



Bears4Rare steal the show at Waterloo Station

If you were catching a train or arriving at London Waterloo Station on 15 March you would have noticed that the teddy bears had taken over.

"Bears4Rare" was an initiative to bring public attention to the difficulty patients with rare diseases face when accessing treatments, and to inspire action from policy makers to address the inequality of access to medicines for people with rare diseases. It was an action from Shire Pharmaceuticals, in collaboration with several rare disease patient groups – including Hypopara UK.

Isabel Wray, Aisling Duffy and Claire Butchers from Hypopara UK were at Waterloo, to meet Verity and team from Shire.

'There were 1,000 teddy bears and they were very popular!' says

Hypopara UK CEO, **Liz Glenister**. 'Each gorgeous teddy was tagged with a real patient story (quite a few from Hypopara UK members – thank you!) and together they represented the number of people living with a rare disease passing through the station every hour – roughly 1,000. [1] Yes, more than you'd think.

'It was also designed to get people who were waiting for a train to think about the wait that a person with a rare disease has for a diagnosis or access to treatment.'

Rare conditions affect approximately one in 17 people in the UK [2]. Although these 3.5 million people are living with lots of different conditions, many face similar challenges with access to care and medicines. Only five percent of them have approved treatments. *Continued on page 3...*



How far around the world will our social butterfly fly? 1 June is world Hypopara Awareness Day! Find out how you can join in on page 3

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Letter from Liz

Hello everyone,

Spring is sprung and I hope you have all been enjoying an unexpectedly early dose of vitamin D. At Hypopara UK everything is blossoming profusely and we're working very hard to keep up!

I need to let you all know that I am starting to think about when to 'retire' and hand on the running of our growing organisation to someone younger. There are still goals I want to achieve to make our lives more manageable before I go, including seeing the PTH campaign to fruition and developing a home tester. I'd also like to bring all UK members together for a Patient Information Day as so many of you have been asking to do. Watch this space....

Here's a quick round up of our activities since January and a look at what is planned for the rest of the year.

Rare Disease Day

We were heavily involved in Rare Disease Day this year and were able to raise awareness about hypopara more widely than ever. We were featured in the press with patient stories of **Isabel Wray** and **Vincent Thorpe Tavares** in *The Guardian* and online, an ad in *Public Sector Today* - an NHS publication - and a local radio show at MeridianFM. We were involved in the popular Shire "Bears4Rare" campaign at London Waterloo Station, and we were superbly represented by our Scottish members at Holyrood for the annual parliamentary reception there. Read more on page 8.

Conferences

We have attended two conferences already this year, in London and Birmingham. **Jane Compton** was the lynch pin at both events with **Aisling Duffy**, **Steve Compton** and **Christine Kirk**. **Isabel Wray da Silva** and **Mari Hartgen** are heading to Lisbon for the European Congress of Endocrinology ECE2017 in May. There they will be sharing our stand with **Natalie Grosset** (France) and **Cristina Galligani** (Italy) who will be representing our new **Hypopara Europe Network**. We will also be sending leaflets to the International Symposium on the Calcium-sensing Receptor (CaSR) in

Florence, also in May, and attending the annual Society for Endocrinology meeting SfE/BES in Harrogate in November. Thank you all so much for your time and dedication. Its hard work preparing for and exhibiting at conference over 3 or 4 days but a very rewarding and valuable experience.

New hyperpara group

We have been looking for ways to properly support our growing numbers of members with primary hyperparathyroidism following the publication of our new leaflet and I am delighted to tell you that you now have your very own Facebook support group called Hyperpara UK. Read more on page 14.

First face to face committee meeting

Thanks to funding from Shire last year we were able to bring the Hypopara UK committee together for our very first face to face meeting which took place in London in March. As Hypopara UK has operated entirely on line since its inception in 2005, you can imagine what an amazing meeting it was for us. A few of us had met up at conferences but we had never been able to all meet together before (we missed you Mandy and Sarah). It was the first time we'd met new member **Fiona O'Shea** who flew in from Dublin with **Blaithin O'Donnell**. After all the hugs and a quick sandwich we got so much work done!

Research

We're very pleased to have been involved in two patient surveys for UK hypopara members recently. We've been delighted with the number of responses, thank you to everyone who took part. Both are now closed but we will keep you posted when the results come out. An international survey for all hypopara members will be sent out later in the year.

We are delighted to be supporting surgeon **Saba Balasubramanian** in his proposal for the next phase of his study on a near infrared fluorescent imaging device.



Fundraising

Several members have been busy raising funds for Hyperpara UK and for special projects such as a waterproof pump for two of our very youngest members - see inside.

You can check the website for more information about our events or how to donate:

Fundraising events <http://www.hypopara.org.uk/getinvolved.php?id=195> and find out about ways Other ways to get involved <http://www.hypopara.org.uk/getinvolved.php?id=32>.

Every little helps!

World Hypopara Awareness Day 1 June

This is our next big event of the year and we ask that you all do your best to support it. It helps to raise awareness about hypopara at a global level as all the hypopara groups and interested parties around the world get involved. This year we will be running a social media campaign called Social Butterfly. Read more inside. (It's also the date I'm due to become a grandma for the seventh time so I need volunteers to help run it this year, please!)

Exciting times! As always, the committee and I want to thank you for all your wonderful support and wish everyone a happy, healthy summer. We hope you enjoy our newsletter.

