HYPOPARA UK IS TEN YEARS OLD!

Get together for our 10th anniversary!

Hypopara UK will be ten years old on 15th July 2015 and we’re planning a nationwide hypopara hug! You can join in the celebrations by arranging to meet up with a fellow member or come along to the group in your local area. Whether it’s a cup of tea, a phone call or a full blown party we hope you will enjoy yourselves and also think about what Hypopara UK has meant to you over the years. If you’ve never met anyone else with hypopara before, now’s your chance. Get on the phone, send an email, make a plan for sometime that week and get involved. Let’s get together!

Mark the occasion with a photo of that hug! Or write down on a card what Hypopara UK has done for you and send a photo of that instead. How many can we get?

Email them to us or post it on our Hypopara UK Facebook page.

The first website and online forum went live on July 15th 2005. Liz Glenister, founder says: ‘I was groping around in the dark, really. I had no idea what would happen but I was determined to speak out about what had happened to me so that other people wouldn’t have to go through that same experience. I’d been told that I was ‘unique’, that there may be only one or two people like me in the world, but I took a chance. I set up the website and wrote the information because there was nothing to be found on hypoparathyroidism anywhere in the UK or on the internet. And I set up an online forum with it because, having discovered the existence of a group in America, I felt sure there must be other patients in the UK too and I wanted to provide a way to find each other and a place to meet. I was expecting 3 or 4 people, maybe, but gaining 100 members practically overnight was a sign of things to come. I was both overjoyed to find others in the same boat and horrified at the extent of the silence about this condition. We’ve been shouting about it ever since.’

We’ve come a long way. Today we have over 1400 members, a significant number for a rare condition, and we are a recognised name around the world. We remain the only official source of information in the UK, informed by patients’ experiences and with the medical backing of our clinical advisory team. Read more inside about how far we’ve come….and where we plan to go.

So, come and meet old friends, make new ones, have a good time and help to raise awareness about Hypopara while you’re at it. Contact Catherine Smith (catherinesmith@hypopara.org.uk) to be put in touch with your local group.

Hypopara guidelines - the journey

They have been a long time in the making but at last guidelines on the diagnosis, treatment and prevention of hypoparathyroidism are on their way and we are proud that Hypopara UK has been involved all the way along this very necessary journey. We raised awareness about hypopara and highlighted the need for a consensus statement on hypopara in 2005. We attempted to bring together, in 2008, an international group of doctors to discuss and develop guidelines but did not have the funds to carry it through. Happily this event has now occurred and we were delighted to be represented. We brought together a group of doctors interested in hypopara in the UK, on our advisory team. We published the first patient information leaflet as the first step towards flagging up the need for guidance. We have made our needs known in every corner of the medical world and kept them alive in people’s minds. It’s been a long battle.

From the International Hypopara Conference in Florence, which Hypopara UK attended, there will be 3 papers and one guideline/commentary produced. These are still being finalised. ‘So there will be a lot written’ says Dr Dolores Shoback, well known hypopara specialist who contributed to both events. The ESE (European Society of Endocrinology) commissioned the Guidelines on the treatment of chronic hypoparathyroidism in adults, which were presented in Dublin last month. Hypopara UK was there. We were invited to contribute to the draft recommendations and the accompanying patient leaflet. The final documents are due to be published any day now.
Hello everyone!

Our 10th issue in our 10th year is cause for celebration and developments in the hypopara world mean that it has been a remarkable year for Hypopara UK. We are on the brink of change and foresee exciting times ahead! Here is a summary of what we've been up to and a taster of what else you can find inside this newsletter.

World Awareness Day and online shop

1st June is World Hypopara Awareness Day, the day when the global hypopara family unite. To celebrate, we launched a brand new World Hypopara Awareness Day website at http://www.hypopara-awarenessday.com

We have also opened our brand new online shop and we ran a social media campaign on the day. We loved seeing profile photos of you all flaunting your WHAD t-shirts! You can buy a t-shirt (and more) from our website shop here http://www.hypopara.org.uk/home.php?id=264, or from our Facebook shop Hypopara UK Shop, eBay and from the WHAD website store too. Please support us.

Too late for 1st June? Download the Awareness Day logo to your profile instead and buy a t-shirt anyway. You don’t have to only wear it once a year! Don’t forget to keep checking back to the shop as stock grows.

Hypopara Guidelines

Last year we saw the first emergency guidelines for hypo and hypercalcaemia published and had input into the Thyroid Cancer guidelines and related patient information. The big news this year is that not just one but two sets of hypopara guidelines are on their way. After campaigning for this for 10 years this feels like a massive result. Soon, your doctor won’t just have to take your word for it! I was in Florence at the International Hypoparathyroidism Conference and was invited to submit comments to the European Society of Endocrinology recommendations after they were presented in Dublin, and will also be reviewing the patient information that will accompany them.

Clinical Trials

The PARADOX study was published this year, the first piece of research to look at the burden of illness experienced by hypopara patients, in America. We have been given permission to publish the full paper on our website, for members only. http://www.hypopara.org.uk/resources.php?id=225. Many thanks to those members who participated in a usability study in London for a multi-dose injection pen being tested as a means of delivering PTH. We have been involved in various projects and proposals this year, in particular, with surgeon Saba Balasubramanian looking at ways and means of preventing post surgical hypopara and Raj Thakker establishing a database with phenotyping for hypopara patients. Sadly both bids were turned down by NIHR but the interest in hypoparathyroidism is growing along with interest in rare disease strategies and we are confident that further proposals will come our way.

Patient involvement was again in evidence when surgeon Radu Mihai recently invited us to contribute ideas for future research on thyroid and parathyroid surgery. We expect to be involved in patient surveys about living with hypopara this year so please do participate – your words WILL count. We will email you.

Medical Conferences

This has been an extraordinarily busy year which saw the Hypopara UK butterfly spreading its wings and heading overseas for the first time. We are trying to represent Hypopara UK as much as possible and make our presence felt as interest grows in rare disease, PTH and patient involvement. It seems to be paying off. Judith Taylor and Claire Butchers represented us in Sacramento at the Hypoparathyroidism Association Conference, and Judith also attended the Rare Disease Congress in Brussels. Isabel Wray went to Birmingham with husband and baby too, probably the first ever breastfeeding exhibitor SIE have ever had! Bill Glenister and I exhibited in London, in Liverpool with Mandy and Judith, and in Manchester with Ray Finlay. In May, I was moved beyond belief to find myself in Florence at the first International Hypopara Conference (more later) and the following week saw Ray again, Blaithin O’Donnell and Conor McCallion exhibiting in Dublin at the European Congress of Endocrinology. Still to come, the BAETS conference in October (yes, we have finally been invited to attend the surgeons annual conference!) in Henley and the BES conference in Edinburgh in November.

