Launching Parathyroid UK

We are very proud to announce the launch of our new organization and website on October 1st 2019 when we will be saying farewell to Hypopara UK and introducing ourselves to the world as Parathyroid UK.

The committees and I have been working very hard to prepare for this and we hope you will all be very happy with our new look and our brand new organization.

What does this change mean?
The name Parathyroid UK will reflect the work we have been doing for a long time now supporting and campaigning for patients with both hypopara and hyperpara. It will signal more clearly to new patients, the public and the medical world that, like our fellow endocrine patient organisations (eg thyroid and pituitary), we will be supporting patients affected by all the conditions caused by the parathyroid gland. Our medical advisors feel that this is a ‘very sensible development’. Merging the two wings of our butterfly into a newly registered charity will make it easier to manage for us and help us to deliver a more effective service to you.

Will it feel any different?
Only in a good way! You will still get the same level of dedicated support and we will continue to work behind the scenes to help bring about new treatments and protocols to improve your lives.

Things will look a bit different with the new colours chosen to represent both conditions. Our redesign includes a beautiful new logo (above) by Sophie Burrows, the award winning illustrator who made our old butterfly, and an eye catching new look for our logo (above) by Sophie Burrows, the award winning illustrator who made our old butterfly, and an eye catching new look for our leaflets too, created by the wonderful Creatiff Solutions in Bristol and managed by Isabel Wray da Silva. Working on the rebrand has been very exciting and we hope the changeover will go seamlessly and managed by Isabel Wray da Silva. Working on the rebrand has been very exciting and we hope the changeover will go seamlessly and a clear pathway for new patients. It includes both hypopara and hyperpara sections and should be much easier to find your way around. Please have a look and let me know what you think. Some pages are still be added to, and of course it will be an ongoing project, but if you spot any glitches or have any requests just let me know. I do hope you like it - I see it as my parting gift to you all! Our new URL will be [www.parathyroiduk.org](http://www.parathyroiduk.org)

Support Groups
The names of our UK facebook groups will also be changed but don’t worry you will still be able to find us. Search for Hypopara @Parathyroid UK or Hyperpara @Parathyroid UK. Europe and World groups stay the same. The forum will no longer exist, all our support has now migrated to facebook by popular demand.

Membership
New members will now be able to register online on our new membership form. Current members won’t need to re-register unless you wish to amend your contact or medical details or sign up to receive emails and newsletters (if you had trouble getting this copy). We use your medical details anonymously for research purposes or to invite you to clinical trials. We take your security very seriously indeed and conform with data protection laws. Your details will never be shared with anyone else without your express permission.

Will we still have World Hypopara Awareness Day?
Yes, and we will still be running the annual social media campaign too. If you are a hypopara patient you need not worry - nothing will be changing for you. Our commitment to hypopara will be as dedicated as ever.

Our brand new website!
For two years I have been working with the lovely Ben Blankley of Charity and Biscuits, a brilliant web designer for charities such as Comic Relief, on a brand new website which will go live on October 1st. Our aim was to make it more contemporary and user friendly while providing the same level of up to date, reliable information and a clear pathway for new patients. It includes both hypopara and hyperpara sections and should be much easier to find your way around. Please have a look and let me know what you think. Some pages are still be added to, and of course it will be an ongoing project, but if you spot any glitches or have any requests just let me know. I do hope you like it - I see it as my parting gift to you all! Our new URL will be [www.parathyroiduk.org](http://www.parathyroiduk.org)

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We send grateful thanks to...  
...the lovely Ivor Humphreys who worked so hard on the Hypopara UK websites and forum which he made and ran for us entirely for free. Thank you Ivor, we’re so grateful for your endless patience, commitment and kindness over 15 long years. What you have done for us really was a true act of charity and we shant forget you!
Dear all, it's been two years since you received a newsletter so we've presented you with a round-up of events in this issue and will try to keep it brief! It is a time of big change so thank you for your patience while we have been going through this metamorphosis. As you can imagine there has been a lot to do but we are very excited at all the new and positive changes ahead.