Love to all, Liz

lizglenister@hypopara.org.uk

Bears4Rare steal the show at Waterloo Station

Continued from front cover...

Emerging data from the Equity and Access Report [3] (initiated and funded by Shire) show that people with rare conditions in the UK fare worse than their counterparts in other European nations when it comes to accessing new medicines. For example, patients in England can wait, on average, over two years for life-changing treatments, and only 48% of new treatments approved by regulatory authorities from the last 15 years are routinely funded on the NHS (vs 93% in Germany).

The Bears4Rare campaign was timed to coincide with a Summit organised by Shire in London which gathered around 100 policymakers, parliamentarians, clinicians and representatives from the patient community. They wrote, 'The goal of this event is to galvanise opinion around the process for reviewing medicines for rare conditions and to create action plans to address the ongoing delays. Together the noise generated by the Bears4Rare campaign and the targeted outreach to influencers at the Summit will highlight the inequality in access to rare disease medicines.'



NICE and NHS England, who are responsible for determining which treatments are available to patients, pledged to review their evaluation processes.

References

1. Average Wednesday footfall in Waterloo =400,000, translating to 16,667 per hour. 1 in 17, 1,000 of whom may be living with a rare disease
2. Rare Disease UK. What is a rare disease? Available here: <http://www.raredisease.org.uk/what-is-a-rare-disease/>
3. Equity and Access: Making the UK a Rare Disease Leader. (2017) Commissioned and funded by Shire Pharmaceuticals and developed in collaboration with an external steering group.

How far around the world will our social butterfly fly?

World Hypopara Awareness Day on 1 June is our biggest awareness event of the year and always an exciting one as we link up with hypopara patients around the world. Please look out for publicity and do your best to support us and get involved.

Several events will be taking place around the world. As well as making a splash in the press we will be running our annual social media campaign on Facebook. This year, it is called "Social Butterfly". We will be selling butterfly pins for you to buy or you can draw, paint, or take a picture of a butterfly to hold in your selfie. There will be a children's butterfly art competition too. Last year it all got very exciting with smiling faces from all over the world popping up on the World Hypopara Awareness Day Facebook page over 24 hours. Brazil were clear winners last year –which country will post the most selfies this time?

Keep up to date with other world hypopara events such as the "Walk around the world" event being run by the USA Association at the World Hypopara Awareness Day website here www.hypopara-awarenessday.com

Win a bear!

Hypopara UK is one of the lucky patient groups who will be hosting some teddy bears after their arduous commute from Waterloo on Southern trains! Look out for their appearance on our website – and find out how you can win one to come and live with you!



Keep an eye open for butterfly pins which will be available soon in our web shop and where you can also order Hypopara mugs, caps, and t-shirts:

<http://www.hypopara.org.uk/getinvolved.php?id=264>

Fundraising



Rusty Nuts are home with over £1,600 raised!

Steve Compton and Paul Chapman aka the “Rusty Nuts” recently joined the 17-day, Rust 2 Sahara rally, jointly coaxing a 20-year-old Volvo 3,500 miles across some pretty rough terrain from Edinburgh to Morocco and back with the aim of raising money for Hypopara UK and Say Aphasia.

Steve’s wife Jane, who is a trained nurse, acquired hypopara after surgery for primary hyperparathyroidism, and has been an active member of Hypopara UK since her diagnosis assisting the organisation and representing Hypopara UK at conferences.

At the time of going to press, the lads were safely home having experienced some great adventures and having raised £1,665 to share between the two charities.

<https://www.justgiving.com/crowdfunding/RustyNuts-Team>

Annie’s ride

Annie Farrell and friends are taking part in the “Do it for Charity” London to Brighton Cycle Ride to raise money for Hypopara UK. The ride takes place on 17 September 2017 and covers the 54 miles from Clapham Common in London to Madeira Drive on Brighton sea front.



Annie writes: This condition has very little understanding and the long-term medication I have to take to keep me functioning normally can be very damaging to my body if it is not monitored closely. Without support from Hypopara UK I would not have as good an understanding of my condition as I do.

Most doctors have not even heard of this condition. They do not understand its complications and the impact it can have on everyday life. One day I hope this fabulous charity will be able to produce home testing kits or maybe (just maybe) even a cure. But for now I would like to give them as much support as I can.

For more information or to donate, go to: <https://mydonate.bt.com/fundraisers/anniefarrell1>

Alfie’s pump!

Hypopara UK has also been supporting the Lofthouse family who have been raising funds to buy a waterproof pump for their son Alfie.

Just before we went to press we heard that Alfie’s fund had topped the £10,000 target. We are so happy for them and wish Alfie and his family all the best for the future!



Vincent's pump

Hypopara UK is supporting Vincent's family to spread the word and raise money for a waterproof pump.

His mum **Christabel writes:** "Vincent's life outside a hospital is possible only with the help of a pump strapped to his body that continuously infuses medicine, fitted by an amazing doctor at Great Ormond Street. With the help of Hypopara UK, we were put in contact with world specialists to treat his condition. However, this pump is not waterproof as and he grows older he has realised that he is different from other little boys. Vincent's pump is battery powered and he cannot get his device wet. He cannot jump in puddles, paddle in the sea, play in a paddling pool, play in the mud or go swimming. If his pump is to get wet or near moisture, it may get damaged and he would become very unwell and need to be hospitalized.

"He can only take the pump off very briefly to wash every few days. Any longer and it would cause illness."