Natpara

Natpara, the full length parathyroid hormone (PTH 1-84), was finally approved by the FDA in the US in January and the first American patients have been receiving their kits this month. In Europe, the European Medicines Agency (EMA) validated and initiated its review of NPS Pharma’s marketing authorization application for, what will be known in Europe as, Natpar. We have been working closely with NPS who have recently been taken over by Shire. Just before Christmas, Isabel, Judith, Bill and I gave a presentation in Marlow to the entire NPS company, including European staff, about living with hypoparathyroidism which we were asked to do in order to help them towards a better understanding about why their product is needed. We wait for news from Europe….

Fundraising

Claire Butchers applied to her employers, Lloyds of London, who give awards to employees who do voluntary work with charities and won an award for us of £2,000. Fantastic! Bill accompanied her to the reception and presentation. Not only that, she had a word and they followed it up recently with another £400. Thank you to Lloyds and great work, Claire! We have had 2 sponsored events taking place recently - a sponsored 26m toddle by Isabel Wray’s son Rafael, and Gillian Adams’ brother did 40k over 4 weeks. You can still support them by donating. We have been very short of fundraising events this year so please do look at the website page and see how you could help. We also need someone to take on the Fundraising Officer role, please. Any offers? You need initiative, ideas, organisational ability, must be handy on the computer and social media, able to write good publicity and persuade and encourage others! 2-3 hours a week max.

Endocrinology recommendations after they were presented in Henley and the BES conference in Edinburgh in November.

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News from our Medical Advisors

Dr Rachel Crowley
Dr Crowley is an endocrinologist at St Vincent’s Hospital in Dublin where she will be working with the Irish branch of Hypopara UK. In 2008 she was shortlisted for the prestigious IJMS/RAMI award for the best published paper in the category of Endocrinology and Diabetes

Professor Raj Thakker
We congratulate Professor Thakker on his wonderful achievement in becoming a Fellow of the Royal Society, where he delivered a lecture on ‘From Rhinos to Molecules’ about where the discovery of the parathyroid glands has led to. He will be giving this talk again at the BES in Edinburgh so we may be lucky enough to hear it then. We are extremely proud to have Professor Thakker on our Advisory Team. Last summer he put in a bid to establish a database with phenotyping for patients with hypoparathyroidism, to help future clinical trials and assessments of biomarkers. We were disappointed this wasn’t successful but hope it will be in the future. Prof Thakker was also a speaker at the international hypoparathyroidism conference in Florence.

Mr Radu Mihai
Surgeon Radu Mihai wrote to all surgeon members of BAETS and ENT-UK in March, asking for their views on possible research projects of interest in the field of thyroid-parathyroid-adrenal-NET pancreatic surgery. This invitation was also extended to patients and their representatives. Our members sent in many good ideas and we look forward to the outcome.

Mr Saba Balasubramanian
Surgeon Saba has been working hard to find ways to prevent post operative hypopara. He has been working on the development of a prediction tool to enable implementation of directed treatment, a study of intra-operative devices aimed to increase ability to identify and preserve normal parathyroid glands, and a study of an imaging device with intravenous Methylene Blue for use in thyroid and parathyroid surgery. He is also hoping to carry out a study on the prevalence, severity and outcomes of hypoparathyroidism in the general population in the UK, in conjunction with Hypopara UK and is currently looking for funding. You can read his paper on predictors of post surgical hypoparathyroidism here http://www.ncbi.nlm.nih.gov/pubmed/24780788 or via our website here http://www.hypopara.org.uk/resources.php?id=225

Dr Gittoes, Dr Selby, Dr Turner
These advisors continue to educate new consultants and trainees about hypopara at Clinical Update meetings and others every year which Hypopara UK attends. Though we didn’t make it this year, Dr Turner kindly added our logo to their powerpoint presentation slides thus giving us a presence! He has also developed the Emergency Guidance for Acute Hypo and Hypercalcaemia for health professionals which may be accessed via our website here http://www.hypopara.org.uk/resources.php?id=249

Dr Gittoes and Dr Selby also see a number of our members from around the wider Manchester and Birmingham area, who, failing to be adequately supported by their local endocrinologists, are referred by their GP’s. Members are proving over and over that they would rather travel to see a specialist experienced in managing hypopara, in order to feel in safe hands.

Dr Jeremy Allgrove
Dr Allgrove was praised by hypopora UK members this year after he stepped in for a dramatic rescue! Read Vincent’s story here.

Professor Bill Fraser
Last but certainly not least, our lead Prof Fraser also attended the Florence conference where he posed many questions to speakers, ensuring a good discussion ensued. Prof Fraser is still waiting for MHRA studies to be finalised so that he can commence the oral PTH clinical trial here in the UK. We will keep you posted.

Money matters
We have been very fortunate to receive two grants from NPS/Shire in this period which are being used to keep us going and provide the usual needs, materials, conferences etc. We welcome our new volunteer accountant Andy Smith on board who will be looking after the accounts and gift aid for us now that our income is getting a bit bigger. As we have properly made it over the £5,000 mark for the first time we can now apply to become a fully registered charity and we are meeting with Andy this month to start the ball rolling. We continue to survive on donations, grants and our own fundraising. We have given £500 each to Hypopara Australia and Hypoparathyroïdisme France as start up grants. This is the way that the US association helped us in 2005 so we’re paying it forward and growing the hypopara family. Otherwise, income goes directly to keeping the office going, providing information, patient support and awareness raising that is such an essential part of our work.

Rare Disease Day
This year we focused on our youngest member, the amazing baby Vincent, to highlight rare disease and his picture appeared on the Rare Disease Day website. Read his story inside.

Advocacy
We are happy to report that our advocacy letters in support of those claiming or appealing benefits seem to be helping. Not in every case but certainly some. With a rare disease we feel it is important for us, as a patient organisation, to back up our members and furnish an explanation of the condition and how it affects them, which we feel is not something your average healthcare assessor always understands.

Local Groups
Committee member Lisa Burke organised the first ever group meeting which was held in London last summer, a great success! More are on their way. Lisa is now back in full time work and Catherine Smith has kindly taken over as our new Local Groups Co-ordinator. Please get in touch with her at catherinesmith@hypopara.org.uk if you would like to join your local group. The new Ireland group is being set up by Blaithin O’Donnell in Dublin. Groups will be meeting around the whole country in due course, so if you live in Ireland or Northern Ireland you can email blaihinthodonnell@hypopara.org.uk

Committee News
We are very sad to say goodbye to Bridget O’Connor and Emma Thomas who gave us so much of their time and effort and we also send our warmest wishes to Judith Taylor, Claire Butchers and Su Clifton who are all taking health breaks at the moment. We are delighted to welcome Blaithin O’Donnell to the committee as our new Ireland Co-ordinator.

