HYPOPARA UK NEWS

EMPOWERING PEOPLE WITH PARATHYROID CONDITIONS

Why a sledgehammer can’t smash our butterfly
A personal letter to members from CEO, Liz Glenister

On a Sunday morning in early April last year, the phone rang. I didn’t recognise the number so I let the answer phone pick up. ‘Hello, my name’s Stuart Coulson and I’m calling from a company called Secarma...’ which he proceeded to spell out. ‘Great, a cold caller on a Sunday morning!’ I thought and was heading downstairs when I heard the words ‘...and your Twitter account has been hacked.’ Was this for real? I hesitated. ‘I’m an Information Security Professional and your patient database has been leaked.’ My blood ran cold. ‘Look up LulzsecWiki on Twitter; I’m afraid you’ve got a pretty big issue going on here.’ I picked up the phone and was launched into a nightmare that lasted 4 months.

Hacked off
Lulzsec are a notorious hacking group, an offshoot of the Anonymous collective, who hack for the ‘lulz’ or laughs but it was about as far from funny as you can get for us. The group had closed down the CIA server that very same morning - which did at least make us feel that maybe we couldn’t have been any more careful. They hacked into our patient database (apparently under the impression that it was a UK hospital database as part of an ongoing April Fool raid on the NHS), dumped the information (user names, passwords, medical details etc) in a site called Pastebin and then posted the link on their Twitter account, announcing the deed to the world with the word ‘Enjoy’. I was completely shocked and devastated. As was Ivor, our webmaster, and the executive committee. We have always taken the security of our members very seriously indeed and were extremely worried. We barely slept for the next week as we took every step possible to track down and remove data, inform and protect our members.

Wonderful webmaster
We were supported at this point by our wonderful webmaster, Ivor Humphreys. Ivor has given years of his time to us voluntarily and had to shoulder this burden while driving miles back and forth to care for his mother who was severely ill. He was a complete and utter star. It was an extremely stressful and difficult time involving a huge amount of work but Ivor left no stone unturned and saw us safely through to recovery. We will always be grateful for his loyalty, his dogged persistence and especially his uplifting humour.

Superheroes to the rescue
We discovered that there was an entire community out there that we had not known existed and to whom we owe everything: the information security professionals. They are truly the superheroes of today, looking out for us and guarding against hackers. They had already taken steps themselves and we worked with them over the months, being guided through a quagmire of legalities and technicalities and out the other side. We had a massive amount of support from professionals who appeared out of the blue like this to offer help and advice. I would like to take this opportunity to publicly thank everyone who helped us and gave so freely of their expertise and time, particularly Stuart Coulson of SECARMA, online security specialists http://www.secarma.co.uk/about.html and James Cleeter of the Computer Security and Incidence Response team for JANET, the UK’s network for education & research communities https://www.ja.net/about-janet/about-us. I had an email from Stuart at Christmas whose personal delight in seeing us get back up and carry on I found very touching. Without him we probably wouldn’t be here. There are a lot of good guys out there too.

All these agencies were horrified that a small patient support charity had been so unusually targeted in this way and many articles appeared in both IT and healthcare press about the incident. You can read a typical summary here in PHIprivacy.net which reports and investigates health and medical related privacy breaches http://www.phiprivacy.net/uk-support-organization-hacked-data-leaked/. Thank you to author ‘Dissent’ who moved fast to highlight our plight.

New forum
So then began the arduous task of choosing, and setting up a new forum. For this I would like to thank Ivor Humphreys, for the initial phase, and Mandy Mainland, forum administrator, and Su Clifton and Lisa Burke, forum moderators who worked long and hard to see it through to going live as swiftly as possible. They did a really fantastic job. We chose to look on this enforced shut down as an opportunity for positive change and we think the new forum is greatly improved! We hope you like it. Although each of you has received an email about it, not everyone who had registered on the old forum has yet re-registered on the new one so if you would like to show your support for all our work we’d be really pleased if you would go and sign up now. www.hypopora.org.uk/board

