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World Awareness Day 2011

Together we can make a difference. HPTH organisations in America, Norway, Germany, Bahrain and Australia are joining together with HPTH UK for the first time to celebrate WORLD Hypoparathyroidism Awareness Day on June 1st. How the HPTH support network is growing! We are especially pleased to welcome the newest group, HPTH Australia, fittingly established by Sharon Bassell on Rare Disease Day. This new date has been chosen to tie in with the annual HPTH conference which is held in America annually during this week and to which you are all invited.

Inside this issue you can read articles from James Sanders, Halla Ruth Vidarsdottir and others about what Awareness Day means and why raising awareness about Hypoparathyroidism is so important.

Here in the UK, our focus this year is on surgery, so to mark Awareness Day we have chosen to highlight the stories of patients with post surgical Hypoparathyroidism - read their interviews on pages 8-10.

Tell us your story!
We invite you to become part of our awareness raising collection of YouTube video stories - simply go to YouTube and make a video telling us your story. Then send us the link so we can put it on the website and on our new HPTH UK YouTube channel.

Watch the first video stories here http://www.youtube.com/user/HPTHUK1

If you prefer, you can add your own story to our online forum board called ‘Our stories’ or fill in the questionnaire inside this newsletter and post it back. We hope that many of you will join us in this project to let the world know about Hypoparathyroidism.

Liz Glenister
Director
liz@hpth.org.uk
Dear members and friends,

Welcome to the 6th issue of HPTH UK News, a special Awareness edition which I hope you will find interesting. HPTH UK is a small charity with a big heart – you. It is for you and about you. You are at the centre of everything we do here and the focus of all our activities whether we are campaigning for recognition, seeking funds to keep going, raising awareness about your needs at conferences, or helping you sort out your levels on the forum. You are what it’s all about it, and we need to make sure that your views are properly represented. To do this we need your feedback. Are we getting it right? Do get in touch and let us know what you think and if you have any opinions, questions, comments or suggestions about what we are doing, we’d love to hear from you.

Focus on Surgery

This year our focus is on surgery and we will be using Awareness Day to highlight the potential dangers of neck surgery and to promote new research into safer methods of surgery. We are currently talking to BAETS (the British Association of Endocrine and Thyroid Surgeons) and hope to raise awareness amongst surgeons about Hypoparathyroidism. We were invited to comment on research being undertaken by the University of Sheffield into thyroid and parathyroid surgery and we shall also be attending the International Multidisciplinary Thyroid & Parathyroid Meeting at the Royal College of Surgeons in London in June. Inside this issue you can read interviews with some of our members with post surgical Hypoparathyroidism.

Rare Disease Day

Mandy went to the Scottish Parliament and Judith was at the House of Commons in London to attend the annual Rare Disease Day events. More inside.

PTH 1-84 Clinical Trial

The NPS “REPLACE” clinical trial on the use of PTH 1-84 as a treatment for Hypoparathyroidism has almost ended and the last two patients will finish in July. We are indebted to all the HPTH UK members who so generously volunteered to take part and, in doing so, made such a valuable contribution to the future treatment of all HPTH patients. Our grateful thanks also go to Professor Bill Fraser who so kindly agreed to take on and run the trial for us in Liverpool, to research nurse Ya-Wen Jessica Huang for her support and to Dr Brian Shine in Oxford who helped to get the ball rolling. We will let you know the results as soon as we hear them.

Membership

Our admin & membership officer, Claire Sale, has been working hard analysing our database and is in the process of providing us with some interesting figures. So far we know that around 30% of our membership has post surgical hypoparathyroidism. We now have over 750 members and are growing steadily. The forum continues to be an important place for members to come and talk to each other, let off steam, get advice, discuss problems and learn how to manage their calcium levels. It is a great way to get to know new members. Our Facebook groups are thriving and we currently have 389 in our worldwide group and 76 in our UK group which we use to circulate news of local events and get to know each other with photos which our forum can’t support. We have also helped to setup HPTH Australia with Sharon Bassell which uses our forum and also has its own Facebook page.

Conference

In April, I attended the British Endocrine conference in Birmingham with other committee members Judith, Mandy, Bridget and Bill. This was the first time we had all met together as we communicate from all around the country online (HPTH UK had been entirely set up, built and run in this way) and so our very first committee meeting was quite an emotional one. Read about our week inside.

Fundraising

To help us continue the work we are doing to support patients with all types of parathyroid conditions, as well as post surgical Hypoparathyroidism, we were delighted to be represented at the London Marathon in April this year as our main fundraising event for 2011. Liam Sale ran his first full marathon on behalf of HPTH UK and the Willow Foundation and you can read his story inside. Thank you so much to everyone who donated and supported Liam in this fantastic undertaking and huge thanks to Liam himself. It meant a great deal to us, Liam.

Thank you to everyone – patients, families, friends and professionals - who so kindly continue to support us. I wish you all a very happy summer soaking up your vitamin D!