Thank you
As always, I want to thank you, our members, for your patience and support. There has been much illness this year and with such a small team of people (who have hypopara themselves) and with so much happening for Hypopara UK this year it has been a mammoth task to get the newsletter out again so I hope you will forgive the delay. I also want to thank our committee for all their hard work this year which has made such a difference. There couldn’t be a nicer bunch of people. We are all looking forward to finding out what next year will bring. Onwards and upwards!

Warmest wishes to you all

Liz
Hypopara guidelines - the journey

First International Hypoparathyroidism Conference, Florence. May 7-9th - Liz Glenister

In early May, Bill and I boarded Eurostar at the start of what would turn out to be an extraordinary adventure. I was anxious because it had been many years since I had travelled anywhere but also very excited because not only was I going to meet people I’d been working with online for 10 years yet never met, but we were all going to the first ever international conference dedicated to hypoparathyroidism. How could I not go?

We had a magical train journey over the Alps to Florence, where the conference was being held, a place I had always dreamed of visiting. It didn’t disappoint. On the steps of the Duomo, above the groups of Japanese tourists with selfie sticks, we waited for Helen Dahl Hansen, President of the Nordic Hypopara Organisation, and her husband Erik. What a joyful, tearful meeting! How much we had to talk about! With both our organisations reaching their tenth anniversary this year, our meeting seemed a fitting celebration. The next day I met James Sanders, President of the USA Hypoparathyroidism Association and that was a very emotional meeting too!

Later, Gudrun Ruth Viddarsdottir, founder of the erstwhile Hypopara Europe, arrived from Iceland with her twin daughters Halla Ruth (of early PTH fame) and Silija, completing our little group of hypopara pioneers. I can’t really find the words to express how we all felt, it was a wonderful moment in all our lives - one that none of us had ever thought would happen and one that we shall never forget.

The conference was held at the beautiful Palazzo Ximenes Panciatici, home of the Fondazione Menarini and was brought into being by Professor Maria Luisa Brandi of Florence. I’d first discussed the idea of guidelines and an international conference with Professor Brandi back in 2008 so I was extremely happy to see this event finally take place, especially with the Hypopara UK banner standing proudly at the door.

There was an eminent gathering of endocrinologists from around the world, including members of our own advisory team, Professor Raj Thakker who gave a most illuminating talk on genetics and hypopara, and Professor Bill Fraser who was notable for his pertinent and revealing questions. Representing patients, James Sanders told his own story, making a powerful plea for our voices to be heard and Helen described emphatically the need for patient empowerment. They talked about the history of the hypopara organisations, including Hypopara UK of course, and our shared hope for the future. Over 3 days, every possible aspect of hypopara was discussed and I found it a completely fascinating experience. This was hypopara history in the making and I felt honoured to be there.

Prof. Maria Luisa Brandi described the event as ‘the first international conference bringing together the world’s foremost researchers to discuss diagnosis, management and treatment of hypoparathyroidism. The work of the conference was enlivened by panel meetings on the major themes discussed at the plenary session, which aimed at producing joint documents, true points of reference for new shared guidelines for hypoparathyroidism management. The event accompanies the scientific community’s renewed interest in a condition that has been “forgotten” for too many years.’

Read the rest of her speech here along with the highlights of the conference, including some of the abstracts, which I think you will find fascinating: http://www.en.fondazione-menarini.it/Archived-News/2015/1st-International-Conference-on-The-Diagnosis-Management-and-Treatment-of-Hypoparathyroidism/Highlights

If you sign up here then click on ‘Archived News’ you can also read the entire abstract book and watch video interviews with some of the doctors. Really worth doing! http://www.en.fondazione-menarini.it/

News about Natpara (Natpar)

In January we had the news we were waiting for. The US Food and Drug Administration approved Natpara to control hypocalcaemia in patients with hypoparathyroidism. Natpara, a bioengineered replica of human PTH, is now available in the USA and the first patients are beginning treatment this month.

The approval was supported by 12 pharmacology studies and four company-sponsored efficacy and safety studies. The pivotal Phase 3 study, known as REPLACE, was a randomized, double-blind, placebo-controlled study and the largest clinical trial conducted to date in patients with hypoparathyroidism. Our grateful thanks go out to the ten members of Hypopara UK who took part in this trial (and were the second largest cohort after the USA).

This news marked an important milestone in the treatment of hypoparathyroidism and we now hope for a positive outcome in Europe. In December last year, the European Medicines Agency (EMA) validated and initiated its review of NPS Pharma’s application for Natpar, as it is to be known in Europe.

NPS Pharma has recently been taken over by Shire. So far this has proved to be a seamless transition.

"It is hoped that the commitment to patients, the passion for developing new treatments and the efforts to raise awareness will be enhanced," says Liz Glenister.
Fascinating papers on the calcium sensing receptor, pseudohypopara, PTH assays, PTH actions, genetic forms of hypopara, imaging, and refractory hypopara were presented. These were quite dense for non medics but you can read them in the abstracts link below. Other papers were given on the epidemiology of hypopara in the USA, Russia and the EU but not the UK which highlights the need for these studies here, as well as a quality of life survey and a UK patient registry.

New treatments are on the way! A favourable report was given by Dr Winer on the use of the insulin pump with parathyroid hormone 1-34 (Forteo) on patients with post surgical hypopara and children with congenital hypopara. There was less fluctuation than when injections were used, less need for magnesium supplementation and urinary calcium excretion was reduced. For APS-1 patients, delivery by injection or pump multiple times daily provided effective management. Dr Bilezikjian reported on the PTH studies over the years with particular emphasis on PTH 1-84, as being able to replace ‘what is truly missing’. Safety is still a concern (approved by the FDA with a warning due to bone cancer in rats given massive doses) but he stressed that over 12 years of trials no signs have appeared in humans to suggest increased risk of osteosarcoma. The oral PTH trial to be run by Prof Bill Fraser will go ahead and is waiting for tests to be finalised.

Of particular interest to us were the many points which emerged from the talks on the causes, treatment and management of various types of hypopara. It was good to hear doctors backing up our findings with their own, and fighting our corner, even if they weren’t in total accord over some of the detail. There was some disagreement, for example, over whether pre-operative vitamin D deficiency presented a risk factor but most studies agreed that the need for continuous calcium and vitamin D defined permanent post operative hypopara. In Italy, Dr Bellantone described the use of PTH measurements in overcoming the difficulty of predicting which patients would need post operative treatment. I was sorry to hear from Dr Dralle that auto transplantation had not been effective in Germany where up to 7% of total thyroidectomy cases end up with permanent hypopara - the second most frequent cause of thyroid surgery related malpractice claims. He stressed the risks of renal problems and basal ganglia calcifications, the latter finding being reiterated by Dr Mannstadt of USA who also mentioned risk of cataracts and dental problems due to bone issues. He carries out tests every 3-6 months in well controlled patients, annual 24 hour urine test and a kidney ultrasound as a baseline and then 5 yearly.