"We would love to replace his pump with a waterproof alternative so that even if he can never be like a normal little boy, he can feel a little bit like one and experience activities that other children take for granted."

If you would like to help Vincent, go to: <https://www.gofundme.com/vincent-waterproof-pump>

Rare Disease Day 28 February 2017

Every year rare disease groups come together around the world to raise awareness about rare disease. This is the tenth year and the focus was on research.

We work closely with specialists to support their research. At the moment that involves stem cell research and surgical interventions. We sent out two patient surveys which aim to highlight information about our quality of life.

In addition to the Bears4Rare campaign (see lead story) we were also featured in the Mediaplanet-UK Rare Diseases Campaign in *The Guardian*. Patient stories highlighting three types of hypoparathyroidism were featured in the issue.

Isabel Wray da Silva's story is about her experience living with post-surgical hypoparathyroidism, while Vincent Thorpe Tavares's mum Christabel talks about him being born with a very rare genetic form. You can read both stories here:

<http://www.healthawareness.co.uk/rare-diseases/a-focus-on-hypoparathyroidism>.

The charity Climb featured another of our members, **Harriet Macleod**, talking about her pseudohypoparathyroidism here:

<http://www.healthawareness.co.uk/rare-diseases/living-with-pseudohypoparathyroidism-php>

Parliamentary Reception

Two of our members, Anne Cusack and Stephanie Agnew, represented us in Scotland this year at the Rare Disease Day reception at Holyrood on 1 March.



Anne and Stephanie

The ambassadors

Raising awareness of hypopara

Fiona O'Shea and **Mari Paz** signed up last year with four others to train to become hypopara ambassadors. Here they give some insight into the training and their personal experience.



Left to right: Natalie, Mari, Conor, Fiona, Isabel and Cristina

Fiona writes: In November 2016 six people met for the first time in a hotel in Vienna to commence training to become ambassadors for hypopara. Those six people were: **Natalie** from France, **Mari** from Spain (although originally from UK), **Cristina** from Italy, **Isabel** from the UK and **Conor** and myself from Ireland.

So, why did we sign up?

- To raise awareness of hypopara
- To help give patients and carers the knowledge and motivation they need to be empowered about the condition
- To help health care providers understand the patient perspective

The training was highly emotional but fun. The three main outcomes of this initial training were:

- Our stories - we each wrote about our own personal journey with hypopara and we were trained in how to share this at speaking events
- Our videos - we made individual videos about the impact hypopara has had on our lives
- Our photos - we were treated like celebrities. We had a beautician and hairdresser who helped prepare us for photoshoots, which will eventually be used to raise awareness

The whole experience for me personally was overwhelming, I had never met anyone with hypopara before and to be suddenly in the company of five other hypopara patients at the one time, while it was fantastic it was also highly

emotional. I feel honoured to have listened to the life stories of Conor, Natalie, Isabel, Mari and Cristina. During the weekend we laughed, we cried, we compared, we shared, we listened, we talked, and we 'got' each other. There was a very special connection and some great friendships have been formed.

We have already started some projects to raise awareness about hypopara, we have attended patient workshops with Shire, we have attended conferences and speaking events where our stories have been shared and testimonial videos have been created. There are many more projects in the pipeline for the year ahead.



Mari Paz speaking at a meeting of Shire's European employees

Mari writes: My journey with hypopara began at the age of 16 with a diagnosis of Graves' Disease. A year later I had a thyroidectomy which resulted in hypopara, hypothyroidism and bilateral damage to the vocal cord nerves, leaving me with very little voice and a 2mm airway. This resulted several years later in an emergency tracheotomy which is now permanent.

In 2008 I volunteered for an experimental nerve transplant in France. They removed the damaged nerves and transplanted a section of my phrenic nerve from my diaphragm. Recovery was long and slow but at least now I have a voice. It was hoped I would be able to have the tracheostomy closed but this hasn't been the case.

I have now had hypopara for 38 years. For 37 of those years I thought I was the only one. It wasn't until I joined a programme to raise awareness of hypopara that I finally got to meet Fiona, Isabel, Connor, Natalie and Cristina. The opportunity to meet up happened last year at an event organised by Shire where we were helped to write our stories. It was an emotional meeting but we had some laughs too and we have our very own mannequin challenge video to prove it.

That same year I found out about Hypopara UK, Hipopara España, and a network of supportive and friendly people, all with either hypo or hyperpara. Now with the addition of the Hypopara Europe Network we are an ever-growing international family and I no longer feel alone.

In February this year, three of us - Fiona, Cristina and myself - had the opportunity to attend Shire's hypopara workshop. It was an opportunity to help Shire understand first-hand what it is like living with hypopara and to find ways that could help improve the management and understanding of our condition.

I recently had the opportunity of speaking at a meeting of European employees for Shire Pharmaceuticals. It was my first speaking event to raise awareness of hypoparathyroidism. This event gave me the opportunity not only to tell my story, but to emphasise the importance of organisations like Hypopara UK in supporting people living with our condition. Due to the lack of consistent and/or correct information, patient groups are a lifeline for most, if not all, of us.

I now live in Spain and being half Spanish and speaking fluent Spanish I am able to help with the newly formed Hipopara España Facebook page. In March we were invited to a patient focus group in Madrid. Arantxa and I attended and the outcome seems positive. They have offered to help us start the Hipoparatiroidismo España Association which is exciting and we are ready for the challenge.