Of course, saying farewell to Hypopara UK which has had such a big place in our hearts and lives for so long will feel a bit sad. It started from nothing and put hypoparathyroidism on the map, bringing together people from all over the world who had been struggling alone and fighting their corner. But we strongly feel that merging hypopara and hyperpara will be a positive move for us all and gives us real potential to make a difference to the lives of many more patients. I’d like to thank everyone who has been involved with Hypopara UK over the years and welcome everyone who has joined us to create Parathyroid UK. Together we will be making our mark on the endocrine world and moving on to even bigger and better challenges!

As many of you know that I was diagnosed with breast cancer last summer so I had a few months off while I recuperated. I’d like to take this opportunity to thank you all so much for all your love and good wishes which meant such a lot to me. Huge thanks especially go to the Hypopara UK committee who suddenly had to take on much more work. I’m back now but as my cancer was the recurring kind and I will be 65 this month, I feel the time has come for me to put my health and family first and step down. It was with very mixed feelings that I announced my retirement at the AGM held earlier this year. It will be very hard to say goodbye but it’s time to go. And now we have more big news! We'll be back as Parathyroid UK News in May 2020. Meanwhile, take care and love to you all.

We have a lot of news to catch up on so here’s a brief summary and you can read my CEO report online in full on the new website.

**March 2017 - 2019**

**Patient Benefit**

- Our aim at Hypopara UK is to meet the needs of our members as best we can. To that end we get involved in research, raise awareness and seek funds to ensure that we deliver reliable information, provide appropriate education and caring support.
- The last three years have seen a massive increase in what we have been able to achieve.
- Today we have round 2,500 registered members and a worldwide reputation.
- As well as online support groups where members can get help learning to manage their calcium levels there is a telephone helpline, and we are setting up regional groups where people can meet face to face.
- In terms of education, there are award winning leaflets and a well respected website with a new and updated version on its way.
- The Hypopara Emergency Card is ready!

**Treasurers’ report**

Bill reported that as of 31st Dec 2018 we had £18, 865.75 in the bank. This is due to the donation from Shire/Takeda of £26,000, sponsored events £2,921, Regular donations from members, £1,119, Individual donations from members £530.16, Charities trust £700.25, Easy Fundraising £73.3.0 Thank you to everyone who has helped raise funds which are being used for awareness, conferences, projects, new website, printing and distribution and keeping us going.

**Conferences**

We have exhibited at all the BAETS and SIE BES, Clinical Cases, Clinical Update and Endocrine Nurses Update conferences in the UK as well as the European Society (ESE) Conferences abroad. Read more on the ‘Out and About page.

**Research**

From NICE guidelines from hyperpara to the Natpar hypopara trial, we have been heavily involved in research over the last two years - see more on the Research News and Hyperpara News pages.
Hypopara UK has come a long way from its humble beginnings back in 2005 where it was borne out of the desperate need of one individual seeking answers to her debilitating condition that had very little or no recognition in the medical world – this we all know to be our very own CEO, Liz Glenister!

Refusing to believe she was ‘unique’ in the UK, Liz set up an online forum to find other patients and a website to provide information. A basic committee was set up and Hypoparathyroidism UK (known as HPTH UK) was born. She brought together a team of doctors who are still with us today, and wrote the first ever patient information leaflet for patients and healthcare professionals. She then set about raising awareness about hypoparathyroidism which was barely recognised in the medical world at that time and brought people together from around the world to begin research into parathyroid hormone.

Since then she has been involved in groundbreaking hypopara research including the publication of various management and emergency guidelines with the SfE, BTA, BAETS and the ESE.

Later, we became Hypopara UK, an easier name to use and a formal committee was established. Everything had been done online from the start, due to health and financial limitations – and still is. (Our first face to face committee meeting was held in London in 2016). In those days there was no suitably established social media platform such as the plethora we have now but thanks to the success of the group we have led the way and have a good following on Facebook, Twitter and Instagram. This has helped us to establish groups and networks around the world which not only provide support for patients where there is none but also helps our global voice to be heard by healthcare professionals, researchers and sponsors.

Fast forward to 2019, and we now have around 2,700 registered members.

In addition we provide the following: (i) online support groups that provide help in teaching ways to manage calcium levels as well as a telephone helpline; (ii) award winning leaflets and a well-established and respected website – with a new and very much updated version expected any day!

Furthermore, the last few years have seen us developing the Hyperpara side of the organisation and consequently in March 2017 we were joined by a Hyperpara team. This led to the setting up of the first Hyperpara UK support network on FB which is thriving. This year we were proud to be invited to help write and review the first NICE guidelines on Primary Hyperparathyroidism.