He stated that a key aspect of ongoing follow up is to ‘engage the patient as a partner in his or her care’ and for patients to have a basic understanding of the condition and the signs and symptoms indicative of complications. It was a wonderful thing to hear a doctor explain to a room full of doctors that the patient might actually understand more than their own doctor due to the rarity of the condition, and that care from a specialist or provider familiar with the treatment is critical.

Dr Cusano from Columbia, New York explained calcium and vitamin D therapy in detail. It does not always maintain serum calcium levels and long term use can cause renal problems and soft tissue calcifications. It does not improve quality of life or reverse the abnormal low bone modelling in hypopara. Calcium carbonate should be taken with meals but calcium citrate may be taken at other times and is more effective with PPI’s or if constipation is an issue. Natural forms are not recommended as they contain lead. Amount required varies greatly from 500-1000mg 2-3 times daily. Calcitriol reaches peak concentration 3-6 hours after taking and serum calcium concentration is increased within 1-3 days. The elimination half life is 5-8 hours in adults and a typical dose is 0.25-2mcg daily in divided doses. Alphacalcidol is activated in the liver and reaches peak at 1-3 days with a longer offset of 5-7 days. A typical dose is 0.5-3mcg. The half life of vitamin D3 is 2-3 weeks. Thiazide therapy effects calcium excretion within 3-4 days and the dose is 25-100mg daily. Higher end doses are needed to reduce urinary calcium but this can also reduce potassium levels. Prof Thakker raised the importance of potassium testing as standard and Prof Fraser the need for red cell magnesium testing. Dr Rubin emphasised the need for magnesium correction and frequent calcium testing. He stated that as ‘a normal level of ionized calcium is critical for many vital cellular functions, acute hypocalcaemia in hypopara patients can be a life threatening emergency.’ He called for acute management to be guided by ‘the level of serum calcium and most importantly by the nature and severity of the symptoms’ and advocated IV calcium as a means to safely increase levels and relieve symptoms.

Nutritional aspects were detailed by Dr Rizzoli of Switzerland which makes for an interesting read to those of us who are trying to achieve stable calcium levels with diet. He is an advocate of dairy products, particularly milk and live yoghurt, as calcium is better absorbed with protein and they also contain more calcium, magnesium, potassium, zinc and protein per calorie than any other food. They do contain high levels of phosphorous too however so be moderate. He recommends calcium is always taken with a meal. Magnesium deficiency and the foods which help bone resorption are also discussed.

Read more here (Archived News)
http://www.en.fondazione-menarini.it/

Liz Glenister
The European Society of Endocrinologists holds a conference each year where advances and research are presented and discussed. This year ECE 2015 was held in Dublin’s convention centre with 3000 attendees and Hypopara UK were one of the six European patient groups that were invited to attend and to create awareness among the medical profession and ask them to spread the news to their patients about their support groups. As I received 3 volunteer days from my employer (Carlson Wagonlit Travel) I was able to attend all 5 days of the conference.

Ray Finlay flew over from the UK for the day to help me set up and show me the ropes and the following day Conor McCallion interrupted his exam studies to travel down from Belfast and help out for a few days also. Conor stayed over with me and survived the O’Donnell family experience and helped celebrate my birthday on the Monday with pizza and prosecco! He is now ‘one of the family’ and was delighted to have finally met a fellow Hypopara person. The conference was a great success for us and as there were many Irish endocrinologists there with the event being held in Dublin this year, I was able to create contacts which will enable me to liaise with many more Irish Hypopara sufferers.

We were struck by the relatively low attendance of UK endocrinologists but the high number from other European countries, particularly Spain, Greece and various eastern European countries. We had many conversations about how Hypopara is treated in their countries and noted many of the eastern European countries’ reliance on one or two medications due to the cost involved with others. Alfacalcidol was a popular drug but some endocrinologists said how some patients did not respond well yet Calcitriol was too expensive to prescribe and/or they were not allowed by their governments to prescribe for cost reasons. In further conversations regarding the new PTH drug currently seeking European approval they expressed concern about the cost and wondered if they would ever be able to prescribe it to those patients that don’t respond well to other drugs.

We also got to sit in on some of the lectures and met many of the presenters, establishing vital links with them. Of particular interest were 2 lectures on the new guidelines for treatment of Hypoparathyroidism which were led by a multidisciplinary team, including a Spanish ENT physician Antonio Sitges-Serra, Dolores Shoback from the US (she presented the study on PTH trial the previous day) and Jens Bollerslev from Oslo. Areas covered included treatment post surgery, ongoing and during pregnancy.

These guidelines are being refined and will be sent to all European endocrinologists but Conor and I were so pleased to see an alignment on many of the guidelines with what we have been promoting in Hypopara UK: intake of magnesium, vitamin D and blood tests a minimum of every 4-6 months, even for stable patients. Our own Liz Glenister is also providing input on these guidelines and Antonio Sitges-Serra congratulated Hypopara UK on our proactive and partnership approach. He knew all about us and says he regularly talks about us as an example of a great patient support group!

As Natpara PTH is not yet available in Europe it did not form part of the guidelines but of course these can be revised in the future to incorporate PTH as this will be a useful addition to the toolkit. Overall the conference was a great success, building on previous partnerships with the endocrinology community and hopefully by ECE 2016 in Berlin we will have more advances to shout about.

Blaithin O’Donnell

ESE Guidelines on the treatment of chronic hypoparathyroidism in adults, Dublin

The draft recommendations presented in Dublin have now been reviewed by doctors and patient organisations around Europe, including Hypopara UK. The final guidelines document will be published any day now so keep an eye on our website.

In the absence of guidelines and regular testing, patients have had to work out their own means of survival over the years and identify their own strategies for self management. We know what works. I wasn’t expecting to see these same strategies recommended in the draft guidelines but they were there, very many of them, and that filled me with hope for the future. We are being listened to.

Final thoughts…

Patients will now have official support from two sets of guidelines, and doctors, trying to deal with a rare condition, will have professional guidance that explains how fluctuating calcium levels affect us. I hope this means that your visit to the doctor will be less of a battle and your symptoms will no longer be brushed off so easily. ‘No, I’m not talking nonsense – look, it’s in the guidelines!’ I hope that the two sets of guidelines support one another; I hope that what remains in the final versions is what we want to see, and reflects our needs accurately; I hope that doctors will take on board the call for necessary testing, adequate vitamin D and magnesium levels and “personalised treatment that focuses on the overall well-being and quality of life of the patient.”