Special thanks
I want to thank our fantastic committee who do such a wonderful job (please remember we all give our time voluntarily) and everyone who supported me while I was off sick for a few months last year, especially my husband Bill Glenister and youngest daughter Kate Fletcher (whose piece on hypopara you can read inside). I’m back now and very excited by the way Hypopara UK is taking off. Above all, I want to thank you, our truly marvellous members. Far from losing you all as I had feared, I was overwhelmed with an outpouring of support from so many of you. I was staggered. There was doubt in the IT community that we could survive the hacking but they clearly didn’t know our members. You never lost faith. Your kindness really kept me going and gave me the strength to carry on and I thank every single person who took the trouble to write to me or call. Of 1100 members we only lost 2 which I was staggered. There was doubt in the IT community that we could survive the hacking but they clearly didn’t know our members. You never lost faith. Your kindness really kept me going and gave me the strength to carry on and I thank everyone who wrote to me or called. Of 1100 members we only lost 2 which I was staggered. There was doubt in the IT community that we could survive the hacking but they clearly didn’t know our members. You never lost faith. Your kindness really kept me going and gave me the strength to carry on and I thank every single person who took the trouble to write to me or call. Of 1100 members we only lost 2 which I was staggered. There was doubt in the IT community that we could survive the hacking but they clearly didn’t know us. You never lost faith. Your kindness really kept me going and gave me the strength to carry on and I thank everyone who wrote to me or called. Of 1100 members we only lost 2 which I was staggered. There was doubt in the IT community that we could survive the hacking but they clearly didn’t know the IT community that we could survive the hacking but they clearly didn’t know the IT community that we could survive the hacking but they clearly didn’t know

The new brand will launch on 28th February as our way of marking Rare Disease Day 2014.

Our butterfly lives on!
Hello everyone! It’s been a while since the last issue due to the combined effects of the security leak, ill health and volume of work but we’re back with a bumper issue for the New Year which I hope you will enjoy. Thank you all for your continuing support - it has meant such a lot to everyone who worked so hard to keep Hypopara UK going. Here’s a taste of what you can find inside...

New Brand Launches on Rare Disease Day

HPTH UK is no more, we are now Hypopara UK and will launch our new name and website URL on February 28th 2014. Our new look won’t be too different but stronger and cleaner, which we hope will signal a new era for us as a charitable organisation. This has come about thanks to Isabel Wray, grateful hypopara patient who is currently working with us on some very exciting initiatives! Please go to the new website and sign up as a member if you haven’t already done so.

New Forum

On July 15th 2013 our new forum went live exactly 8 years since the old website and forum first made their appearance on the internet. We hope you like it. It was the result of 4 months work after the security leak forced us to close down the old one and relaunch. We looked at it as an opportunity to update and make some positive changes and we think its a great improvement. If you still haven’t signed up, please do so now because your old membership will lapse this year and membership gives you access to the website member pages, news updates, clinical trials etc. You can do it right here and now – its quick and free! http://www.hypopara.org.uk/board/

Medical Advisors

We are honoured to welcome to our team of clinical advisors surgeon Radu Mihai (Oxford), and consultant endocrinologists Dr Peter Selby (Manchester), Dr Jeremy Turner (Norwich) and Dr Duncan Brown (Cornwall). We introduce them inside.

Clinical Trials

We are entering a very exciting period! Read about the clinical trial to be run by our own Professor Bill Fraser in Norwich on the use of oral PTH 1-84 for hypopara patients. We are still recruiting for this trial but it is hopefully due to start in March 2014 so get your skates on if you want to apply. Also find out what is happening with the progress of the injectable form of 1-84, Natpara, that some of you trialled in 2010. At last, our time is approaching…..

Guidelines

Slowly but surely we are getting the word out there. We are currently working with the Guidelines Development Group (GDG), chaired by Dr Petros Perros, to review the current (2007) BTA Thyroid Cancer Guidelines and ensure that hypocalcaemia and post surgical hypopara are properly addressed this time. The SfE have recently published emergency guidelines for acute hypocalcaemia and hypercalcaemia and we hope to start work with them soon on the first guidelines on the management of hypopara. A patient survey is in the pipeline as a first step towards this so keep an eye on your inboxes – your experience will be needed.

Medical Conferences

We were invited to exhibit at several conferences held by the Society for Endocrinology. In 2012, we were at the Endocrine Nurses meeting in Stratford in September and again in November at the Clinical Update for junior doctors in November. In 2013, we took our wares to the annual international BES endocrine conference week in Harrogate, in March. In November, volunteers Harriet Lupton (retired GP) and Jeanette Jones did a great doctor/patient double act at the Clinical Update in Bristol. As we are a founding member of the Thyroid Cancer Alliance, Judith (as TCA Secretary) was able to represent us when she flew to the European Thyroid Association conferences in Pisa, September 2012 and Leiden in Sept 2013, and the World Congress on Thyroid Cancer, Toronto in July 2013.

