happened.

Most of all I would like to thank my wife for putting up with me all these years. In addition to working long hours over sixty miles in the desert nearly every day, she has put up with all the work I have done for the Association. Some would say it would have made my life easier, had I decided it was enough for me just to know my five sons, and my younger brother who have all been diagnosed with Hypoparathyroidism.

If I had taken that road I would never have know Halla Ruth, Ruth, Roger, Hassan, and the countless others who have become "My warrior heroes." For that I thank you. I thank each of you for making my life richer and more fulfilling than it would have been otherwise. Thank you for being a part of this marvelous journey. Thank you for being part of this growing world wide Association, linked together by a rare medical disorder..

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**\*The [letter](#) which follows has been approved by Dr Adams and is for those of you who wish to explain to your GP ways in which you could manage your HPTH together and is to be used in conjunction with her own letter that you will find on the website.**

**The [poster](#) which follows that is also for you to download but we are asking each of you to put one up in your surgery or clinic to help publicise HPTH UK for new patients (and doctors) (Poster design by Alice)**

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## Treating Hypocalcaemia

### Advice for patients and doctors

Hypoparathyroidism UK is an information website and patient support group affiliated to the Hypoparathyroidism Association, a registered charity. We have produced this leaflet to help doctors and their patients with Hypoparathyroidism who are working together to find a viable treatment. Attached is advice from our resident GP, Dr Denise Adams, who herself had HPTH.

Hypoparathyroidism (HPTH) is a rare condition which occurs where there are inadequate or ineffective levels of parathyroid hormone and may be due either to a congenital disorder or as a direct result of thyroid or parathyroid surgery.

- Dealing with a rare condition is often difficult for both doctor and patient particularly as individuals with HPTH may experience many different symptoms. Often a patient will be more informed about a rare condition than the doctor but this should not be interpreted negatively by either party. With HPTH, it is important to be able to work together, so that appropriate treatment may be found for what may be a very individual set of symptoms. Reaching a diagnosis may take time and learning how to manage medication once diagnosed can be very demanding so patience and tolerance is needed on both sides.

While many patients with HPTH have few problems on medication others experience continually unstable calcium levels due to hypocalcaemia.

- We have found that many of our members, particularly those who had neck surgery, experience dramatic hypocalcaemia and hypercalcaemia despite taking a regular dose of medication. It is not understood why this happens (although factors such as infections, other medication, oestrogen, exercise, dehydration, absorption problems, stress and diet can all have an effect.) It is very distressing for the patient and has a detrimental effect on their quality of life; some people become housebound as hypocalcaemic episodes can be so unpredictable and so devastating to cope with.
- Symptoms of hypocalcaemia range from the mild (tingling, muscle twitches, numbness, blurred vision and head sensations, irritability and sensory distortion to the very unpleasant inner vibrating stage through to a full blown tetany which includes severe dizziness and disorientation, severe muscle spasms affecting the whole body, inability to communicate clearly, feeling cold, severe anxiety and eventually seizure. This can come on slowly or happen very suddenly within ten minutes.
- Symptoms of hypercalcaemia include a gradual fatigue, heat, thirst, heaviness of limbs, hip and bone pain and nausea through to a severe headache, vomiting and inability to stay awake. This is often harder to recognize at first and may take longer to resolve.

Because of the unpredictability and speed of onset, patients need to learn to recognise their symptoms in order to manage their own condition as far as possible.

- We have found that monitoring symptoms carefully, perhaps with a diary, can help the patient identify whether their symptoms are those of high or low calcium. This, in turn, means that the patient can then self medicate to keep as stable as possible.
- Self medication should always be carried out with a doctors guidance. It is important to know that different people will experience different symptoms at the same levels - this is an extremely individual condition.
- It is unusual to need to take or drop more than 1 extra calcium tablet but taking such action at the onset of symptoms can prevent a hypocalcaemic or hypercalcaemic episode from developing.
- Sometimes no extra calcium is required but all that is needed is to spread the dose evenly over the day. At other times it may be sufficient to take more of the day's dose at the onset of an attack without actually needing to take any extra.

However well a patient learns to recognize their symptoms, self - medicating is not possible, or safe, with out regular blood tests and their doctor's guidance.

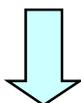
- Most patients experiencing these swings can, in time, estimate quite accurately their own calcium level . However, this is not always possible - it can very difficult to distinguish what is going on at times- or desirable as a mistake could be dangerous and no patient should feel that they are being left alone to deal with this difficult and frightening condition. It is therefore essential that their doctor provides a back up service in the form of regular blood tests to help the patient confirm their suspicions that their calcium may be rising or falling. This will help the patient adjust the dose more accurately and also gives the doctor a clear picture over time of what is happening.
- Ideally, blood tests would be carried out with home testers but until this becomes possible, surgeries are best placed to assist the patient. In an increasing number of surgeries, arrangements are made with the practice nurses to take blood from the patient when necessary, usually 2 or 3 times a week in urgent cases and to call the lab to ensure an urgent same day result. This means the patient can call the surgery for the result and then adjust their dose safely. This procedure has helped to prevent the need for A&E visits and urgent IV treatment for hypocalcaemia which occur where the patient has not been monitoring their condition in this way.
- Finally, when reading blood test results it is most important to know that patients *can* and *do* experience symptoms within the normal range.

We hope you find this helpful. If you have any comments please contact : Hypoparathyroidism UK [www.hypoparathyroidism.org.uk](http://www.hypoparathyroidism.org.uk) or email [info@hpth.org.uk](mailto:info@hpth.org.uk)

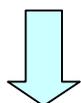
# Hypoparathyroidism



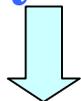
**Have you had thyroid  
or neck surgery?**



**Are symptoms of low calcium a problem?**



**Do you have Hypoparathyroidism or a  
related parathyroid condition?**



**Are you looking for information  
and support?**

**[www.hpth.org.uk](http://www.hpth.org.uk)**

**Visit our free online service offering:**

- ◆ **Help in managing a rare disorder**
- ◆ **Friendly & helpful online support**
- ◆ **Advice from our panel of doctors**
- ◆ **Latest research and medicines**
- ◆ **Newsletter , leaflets & welcome pack**

# AND FINALLY.....

## How You Can Help

As we are such a small team we are grateful for any support you can manage. Maybe you have professional skills you could offer? Or just a spare hour here and there? We need help with the website, research, design, publicity, fundraising and sponsorship, organizing a conference, becoming a non profit organization and the forum. We would be very happy to hear from you with any ideas you may have too.

Are there ways we could improve this service? Please let us know – we would appreciate your views and comments.

**We are also starting to accept donations which may be made payable to HPTH UK and sent to HPTH UK c/o EJ Glenister at 6 The Meads, East Grinstead, West Sussex, RH19 4DF.**

I hope you have found this newsletter useful

Best wishes to you all

Liz