We’ll keep you posted!

Liz Glenister
New website launched
We launched a new website dedicated to World Hypopara Awareness Day. It features the various butterfly logos of all the world's current and up-coming hypopara organisations which, when clicked, link to their websites. The website was set up by Liz Glenister, as a visual reminder to the internet world of our global presence and as a means of helping new patients to find their own country's organisation. ‘The global hypopara family is growing and it’s very exciting to see new organisations being set up around the world. I was looking for a way to make our presence known to new patients, researchers and pharma, and the website seemed like a good idea,' says Liz. ‘We have fantastic feedback from all the groups involved and look forward to more organisations being registered soon.’

The website also has its own shop where you can buy the official World Hypopara Awareness day t-shirt. Proceeds from this site will go towards a Global Awareness Fund and help to maintain the website.

Visit the new Awareness Day website here
http://www.hypopara-awarenessday.com/

Hypopara UK shop
We also set up our first online shop run by committee member Gillian Adams and which also sells the World Awareness Day t-shirt, amongst other things. New items will be added so keep on checking back! Proceeds from this shop will go to Hypopara UK. You can access the shop from these sites below and if you have any questions please email Gillian at shop@hypopara.org.uk

Hypopara UK Shop on Facebook

Hypopara UK website shop here
http://www.hypopara.org.uk/home.php?id=264

Hypopara UK eBay shop. Log in and go to http://www.ebay.co.uk/usr/hypoparaukshop

Facebook campaign
We also set up a World Hypopara Awareness Day Facebook page, brilliantly administered by Gillian Adams, which received thousands of visitors. Then we ran a t-shirt campaign which was really successful. Thank you to everyone who joined in with our Awareness Day Facebook campaign by buying a t-shirt and posting a photo of themselves on our Hypopara UK page. Loads of you also switched your profile picture to our beautiful World Awareness Day logo, produced by committee member Isabel Wray last year. The day was exciting and moving as we watched hypopara friends from all around the world post their photos. As Gillian posted on the day 'It is amazing to see so many people liking, commenting and raising awareness of Hypopara and parathyroid conditions on here today! It is truly awesome and I feel part of something very special! Thank you to everyone who has visited this page and left a message, a photo or even just a like!'
Welcome our new Local Groups Co-ordinator...

Catherine Smith

I have been recently diagnosed with HDR syndrome which has caused me to be partially deaf with impaired kidneys since childhood and to develop hypoparathyroidism in my 30s. I became an insulin dependent diabetic as a teenager. The original kidney issues and diabetes led to renal failure so I had a kidney and pancreas transplant in 2008. I feel very fortunate to have had my three sons despite various medical problems. In a former life, I was a Physics/science/maths teacher but I retired due to ill health when I was 47 and now I’m a sucker for volunteering! If you would like to join a local group and meet up with others face to face, email me on catherinesmith@hypopara.org.uk and I will put you in touch with your local co-ordinator. Meetings will be informal to start with and it will be up to each group whether they choose to be a social group or do some fundraising or even hold an awareness/information meeting, or all three. Either way, come along and find a hypopara friend to celebrate our tenth anniversary!

...and our new Ireland Co-ordinator!

Blaithin O’Donnell

I’m sure you’re all familiar with our lovely Blaithin by now! She’s been a staunch supporter of Hypopara UK for some time. However, she has also recently taken on the role of our Ireland Co-ordinator so we’d just like to say welcome and thank you!

blaithinodonell@hypopara.org.uk

New hypopara patient organisations around the world

As you know, Hypopara UK has founded two new hypopara organisations (Australia and France) and supported them along the way. They are now standing alone and proud! You can visit these and other organisations on the new World Awareness Day website at www.hypopara.awarenessday.com

Hypopara Australia

Hypopara Australia was founded in 2011 and was initially run by Aussie Sharon Bassell who set up the Facebook page. She is now on the committee and runs the lively Facebook group too. The website was set up by Jo Thorburn and the new Chair has brought together a committee who are working hard to establish the organisation and their board of medical advisors. On page 9, Chair Tommy Ravlic introduces himself and shares his personal journey with hypopara.

Hypoparathyroidism France

Founded in 2014, the French hypopara organisation is now officially registered. Congratulations to President Natalie Grosset–Holenka and Vice President Beatrice Le Chevert who have worked so hard to bring this much needed organisation into being. They have two consultants already on board, one who led the Natpara tests in France and the other, the only paediatrician specialised in Hypopara in France. The new website is about to be launched at www.hypopara.fr. Keep checking, it will be there soon! For further information or to contact Natalie please email association@hypopara.fr

Meanwhile they operate a busy hidden Facebook group where they and their committee support all French speaking hypopara patients around the world.


NEW SCOTTISH HELPLINE

Thank you to Gillian Adams who has completed telephone helpline training and established a new helpline number, primarily for our Scottish members.

01475 522576

HYPOPARA • AUSTRALIA

HYPOPARATHYROÏDISE FRANCE
It only took 43 years for me to speak to somebody that has the same disorder with which I was born. That is – by any stretch of the imagination – a rather long time. In fact, the conversation took place on my 43rd birthday. You see, I have never until recently seen or spoken to another patient with hypoparathyroidism. I had spoken to my parents who were my primary carers. Endocrinologists and doctors were the other people with whom I dealt. But at no point did I have this conversation with somebody that felt the same way, knew the disorder intimately and was able to have true empathy for its effects. The ability to have the conversation with somebody who knows what the condition is and how it affects a person was a godsend, a moment that will remain unforgettable. Up to that point I felt completely isolated and at times prone to a touch of depression.

Why?

You would think being surrounded by loving family and friends that it would be easy to handle having hypopara and that familial support would lend itself to you feeling better about your chances of fighting the disorder. That is true to an extent. Familial support is important, but nobody in a family can truly share the feeling of the disorder with you unless they have experienced it themselves. No member of my family has hypopara, you see. I have had it since birth and have grown up with the routine of blood tests, visits to specialists, periodic adjustments of doses of medication and at times panic attacks about symptoms that were not hypopara related. I am what I refer to as ‘limited edition’ in my family and the disorder has very much shaped the lifestyle of the family during my childhood. I was one of only two infants diagnosed with hypopara at the Royal Children’s Hospital in Melbourne, Australia in 1971. What readers must remember is that around that time any treatment of infants with the condition was experimental. Doctors were only beginning to get their hands around what the treatment should be for infants in order to ensure the disorder is reined in and the infant can be stabilised.

My parents went through hell. Both were learning English at the time and struggling to come to terms with the fact their newborn son had something rather odd. The medics did all sorts of tests to attempt to work out what was wrong with me at that time. I fell into at least three comas during the attempts by doctors to treat me and stabilise the condition. My parents were at one stage told that the best prognosis for me was that I would be retarded and might need to be placed in a home. So much for the medical fraternity’s knowledge of the implications of hypopara for infants at that time.