Awareness

In September 2013, we were represented by 2 committee members at British Thyroid Foundation local group meetings. Emma Thomas spoke at the London meeting at the Royal Free hospital while Bridget O’Connor attended the Nottingham BTF meeting at Kings Mill hospital and both meetings were well attended. You may already have heard Emma speak as she was interviewed on the radio in June 2012 talking about her own battle with post surgical hypopara, as part of our awareness day activities. We continue to mark World Hypoparathyroidism Awareness Day June 1st by publicising and adding to our collection of patient stories called the ‘Living with Hypopara’ project which you can read here http://hpth.org.uk/hpth.php?id=204

Fundraising

We are very moved by the amazing efforts you have made to help us stay afloat. In August 2013, Rob Healy ran, cycled and swam his way through the Salford Triathlon despite several hospital admittances and beat his target to raise a magnificent £1,007. Proud of you, Rob! In July, Isabel Wray had a cake and Brazilian cocktail party at work, raising awareness and £200 at the same time. Su Clifton and Mandy Mainland gave me a wonderful surprise by producing our first Hypopara UK calendar. Now is not too late to get one! http://www.hpth.org.uk/home.php Finally, superstar Bridget O’Connor sang in the New Year and her 60th birthday raising £500 to share between us and BTF. What a wonderful lot you are! So....who’s up for this year?!

Committee News

We are delighted to tell you that we have 5 new committee members. Su Clifton and Lisa Burke whose dedication to the forum knows no bounds, Gillian Adams who does a great social media job for us on Facebook; Emma Thomas took to the airwaves in her awareness role and will be getting involved in our fundraising too, and Isabel Wray whose generous offer to rebrand us you will soon witness. Gillian and Isabel have also both had baby boys in this time – congratulations to you both!

Thank you again to everyone who has helped us through this difficult time. It’s very nice to be back and I’ve begun the new year as a Grandma twice over which is an added joy. May 2014 be a fulfilling but stress free year for us all.

With warmest wishes to you all,

Liz
In October, findings were published from the REPLACE trial which confirm the potential of Natpara® as a parathyroid replacement therapy for adult hypoparathyroidism. Further findings also suggest that Natpara® has a beneficial effect on bone health in patients with hypoparathyroidism. Read all about it here - http://www.npsp.com/investors-pr?trxml_v=nrd&trxml_nr_id=1861914 and here - http://www.npsp.com/investors-pr?trxml_v=nrd&trxml_nr_id=1861915


NPS also issued a further press release last month to state that the FDA had accepted their Biologic Licence Application for Natpara® for the treatment of hypoparathyroidism. The goal date for their decision is 24th October 2014. Read the full press release here - http://www.npsp.com/investors-pr?trxml_v=nrd&trxml_nr_id=1888882

We will be working closely with NPS to introduce Natpara® when the time comes - watch this space!

We are very pleased to announce that following a meeting in London in January, NPS is willing to offer support to Hypopara UK to help further its work for patients in the UK.
In July 2013 I attended the World Congress on Thyroid Cancer in Toronto, Canada on behalf of the British Thyroid Foundation and Hypopara (HPTH) UK along with nine other representatives of member organisations of the Thyroid Cancer Alliance.

This Congress was a fantastic opportunity to learn about the latest developments in the diagnosis and treatment of thyroid cancer, to meet old and new friends, and to exhibit our patient support materials.

The TCA held its AGM during the Congress and also hosted a dinner for some of our medical advisors.

We attended many of the scientific sessions and despite the 6am start we all turned out to support Kate Farnell who is the TCA President and Founder of the Butterfly Thyroid Cancer Trust, who took part in a breakfast symposium on ‘Optimising Patient Care’ chaired by thyroid cancer guru Dr Mike Tuttle.

It is a sign of how the times are changing that patient advocates are now getting involved as speakers and presenters at medical congresses.

Our Hypopara leaflet has travelled the world! We exhibited copies on the TCA stand and there was a lot of interest from the Congress delegates. Many of them took leaflets and acknowledged that hypoparathyroidism is an issue in their own countries, as well, and that greater efforts need to be made to limit its occurrence as much as possible by ensuring that thyroid surgery is always performed by specialist surgeons experienced in thyroid and parathyroid surgery.

The TCA exhibited on stand #509 and we gave out copies of the first issue of our newsletter, TCA News, which you can download here. It includes an article about HPTH UK.

The TCA participants were: Kate Farnell (Butterfly Thyroid Cancer Trust, UK), Joan Shey (Light of Life Foundation, USA), Beate Bartés (Vivre sans Thyroide, France), Helen Hobrough (Thyroid Cancer Support Group, Wales), Carmen Villar (AECAT, Spain), and Soledad Rodríguez Perea (ACTIRA, Argentina), Mary McGarry (Thyroid Cancer Support, Ireland), and Jo Grey (Association for Multiple Endocrine Neoplasia Disorders - AMEND, UK), and myself. Christine McTigue of BTCT attended as our scribe.

At our AGM Kate was re-elected as President, and myself (Secretary), Helen Hobrough and Soledad Rodríguez Perea continue in the board. Joan Shey has stepped down as Vice-President.
OUT AND ABOUT WITH HYPOPARA UK

Nottingham Awareness Meeting 2013

A very informative evening was held with around 30 guests attending the thyroid/parathyroid awareness event. After the presentations a question and answer session followed and the good doctors spoke with patients on a one to one basis for those who wished....