Liz Glenister
Director
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USA

The HPTH Association will be holding it’s 5th International Patient Conference in Maryland, USA on June 2nd-4th 2011. There is a full schedule of talks by doctors on subjects such as ‘The effects of HPTH on the kidneys’, ‘HPTH in children’, a review of ‘current clinical research in HPTH’ from NPS Pharmaceuticals, and much more. All are welcome to attend, and further details may be found on their website here http://www.hpth.org/support-services/conference

Australia

HPTH UK has been working with Sharon Bassell to help her set up the newest group to join the Association – HPTH Australia. Sharon is a Clinical Nurse Consultant in Medical / Rehabilitation and has post surgical HPTH herself. The group was fittingly launched – as a Facebook page for now – on Rare Disease Day. Welcome Australia!

Germany

Last November, Frauke Sieger, the Director of the German HPTH group called InSeNSU (www.insensu.de) presented this abstract to 120 endocrine surgeons in Osnabück and it is now printed in Langenbeck’s Archives of Surgery.: http://kongress.porstmann-kongresse.de/caek2010/ pro/index.asp?site=abstractview&CID=6&lan=c The German surgeons discussed how to prevent postoperative Hypoparathyroidism and they really seem to have understood how much HPTH patients suffer. Frauke says that InSeNSU were ‘glad about them caring’. In March, InSeNSU attended the annual meeting of endocrinologists in Hamburg.

Thyroid Cancer Alliance

HPTH UK has just become a member of the newly formed Thyroid Cancer Alliance which had it’s inception in Toronto in 2009 at the International Thyroid Cancer Congress. Kate Farnell of the Butterfly Thyroid Cancer Trust is its President. She writes: ‘Leaders of eight well respected Thyroid Cancer Support organisations from South America, USA, Canada, France, Germany, The Netherlands and the UK met to discuss how working together could improve things for our patient cancer group worldwide. Our first joint project was the first ever International Thyroid Cancer Patient Survey in which your members took part! This work was the result of twelve months work and culminated in our being invited to present the results to 850 Thyroid Cancer clinicians at the International Thyroid Congress in Paris, September 2010. This was a first for TC patients to be heard on this scale! The presentation was huge success and has lead to much discussion amongst the medical community about the need for change. It has also facilitated the extension of other invitations to share our experiences with the clinicians and an invitation to be part of the advisory panel on the latest clinical trial on Thyroid Cancer in the UK. Furthermore we hope to have our results published in a Medical Journal soon. TCA is dedicated to working together towards providing support, information and encouragement to those affected by the disease throughout the world.’ The first AGM is to be held in New York in October 2011 and HPTH UK hope to send a representative to take part.

Thyroid Cancer Support UK

Set up by Liz Glenister and Ruth Pink in May 2005, this yahoo group is for people who are affected by thyroid cancer, to support and encourage each other and to share experiences. Judith Taylor and others now moderate. http://uk.groups.yahoo.com/group/thyroidcancersupportuk

RARE DISEASE DAY 2011

WESTMINSTER RECEPTION 28TH FEBRUARY

I was privileged to attend a reception in Westminster on Monday, 28 February to mark Rare Disease Day, along with over 150 delegates from a wide range of patient support and advocacy organisations, healthcare and industry. Around 25 MPs and peers attended.

The purpose of Rare Disease Day is to raise awareness, both among policy makers and the general public; to call for rare diseases to be seen collectively as a health priority; and to provide a voice for people with rare diseases and their families.

Among the things that rare diseases often have in common are that they are challenging to diagnose, and it is equally challenging to find support and information from people with similar problems. Jayne Hughes, mother of Amy and founder of Amy and Friends, a support group for Cockayne syndrome, spoke of her challenging experience getting a diagnosis for Amy. It took over ten years and Amy was only finally diagnosed when they attended a Cockayne syndrome conference in the United States at the invitation of a doctor in Boston who had read about Amy’s symptoms. On her return home to the UK, Jayne set up Amy and Friends and has now made contact with over 100 families.

Earl Howe, the Parliamentary Under-Secretary of State for Quality at the Department of Health, and the Shadow Health Minister, Liz Kendall MP, both spoke at the event, which was hosted by Julian Huppart, the Liberal Democrat MP for Cambridge.

The Chair of Rare Disease UK, Alastair Kent, OBE, presented Earl Howe with a new report published to coincide with Rare Disease Day entitled Improving Lives, Optimising Resources: A Vision for the UK Rare Disease Strategy. He said: ‘Many people living with rare diseases and their families have to go through years of medical tests and procedures before an accurate diagnosis can be made.

‘The results of this survey hammer home the need for a coordinated UK-wide strategy for the diagnosis, treatment and research of rare diseases.

‘This is a hugely important issue that needs to be tackled; patients and families should not have to face an inequitable level of care from the NHS because they have the misfortune of their condition being rare’ he said.

Rare Disease UK is a joint initiative of Genetic Alliance UK (over 130 patient organisations supporting those with genetic disorders) and other organisations.

Judith Taylor
Public Affairs Officer
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28th February 2011 marked the 4th annual Rare Disease Day, and Rare Disease UK held parliamentary receptions throughout the UK in Scotland, England, Ireland and Wales. HPTH UK was represented at the Scottish and English events, by Mandy Mainland and Judith Taylor respectively.