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It goes without saying that I have not seen the inside of a home and my career has been nothing short of remarkable given what some individuals had forecast would be the case with me.

There were activities that were out of the question for me because of the delights of fatigue and the need to rest up as a youngster. Sport could only really be tolerated in short bursts while other children were able to do more in the sporting department. I spent my time behind the covers of books, writing stories, learning music and writing songs. Music is a passion of mine and that was in part due to the fact my parents brought me up to learn the organ and piano. Quite apart from the cultural benefits, playing these instruments actually helped strengthen the muscles in my hands and as such over the years there was less of a chance of tremors making too much of a hassle. My fingers are as strong at this time as they were when I first began to play the piano and organ. There were therapeutic benefits to music from the point of view of exercise. It also taught me a means to deal with the isolation this disorder was going to make me reflect on for much of my life.

Nobody understood what the disorder meant. Nobody really understood why I got sick or lost my voice as a teen. It marks you as different and as such schoolyard taunting for no good reason becomes the norm. While I have eye trouble that can be dealt with individually and partial hearing loss, both of these were in some form due to the fact that my main hassle health-wise was hypopara. All of these things are interlinked, which is why it infuriates me still to this day to hear that people are being sent to individual specialists and not being treated holistically as a person with a disorder that has many different ways in which is can affect the patient.

Do I get symptoms of hypopara still even though I have had it since day one? The answer is most definitely. Forget a dose of calcitriol. I will feel that by midday. Fail to take the calcium dose by mistake the night before and I feel a bit of tingling about the face. All of these things are interlinked, which is why it infuriates me still to this day to hear that people are being sent to individual specialists and not being treated holistically as a person with a disorder that has many different ways in which is can affect the patient.

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Life for the current time is full and has its challenges. I have to some degree been successful in not allowing the disorder to completely dominate my life but I concede that things can be unpredictable. That’s why I am dead keen to pack as much in as I can while the going is relatively good. Who knows will happen further down the track!

Tommy Ravlic
Judith’s journey
In June last year, Claire Butchers and I travelled to Sacramento to represent Hypopara UK at the 8th International Conference on Hypoparathyroidism. We travelled out separately. Sacramento is not an easy destination from Europe, so to avoid hanging around airports while we waited to transfer to a local flight, we met up at San Francisco airport and picked up a rental car to drive ourselves to the conference hotel.

Nearly 200 patients and carers attended the conference and it was an amazing experience to meet some of the people we know from Facebook and from the various online hypopara forums face to face.

I was impressed by the way the conference was organised and by the stellar line-up of clinical experts, many of whom I knew by reputation. This was cutting edge information, some of it not yet published, and the speakers took the issues faced by hypopara patients seriously, treating them to a great extent as partners rather than patients. As a former scientific and medical publisher I consider myself fairly well grounded in edge information, but it was very reassuring to see this quality on such a large scale.

The few days that the conference was on for was packed full of different speakers, some of whom were patients telling their stories and more importantly, doctors knowing, understanding and giving advice on how to handle and monitor our condition. I still cannot believe that there were so many there who had hypopara through surgery!

The conference gave Claire and I a lot of information to think about, and was also a great learning experience in how to organise a patient conference as we hope to run our own patient conference in the UK in the near future.

Judith Taylor

Claire’s journey
I was lucky enough to be chosen to represent Hypopara UK for the 8th Annual US Hypopara Association Conference in June of this year. I was as anxious about my journey to the States as I was about attending the conference. The first morning of the conference was a very surreal moment for myself as I looked around the room of about 200 people all with various forms of Hypopara - up until that moment I had only met three other people like myself! The truth was brought home further by them getting all those that have non-surgical hypopara to stand up. Those left sitting down, which was more than three quarters of the room, were all post-surgical hypopara - it was like being part of the medical profession’s best kept secret! I still cannot believe that there were so many more than we have learned is the case in the UK. However, several doctors I spoke with at the conference said the figure is probably higher than this, at around 7%. Claire and I were given a spot on the programme to talk about the work being done by Hypopara UK and Clare spoke movingly of her own personal journey – like many others we met at the conference, Clare has permanent hypopara after surgery for thyroid cancer.

My own story is a bit different. I have “been there, done that, didn’t quite get the t-shirt”. I have had two surgeries for thyroid cancer, several years apart. The first resulted in the loss of one parathyroid gland. I had mildly low blood calcium and was told to drink milk regularly but I never experienced anything worse than mild tingles. I knew nothing about this, other than the fact that my calcium levels were routinely tested every time I had thyroid blood work. Then, decades later, I developed primary hyperparathyroidism (caused by one overactive parathyroid gland) and needed yet another neck operation. I now have just two parathyroid glands but thanks to the combined skills of three endocrine surgeons and some good karma they both work.

It is thanks to James Sanders and his team that I learned that Liz Glenister was starting up a UK hypopara group. I had joined Hypoparathyroidism Inc in the early days following my parathyroid surgery as I was looking for information about patient support for primary hyperparathyroidism, both to offer my help and to learn more about the condition myself. James placed an announcement from Liz in his newsletter and I contacted her offering to help with the UK group. So it was a special privilege to meet James in person.

The few days that the conference was on for was packed full of different speakers, some of whom were patients telling their stories and more importantly, doctors knowing, understanding and giving advice on how to handle and monitor our condition. I also made some lovely new friends whilst attending this conference who each shared their very own unique and personal stories with me. However, the most terrifying part of the conference was when Judith and myself were asked to give a short presentation about Hypopara UK and ourselves. Judith started with a good overview of the charity, who we are and how we operate to assist those diagnosed with hypopara. This was then to be followed by “my story” or what should probably be better known as “my journey”. It was tough to share something so personal with so many people that I did not know. I remember looking out into the audience to see people with knowing faces and tears in their eyes. All of a sudden I found it very hard to continue and thank goodness Judith was there to give me words of encouragement and hold my hand to get me through the rest of my story.

I am so pleased that I was able to attend the conference and that I overcame many of my different fears associated with hypopara by doing so. Even now I still talk to lots of different people about my time at this conference and the memories will stay with me always.

Claire Butchers

We are grateful to NPS Pharma for financial support towards sending Judith and Claire to the conference.
What's been happening in our new online shop?

Well, what can I say? It was a bit of a hectic run up to World Hypopara Awareness Day! It started at 3am one morning early in May, when I suddenly realised I had started, but not completed the online order for the t-shirts! (Let's just blame my hypopara brain fog and NOT my age!)