Professor Devaka Fernando, Consultant Endocrinologist, spoke first on all things thyroid - anatomy, histology, thyroid hormones, types of goitre (toxic and non toxic), hypo/hyperthyroid, Hashimoto’s thyroiditis and post partum thyroiditis, anti-TSH antibodies and the treatments and causes of disease. His talk was given at a level that was easy to understand and he provided the opportunity to ask questions.

Mr Keshav Nigam, Consultant Surgeon, spoke next on thyroid treatments and surgery, including - when you need surgery, types of lumps, surgery for goitre, symptoms, red flag symptoms, nodules/lumps, fine needle aspiration, thyroid cancer, risk factors, thyroid cancer treatments, surgery, drugs, radioactive iodine investigations, pre-op treatments and post-op complications. He also pointed out that thyroid cancer is the fastest growing cancer in the USA. Mr Nigam also provided the opportunity to ask questions.

Mr Irfan Akhtbar, Consultant Surgeon, spoke lastly on parathyroids - what they are, what they do, and where they can be found. Also how they evolve and what the signs and symptoms are of high and low calcium and he discussed parathyroid surgery. Mr Akhtbar focused for some time on hyperparathyroidism and the symptoms, using the term GROANS (feeling awful) BONES (as they hurt so much) STONES (risk to kidneys) and MOANS. I thought this was a good way of describing when you go too high! Again, Mr Akhtbar presented his slot at a level that was understandable and provided the opportunity to ask questions afterwards. When I was on the stand before the presentation started, a gentleman came to find me as he had recently been diagnosed hyperparathyroid and just could not believe how devastatingly calcium (either high or low) could effect us. I had a job convincing him how it affects me and gave him a copy of the summer BTF newsletter with ‘My Story’ in it to read while waiting for the presentation to start. He came to me afterwards and was hugely grateful for the information as understanding is half the battle!

Bridget O’Connor
Fundraising Officer

Thyroid Cancer Alliance in Leiden

In September, Carmen Villar of the Spanish thyroid cancer patient support organisation AECAT and I went to Leiden, in The Netherlands, to represent the Thyroid Cancer Alliance at the European Thyroid Association conference.

Once again we displayed the patient leaflets from the TCA’s member organisations including the Hypopara UK leaflet.

Carmen and I also took part in the first Thyroid Cancer Awareness run, a 3km run through Leiden in the early hours of the morning. Well, we did a gentle jog, and were shown a short cut so that we were able to arrive back at around the same time as the more experienced runners…

Judith Taylor
Public Relations Officer
Hypopara UK

and

Secretary/Director
Thyroid Cancer Alliance

Patient stands at the European Thyroid Association conference in Leiden – from left to right, Thyroid Federation International, Schildklier Organisaties Nederland (the Dutch umbrella organisation of thyroid patient groups in Holland) and the Thyroid Cancer Alliance.
PUBLICATION OF SURGEON OUTCOMES DATA - WHAT DOES IT MEAN?

In June 2013, 3,500 surgeons published details about their performances which patients can now read for the first time. The Royal College of Surgeons hailed this as a landmark and a ‘watershed moment for surgery’ and said on their website that ‘the innovative move will drive forward improvements in care and enable patients to understand far more about the nature of a surgeon’s work and their recovery after an operation.’ You can read more here: http://www.rcseng.ac.uk/news/rcs-hails-landmark-publication-of-individual-surgeons2019-outcomes-data/?utm_source&utm_medium&utm_campaign=.Uc3A2_nVCSoHPTH

But what does this mean exactly for patients? I have asked our new clinical advisor, consultant endocrine surgeon Radu Mihai to explain. I am delighted to publish his comments below and to say that we both hope that this will be the start of a positive and open relationship between us and BAETS and lead to beneficial changes for us all - Liz Glenister

‘The recent landmark publication of the workload and outcome parameters for ten surgical specialties is a radical move towards increased scrutiny of surgical practice in the United Kingdom. The Royal College of Surgeons led this process and on 28th June the first data set was published online (http://www.nhs.uk/choiceintheNHS/Yourchoices/consultant-choice/Pages/consultant-data.aspx), with further updates and expansion expected to occur yearly. As stated on the RCS website, this should ‘enable patients to understand far more about the nature of a surgeon’s work and their recovery after an operation. The initiative means that people undergoing certain surgical procedures can look up their surgeon and unit and see how many similar operations they have performed in the past year, and how they compare with others on a number of different measures or ‘indicators.’