This year’s theme was ‘Rare but Equal’, focusing on the issue of rare disease patients having the same right to services and information as those with more common conditions, and highlighting areas within the healthcare system that could be improved upon for rare disease patients.

The reception held at The Scottish Parliament was hosted by Jackie Baillie MSP, Shadow Cabinet Secretary for Health and Wellbeing. Ms Baillie gave an opening speech, welcoming everyone and thanking them for attending. She showed surprise at the number of people affected by rare diseases - over 300,000 in Scotland alone, and 1 in 17 people across the UK as a whole will be affected at some point in their lives...not so rare at all! Rare Disease UK launched their report Improving Lives, Optimising Resources: A Vision for the UK Rare Disease Strategy at the Rare Disease Day receptions, and Ms Baillie discussed this, saying that the recommendations within the report should be seriously considered. Ms Baillie then went on to introduce the first speaker of the evening, Karen Ferguson, founder of Confer, the Scottish charity for neurofibromatosis.

Karen spoke of her own personal experience of coping with a rare disease, and also told of the difficulties she encountered when her son was first diagnosed. In particular, she spoke of problems within the education system, as learning difficulties are associated with the condition, and a lack of awareness amongst teachers is a problem. She did acknowledge that there had been improvement in this area recently, but that more understanding and support is vital, with particular attention needed to help with finding and maintaining employment.

The second speaker of the evening was Dr Lindsay Mitchell, who spoke of her encounter with a rare disease patient early in her career, which inspired her to learn more about the condition and has led to the opening of a Scottish clinic for these rare patients. She also discussed the lack of funding for rare disease medications, and asked for Rare Disease UK’s help in calling on the Scottish Government to ensure funding for treatment for her patients in Scotland.

Next to take the floor was Alistair Kent OBE, Chair of Rare Disease UK. He discussed RDUK’s report Experiences of Rare Diseases: An Insight from Patients and Families. This report shows that nearly half of all rare disease patients have to wait over a year for diagnosis, with 20% waiting up to five years, and 10% waiting over ten years. He then went on to talk through the Improving Lives, Optimising Resources report, outlining the five chapters which look at research, prevention and diagnosis, commissioning and planning, patient care, information and support and delivering coordinated care. It delivers many recommendations to help improve the area of rare disease, for both patients and those working with them. He also said that implementing these recommendations would be very beneficial to the NHS in the UK by ensuring a more effective use of resources. He thanked all those who contributed to the report, which is based on the largest ever consultation about rare diseases in the UK, with over 1000 people contributing to its development. He then presented the report to the final speaker of the evening, Will Scott, from the Scottish Government’s Long Term Conditions Unit.

Will praised the RDUK report, saying that it was all the more powerful as it was based on patient experience. He also highlighted numerous examples of good practice in Scotland, suggesting that these could be used as models for future changes.

He then discussed the Scottish Government’s approach to anticipatory care, which is hoping to improve the diagnosis of rare disease patients, as well as the managed clinical networks which create better links between all those involved in a particular condition.

Will went on to discuss the importance of psychological and emotional support for rare disease patients, and said that the Long Term Conditions Alliance Scotland will shortly be publishing a report on this subject. He closed by saying that the Scottish Government has published its Quality Strategy and this creates a good basis to work with RDUK to take forward the recommendations.

Both of these reports can be downloaded from Rare Disease UK’s website - www.raredisease.org.uk

HPTH UK would like to thank Rare Disease UK for all their hard work organising these events.

Mandy Mainland
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Thanks to RDUK for supplying me with the details for this report - Ed.
In April, HPTH UK exhibited at the 2011 Society for Endocrinology British Endocrine Societies Conference which was held in Birmingham at the International Convention Centre.

It was a week I shall never forget and was extraordinary for me for two reasons: I was going to meet the HPTH UK committee and the HPTH medical advisors in person. If that sounds strange to new readers of this newsletter, I should explain that HPTH UK was set up and run entirely online since its launch in 2005 and though I had got to know the people I work with very well by email and phone we had never all met in person, and nor had I ever met any of the wonderful doctors who give up their time to work with us. So it was with great excitement and a little concern in case my HPTH let me down (I rarely travel away from home) that I set off to Birmingham with my husband and committee member, Bill.

We meet at last!
Mandy and Judith were old hands having taken the show to Manchester last year but for Bridget, Bill and I, this was to be our first experience of conference. Judith, not having HPTH and being our ‘out and about’ person, had met everyone before but the rest of us had never met. Bridget and Judith did a great job setting up on Sunday and manned the stand on the opening day, Monday, talking to the doctors who enquired about Hypoparathyroidism and giving out leaflets. Bill and I arrived that afternoon from Sussex and Mandy arrived late that evening all the way from Scotland. It was just amazing to meet first Bridget and then Mandy at last, having worked with them both for 3 years now. It was all very emotional and hard to speak much at first but after that I don’t think we all really stopped talking all week. There was so much to say – and it was so much easier than doing it all by email! That night, before Bridget went home to Nottingham and Judith switched to the BTF stand, I managed to pick up a cold and Mandy was pretty unwell too. By the end of the week we were exhausted. The days were long and tiring for anyone let alone symptomatic HPTH people and we had been tired before we got there with the considerable preparations involved. I managed to pick up a chest infection on day two and Mandy was pretty unwell too but despite that we all felt that it had been a great success.