On the back of this “merger” of these two groups, the Committee voted to change the name from Hypopara UK to Parathyroid UK – thus allowing us to reflect the all-encompassing nature of the new organisation and the work we do for both conditions.

Setting up regional groups that provide members with opportunity to meet face-to-face; Patient Information Day – funding has been obtained;

Our Emergency Card is ready!

We are at last in a position to set up a board of trustees and register as a charity with the Charity Commission.

All this reflects the proactive nature of the group - there's clearly been no resting on any laurels here! What makes this success doubly sweet is the challenges of managing the many hypopara symptoms and still establishing a well respected and highly knowledgeable group that is there for others who find themselves in a similar situation.

By Hasmeeta Mahandru, Editor

Hypopara Groups

Our new Regional Groups co-ordinator is Sophie Worthington. Please contact her via the Hypopara facebook Group if you would like to join a group or start one up. For the moment these groups necessarily cover large areas! Our local organisers are:

Scotland Gillian Adams
Ireland & Northern Ireland Fiona O’Shea
Wales Sophie Worthington
South Catherine Smith
London Sasha Marshom
South East Heather de Souza
South West VACANCY
North East Gillian Casson
North West VACANCY
Central Jayne Jackson
Eastern Ruth Irwin

Hyperpara Groups

If you would like to get involved please contact Julie Tebb via the Hyperpara facebook Group.
Research News

I try to keep parathyroid conditions at the forefront of researchers’ minds and am always very pleased to be invited to provide the patient experience when studies take off. Here are some of the things I am, or have been, involved with over the last 2 years:

- **NICE guidelines on Primary Hyperparathyroidism** published May 2019
- **NIFTY study near infrared fluorescent imaging** Mr Saba Basubramaniam. Ongoing. On Steering Committee.
- **Protocol for detection and management of post-thyroidectomy hypocalcaemia in all surgical centres around the UK – Saba Basubramaniam.** This is a really important initiative that hopes to standardise post-surgical treatment all over the country. We have just scoped out the basic points so far.
- **Thyroid Cancer Consensus Statement** (an update of the 2014 thyroid cancer guidelines) being developed by the British Thyroid Association (BTA). Saba and I are working on the parathyroid chapter and will also be writing the accompanying patient information leaflet.
- **The Hypopara Research Foundation** in the USA has grants available for two projects 1) a calcium home tester and 2) parathyroid stem cells. I approached them and, once I got the go-ahead, invited 2 UK doctors, who I knew were working in those fields, to apply, which they duly did. Fingers crossed!!
- **Is calcium supplementation always needed in patients with hypoparathyroidism?** Ahmed Al-Sharefi, Elizabeth Glenister, Margaret Morris, Richard Quinton. Feb 2019 Clinical Endocrin. Our UK support group has, for many years, advocated the reduction or calcium supplements in accordance with specialist advice to reduce the risk of kidney problems and hypercalciuria. We find that maintaining good levels of Alfacalcidol, Vitamin D3 and Magnesium enable sufficient calcium to be acquired from the diet without the need for much (or any) calcium tablets. These we tend to take only for occasional top-ups or for emergency use. This protocol caught the notice of Dr Quinton and Dr Al-Sharefi after a patient asked to come off their calcium medication and they carried out a study. Many of you participated in a survey about your medication and the result is this study of which I am honoured to be named co-author. [https://onlinelibrary.wiley.com/doi/abs/10.1111/cen.13955](https://onlinelibrary.wiley.com/doi/abs/10.1111/cen.13955)
- **The impact of permanent hypoparathyroidism on quality of life** Charlotte McIntyre, Aimée Di Marco, Jeremy Cox, Steve Robinson, Fausto Palazzo, Neil Tolley Imperial College Healthcare Trust. This was a study on our group which was presented at BAETS and published in Dec 2017.
- **Living with Chronic Hypoparathyroidism.** Our UK quality of life survey (joint project by me and Shire) is available in booklet form and is very popular at conferences. Nov 2017. Burden of Illness Among Patients With Chronic Hypoparathyroidism Not Adequately Controlled With Standard Therapy by Self-Perception - Shire/ Takeda. I am co-author with a group of international doctors on this QoL study analysing the results of a global survey. Hopefully soon to be published. We have worked on this for 2 years and it has been presented at several conferences worldwide.
- **Advanced Practice in Endocrinology Nursing Textbook** I was invited to contribute the hypopara and hyperpara patient experience to the parathyroid chapter in the first ever nursing textbook on Endocrinology, now published. Congratulations to Sofia Lahana and all involved.
- **Fiona Smith represents us at the Strategic Research Priorities in Paediatric Endocrinology meeting in Birmingham.** Ongoing. The aim is to develop a portfolio of research priorities to be used to leverage funding for research in rare children’s endocrine conditions, to try and improve treatments.
- **LATEST NEWS!** I will be joining the ‘Bone and Calcium Network’ meeting at the BES in November to further build relationships between Parathyroid UK and our endocrinologists. Prof Jeremy Turner is planning a national audit of management of hypopara in centres around the UK which will be another vital piece of work.