The British Association of Thyroid and Endocrine Surgeons (BAETS) has been selected in the first wave of publication of such data because of its long-standing commitment to audit and nation-wide data collection about thyroid, parathyroid, adrenal and pancreatic operations. This process was first established in 1999 and since 2004 it has functioned as an online web-based registry. Four national reports have already been published by BAETS since the establishment of this audit, the most recent in 2012 (www.baets.org.uk) and the information was accessible to the public in anonymised format. The major change introduced by the recent publication is that now the details of a named clinician or hospital can be accessed by all those interested. A total of 125 surgeons gave their explicit consent to publish these data, none withheld consent and no reply was received from 17 surgeons. Data derived from over 13,000 thyroid operations was analysed.

One of the aims of this publication is to determine the appropriate standard for a surgeon, and to define acceptable and unacceptable variation from best practice. The data about ‘outliers’ (i.e. surgeons whose individual performances appear to fall outside defined limits) will be checked and re-examined to ensure the appropriate risk-adjustment has taken place. Once this has been done, if the surgeon is a true outlier each surgical specialty has a process in place to provide support and additional training where necessary.

Late hypocalcaemia (i.e. hypoparathyroidism) after total thyroidectomy is the commonest reported complication. The overall incidence is about 9%, with much greater variation between surgeons than with other outcomes. The definition used in this report is ‘the need for calcium +/- Vitamin D supplements to maintain normocalcaemia at six months following surgery’. This is intended to be a useful measure of permanent parathyroid damage but it can be difficult to interpret for a number of reasons. Some patients may be taking calcium supplements for reasons unrelated to their surgery (e.g. pre-existing vitamin D deficiency) and not all patients taking supplements at six months will require them indefinitely. Furthermore, follow-up protocols vary between surgeons depending on local service provision (when long-term follow-up is managed by endocrinologists, for example) and opinion (whether or not slightly low blood calcium levels require treatment). Such considerations may therefore lead to artificially high rates of late hypocalcaemia being recorded in some instances.

It is important to interpret these data with caution and as part of a constructive process. Some surgeons will have to analyse their practice and identify ways of improving their own results. The data should also encourage multi-centre studies to be organised in order to determine the protocols with best outcomes for patients. Patient support groups should be given the opportunity to be partners in this process. Those reading the recently published data should become involved in the process of improving patients’ care and avoid the (easy) temptation of criticising surgeons whose results appear to be outside the accepted variability in outcome.

I hope that in coming years we will look back at this landmark event and see it as the beginning of a constructive process between the surgical profession and the public and not at all as an open invitation to ‘witch hunt’ by dissatisfied patients.

Radu Mihai

[Image of Radu Mihai]
Canadian PHP patient’s speech raises funds for hospital

I first heard about Rebecca Gingell through her mother Lois who I came to know over the years on the forum as she searched for information help her daughter.

Rebecca has PHP or Pseudohypoparathyroidism type 1b and had developed secondary hyperparathyroid bone disease as a result of inappropriate treatment. Both Rebecca and Lois are extraordinary people who don’t give up easily!

After a very lengthy stay in Vancouver Coastal Health Hospital Rebecca was asked to be the spokesperson for their Christmas fundraiser, the biggest fundraising event of the year. They made a promotional video of her story as well. She was asked not to elaborate on her condition but to keep it in layman’s terms, which she duly did.

Rebecca wrote and gave a wonderful speech about the care she had received and raised a remarkable amount of money in doing so. She said ‘I have a very rare disease. Rare diseases come with unique challenges for everyone. It is often new territory, with no easy answers, and unusual needs. Because there are so many unknowns, it can be frustrating and difficult for both the caregivers and the patient. Good care requires special people. People who are willing to reserve judgment, problem solve, and persevere. I was very fortunate to be cared for by a team who did all of this, and more.’

Her story also appeared in the Delta Optimist newspaper which you can read here http://www.delta-optimist.com/angels-at-work-in-her-corner-1.766181

Watch Rebecca on the video on our own You Tube channel here http://www.youtube.com/watch?v=L6lkA527aQ&list=FLL67GZlp4dNQn6s_dddYv4A

Hypopara: From The Outside Looking In

A cancellation here, a change of plan there. Some days are even completely written-off. Living with Hypopara isn't easy for those with it, or for those around them.

From the outside, there's not much to see; a normal person, no discernible disabilities or limitations. But this is the problem with not only an 'invisible illness', but a rare one too.

Besides the inevitable symptoms, stresses and sufferings, there's also the everyday setbacks and issues that make living a 'normal' life that much harder. Your independence is stripped from you and you become a shell of the person you once were. The smallest, simplest of things can seem like mountains to someone with Hypopara. The frustration gets overwhelming and you feel pathetic having to let people down over and over again. Of course, I only know all of this because my mum has Hypopara.

An adventurous, fun and independent person, there's not much my mum hadn't seen or done in her younger life, but getting diagnosed when I was only a few years old, Hypopara mum is the only mum I can remember. Growing up, I have memories of her having to plan 'rest days' in between days out or events. I am what some would call a 'home bird' and I think this is partly down to having a parent with this condition, but actually, if you look at it from another perspective, I think I've been extremely lucky to have her around so much (not being able to work) - we spend a lot of time together and as a result, are very close.