In May I will attend, along with Isabel, Natalie and Cristina, the European Congress of Endocrinology in Lisbon. I'm looking forward to helping spread the hypopara awareness message and to the day all doctors and endocrinologist have at least basic knowledge of our condition and maybe one day a home testing kit and the creation of a specialist centre.

Introducing the Hypopara Europe Network



Some of the ambassadors will be attending the European Congress of Endocrinology (ECE2017) in Lisbon this month where we will be introducing the newly formed Hypopara Europe Network, a collaboration of European hypopara groups working together to raise awareness and improve lives of hypopara patients throughout Europe (see previous issue, page 4).

The Hypopara Europe Network is currently comprised of patient groups from the UK, Ireland, France, Italy, Spain, Denmark and Iceland. It aims to work closely with endocrinologists who specialise in calcium homeostasis and bone metabolism; raise awareness; advance research; and offer support and information to patients and professionals.

Hypopara UK and Hypopara Europe Network will be sharing a stand in the Patient Support Group area at ECE2017 to raise awareness about their activities. Representatives will include **Isabel Wray** (UK), **Mari Hartgen** (Spain), **Natalie Grosset** (France) and **Cristina Galligani** (Italy). Delegates will be able to order patient information leaflets in English, French, Italian, Spanish, Danish and German.

Local Groups

Our local groups' coordinator is **Catherine Smith** – please contact Catherine on catherinesmith@hypopara.org.uk if you would like to join a group or start one up in your area. Until we get more offers these groups will necessarily cover large areas! Please help – we still have three vacancies! Please contact the group leaders in your area to find out more:

Scotland Gillian Adams
gillianadams@hypopara.org.uk

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Blaithin O'Donnell**
blaithinodonnell@hypopara.org.uk

Wales Sophie Worthington
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South Catherine Smith
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Eastern Ruth Irwin
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**Primary Hyperparathyroidism (all regions)
Judith Taylor**
judithtaylor@hypopara.org.uk

Out and About

National Clinical Cases Meeting

Jane Compton and **Aisling Duffy** attended the Society for Endocrinology's National Clinical Cases Meeting in London, 27 January 2017. At these meetings, trainees present cases and the discussions that follow highlight why these cases are of interest to the wider endocrine community and how they advance our understanding of the specialty.

Jane and Aisling attended a presentation by **Dr Rebecca Corrigan** from Bart's who described a case of a young girl with hypercalciuric hypocalcaemia (very rare, and the opposite of hypocalciuric hypercalcaemia).

Jane writes: Dr Corrigan described how a 16-year-old girl had benefited from PTH given via infusion pump to stabilise her calcium levels. Previously her quality of life had been abysmal with frequent hypocalcaemic seizures and she had spent almost a third of her young life in hospital. Her mother had the same condition and was in end stage renal failure and on dialysis awaiting a transplant. The girl had suffered immeasurably and had a poor education, as well as a lack of friends and peer group. A year since starting PTH, she has had no hospital admissions and has a boyfriend as well as attending college.

We thought this was an inspirational story and one that some of our members would be interested to hear about. This case demonstrates the dramatic clinical improvement and smaller PTH doses that can be achieved with a continuous PTH infusion. It also shows the potential variability in PTH delivery between different infusion pumps.

This presentation was well received and won first prize. I spoke to Dr Gorrigan after her talk and she was very interested to hear that I am on PTH, and I was able to press upon her how much it had improved my quality of life. It was just fantastic to speak to someone who gets it!

[A longer and more detailed description of Dr Corrigan's presentation is available to readers who would like to know more – please contact the Editor.](#)



Pictured above – Jane and Aisling

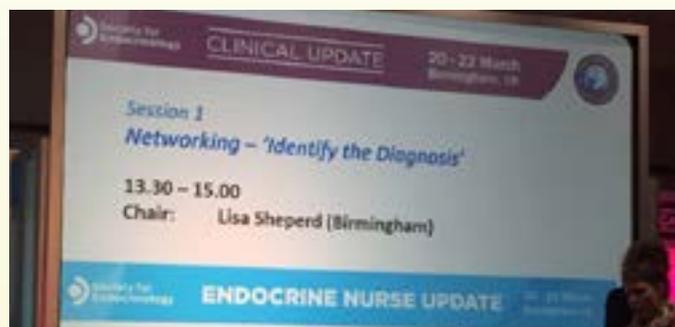


Clinical Update and Clinical Nurses Update

Jane and Steve Compton along with **Christine Kirk** attended the SfE Clinical Update and Clinical Nurses Update meetings on behalf of Hypopara UK in Birmingham 20-22 March 2017. Jane has sent us this account of the meetings and the lectures she attended.

Jane writes: This was a really fruitful few days, and overall I felt that we got our message across to lots of the doctors and nurses present, as well as making good connections with some of our advisers.

Monday was crazy busy and we had so much interest,



particularly from the nurses, but it has to be said from lots of doctors too, and many of our leaflets were given out, and lots of orders were taken for clinics spread far and wide.

In the afternoon, there was a seminar for the nurses called "guess the diagnosis". I was asked to be one of the "patients"

in this exercise (there were 6 or 7 “patients”), and rather like speed-dating we spent ten minutes at each table of about ten nurses describing our symptoms (with an endocrine nurse specialist facilitator prompting the nurses). This was hugely enjoyable and a brilliant PR experience for us as I was able to demonstrate and describe (to every nurse there) the symptoms of hyperparathyroidism, and once they’d guessed that, I went on to explain what it was like to live with hypoparathyroidism. I used this opportunity to impress on them firstly the misery of high calcium and how that makes you feel, and the challenges of hypoparathyroidism and in particular the need for regular blood testing, and the need for results on the day so adjustments can be made. You have no idea how satisfying that was! To be able to get those messages across to a receptive audience of endocrine nurses was a gift and I relished it.