All week from 7am to 7pm, new papers were being presented and lectures were being held in the lecture halls, some of which we were able to find time to attend - fascinating. Vitamin D is definitely still a hot topic. The UK population is not only deficient in Vitamin D but also in iodine, we discovered. Around the walls of the main hall were posters of studies on every endocrine subject under the sun – except hypoparathyroidism. Something that needs addressing in the future!

Support Group Meetings
Two meetings were held for Patient Support Groups. The first was a talk from Rare Disease UK about the valuable work they do campaigning for a rare disease strategy and raising government awareness of the many rare diseases in the country. The second was held by the Society for Endocrinology to discuss issues affecting support groups. Discussed were: ways in which SfE can support groups; running a small charity in the current economic climate; clinical research and patient involvement; the SfE’s new website for the public entitled ‘You and Your Hormones’ which was launched at this conference. You can visit the website at www.yourhormones.info and we would be interested to hear from you if you have any comments. Please email liz@hpth.org.uk

Tired but happy
By the end of the week we were exhausted. The days were long and tiring for anyone let alone symptomatic HPTH people and we had been tired before we got there with the considerable preparations involved. I managed to pick up a chest infection on day two and Mandy was pretty unwell too but despite that we all felt that it had been a great success. Awareness had been raised. The word ‘hypoparathyroidism’ is out there and getting better known every year. More patients and doctors know about HPTH UK. If you’re reading this, Lee – hello!

At the conference
The rest of the week was spent largely meeting doctors, known and unknown, and explaining HPTH to them from the patient viewpoint. It was interesting how many endocrinologists had queries about managing the condition and we are very grateful to them for being so open and for taking the time to come and talk to us in a busy schedule. I would especially like to thank our very own Bill Fraser, who is running the PTH trial for us, as well as Nick Shaw and Simon Pearce who have always stepped up when asked, for coming to say hello. It was wonderful to actually meet face to face at last. The one face I had met before was Abhi Vora of the Society for Endocrinology who has a genius for putting us in touch with the right people and on this occasion introduced me to Mo Aye who had worked with me on the Patient Information Leaflet. I was delighted to meet all these kind people and to be able to thank them personally for all they have done for us. We also met colleagues running other endocrine support groups, both ones we work with regularly - Amend, Rare Disease UK, Genetic Alliance UK, British Thyroid Foundation – and ones new to us too such as Turner’s Syndrome, Pituitary Foundation and Addison’s. And we met patients. During a quiet spell one of the conference event stewards approached us. He had noticed the stand in passing and come back to see us in his break. Lee has post surgical hypoparathyroidism after parathyroid surgery 30 years ago and was very pleased to find out about HPTH UK. He had never been given any information (well, there wasn’t any before us) and he was quite well on his medication but he wanted to know what the long term effects of HPTH might be. We were able to help Lee and give him some leaflets and he has since become a member of HPTH UK. If you’re reading this, Lee – hello!

Continued overleaf....
HPTH UK AT THE BES CONFERENCE

Best of all, we had met each other. It’s pretty rare to meet another person with HPTH and here were 3 of us. One day, when we have enough funds, we will have our own HPTH UK conference and get you all together! It made us realise how important it is to keep on doing what we do – but if you would like to join us, we’d love some help!

(Special thanks to Bill for getting me there and being a total star.)

Bridget writes - ‘It was a privilege to represent HPTH UK at the Society for Endocrinology conference in Birmingham, especially as the occasion arose to combine with it our very first committee meeting. At the conference many doctors and endocrinologists and all things endocrine come together. I was surprised by the number of endocrinologists who made a bee line for our stand to gain information and to leave their contact details the better to help their patients. One endo in particular, sticks in my mind who explained that in his country 60% of thyroid patients are treated with surgery instead of medication so hence they have a large number of HPTH patients. Many of the lovely doctors that are part of our clinical advisory team came to say hello which was nice, we asked them questions to help build a picture of how best to help HPTH UK members and fellow patients. A special thank you goes to The Society for Endocrinology for giving us the stand and the chance to fly the flag for HPTH UK. At the conference the Society launched their ‘You and Your Hormones’ page on their web site. It was demonstrated to me and I found it full of useful information on hypoparathyroidism. It was lovely to meet all the other exhibitors too. One thing became apparent as time went on - something that I never realised before - and that is that HPTH UK is run by a very special crowd of people who are all ill themselves but still manage to do a wonderful first class job.

One of the highlights for me was our very first committee meeting. After years of communicating through various channels we all finally met face to face. What a memorable occasion! Credit must go to our dear Liz, founder of HPTH UK. She was SO proud after all the hard work that has brought HPTH UK to where it is today. Never have I been among such lovely people (who I will never forget) all brought together by one thing in common - HPTH! I, for one, certainly hope that this meeting will be the first of many.’