My mum is certainly no less of a person because of this condition, but it's sometimes difficult to see her dreaming of things she wished she could do now.

Living with someone who has Hypopara has taught me a lot. To be understanding, to not be judgemental, and to be totally caring. Throughout the hard times, though, it helps to see the funny side of things sometimes - who else do you know who has to carry slices of 'emergency cheese' and apricots around in their handbag for that instant calcium boost? Or the regular remarks like, 'I'll have white bread please, I'm too high for brown'. Juggling her body's highs and lows can be exhausting, but she is slowly beginning to realise that sometimes she needs to put herself first.

There are, of course, some good points to living with someone who has Hypopara - all of which I've learnt through my Mum's own self-taught knowledge on the subject. I've learnt so much about food on a nutritional level, I've learn a lot about how our body works and deals with what we put in it and I've learnt that if you want to do anything in this world, you can.

After years of battling with doctors and consultants, wrong diagnoses and getting told there's nothing wrong with her, my mum realised that awareness needs to be raised for Hypopara. Now 8 years down the line, Hypopara UK has worldwide charity status and is helping people with the same struggles everyday.

Kate Fletcher (Liz Glenister’s daughter)
I hadn’t been up to London since the Olympics began, thinking it would be a bit of a nightmare but I was impressed. The city was in its best party frock. Even the normally grim London Bridge station was in celebratory Olympic mode, posing in pink at the base of the glittering Shard. The journey to Excel on the Docklands Light Railway, full of partygoers, took us past the Tower and the futuristic cable car swinging over the river from Greenwich where my twins had been born, towards the East End where I’d lived as a young teacher. As a Londoner born and bred, I love coming back to my home town, it’s in my blood. Like most Londoners I’d expected the worst when the Olympics hit town and then been completely enchanted. The London Paralympics set a precedent.

Excel was pretty amazing and the organisation by the ever smiling Games Makers was remarkable. One of those Games Makers was our own indefatigable Judith Taylor who, as luck would have it, was volunteering at Excel that day so we were able to meet. Excitement was high as we took our seats. The warm up man chose my husband Bill to interview on camera about the weight of a washing machine. A strange question unless you know that we were there to see the powerlifting at which Bill would clearly not excel! We weren’t just there to be part of the most extraordinary Paralympics ever, but to see an extraordinary Paralympian, one of our very own members, Mary Stack.

Mary is a veteran of the Paralympics as she explains: ‘I competed in the 2012 Paralympic Games, I am a Paralympic Powerlifter. This was my 4th Games. 2000, 2004, 2008, 2012. I compete with a condition called Pseudohypoparathyroidism. Although having it since birth it has only made me a stronger person!’

The atmosphere in the huge, packed room was electric as the competitors made their entrance. One by one the Paralympians lay on the bench, were strapped on and the weights lowered. One by one they took their turn to lift the best weight they could, over 3 separate attempts.

Only Mary took the time to compose herself and breathe first, which you can see her doing above. There was total silence.

As the scoreboard showed each result, the tension grew and the noise of the cheers and yells was deafening. After a nail biting competition, with placements changing with each round, Mary was placed 4th, lifting 135kg. That’s 4th in the world – an amazing achievement. We were so proud of her!!

Mary was kind enough to agree to meet us afterwards so after all the regulatory testing had been done she was escorted out to sit with us and we had a great chat. It turned out we both had Irish heritage and Mary was heading off for a few days break to Dublin. I asked Mary how she felt and she was a little disappointed she had come so close but was determined she would be back for Rio! In the words of Hypopara UK, Mary, ‘keep on keeping on’. 4th in the world sounds pretty amazing to me!

So, what’s next for Mary? ‘I am currently in training for my 5th Paralympic Games (2016). This April I will be competing in Dubai in the United Arab Emirates at the World Championships.’ We’ll all be watching you Mary and cheering you on – thank you and good luck! You’re a star!

It was a real honour to meet Mary. She is a lovely person with a great sense of humour and even greater mental and physical strength. A tiny person who pushes herself to extremes and then gets up and calmly does it all over again. And again. Her persistence and determination is, quite simply, astonishing. As a world class athlete, she wears her fame humbly, raising awareness for Pseudohypoparathyroidism, the rarest of our rare conditions, giving her time to help train and educate young people about sport and sending a powerful message about positive attitudes to disability. Mary is an extraordinary woman, an example to us all, and we are privileged to have her as an international member and supporter of Hypopara UK.