After the session, all the nurses said how useful they found the seminar, as it really got them thinking about the different endocrine conditions they had to work out. They said it was much easier to remember ‘real’ patients that a dry chapter in a book, so they were going to feedback for more sessions like this at future conferences and we should too! Of course, I shamelessly plugged Hypopara UK at the session, and we were very busy at the booth afterwards as a direct result. The next day, **Professor Neil Gittoes** (Birmingham) did an excellent talk on the management of hypoparathyroid patients and some of the nurses fed back to me that they now have a greater understanding of our

condition and so this is all excellent news. We also had the pleasure of meeting **Dr Rachel Crowley** (Dublin), who is a new advisor for Hypopara UK. She ran the parathyroid and calcium metabolism workshops with **Dr Peter Selby** (Manchester).

There was a fascinating talk on a patient who had a giant parathyroid cyst that caused him to have severe hyperparathyroidism. The management of patients with high calcium was discussed in detail at these lectures. Although I could not understand everything and the chemistry involved, it was quite heartening to hear the discussions amongst the doctors as to how to treat patients with high calcium in an acute setting.

One discussion was about normocalcaemic hyperparathyroidism, or as Dr Selby said ‘levels of calcium that are “not that high”’. I was in that position when I was hyperpara, and I was disappointed to hear him recommend a “watch and wait” approach for such patients. After the talk I mentioned that I had experienced a very frustrating couple of years being “watched” in clinic to see if my calcium went up any higher, and quite a few of our members are in that exact position now. I think it did give him a little food for thought, as in the very next lecture he gave, he added that in those cases maybe such a patient would benefit from a trial of cinacalcet (to try and see if they got relief from lower levels of calcium and hence be good candidates for surgery), something, I think, which would go a long way with some of our patients.

At another lecture, Dr Crowley spoke of managing hypopara in pregnancy and an interesting discussion followed about how these women need careful management by an endocrinologist and obstetrician and even inpatient management of levels if necessary with weekly calcium levels. As some of our patients have described, she explained that calcium rises in pregnancy and the woman may need less drugs, and less whilst breastfeeding too. Again, the message was all about careful monitoring and management.



Dr Rebecca Corrigan from Bart’s gave a presentation of the case she had presented in London (see report on the National Clinical Cases Meeting).

Additionally, I attended a lecture on MEN1/MEN2 as I have a clinical diagnosis of MEN1 (parathyroid and pituitary) and these were also very interesting and informative, and may be of interest to our members who are afflicted with these conditions too.

All in all, this was a very positive experience and a successful conference.

Calendar of events

Hypopara UK will be represented at the following meetings later this year:

20-23 May 2017

European Congress of Endocrinology, Lisbon, Portugal

9-12 September 2017

European Thyroid Association, Belgrade, Serbia (via Thyroid Cancer Alliance)

6-8 November 2017

SfE BES - the annual conference of the Society for Endocrinology – Harrogate

'Cleo has given me back my life'

Jan Cobley had surgery for hyperparathyroidism and now has hypoparathyroidism. But she doesn't let it get her down, especially with her dog Cleo at her side!

In 1999 Jan Cobley and her husband Jim had decided to invest in a rental property in Portugal when their plans had to go on hold while Jan was admitted to hospital with very high calcium. After endless battles for treatment, Jan had surgery on her parathyroids for what turned out to be hyperplasia so all her parathyroids were removed. She was in hospital for two weeks while her calcium was stabilised, and was sent home with just one calcium tablet a day.

Meanwhile they had decided to go ahead and bought their restored farmhouse in Portugal in 2000 and had started to visit it with their dogs a few times a year. Jan was still feeling very unwell and her endocrinologist told her that he suspected MS and proposed sending her to a neurologist when she returned to the UK following her next visit to Portugal. It was while she was there that Jan's husband sought out a German endocrinologist who diagnosed low calcium and hypoparathyroidism. It was a lightbulb moment for Jan!

Jan writes: 'We were spending more and more time in Portugal. It became obvious that my hypoparathyroidism was happier in the sun. I was at that time taking 12 alfacalcidol and up to over 30 Adcal tablets to maintain

a good level in the UK. It was crazy. I take Pariet daily for hiatus hernia which affects the absorption of any medication. Then, out of the blue, we had an offer for the UK property we had owned for 35 years. That was the turning point. We found a property in Torquay for my Mum and Dad, our daughter and family decided to join us as Julie has serious eye problems, and we moved to Portugal in 2004 with our Bearded Collie - Lennie; our Old English Sheepdog - Sandy; and my baby Old English Sheepdog - Chloe. 'Now 70 we are both still working here with our daughter.

'I have loved dogs forever. My more in depth relationship with dogs began with my Bearded Collie, Lennie, way back in 1991. He developed various autoimmune conditions over a few years. The vets were out of their depth so I unleashed my research life. Lennie had OCD of his front leg, EPI, his pancreas stopped working and then he had Addison's disease - all before he was four years old. He was given weeks to live. I kept him alive, by research and caring for him 24/7. He added hypothyroidism to the mix at ten years old. I learnt to work out what was going on with him. Since then, I have recognised and saved the lives of many dogs by pointing people in



Jan and Cleo

the direction of Addison's. I have been correct every time.