I was sick with worry that they wouldn't be ready on time, but thankfully Clothes2order were very efficient and had them done very quickly and the orders for WHAD t-shirts came in nice and regularly over the next fortnight. We now have WHAD t-shirts being worn in Canada, Denmark, Holland, Portugal and the US as well as here in the UK. Fantastic!!

I was also very lucky to get some bumper stickers and envelope stickers produced by my younger brother through his employer and these were donated to the group. So keep a look out for the Hypopara butterfly on the rears of cars in front of you and on your mail.

Now, after all the celebrating of World Hypopara Awareness Day which was a HUGE success thanks to the hard work of everyone involved, we need to look to the future. What next? Well, raising awareness and spreading the word about Hypopara and Parathyroid conditions is still necessary and the shop is hoping to get in some new merchandise in the form of Hypopara UK pens, pencils, shopping bags, tea towels and some new t-shirts with a couple of new designs, to do this.

I would like one of these designs to be the result of a competition!

I would like all our younger members (17 and under) to come up with a new design for a t-shirt specifically for young people. Something that they can identify with and sets them apart from us…more mature members. The winner will have their design put on the t-shirts, will also win a prize and will be announced on the website. The design should fit on an A4 piece of paper. Designs should be emailed to shop@hypopara.org.uk before the end of August and the winner will be announced in September.

Good luck!

Gillian Adams

Hypopara UK Online Shop

The Hypopara UK shop is finally up and running and it's busy!! Orders are coming in from across the globe for our new Hypopara Awareness Day t-shirts.

Also available are car bumper stickers (which were produced by Swordfish Signs of Greenock and the first order donated free of charge) and hand made Hypopara Bracelets.

Our t-shirts are available via the website shop and we will be adding more stock there soon, but if you wish to purchase anything else in the meantime, please check out our Hypopara UK Shop's Facebook page and email orders to -

shop@hypopara.org.uk

Everyone at Hypopara UK would like to say a massive thank you to Gillian Adams for all her hard work this year - setting up and running our new shop, undergoing training to establish the Scottish helpline….and not forgetting all the hard work she does moderating our Facebook group!

Gillian, you’re a wee star!

DON’T FORGET!

You can connect with us, and others with this condition via Facebook, Twitter and our members forum. We’d love to meet you!

Warning to all labs!

Susanna from our Facebook group got in touch to tell us about a problem she encountered....

The bio-chemistry lab at her hospital changed their range without notifying the endocrinology department, so she was given the wrong advice. She was off work for a month, very ill. Her endocrinologist has since given the lab a presentation on what happens to patients if the range is wrong and the wrong medication is prescribed.
Hypopara and pregnancy

Will I be able to get pregnant? How will the hypopara affect the pregnancy and birth? Will I be able to make my own birth plan? Can I breastfeed?

Living with hypopara is challenging, especially as it often affects young women of childbearing age. There is little research in this field and many doctors have never had to manage a hypopara woman, let alone a pregnant one! So last year we decided to focus our ‘Living with hypopara’ campaign for World Hypoparathyroidism Awareness Day on how hypopara affects pregnancy, birth, and breastfeeding. We asked four young women to talk about their experience of pregnancy and childbirth. Could they do it? They replied unanimously – “Yes we can!” These stories show how they each met this demanding challenge with a positive attitude - and the most beautiful results!

Isabel’s story
Isabel has had permanent post-surgical hypopara following a total thyroidectomy due to thyroid cancer in 1988. As a result of her long-term medication, she also has stage 3 chronic kidney disease. She prepared thoroughly for her pregnancy and consulted her doctors beforehand. Her calcium, alfacalcidol and thyroxine were steadily increased from the second trimester. Her pregnancy went well, and her kidney function became the best it had been in over 10 years, but at week 38 her blood pressure shot up and she was induced at 40 weeks. Baby Rafael was born by C-section.

She says: “Postpartum, my calcium levels continued to rise quite rapidly so my medication was reduced. It was very difficult for me to be hypercalcaemic and to be breastfeeding as the breastfeeding hormone was causing my calcium levels to rise. I persevered though and it took about three months for my calcium levels to stabilise. I was still exclusively breastfeeding five months after the birth. My advice to my fellow hypopara patients who may be pregnant, or thinking of becoming pregnant, is to insist on regular blood monitoring and be prepared; have a detailed birth plan that you can discuss and a care plan in place that you are happy with. Also be prepared to deviate from your birth plan regarding actual delivery and most of all, enjoy your pregnancy.”

Gillian’s story
Gillian was diagnosed with hypopara in July 2011 after a total thyroidectomy for Graves’ disease. She became pregnant in 2012. Her calcium levels remained stable and increased slightly but were never a cause for concern. She gave birth to a baby boy, Duncan, and was still breastfeeding 15 months after the birth!

Gillian has three older children who were born before she acquired hypopara and says “hypopara didn’t make the experience of pregnancy and birth any worse for me than my earlier three births. Don’t let it put you off trying to conceive!!”

Alyson’s story
Alyson was diagnosed with hypopara in February 2007 following a full thyroidectomy for Graves’ disease. Her hypopara did not cause any problems during pregnancy or labour but she was monitored carefully throughout. At eight weeks following the birth, her calcium had become very high and she ended up stopping all medication for around four months, but very slowly symptoms returned. She is now back on medication. She breastfed and was concerned that the calcium medication could be an issue but was assured that this was not going to be a problem and was still going nearly a year later.

Alyson says: “Whilst I have received great care, I think that it is vital that GPs and midwives are made more aware of this condition and how potentially serious it can be. I also think there should be a protocol for postpartum testing and research done on postpartum hypopara mothers as there seems to be a common theme of high calcium levels post birth but with limited understanding as to why this happens.”

Blaithin’s story
Blaithin has permanent hypopara following surgery for papillary thyroid cancer in 2002. She has since had two children, one born in the UK and one in Ireland. Her meds did need to be increased throughout the pregnancy and throughout the breastfeeding period on both occasions, but one side-effect of the pregnancy was that her hypopara symptoms like pins and needles, tingling, and muscle cramps virtually disappeared.

After the first birth, she says: “My Endo said that it wasn’t known whether the levels of alfacalcidol that would transmit to the baby in the breast milk would increase the baby’s calcium levels too much, so we came up with a plan to test the baby’s levels a few weeks after I started breastfeeding.”

To read their stories in full, please visit our website

Familial hypoparathyroidism
Be aware of your calcium levels if a family member has already been diagnosed with hypoparathyroidism. You could have it too. Family members should all be tested and genetic testing may be required as well.
Meet Our Members

Welcome Vincent.....

Vincent is our youngest member and is very special. We published his story on our website to mark Rare Disease Day on 28 February.

When this picture was taken he was only six weeks old and had already led a very full life.

Vincent started having throat spasms and seizures at five days old. He was found to have a serum calcium level of 1.1. The local hospital followed emergency procedure but the calcium kept falling.