Mary is funding herself to get to the World Championships in April. You can help her get there by contributing to her airfare and hotel accommodation here:

http://www.gofundme.com/help-mary-go-to-worlds

Liz Glenister
HYPOPARA UK REGIONAL GROUPS

As our community continues to grow, we are currently trying to set up regional Hypopara groups to give our members a chance to get to know others in their area, and benefit from some local support. If you would like, we can also arrange Awareness meetings and organise speakers.

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

Hacked Off
Su Clifton

We came across some hackers
I won’t reveal their name
Hacking on the internet
What a pointless claim to fame

They saw our little website
And thought ‘oh how divine
Lets rummage through their details
Then we’ll post them all online’

Secarina was our saviour
To guide us through this mess
Like knights in shining armour
To our damsels in distress

Stuart Coulson helped us out
Thank you most sincerely
Now no fine from ICO
That would have cost us dearly

Beefed up our security
Got a brand new forum
Usernames and passwords safe
All moderators awesome

So if you are a hacker
Please leave our site alone
We ask you most politely
As to us it feels like home.

TELEPHONE HELPLINES

01342 316315

OR

01623 750330

Hypopara UK has signed the petition:

As a patient you can sign the petition too:

http://www.alltrials.net/
HYPOPARA UK CALENDAR 2014
Su Clifton

I had a eureka moment and it was nothing to do with my bath water and it certainly didn’t involve me running naked through the streets! I wanted to try and raise some money for Hypopara UK. Over the years, I’ve received a lot of help, advice and support and I wanted to give something back. People have performed many wondrous feats to raise money - running marathons, competing in triathlons and jumping out of aeroplanes. I wanted to do something butch, brave and heroic and so it came to pass that I opted for producing our first ever calendar. Now, I can sense you questioning how this is, in any way, butch, brave or heroic but let me tell you – you can get a very nasty paper cut from a calendar if you’re not careful!

I found a printing company (www.colourcalendars.com) who assured me that even a numpty like me could produce a fundraising calendar. So, with their guidance and support I cracked on with my mission. I roped Mandy in to help me in my brave quest. The initial plan was to have a competition so that all our members could submit photos. However, time was against us, so Mandy and I had a look through our photo collections to see what we could put together. It was at that moment that panic set in. All I could find were photos of my geriatric Jack Russell Terrier wallowing in a muddy puddle and who wants to see that? At this rate the calendar was going to be photos of our cats and dogs in various poses. We persevered, stuck to our task and eventually we came up with a great selection of photos.

We then passed our photos, logos and special dates to the printers who pieced together and designed our calendar for us. Not known for blowing our own trumpets but we have to say that the final result is absolutely brilliant. We are really pleased and proud of our first calendar and we really hope that you like it too!

Oh and for anyone that did want to see a photo of my geriatric Jack Russell Terrier wallowing in a muddy puddle, here you go!

‘ROCK AROUND THE MIDNIGHT CLOCK’
Bridget O’Connor

I decided in the summer to celebrate my birthday my way - the way I wanted to. Following my thyroid/parathyroid experience I am living with two chronic long term conditions. I looked for a positive interest and a work/life balance and decided to take up my passion for singing. I also wanted to promote how living with a long term condition can have a positive side. I truly believe that for me personally, being positive through singing and doing what I love helps me so much.

I perform at my local college in The School of Rock every week which culminates in a live performance. We did ‘Merry Rockmass’ on Dec 13th 2013, and the members very kindly let the BTF and Hypopara UK be the charities to benefit from a collection after our performances where we raised a fabulous £50! I performed 5 songs on the night and doubled this amount through my lovely friends at Sure Start through sponsorship.

Without a doubt I could not have done any of this without the support of my lovely music tutor James Mills. James gave me confidence and has taught me so much. I am carrying on into 2014 with my lessons and James has very generously offered his time and expertise to RECORD (yes RECORD!) me and him performing together on a CD with a set list of songs sung on New Years Eve and some new ones, along with the artwork for a CD cover to sell and all the proceeds to go to BTF and Hypopara UK. I cannot believe his very generous offer, I AM SO EXCITED!! Watch this space …..

My charity pages at www.bmycharity.com/rockaroundthemidnightclock and www.justgiving.com/Bridget-Rae-O-Connor are still active for people to donate if they wish.

I dedicated ‘Run’ to the BTF and Hypopara UK. The lyrics can be interpreted in different ways to different people but for me personally, following my horrendous surgical experience and then finding support from you lovely people in my two charities - along with the calls I receive running the helpline supporting and helping fight the corner for people who aren’t getting the help they deserve - it says it all! It was hugely emotional when I had finished as it was the last song as well. What a special night!

“Light up, light up, as if you have a choice
Even if you cannot hear my voice
I’ll be right beside you dear
Louder, louder, as we run for our lives
I can hardly speak I understand
why you can’t raise your voice to say....”