BES 2012
BES 2012 will be held in Harrogate, 18-22 March 2012.

Liz Glenister
Director
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MEET OUR MEMBERS

Hello, my name is Conor McCallion and I am 14 years old.

I have had hypoparathyroidism since I was 3 when my childminder’s daughter witnessed me have a seizure. I obviously can’t remember a lot of back then but from what I have heard from my parents and nurses, I was pretty ill. It took a few weeks for the doctors to diagnose me and at first they thought it to be epilepsy or some brain problem. When I was diagnosed it took a while to get me stabilised but after I was quite well for a good period of time. This was till I was 6 years old when I once again presented to the hospital as very ill. However this time I was thirsty all the time, urinating a lot and sweating whilst sleeping. This time, my doctors were on the ball and figured out that I had Addison’s disease. They were looking out for this as it was another linked illness to hypoparathyroidism as well as diabetes. It took a while to get the balance right this time as the treatment for my Addison’s, hydrocortisone, drove my calcium down. Since then, I have been on a lot of medication each day and have been over for regular blood tests, but unfortunately, the last 3-4 years have been very unstable. I have not been having a straight spell of more than two months without having to be admitted to hospital. I have been over for bloods twice weekly for the last few months, but I have to remember that I have it a lot better than other people. I still have a good quality of life, I have friends in school, I get good grades, I try my hardest at everything and I am in a good routine of getting bloods done and taking my medicines so don’t think I could live any other way. If anyone has any questions or have similar experiences I would be happy to talk. It would just be nice to chat to someone my age who has the same problem :)

Thanks for your attention,
Conor

Conor can be contacted via our forum - Ed.

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.
Is this where our journey began?

world.

since 1994, possibly the longest of any living person in the hypoparathyroidism. She has been on the same basic regime the first child in the world to receive PTH (1 clinical trial at NIH. On January 5, 1994, Halla Ruth became connected with Dr. Winer, who accepted Halla Ruth into her diagnosis and to find help for her daughter. Her journey, but it took her mother over four years to come up with a Halla Ruth Haldorsdottir was born with hypoparathyroidism, tributary which eventually "connected" to the main river?

Is that where our journey began?  Or was it along a different more differently.

One could easily argue the beginning of our world began in 1880 when Ivar Sandstrom, a medical student in Sweden, discovered the parathyroid glands. Dr. John Potts, Harvard Medical School and Massachusetts General Hospital discovered the sequence of the complex parathyroid hormone, which eventually enabled medical science to duplicate the hormone in the laboratory. Dr. John Bilezikian, Columbia University College of Physician and Surgeons; and Dr. Michael A. Levine, formerly at John’s Hopkins University and currently at the Children's Hospital of Philadelphia, and other leading experts in hypoparathyroidism have devoted much of their professional careers trying to understand hypoparathyroidism and how patients can be effectively treated for the disorder.

Dr. Karen Winer, National Institutes of Health, in the early 1990's, asked why parathyroid hormone couldn't be used to treat hypoparathyroidism and proceeded to conduct a series of clinical trials which not only proved that PTH (1-34) could treat hypoparathyroidism, but also showed patients would be able to live a more normal life with the treatment.

Is that where our journey began? Or was it along a different tributary which eventually "connected" to the main river?

Halla Ruth Halldorsdottir was born with hypoparathyroidism, but it took her mother over four years to come up with a diagnosis and to find help for her daughter. Her journey connected with Dr. Winer, who accepted Halla Ruth into her clinical trial at NIH. On January 5, 1994, Halla Ruth became the first child in the world to receive PTH (1-34) to treat hypoparathyroidism. She has been on the same basic regime since 1994, possibly the longest of any living person in the world.

Is this where our journey began?

In November 1973, Dr. Martin Nusynowitz and Dr. Melvyn H. Klein published titled "Pseudidiopathic Hypoparathyroidism: Hypoparathyroidism with Ineffective Parathyroid Hormone" in the American Journal of Medicine. Dr. Claude D. Arnaud published an editorial, titled "Parathyroid Hormone: Coming of Age in Clinical Medicine" in that same issue.

Is this where our journey began?

The Hypoparathyroidism Association began as a quarterly newsletter in August 1994. Similar associations sprang from our association in the United Kingdom, July 2005; the Nordic HPTH Organization, November 2005; Bahrain (Middle East), January 2009; and InSeNSU (Germany), April 2004.

Is this where our journey began?

The first International Hypoparathyroidism Patient Conference in April, 2006, brought physicians and patients together in one location for the first time. Hypoparathyroidism was finally noticed, and noticed by those present who were able to do something about the disorder, which was not well understood by the medical community. Patients connected with physicians who not only understood hypoparathyroidism, but several of the patients were enrolled in clinical trials at NIH and at Columbia University College of Physicians and Surgeons. Those present also were able to see what happens when a hypoparathyroidism patient goes into a seizure because of low serum calcium. This, incidentally, was not planned, but did capture the attention of all of those present.

Is this where our journey began?