Hypopara UK stepped in to recommend a specialist and Vincent was transferred to a major teaching hospital under the care of one of our advisory team, a paediatric endocrinologist who specialises in calcium homeostasis.

Vincent had a pump fitted to deliver parathyroid hormone directly, like an insulin pump. He is now maintaining levels of 2.1 without supplements. At six weeks, he was still on diuretics and must have an operation to remove the cataracts which developed due to the severe hypocalcaemia, but he is alive, on the mend and, as you can see, absolutely adorable!

It turns out that little Vincent has a very rare disease indeed; a rare form of a rare disease, in fact. He has a genetic form of hypoparathyroidism caused by a calcium receptor mutation of which there are over 300 types. Vincent's type is the second only reported case in the world. After a normal pregnancy, and with two sons already, this news was quite a shock to his family.

We'd like to thank the two consultants on our advisory team who responded immediately to our call: Dr Nick Shaw in Birmingham gave early advice and Dr Jeremy Allgrove who is now looking after Vincent at Barts Hospital in London. This is a heart-warming story but could so easily have turned out differently.

Vincent has had his cataract operations now and despite some initial concern he is fixing and following well. Here he is in his new glasses. His calcium levels remain stable thanks to his new pump which you can see in his left pocket.

Hurray for Vincent!

Marie’s story

I feel I need to share this experience with you and raise awareness of the potential outcome if this condition is not diagnosed early.

Early May bank holiday Sunday in 2014, my Mum took the dogs for a walk as usual, as she does every other day. She didn’t feel herself but not exactly unwell. She had experienced a couple of falls over the previous two weeks and was having treatment for a possible ear infection. She did her usual walk along the river and up the castle yard steps in Knaresborough with a family following behind. She let the dogs off the lead to climb the steps and they waited for her at the top as usual... She reached the top and bent to put the leads on and collapsed straight on her face. The family following her were seconds behind and turned her over realising she was in a bad way. She took three breaths and her heart stopped. Luckily the daughter had done a course in first aid and started CPR, at which point a couple were passing the entrance to the castle yard steps and realised Mum was in need of urgent help. Again, luckily she was an off-duty paramedic and her husband was a retired paramedic and they took over CPR but unfortunately with no output. The ambulance arrived ten minutes later and shocked her back to life but had a hard job ahead of them to keep her going until they reached the hospital. I believe it took five attempts during that time but they persevered and succeeded. A&E were amazed she had made it that far and were full of praise for the people on the scene and the paramedics in the ambulance. When we arrived at the hospital they were still at a loss as to what had happened and were unsure if it was her heart or the growth in her head but were concentrating on the heart to keep her alive.

Over the following couple of days it was still critical until my brother realised the hospital had put her on a drip for calcium which they had rightly identified she was low in. He pointed out that he was hypoparathyroid. They did more tests and diagnosed her with the same condition and started to treat her accordingly which is taking some time to regulate but is improving day by day. The cardiac doctor was pleased to have found the cause for the collapse but also very concerned that this is so rare and wasn’t diagnosed before it got to the stage of cardiac arrest and is now looking to do a case study of her to show what can happen if this goes untreated.

My Mum is a very lucky lady as are I and my family who could have been reporting a very different story but very happy to be able to share this one. However, in our case it could be hereditary and I am to be tested. If I prove positive my children will also be tested which is good as it will be diagnosed and treated accordingly but the symptoms can be mixed up with lots of other conditions and the blood test for this condition is not undertaken as a matter of course.

Marie Sadler
Committee member Isabel Wray and her family have been absolute star fundraisers! Isabel held another Brazilian Cocktail Party at her work (faabulous idea darling!), and her son Rafael did a sponsored toddle to raise money...see below :)

Between them, they have raised £1223.50!

We’d also like to say a big thank you to Isabel’s employer, Partners Andrews Aldridge, part of the Engine group, for being so supportive of her and her dedication to Hypopara UK, and for being such good sports to help out with her fundraising efforts. It’s very heartening and encouraging to know that there are good guys out there!

You’re never too young....

The old adage is true! We have our youngest fundraiser ever! 18 month old Rafael, whose Mum has Hypopara, has already started fundraising. He took on the challenge to attempt a 26metre ‘toddle’ to raise money and awareness for Hypopara UK - and won!

Here he is in training...

...and celebrating his victory!

You can still support Rafael via his shareagift fundraising page - http://www.shareagift.com/Pages/14891

Rafael, you’re a little star!!!
Thank you Lloyds!

Thank you to Lloyds of London, who grant awards to employees who volunteer with charities - committee member Claire Butchers applied to them and won Hypopara UK an award of £2000!

Bill Glenister and Claire attended the reception where the award was presented.

To make things even better, Claire followed it up and they recently awarded another £400! Well done!

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.

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

Download a Gift Aid form from our website here - http://hypopara.org.uk/Files/single-donation.pdf

Don’t forget you can donate via the PayPal button on our homepage! www.hypopara.org.uk

Remember to raise money for Hypopara UK every time you shop online by using www.easyfundraising.org.uk

TELEPHONE HELPLINES - 01342 316315 OR 01475 522576
Hypopara UK is run entirely by volunteers. We have no paid staff at all, and most of us are coping with Hypopara 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 - lizglenister@hypopara.org.uk

TRAVEL ADVICE AND INSURANCE

IF YOU ARE TRAVELLING ABROAD ALWAYS:

- Take an extra supply of your medication with you in case of loss, delays or theft
- Carry your medication in your hand luggage, with prescription labels visible
- Drink plenty of water to prevent dehydration
- The Foreign Office offer a very useful ‘Know Before You Go’ checklist which helps you plan your trip, with country-specific advice and tips. Their travel advice checklist for disabled people is also helpful, particularly the medication section.

TRAVEL INSURANCE

- Travel insurance is a vital part of your trip, and your responsibility to arrange. If you don’t have it, you may have to pay thousands of pounds in medical costs if you fall ill outside the UK.
- Always inform insurers of pre-existing conditions and medications.
- Be aware - always check the small print for terms and level of cover.
- The European Health Insurance Card (EHIC) allows you to access state-provided healthcare in all European Economic Area (EEA) countries and Switzerland at a reduced cost. It is NOT an alternative to travel insurance and does not cover all your costs in an emergency.
- For details about appropriate travel insurance and specialist brokers, we refer you to an excellent leaflet produced by Genetic Alliance UK: A Guide To Travel Insurance
- We recommend two companies: AllClear Travel and Insurancewith. You should always shop around and compare companies before purchasing insurance. Please do let us know if you find another company worth recommending to our members.

IF YOU NEED HELP IN AN EMERGENCY

Contact the Foreign Office who give details of embassies and assistance.

The advice line number is +44 207 008 0000