by Liz Glenister

**NATPAR® Update**

As most of you will already be aware, there is currently a Phase 4, doubleblind, placebo controlled clinical trial (called BALANCE) in progress to assess the symptom improvement and metabolic control in hypopara patients using rhPTH(1-84). This trial is still recruiting if anyone is interested in taking part. Find further information and eligibility/exclusion criteria here - [https://clinicaltrials.gov/ct2/show/NCT03324880?recr=2&cond=1&hyponparathyroidism&rank=2](https://clinicaltrials.gov/ct2/show/NCT03324880?recr=2&cond=1&hyponparathyroidism&rank=2).

This trial has been running for quite some time already and a few of our UK participants have now completed it and a second wave of subjects are beginning their journey! A trial is always a big commitment and often quite a hard journey, particularly a placebo controlled trial, so we created a separate private Facebook group to follow and support our UK members who are taking part and to give them a private space to chat with others who know how they are feeling. If you have passed the screening phase and been accepted onto the BALANCE study to start injecting the study drug, please come and join us at the UK Natpar Patients group on Facebook.

We’ve had varying results so far but obviously everyone is still in the dark as to whether or not they received the genuine medication or the placebo! We’ve also been keeping up with Chris Short (who tells his story in this issue) during his journey onto NATPAR® and his results have been resoundingly positive!

You may have also heard recently that there has been a recall of NATPAR® in the US, due to FDA concerns over a potential issue with the cartridge delivery system. We sympathise with our US members who have been affected and hope that this is resolved quickly for you. Takeda is advising patients to contact their healthcare provider to ensure they discontinue the medication safely and they are working with the FDA to resolve this issue and resume supply as soon as possible. Takeda have assured us that the EMA (European Medicines Agency) have conducted their own risk benefit analysis and in their opinion the safety profile remains the same and will take no further action.

by Mandy Mainland
OCDEM is quite unique as an academic, clinical, teaching and research centre, purpose built in 2003 to bring together teams of scientists, clinicians and healthcare workers, and funded by the NHS, University of Oxford, Novo Nordisk and Takeda. It’s a collaborative venture in every way. It’s also a perfect example of design meeting purpose. Downstairs are the clinicians, the clinics, waiting areas and wards for patients, upstairs are the academics, the researchers, the laboratories, the administrators and offices all working collaboratively to one end. It makes so much sense. We stood with Prof Thakker looking down into the atrium as he explained how passionately he felt about the place. ‘It’s innovative, holistic, and everything we need is right here. We can be working on tests in the lab up here and have the patient in the ward just down there. Or I could.’ Sadly the ward was closed as part of the NHS cuts but the work that goes on here – and must carry on - is world class.

Prof Thakker’s Group, the Academic Endocrine Unit, ‘investigate the genetic, molecular and physiological basis of endocrine disorders that affect calcium homeostasis, and endocrine tumour development. By identifying and understanding the underlying mechanisms, they aim to establish better diagnostic methods and develop novel targeted therapies for these disorders to improve patient care.’ They study 3 areas: endocrine tumours (MEN), kidney & skeletal disorders and calcium receptor (CaSR) disorders. It was a privilege to be invited to take part in a seminar led by Prof Thakker on ‘Hypocalcaemic Disorders’ with excellent slides presented by Dr Victoria Stokes, Endocrine Registrar and Clinical Research Fellow. A wide ranging discussion ensued. It was fascinating to hear such an academically knowledgeable group and in turn give the patient perspective to their questions, such as what a hypo felt like.