'Sandy and Lennie both needed natural hypoallergenic dog food, but we could not buy this in Portugal. We consulted the company. They said - why don't you become the Portuguese distributors? That was 2004. The rest is history. We now run a company called Paws4Pets which sells only natural doggy products, I wrote for the local paper every week for over nine years and also write for magazines, we help rehome dogs, and we run a charity dog show weekend every year.

'The big worry was and is my health. I have high blood pressure caused by my chronic kidney disease which in turn was caused by my hypopara. I have had breast cancer, hysterectomy, and a trapped nerve in my back. The care here is not great. It took ages to find an endocrinologist in Portugal. He changed me to calcitriol as that was their treatment here, and it worked much better than the alfacalcidol, but he left soon after that. I now have a good kidney consultant who refers me for scans and tests and gives me six-month prescriptions when I see him. I have to pay for my all my medication here in Portugal and all treatment.



Cleo Best in Show - Veteran



Jan and Chloe, Cleo, Merlin and Cassie

'And then there was Cleo...

'I had lost my soulmate Lennie, aged 14, in July 2005. I have to admit I lost the plot for six months. Then my friend Laura invited me to see her new puppy, a Portuguese Water Dog. Well we were now living in Portugal! Then I heard of a puppy aged eight weeks old, just two weeks younger than Laura's. The rest as they say is history!

'Cleo arrived. Tiny baby, breed I knew nothing about! Quite mad really. 'Laura decided we would go to Water Trials with our dogs and put them into the show world in Portugal. I had never shown a dog in my life. On my 60th birthday I started to show my Portuguese Water Dog - Cleo. I struggled with my day to day life let alone taking on showing. But Laura offered to take on me! And hypopara! We filled her in on both my medic alerts, my medications etc. She took on so much. She helped me to join her in a different life. This involved being away weekends in hotels and galloping around rings with dogs. Some days I could barely walk let alone gallop! Laura had to take me back to my room many times as I was so ill! But it gave me so much. It gave me a new career.

'Cleo was amazing and still is. She became a Portuguese champion, Portuguese Grande champion, Gibraltar champion, international champion and has been placed many times at Crufts. I was away weekend after weekend in a Portuguese world. She still wins shows at 11 years old. Yes I was often ill, I could be found sleeping in the dog cage with Cleo outside. My friends looked after me and Cleo. I also showed my old English Sheepdog puppy - Cassie - and my second Portuguese Water Dog - Merlin, who is Cleo's brother one litter removed, and who I rescued after he was abandoned in a pet shop. I also have another Old English Sheepdog - Chloe.

'The Portuguese Judges were fantastic. Encouraging me. They had, however, noted that Cleo would often 'amble' not run around the ring. Between us we noticed this seemed to coincide with my bad days. Clever people.

'I was writing weekly articles and was asked to assist with a seminar given by



Cleo the service dog

a UK Dog Whisperer to raise money for a doggy charity. In return she said she would talk to Cleo and her Brother Merlin. So I booked an appointment. I was really ill that day and remember being in so much pain I was sat on kitchen floor in floods, Cleo was beside me, very upset, obviously trying to calm me down. But I was determined to go and eventually got there.

'The Dog Whisperer spoke to Merlin first, that was amazing and so true to fact considering the lady did not know me or live in Portugal. I collected Cleo, took her to the lady and put Merlin back in the car. Cleo was not quite three years old. I returned to find them both deep in conversation. The lady started to tell me what Cleo was telling her. She said, "Mummy is very ill, I know Mummy is ill, she sometimes cannot walk for pain. I want to help Mummy but I do not know how. I stop running when she is in pain but I do not know how to help her". We had an hour's consultation.

'It was after this that Cleo started to alert me to my 'crashes'. She will bark and give me a paw, she got distressed as I didn't know what she was doing. Friends pointed out that this was happening regularly about 30 minutes before I became really ill.

'I have had advice and help from a charity in the UK but the waiting list for assistance dogs or for training is very long and in any case I live half in the UK, half in Portugal so attending classes was never going to be easy, coupled with me not being happy travelling.

'One time Cleo refused to get in the car. She was running around it barking and I had to force her to get in. Thirty

minutes later I felt rough and asked my grandson for my pills. They weren't in the car. I had left them at home which I suppose explained why Cleo would not get in! She watches me all the time, looking back to check on me if we are out for walkies, and following me everywhere. She sleeps beside me with her head near to mine, she calms me. Friends and family remark on her constant monitoring.

'Three years ago Cleo and I attended a dog show in Lisbon, I had bravely driven up, stopping a few times on route. We met up with friends and stood with them when suddenly a huge Royal Canin tent was caught by the wind, it took off fast and headed straight in my direction. The tent hit me on my head pushing me straight back onto concrete and burying me under the tent. Other dogs had bolted but not Cleo who stayed with me. We were both shaking heaps. She was badly injured by the metal tent bars. But she still stayed with me.

'Cleo is now 11 years old. I have very aged parents and I have to travel back and forth to the UK a lot. I get stressed with travel that affects my calcium levels, but when I have to travel between the UK and Portugal, I am much calmer with Cleo beside me. She has given me back my life.'