While we felt it was important to recognize each of the events described in this paper and others not mentioned, we felt we could not choose one day over another. In the end we decided on June 1, not because it was relevant to any of the events described above, but was chosen because the first week in June is when the International Hypoparathyroidism Patient Conference is held in Rockville, Maryland. Hypoparathyroidism is coming of age, not only in clinical medicine but in the lives of patients the world over. We can acknowledge June 1 as World Hypoparathyroidism Awareness Day by celebrating all the previous events which brought us to this day, and celebrate the day by holding our Annual International Hypoparathyroidism Awareness Day, bringing together physicians and patients alike to share common experiences and to continue to make a difference in their lives in the future.

"Is this where our journey began?" I don't know when it exactly began, but for each of us, it began when we were first diagnosed with hypoparathyroidism. The journey will eventually end when each of us can live a normal life with the disorder and not in spite of it. Helping others, inside and outside of the medical community, become more aware of this rare disorder will eventually take us there.
Wednesday 1 June has been designated as World Hypoparathyroidism Awareness Day.

This year we have chosen to mark World HPTH Awareness Day by highlighting the problem of post-surgical hypoparathyroidism and we will be launching a new section on the website where patients share their stories.

There have been recent estimates that as many as two to seven people who have their entire thyroid gland removed may end up with permanent hypoparathyroidism. And many more have low blood calcium or hypocalcaemia following surgery which corrects itself over the following days or months. National surgical registries from the UK (British Association of Endocrine and Thyroid Surgeons (BAETS)) and Scandinavia show that around 30% of patients experience at least temporary low blood calcium, or hypocalcaemia, after having all of their thyroid gland removed.

But we are more than just statistics, and that is why we decided that it was time to share our stories publicly.

To start the ball rolling, Liz Glenister and three of our committee members who have permanent hypoparathyroidism following thyroid surgery - Mandy, Bridget and Claire - have written about their own personal stories and they are included in this newsletter. You will be able read their full-length accounts on the website when the new section goes live. This is the first time that they have shared their experiences quite so publicly. It is a massive step, because it is not easy to relive such painful events. Full-blown tetany is painful and distressing and the trauma can live on for years. But equally painful is the disbelief, lack of knowledge and lack of support that some people have experienced on their HPTH journey.

If you would like to add YOUR story to the website, tell us about your experience and what it has meant to your life and send your story to: judith@hpth.org.uk. Or to add a video story, visit the website or see our YouTube channel here http://www.youtube.com/HPTHUK1.

Here are a few questions to help you get started:

• When did you have thyroid (or parathyroid) surgery and what was the reason?

• What were you told before the operation about possible parathyroid complications?

• When did you first realise something was wrong? What were the symptoms?

• What was the reaction of medical staff? How were you treated?

• When did you realise you had hypoparathyroidism?

• How has your treatment been since then?

• Have you had many highs and lows since then? How do you cope?

• What is your life like now? How has it changed since before your surgery?

• If there was one message you would like to give on World Hypoparathyroidism Awareness Day what would it be?

Bridget’s story: ‘I went through surgery for one endocrine disorder and ended up with another.’

Bridget has permanent hypoparathyroidism following three-and-a-half hours of surgery for an over-active thyroid. She says: ‘The possibility of complications was never discussed with me before the operation. I first realised there was something wrong at five a.m. the morning after. I had tingles in my mouth and roof of my mouth and cheeks, numb face and tongue, tinges in legs and arms, my vision froze and images kept on jerking towards me, I felt like a machine that was getting slower and slower and was going to stop. I was unable to even lift my head off of the pillow or swallow. I managed to press the call button and an on-call SHO came. I was given no medication or intervention but left until my surgeon came to do his ward round some hours later. On my discharge form from the hospital it just said hypocalcaemia …’

Bridget says her life has been completely changed by hypoparathyroidism. ‘I went through surgery for one endocrine disorder and ended up with another. I am lucky to have a very caring GP who leaves my treatment to my endocrinologist as he says they are the experts and will ring him if need be. I can have blood tests when I feel I need one and I am seen regularly by my endocrinologist at my local hospital.’ But, she says, ‘Emotionally it is just a roller-coaster of emotions and physical symptoms which I feel are caused by hypoparathyroidism. I now look for all the positives to try to make sense of ending up with this disorder. But it has scarred me emotionally for life.’

Mandy’s story: ‘My life has changed dramatically’

Mandy was diagnosed with Graves’ disease in 2002 after being incorrectly told that her test results were normal the previous year. She spent some time taking medication, and then had a total thyroidectomy in 2003. She says: ‘I don’t remember exactly what I was told about possible parathyroid damage, but I do know it wasn’t seriously discussed. I think it was just glossed over as something that was highly unlikely to happen anyway. It obviously wasn’t explained properly, as I was confusing tetany with tinnitus! We spent more time talking about possible vocal cord damage.’ She now has permanent hypoparathyroidism.