At the end, Prof Thakker asked me the ‘Big Question’, what one thing affects patients most? I replied that it was the problem of maintaining calcium levels. A long discussion followed about the pros and cons of a home calcium tester, and the possibilities and difficulties of devising one. We then saw some of the Group in action, back at work in the lab:

Sarah Howles, academic clinical lecturer in urology, is interested in how people form kidney stones, and Caroline Gorvin, is a post doctoral researcher focuses on CaSR signalling. They both were part of the team who developed a new calcilytic compound which, their research states ‘will likely be of benefit for ADH2 patients who also harbour heterozygous GNA11 mutations’. This amazing work is sadly without funds. You can read the paper here https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5291742/ Read about Caroline here https://endocrinologyblog.org/2018/09/04/meet-the-endocrinologist-carolinegorvin-expert-in-hormone-receptorcellular-physiology/

Anna Gluck, studying the role of G protein in calcium and glucose homeostasis and Mie Kronberg Olesen working on calcium disorders, are both PhD students here as part of a European training programme, who presented their work in Florence at the CaSr conference in May.

Finally, we had a fascinating tour around the research labs and a chat with Prof Thakker, who continued the discussion about home testers. I felt so inspired by this remarkable man who has taught so many of the top endocrinologists in the UK and still feels a paternal care for them all. His energy and lively curiosity keeps him always asking those necessary questions – and looking for answers. We are very lucky to have him on our advisory board.

This August I was invited back to have lunch with Professor Thakker and Dr Fadil Hannan who is now back in Oxford. This August I was invited back to have lunch with Professor Thakker and Dr Fadil Hannan who is now back in Oxford, and I will revisit in November. We spent a fascinating afternoon hearing about their ongoing work on calcilytics and CaSR conditions Here is a recent paper they have written https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6535143/ We also heard about various developments that were in the pipeline, some way off but some hopefully sooner. We’ll keep you posted. Meanwhile, I passed on your thanks to both these exceptional doctors for all they are doing for patients with genetic conditions and for their incredible passion and lifelong commitment to our cause.

Liz Glenister
Chris’s Story

“I had an estimated 2 years before dialysis with a limited life expectancy.”

When Chris joined the Hypopara support group two years ago his kidneys were failing and he was desperate for help. Here he tells his story in his own words:

“I was diagnosed with Auto Immune Hypoparathyroidism when I was 12 years old (23 years ago) after contracting glandular fever. I was relatively stable managing on Alfacalcidol (One Alpha) until a couple of years ago when I became unstable. I have suffered from severe nephrocalcinosis for the last 16 years where it was common for me to pass at least a substantial sized kidney stone once every two weeks.

I started my fight for Natpar 5 years ago as my symptoms were worsening year on year but I had no idea how urgent my fight for Natpar would become.

Two years ago, as my symptoms started to deteriorate with repeated hospitalisation for IV treatment, I was prescribed Tereparatide but unfortunately I was extremely unstable and after trying it for 11 months I decided to revert back to Alfacalcidol.

At this point my usual Consultant Endocrinologist was off unwell and I had bumped into a retired Consultant who was covering. After my frosty welcome it transpired that he was one of the few experts in PTH disorders and had an incredible plan to stabilise me which, looking back, I have no doubt saved my life.

During a 6 week hospital stint I was told that my kidneys had severely deteriorated and I had an estimated 2 years before dialysis with a limited life expectancy.

This news made me fight for Natpar all the more. Getting it on compassionate grounds wasn’t an option apparently but Liz from Hypopara UK contacted Takeda and passed on information to my endo who was able to apply for the drug through an ‘Individual Patient Treatment Request’. After a lengthy 3 month wait I got the news (the day after I was about to pack work in for good) that I was getting Natpar. I could collect it in a few days.

After being on Natpar for 3 months I have just received the great news that all signs point towards me living a long and happy life and I am no longer deemed terminal.

My work have been fantastic, letting me go to hospital twice a week and supporting me all the way through my journey even to the extent of donating money from their recent Rob Roy Challenge to Hypopara UK (see more about this on the Fundraising page).”