Cleo the assistance dog

Beryl's Story

"The light at the end of the tunnel"



Beryl and Husband

Beryl was diagnosed with primary hyperpara with an adenoma on each side of her neck. After surgery, though, she felt worse, and it turned out only one adenoma had been removed. It took another six months and a second opinion before she had a second surgery. The operation was an immediate success.

Beryl writes: In August 2015 I went to see my GP with headaches, sickness, feeling full and a general feeling of being unwell, symptoms that I had been suffering with for several months.

The doctor was quick to suspect a parathyroid problem but thought it best to eliminate other possible causes first to make sure nothing else was being missed. All alternative investigations came back negative. The next stage was to be referred to an ENT consultant at my local hospital. The scans that followed came back positive, indicating that there was a parathyroid adenoma on both the right and left side of my neck. At last I felt I was getting somewhere.

In August 2016, I had my operation, having been booked in as a day patient. I attended at 7.30 in the morning and after waiting ten hours in a chair, being denied anything to drink or eat, I went down for my operation. Until this time I had

not seen the consultant who was performing the operation but I felt sure that he would have been aware of my diagnosis. I was discharged at 11.30 pm, feeling traumatised by my treatment that day. No discussion whatsoever had taken place about what had been done or if, indeed, the operation had been successful. Little did I know what was to follow.

The following week I felt worse. My symptoms had not abated. I then had to wait six weeks for an appointment with the consultant to discuss my interim abnormal blood tests. I was shocked to the core to discover that the consultant had only focused on the right side of my neck, removing an obvious abnormal parathyroid. No investigation whatsoever had been done by him on the left side. His only comment at the time will ring in my ears forever, namely "Where do we go from here". It was not until I got home that I really felt angry and wanted to challenge him about the situation. My attempt to make a further appointment with him was declined until I had attended for another round of further scans.

At this point I decided to get a second opinion and after doing my own research online I discovered the Hypopara UK and this is where I received the most helpful, understanding and positive advice that I could have had. This led me to make a private appointment with a consultant in endocrine surgery at the Hammersmith Hospital in London. I was informed I had "persistent hyperparathyroidism" which was confirmed with the utmost speed by further scans.

On 2 February, I had a second operation, which resulted in the removal of a parathyroid on the left side together with partial correction to the other gland on the same side. The operation was an immediate success.

I would like to extend my personal gratitude to Liz at Hypopara UK and to my consultant, who have fundamentally saved my life.

My advice to anyone who finds themselves in a similar situation, which in itself is a very complicated and intricate procedure, is to seek a consultant who specialises in this field and who has a proven record.

A RARE connection



Ariana and Hannah

Earlier this year two young hypopara friends who met through Hypopara UK and knew each other only through social media had an amazing and completely unplanned meeting.

Hannah Mullen (see previous issue) and her friend Becky from the UK were on vacation in New York when Hannah contacted **Ariana Feiner** who lives in Atlanta to tell her that her hotel had accidentally frozen all her vials of her very important medicine just as she was about to leave for the next leg of her trip in Orlando. Ariana's family called almost every pharmacy in Orlando that night, but there was none to be found in the city. The pharmacies said they could order it in, but it would not arrive until the end of the week. So Ariana's family arranged for Hannah and Becky to fly into Atlanta Airport, where Ariana could give Hannah some of her own medicine.

Ariana writes: "As soon as their flight landed, my mom and I burst into Atlanta Airport with our arms full of ice packs, medical coolers, and medicine to meet Hannah and Becky at baggage claim. When Hannah and I saw each other from across the hall, we rushed toward each other with arms outstretched to meet the only other person each of us has ever known our age with this rare condition. After six years of talking online, I never thought in my life that I would meet Hannah in person here in the USA. Hannah injected the special medicine right away, and we were all relieved to know that she would soon be alright."



Ariana and Hannah

"Even though we were only able to spend a short time together, it was a wonderful blessing. I am overwhelmed with joy to have been able to help someone in need, and it was an amazing feeling to finally meet Hannah and share such a rare connection. Although we live an ocean away from each other, we are bonded together forever."

This beautiful video was made by Hannah:

<https://www.facebook.com/hannah.mullen.79/videos/10158505271310425/>

Share your story

Your story can inspire others who are living with a parathyroid disease. Whether you have, or have had, hyPOparathyroidism or hyPERparathyroidism or if you, or someone in your family, has another rare parathyroid disorder, we would like to hear from you. Please write to the editor at judithtaylor@hypopara.org.uk. The deadline for copy for the next issue is 15 October 2017.

Welcome to our new committee members!



Joy Foster

Joy writes: 'I was born in Glasgow and despite being brought to England immediately, still seem to have an identifiable Scottish accent! Having studied social sciences at Leicester University, I subsequently qualified and spent some years as a social worker. Most of my working life, however, was spent in teaching and research as a university academic. My PhD research focused on gender issues in management. I have a son and a daughter and for some years my husband and I reversed roles and he looked after the home and children.

'My hyperparathyroidism was first diagnosed when I was in my early forties and my journey in dealing with it is still continuing. Since retiring I have been able to enjoy spending more time with my family, which now includes two granddaughters, exploring the countryside, and pursuing my love of music by having singing lessons and attending orchestral concerts.'

Joy has just been appointed by NICE to serve as a lay representative on the NICE Guidelines Committee on Primary Hyperparathyroidism – congratulations Joy!