Continued overleaf...
She started to feel strange a few hours after the operation. ‘My head felt fuzzy and I had pins and needles all over my body. It got worse over the next couple of hours, it felt like my face was swelling and the pins and needles were so bad that it felt like I had thousands of maggots under my skin, and it felt like every hair on my head was moving. My hands and feet were numb with them and I had trouble walking properly. Unfortunately I wasn’t on a surgical ward due to lack of beds so staff weren’t aware what to expect after a thyroid operation. A junior doctor came to see me but didn’t know how to treat me. By the time the senior doctor came to see me in the morning, I was cramping quite badly and hyperventilating through panic. He tapped my cheek (Chvostek’s Sign) and ordered a calcium drip. I was then put on calcium and Alfalcaldiol.

‘I remained unstable and was off and on calcium drips for 11 days. My surgeon came to see me every day - he explained about the parathyroids and what appeared to have happened, although he seemed certain at the time that at least three out of the four were working correctly when he finished the operation. He sent me home as soon as my calcium remained above 1.80.’

Mandy’s GP basically left her to self-medicate and left her care to her surgeon, who discharged her after a year. ‘Five years after my operation, I went to see a different GP in my practice who asked if I thought I really needed to be taking the calcium meds! This was when I discovered that hypoparathyroidism was not written anywhere in my file at all!’ Her new GP reviewed her meds and listened, and fought to get her an appointment with an Endocrinologist out of her area who had been recommended to her.

She continues: ‘My life has changed dramatically since I became ill. I used to have two jobs, my own flat in a central location, lots of friends and a busy social life. Now I am unable to work, I live quietly in the country with my dog and have become quite isolated. I’ve lost touch with a lot of my friends since I’ve moved away, and I don’t have the energy to go out much now at all. I’m continually tired and feel old before my time. I look back on my life before my operation, and it feels like I’m looking at a completely different person.’

On World Hypoparathyroidism Awareness Day, Mandy says ‘I’d like to remind everyone just how important knowledge is. If all the doctors I’ve met along the way had more practical knowledge of HPTH, I might not have had such a hard time getting treatment.’

“Hope is like a bird that senses the dawn, and carefully starts to sing while it is still dark”
- Anonymous

Liz’s story: ‘I was told it was a very straightforward operation’

Liz had thyroid surgery in 1992 for thyroid cancer. Before the operation, she says, ‘I had no idea what the parathyroids were. They were never mentioned and there was no information available then to help me ask the right questions. I was told simply that it was a very straightforward operation and afterwards I would just have to take a pill a day.’

After the operation, Liz says, ‘I felt very unwell and a couple of days post op had a calcium injection after tetany became more severe. The next day I felt even worse and I started to cramp up in front of a doctor who kept looking at his clip board telling me that at 2.19 the calcium shouldn’t be doing that and really wasn’t that low. My body began to twist up dramatically and a few minutes later I was lying in a total body seizure, unable to move a muscle but conscious – hugely painful and massively distressing. It took me years to get over the trauma.’

She was put on calcium and Alfalcaldiol before going home. ‘For many years I was left to manage my levels myself. I had frequent precipitous hypos and became a regular visitor to A & E for tests and intravenous calcium and was many times denied a blood test until I had a seizure. Finally, ten years after the operation, two people arrived in my life: a new consultant who confirmed the diagnosis of brittle hypoparathyroidism and increased my Alfalcaldiol, and a new GP who arranged for calcium blood tests to be done whenever I needed. Thanks to the new medication doses, my hypos are less frequent. I have more strength and energy and I have started going further afield, always in company, but it’s a big step.’

Not until some years after surgery did Liz actually come across the term ‘hypoparathyroidism’. ‘I was never told I had a condition at all. Years later a registrar mentioned in passing that I had hypoparathyroidism and I was at last armed with a search term. I came across the new USA Hypoparathyroidism Association in 2003 and as I tried to read the website through my tears I knew I was no longer alone in the dark. HPTH UK went online in July 2005 and here we are - to my astonishment we had over a hundred members by the end of the first year and we now have over 750. Never again will people have to go through all this alone - but we have a long way to go in terms of securing better treatment and resources.’

On World Hypoparathyroidism Awareness Day Liz’s message is: This is a real and difficult condition that is different for each person and needs careful long term management and understanding. Patients and doctors need to work together to avoid crises when calcium levels need adjusting and patients need to be sensitively supported to manage their own condition where possible, with regular testing and an online test result checker for HPTH patients like Renal Patient View made available.
**The Importance of an Awareness Day**  
**Halla Ruth**

My story tells how hard it is to get the right diagnosis, the fight to get the right treatment (parathyroid hormone) and all Dr. Winer's work. My story represents all the factors that HPTH is about.

Parathyroid hormone was a breakthrough as a treatment for our disease and we need the world to acknowledge that. We want to get the knowledge out not only about our disease but also so that doctors get to know what treatment works best. Dr. Karen Winer has dedicated her life to OUR disease and is the pioneer of HPTH treatment. She has worked for over 20 years in her research on parathyroid hormone which is the treatment we need to get approved. It is all thanks to her interest in finding a treatment for HPTH that we have the opportunity to get the parathyroid hormone that we lack. This is what we need to focus on worldwide.