“I cannot thank Hypopara UK and the group enough for all their support over the years as without them I doubt I would be here to write this today.”

In May, in between Chris’ hospital visits, his third son, Rhys, was born. Congratulations Chris and Vicki!
Sponsored events

London to Brighton Cycle Ride 2017
Annie Farrell, hypopara patient, and friends who managed the gruelling London to Brighton bike ride in September 2017 and raised a fantastic £1,200

Brighton Marathon 2018
In 2018 Caz Gould, our CEO Liz Glenister’s daughter, raised an incredible £2,163.37 running her first ever marathon, in Brighton, in honour of her mum who had just had surgery for breast cancer. Well done Caz! (Note from Liz – I was there to surprise her at this year’s marathon though!)

A huge thank you to Annie and Caz and congratulations on completing such gruelling races – we’re very proud of you!

We must not forget the people who attempted to fundraise but unfortunately weren’t well enough on the day (something we’re all familiar with) and sensibly had to put their plans on hold. Well done and stay positive – it will happen when your body is ready and we really appreciate the thought.

Company donations

We have also had very generous donations from two lovely companies who employ hypopara patients. It’s wonderful to see this kind of support – huge thanks to them and to the two members who put our name forward for consideration. Don’t forget you can do this too – does your company have a charity of the year?

Ben Love and his two daughters have hypopara and he nominated Hypopara UK to receive funds from his company SSP in London. They generously donated £1,000 in 2017 and then did it all over again in 2018. Thank you!

Rob Roy Challenge

Chris Short, whose story is in this newsletter, has been wonderfully supported through his treatment by his employers at Lookers Audi. On 22nd June, they took on Scotland’s biggest fundraiser, the Rob Roy Challenge and split their fundraising between us and Children In Need, raising £2,740.05 for Hypopara UK. What an amazing job! Thank you to you all!

Other ways to help

We are deeply grateful for every effort to help, however small. Many of you support us by setting up a regular monthly donation.

These range from £2 to £10 and they all add up to make a big difference. Many of you have sent one-off donations online or by cheque in gratitude for the help you’ve received from us which is lovely thank you. We are always very moved to receive donations collected in lieu of birthday presents or flowers at funerals. Thank you to everyone who has contributed so thoughtfully in this way. It means a great deal to us.

You can find various ways to donate here: http://www.hypopara.org.uk/getinvolved.php?id=32

What we do

As an organisation, we have not been idle either. We spend a lot of time writing requests for grants from various bodies. As well as that we support all these events and others (like funds for Alfie’s PTH pump) and make sure you get as many sponsors as you can. To continue all this good work requires a dedicated team and in particular the requirement for a volunteer fundraising officer! If you have the time and would like to take on this role then please do volunteer as this role is particularly essential to help us to carry on all our good work. Help us to help you.

Hypopara Fundraising

We’d like to thank all our amazing members who have helped to keep us going – you really are amazing!
World Hypopara Awareness Day 2019

This year WHAD ran a social media campaign entitled ‘What’s your Number?’. The objective was for members, globally, to get involved and post the length of time they had lived with hypopara. Even more of you joined in this year - 27 countries in all - so we can safely say that 2019 WHAD was the best yet!

Here are some of the brilliant photos that were sent in on the day from all around the world! Thank you to everyone who joined in. Many people said they found it surprisingly emotional to see so many patients sharing their work, telling their stories and chatting to each other from around the world. An amazing day!
The history of World Hypopara Day

WHAD has been running every June 1st since 2010 and has gained significant recognition culminating in 2019 when 27 countries were involved in the annual social media awareness event.

To illustrate the synergy between the different regions - members of the UK and France Hypopara together attended the ECE in Lyon this year with the aim of raising awareness about hypopara to leading endocrinologists across the globe.

Liz Glenister of Hypopara UK first established a Hypopara Awareness Day in the UK in 2006 and invited other countries to get involved, eventually forming World Hypopara Awareness Day in 2010. June 1st was agreed upon to coincide with the annual Hypopara conference held in the USA. The logo was produced by Isabel Wray of Hypopara UK for the free promotion of all hypopara organisations around the world.

Since its inception, the WHAD platform has been used to highlight many Hypopara issues and below is summary timeline of the subjects tackled.