James Mills www.facebook.com/JamesMillsGuitarTuition
Stewart King www.facebook.com/Stewartkingmedia
**FUNDRAISING AND DONATIONS**

**Hypopara UK says thank you!**

We are so very grateful to everyone who has helped us to keep going in the last 20 months since the hacking which put such a strain on our already struggling budget. We have been really touched by your response and your generosity and I would like to extend my personal thanks to every single person who so kindly continues to give every month, donates, fundraises or simply writes to show support.

Thank you – Liz

**Income from May 2012 - Dec 2013**

<table>
<thead>
<tr>
<th>Regular monthly bank transfers (totalling £50 per month)</th>
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<tbody>
<tr>
<td>David Robinson</td>
<td>Aileen Ander</td>
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<tr>
<td>Rosalind Marchant</td>
<td>MT Shaw</td>
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<tr>
<td>David Coates</td>
<td>Claire Butchers</td>
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<tr>
<td>Lisa Burke</td>
<td>Sue Basket</td>
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<td></td>
<td>Jacqui Wilcocks</td>
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<table>
<thead>
<tr>
<th>Donations</th>
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<td>Sandra Minshull</td>
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<td>Susan Snell</td>
<td>Judith Cole</td>
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<tr>
<td>Mr Butchers</td>
<td>S. Firth</td>
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<tr>
<td>Aileen Anderson</td>
<td>Mr&amp;Mrs Partridge</td>
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<tr>
<td>Chris Wray</td>
<td>Julia Moore</td>
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<td>High Street Dental Practice</td>
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<td>MJ Malherbe Jensen</td>
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<tr>
<td>Nailsworth Rotary Club</td>
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<td>Notts Thyroid Support Group</td>
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<table>
<thead>
<tr>
<th>Fundraisers</th>
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<tr>
<td>The Mathers Family Skydive</td>
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<tr>
<td>David Coates Garage Sale</td>
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<tr>
<td>Rob Healy Triathlon</td>
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<tr>
<td>Easy Fundraising</td>
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<tr>
<td>Bridget O’Connor ‘Rock Around The Midnight Clock’</td>
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<tr>
<td>Hypopara UK Calendars (Su Clifton)</td>
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**Grand Total**                                         **£4372.90**

- Salford Triathlon
  - Hypopara UK member **Rob Healy** completed the Salford Triathlon (Olympic distance) on August 18th, to ‘give something back to Hypopara UK’. It was an arduous training schedule, battling his unstable calcium levels in and out of hospital, so please support his effort. So far, Rob has raised more than **£1000!** His online fundraising page is still open if you’d like to donate - http://www.bmycharity.com/hypopara

- **Cakes and Cocktails for cash!**
  - **Isabel Wray**, Hypopara UK member, organised a cake sale at her workplace in July and accompanied them with fabulous Brazilian cocktails! She took the opportunity to explain to her colleagues about Hypopara, and even handed out some leaflets. They raised **£210** between them, and I think a good day was had by all!

- **Garage Sale**
  - **David Coates** combined fundraising with spring cleaning and sold some unwanted items after clearing out his garage and loft, raising £90. Thanks David!

- **‘Rallying Round For Reece’ Update**
  - In the last issue we focused on the Mathers family, who were organising several fundraising events to raise money for Hypopara UK. Lorraine’s young son Reece had been recently diagnosed with Hypopara and they wanted to find a way to help. So they decided to take on a skydive!! I went along to watch them at Strathallan Airfield - they were so brave! It was lovely to meet such a close family and we had a lovely day. Their skydive, and various other events they have organised, has raised over **£1000** - well done guys! What’s next???

- **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.**

- **Don’t forget you can donate via the PayPal button on our homepage!** www.hpth.org.uk
**REMINDERS**

Ice Gems discount available - 10% off when you quote code hpth10 www.icegems.co.uk

Find life insurance via AllClear Life, HPTH is on their list of medical conditions www.allclearlife.co.uk

Emergency medical cards are available from us, priced at £5 each. Contact Liz for further information liz@hpth.org.uk

If you’re heading off on holiday this summer, remember to check out the travel advice on our website http://www.hpth.org.uk/resources.php?id=184

If you’d like to share your story, then please get in touch! Send any stories, poems or suggestions to mandy@hpth.org.uk

You can keep in touch with us via our website and forum, Facebook and Twitter

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

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**CAN YOU HELP?**

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

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

Or perhaps you’d like to consider leaving a legacy? Get in touch if you’d like to discuss this further.

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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!

To find out how you can get involved and raise some money, or send a donation, please click on this link -

http://www.hpth.org.uk/home.php?id=32

HPTH UK has been registered as a charity for tax purposes, so please remember to claim Gift Aid whenever you can!

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**AND FINALLY.... :)**

Seriously, dude...

**is there a name for what’s wrong with you?**