Of course we need to get the knowledge out about our disease so the medical community will be better educated. But though people will get the right diagnosis they won’t get the right treatment unless the hormone is available worldwide. It is very logical that if you lack parathyroid hormone you should be treated with parathyroid hormone like in all other hormonal diseases. This is not rocket science. Getting the PTH approved for Hypoparathyroidism is one of our main goals. Having had the privilege to get the hormone for 17 years has saved my life. Knowing that there is a treatment which I feel so honored to be able to receive and knowing that there are sick patients out there that need it keep me fighting this battle. I will not give up until the hormone is available for everyone who needs it. I know that people that have tried the hormone know what I am talking about.

(Note from Ed - Halla Ruth Vidarsdottir was the first child ever to be treated with parathyroid hormone. Watch her moving video story here - http://video.google.com/videoplay?docid=6567765321871093112#)
It had always been an ambition of mine to run the London Marathon and after 3 years of trying I finally got a place. I remember receiving the “acceptance” letter and was filled with excitement that quickly turned into nervousness when I realised the hard work that would lie ahead. I instantly knew that I would run the marathon for 2 charities that are close to my heart; The Willow Foundation in memory of my brother Adam and HPTH UK in support of my wife Claire.

So 2011 began and so did my training, it was a slow start with the thought of running on a wet winters night not too appealing! The early training paid off when I ran the Tunbridge Wells Half Marathon in February in just under 2 hours – the furthest I had ever ran! This gave me real encouragement and with the weather improving I found I was training harder and even looking forward to running and after my longest run of 20 miles I was ready for the big day....

So on 17th April 2011 I awoke with nervous anticipation of the day that lay ahead. We travelled to London at a time I have never seen on a Sunday morning and after kissing Claire goodbye at London Bridge I was on my own and making my way to the start line... Once there the time flew by and before I knew it I was on my way. The support of people shouting out my name and the excitement combined made the first 13 miles bearable, but then the sun came out, the temperature rose and it became a struggle. At 20 miles the pain in my feet became unbearable and I wondered if I would finish, but seeing my family who had come to support me at the 21 mile mark and seeing Claire and her family at the 22 mile mark gave me the lift I needed and I struggled through and finished in 4 hours, 54 minutes and 23 seconds!

With the mixture of pain, relief, pride and countless other emotions I felt exhausted and promised I would NEVER run a marathon again, but after 2 days recovering I was already planning on doing it all over again!

It is easy to say, but I genuinely believe had I not been raising over £1,500 for 2 amazing charities and not received so many messages of support I would not have got through the latter stages of the run and I am so grateful to everyone who is a member of HPHT UK for this. Until next time....

Liam’s’ Bmycharity page is still open so, if you haven’t done so already, you have a last chance to show your appreciation for all his efforts. Please visit http://www.bmycharity.com/marathonliam to donate - thank you.

If you would you like to run a marathon for us or hold a fundraising event such as a BBQ or coffee morning please let us know – we’d love to hear from you!

Wow Liam! What an achievement! Thank you so much for generously giving your time and energy to help support HPHT UK - Ed.

‘BOGOF’ BRIDGET!!!!
Once again, our Fundraising Officer Bridget O’Connor has come up with an enterprising way to raise money for us! Bridget stored up all her “Buy One, Get One Free” offers throughout the year, and put together two Christmas hampers - raising £45 each for HPHT UK and the British Thyroid Foundation. Well done Bridget, and thank you to Mrs Abigail Croucher, who is pictured with Bridget collecting the HPHT UK hamper.

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

DONATIONS
Dec 10 – April 11
Thank you to all these generous people who donated:

- Makerfield Benefit Centre £110
- Bridget O’Connor £45
- Mrs PM Coburn £50
- Mr & Mrs Deeprose £20
- Mr & Mrs Partridge £5
- Suzanne Frohlick £30
- Peter Goodwin £20
- David Robinson (via standing order) £25

Total £305

This is our total income for this period - we do not get funding, we are run entirely by volunteers and membership is free so every donation counts, however small.

If you would like to set up a standing order we would be very grateful.

Thank you.

EMERGENCY MEDICAL CARDS

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

Then you need our Emergency Card.
We are now producing bespoke emergency cards for our members, priced at £5. One side explains your HPTH and gives emergency instructions, the other side shows your photo and emergency contact details. They are wallet sized and laminated. If you would like a card, please email all the necessary details to liz@hpth.org.uk, or post them, with a cheque made out to HPTH UK.

CANT 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.

“Life expectancy would grow by leaps and bounds if green vegetables smelled as good as bacon” - Doug Larson

GOING ON HOLIDAY?
Have a look at the travel advice on our website. Know what you need to do in advance and get yourself organised so you can just relax and enjoy the break!
http://www.hpth.org.uk/resources.php?id=184

LIFE INSURANCE FOR HPTH PATIENTS

Many of our members have asked us whether we know of companies who deal with life insurance for long term conditions. Thanks to the Genetic Alliance UK who have been working with AllClear Life, we can offer a solution. AllClear Life is a fast online service which can find an indication of the cost that might be involved for you and then introduce you to an insurance specialist. Hypoparathyroidism will be included on their list of medical conditions shortly and more information will be available on our website in the next few weeks. To visit the AllClear Life website, please go to www.allclearlife.co.uk

Found friends on Facebook? Try tweeting too!