2012 – focused on hypopara that was not caused by surgery but could be genetic, autoimmune or idiopathic. Relevant stories were collected that helped spotlight this issue;

2013 – looked at living with hypopara a cause dear to everyone’s heart regardless of how it was caused. Again patient stories were key in raising awareness;

2014 – highlighted women with hypopara and experiences with pregnancy, breastfeeding and childbirth. A subject that is very rarely discussed and very little known in the medical world;

2015 – saw WHAD establish itself in its own right with its own website and online shop which has helped it gain global presence.

2016 – WHAD platform expanded awareness to Switzerland and also educated on diet as an important factor for managing hypopara;

2017 – saw further growth using media as its stage with a radio interview and a Twitter Q&A. Shire pharmaceuticals also helped raise awareness by launching a website for hypopara patients seeking answers;

2018 – Wear blue to say ‘I’m here too’. Hypopara UK hosted the annual social media campaign, a fun event where hypopara patients from all around the world post selfies to the World Hypopara Patient Group on facebook.

Does WHAD make a difference?

As can be seen, WHAD has grown not only in global numbers but in its success raising awareness, promoting more research, educating medical professionals on hypopara and the need for more funding (yes, that ugly, unspoken word but nonetheless a very important one!). In recent years we have seen many more hypopara people and supporters raise funds and awareness through various sponsored activities! Our members have done some stirling work - Chris Short’s firm, Stirling Audi provide charity donation to the tune of £2,740.05. Ben Love’s company generously donated £2,000. In 2017 we saw hypopara patient Annie Farrell and friends raise over £1,200 by doing the gruelling 54 mile London to Brighton bike ride. Read more on the fundraising page.

Will we still do WHAD when we’re Parathyroid UK?

Yes! In answer to your questions, we will still be participating in World Hypopara Awareness Day and hosting the annual social media event even when we are Parathyroid UK. Its very important that a rare condition like Hypopara gets all the publicity it can. We will still be supporting hypopara fundraising events, campaigning for hypopara research, raising awareness at conferences and promoting hypopara research. We’ll just be doing all these things for Hyperpara too.

WHAD 2020

WHAD has clearly helped to raise the Hypopara profile and next year we want it to be BIGGER and BETTER! This is where you, the Hypoparatroopers come in! We would like suggestions on what to do on the next WHAD day. You’ve seen the topics raised to date but what can we do to make it more high profile without compromising our privacy of course.

The person with the best and most original idea will get a Hypopara goodie bag! So get your hypopara brains in action!
Joy Foster writes: This has been a busy year for the hyperpara group as membership has continued to grow. We now have around 300 people contributing to the support group which is active on Facebook and which compliments the charity’s support services by widening access to advice on the condition.

Particularly significant for hyperparathyroid patients this year has been the production by NICE (The national Institute for Clinical Excellence) of a new set of guidelines for the condition. Three of our medical advisors were part of the guideline committee and we also have a lay representative on the panel and consequently were able to contribute patients’ views and experiences directly.

We are very grateful to two members who have raised money by undertaking sponsored activities.

At 14 Ryan is one of the youngest patients of whom we are aware and he impressed us all by successfully completing a three stage sponsored challenge in a day. He and his father set out at 7 am to climb Snowdon, followed this with a 9km bike ride and then took to the water in a kayak! All of this was just 12 months after Ryan underwent parathyroid surgery at LGI Children’s Hospital. An inspiration to all hyperpara patients. Thanks also to Ryan’s mum Claire Marie who is now a volunteer administrator for our Facebook support group.

Julie Tebb ran the London Marathon a year after her surgery too, in an impressive time, and raised an amazing £640 to go towards hyperpara needs. Julie ran ‘for everyone affected by PHPT because I am grateful to be able to run. I am raising awareness of the condition and also funds for Hypopara UK who have been a great source of support and to help them continue their campaigning and support work for people with these conditions.’

We are very pleased that Julie has agreed to Chair the new hyperpara committee and is also very active in the patient support group on Facebook, along with Rae Brown, Joy Foster, Kate Kennedy and Lyn Smith.

Liz writes: Our Hyperpara committee have been working very hard since they joined us two years ago. They are busy growing the Facebook group and are doing a wonderful job creating a warm and wonderful place in which to support members during diagnosis and before and after their operations. They have also contributed to the hyperpara website content.