Fiona O'Shea

Fiona writes: 'I live in Donegal with my husband and our two amazing children. I work full time as an occupational therapist in a Rehabilitation Unit for adults. I love my job and what I do and being a hypopara patient has made me more empathetic and sympathetic towards my patients and the daily battles that they have in their quest to good health.

In 2003 I graduated from university but several weeks later I was diagnosed with acute onset of Hashimoto's thyroiditis which left me struggling to breathe. Within days I had my thyroid removed and so began my journey into the unknown. In 2015 I had a twelve-month period of ill health. As it happens my calcium turned out to be dangerously high.

This is when I decided to take charge of my own health and stumbled upon Hypopara UK. This period of ill health has made me a stronger person. In November 2016 I embarked on a hypopara awareness programme to help highlight hypopara and the long, difficult journey most patients have to embark on and to improve standards of care for the future.' (See Fiona's article on page 6.)

Committee meets in London

The Hypopara UK committee held its first face to face meeting in London recently – not everyone was able to attend unfortunately, but it was an incredible experience for some who had only met on line previously. A lot of useful work was done, under the guiding eye of Mr Bear.



Clockwise: Lisa, Mr Bear, Ray, Judith, Fiona, Blaithin, Isabel and Liz. Bill was behind the camera

Congrats, Ray!

Congratulations to committee member **Ray Finlay** whose team at Astra Zeneca has won the Malcom Campbell Memorial Award. This award is given by the Royal Society of Chemistry Biological and Medicinal Chemistry Sector for outstanding contributions to chemistry. The prize was awarded to Sam Butterworth, Darren Cross, Ray Finlay, Richard A. Ward and Michael J. Waring for contributions to the team that discovered Tagrisso (osimertinib, AZD9291) which has replaced chemotherapy in certain lung cancer treatment. Well done, Ray, we're so proud of you!

Hyperpara group

Do you have hyperparathyroidism? If so, come and join our new Facebook group for people with primary hyperparathyroidism. Search for "Hyperpara UK Group" and request to join.

The group is run by an experienced and committed team of current and cured hyperpara patients to moderate the group and work with **Liz Glenister** and **Judith Taylor** on all matters hyperpara, in particular we want to develop the hyperpara content on the website this year. The group comprises **Kate Kennedy**, **Lyn Smith** and **Joy Foster** in UK with **Rochelle Lambiris** in Greece and **Anja Simonsen** in Norway.

We hope this will be a good solution to the problem of supporting people with different parathyroid conditions. As a member you are of course welcome to join either the hypopara or hyperpara group.

Good luck Hyperpara UK!



Join us on Facebook!



The Hypopara UK closed Facebook group has been in existence for more than nine years and now has over 300 members. It is a caring, friendly and supportive place to be and we have had lots of positive comments about it. It's busy every day with members asking questions, feeding back about appointments, and sharing advice with each other. Many have made friends there and get to know each other quite well. Some meet up in the real world – and in fact our local groups have grown up in response to this demand. Having a rare condition can be isolating but online we are a nationwide family who understand how you're feeling.

We now have a sister group for people with hyperparathyroidism. Our groups are:

- Hypopara UK page (open to all) and Hypopara UK group (closed group for members only)
- Hyperpara UK page (open to all) and Hyperpara UK group (closed group for members only)

If you are struggling, there are probably basic things you and your family need to know about managing your levels and living with a rare parathyroid condition and getting the right treatment that we can help you learn about and that will make a difference to your life. Come and join us and see for yourself – you'll be very welcome!

Here are some of the things people have been saying about the group:

"It feels so so good being part of this site, knowing I've got people who understand how I'm feeling and to know that I have someone to talk to when needs be"

Stephanie

"You have all helped me so much and I feel stronger knowing I can come in here and ask questions.....even if they seem silly"

Tess

"I haven't long joined the group and straight away have found everyone to be extremely knowledgeable, helpful and it's a relief to have the understanding"

Hannah

"As a new member of the group I have found everyone very friendly and happy to help and share their knowledge. No questions is dismissed and nothing too much. As a member of several parathyroid groups this one is the best and makes me feel very comfortable as well welcome. Thanks to all"

Sharon R

"Since finding Hypopara UK and all the advice and support I have received I have been able to ask for better medical treatment, my calcium has remained stable, and although I have had a few times recently when that's not been the case, I now feel aware and confident to manage. Thanks to Liz and you all"

Jane

"I'm a member of several Facebook groups for people with thyroid and parathyroid problems and the things that make this group stand out are the quality of the information and the caring and compassion that everyone shows each other. It is a godsend for people with either hypopara or hyperpara who have just been diagnosed (or have only just learned of their diagnosis after many years of symptoms) and who are looking for information and support"

Judith

To join us on Facebook search for 'Hypopara UK group' or 'Hyperpara UK group'



Hypopara UK

Hypopara UK is the national voice for people affected by parathyroid conditions and the only patient organisation in the UK and Ireland devoted specifically to their needs.

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Hypopara UK News is the newsletter of Hypopara UK. Its purpose is to provide information to Hypopara UK members and supporters and to raise awareness about parathyroid conditions.

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Hypopara UK is recognised by:

British Thyroid Association (BTA)
British Association of Endocrine & Thyroid Surgeons (BAETS)
Society for Endocrinology
NHS Choices

Members of:

Genetic Alliance UK
Rare Disease UK
National Voices
Thyroid Cancer Alliance

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

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Our bank: Santander

Our sort code: 09 - 06 - 66

Our account number: 42582811

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