Hypopara UK have worked hard over the years campaigning to bring about guidelines for hyperparathyroidism so it was a great moment to discover the topic had been chosen for development. I would like to thank Joy Foster who was selected as a lay member on the panel of the NICE hyperparathyroidism guidelines committee. Joy did an absolutely wonderful job and deserves huge thanks for her effort. The role involved a great deal of hard work over a long period of time - not to mention travelling to London for every meeting. Great job, Joy! Lyn Smith and I reviewed the draft comments when they came out in January and the first ever Primary Hyperparathyroidism Guidelines were finally published in May 2019. We hope guidelines for Hypoparathyroidism will be next!
Hypopara UK has always represented hyperpara patients at conferences so we are delighted to have real live patient volunteers joining us now! Joy Foster attended the BAETS 2108 conference in Glasgow (see her report on the Out and About page) and Julie Tebb and Reny Pulling will be attending the Society for Endocrinology BES conference in Brighton in November 2019.

For those that don't know, we were thrilled that our Primary Hyperparathyroidism patient Information leaflet (written by me and Judith Taylor and produced by Isabel Wray) won 'Highly Commended' at the BMA Patient Information awards, attended by Joy Foster, Judith Taylor and Isabel Wray. Now we need to update it in the light of the NICE guidelines.

We are all very excited at the prospect of the hypopara and hyperpara wings of our butterfly coming together under Parathyroid UK and are looking forward to a brighter future for all parathyroid patients.

Read the NICE guidelines on Primary Hyperparathyroidism online or download them here [https://www.nice.org.uk/guidance/ng132](https://www.nice.org.uk/guidance/ng132)
Out and about

Our volunteers have been incredibly busy exhibiting at conferences with surgeons, endocrinologists and endocrine nurses where they work hard to raise awareness, give presentations, network, explain our conditions, take leaflet orders and spot research opportunities. There have been many events since our last published newsletter and not all can be covered as extensively as we would like. Below is a synopsis:

**ECE, Lisbon, May 2017**

In May we exhibited at the European Congress of Endocrinology in Lisbon, along with the Hypopara Europe Network which was launched at the Congress.

Isabel Wray da Silva (UK), Mari Hartgen (Spain), Natalie Holenka (France), and Cristina Galligani (Italy) represented us. Isabel presented her experience of living with hypopara at a satellite symposium “Perspectives on chronic hypoparathyroidism - the patient experience” which was sponsored by Shire.

Isabel writes: “The event attracts a diverse audience of physicians, endocrinologists, nurses, trainees, scientists etc. International experts within the field of endocrinology deliver presentations, lectures and talks.

“It was an honour to be on the panel with both Professor Lars Rejnmark (Aarhus University, Denmark) and Professor Jens Bollerslev (Oslo University Hospital, Norway), both of whom were involved in writing the first ever European Guidelines on managing hypopara.

“I was able to attend the second Shire satellite symposium, “Natpar parathyroid hormone - A new clinical advancement for patients with chronic hypoparathyroidism” and was particularly interested in Professor Bill Fraser’s talk where he presented three patient case studies.”

**BAETS, Belfast, October 2017**

Fiona O'SHea with Gavin Royle (Southampton) & Radu Mihai (Oxford.) Aisling with Radu Mihai and Seb Aspinall

The British Association of Endocrine and Thyroid Surgeons (BAETS) annual meeting in Belfast was attended by our Hypopara representatives - Fiona O'Shea, Ray Finlay and Aisling Duffy O'Connor.

Fiona writes: “There was a lot of interest in the group and what we do, and a lot of leaflets were taken. Some surgeons spoke to us about the incidence of hypopara in their experience. Most admitted that they were not fully aware of the effect that it has.”

The results of a survey we participated in on “The impact of hypoparathyroidism on quality of life” conducted by Charlotte McIntyre, Liz Glenister, Aimee Di Marco, Fausto Palazzo, and Neil Tolley were presented. This showed that the average quality of life in this group of patients is significantly lower than that of the UK population and that a large number of patients suffer with fatigue, role limitations due to their physical health, and overall a low level of general health.

**Hypopara European Network, Amsterdam, October 2017**

Representatives of the Hypopara European Network gathered again in October for a two-day patient meeting organised by Shire and moderated by Anne-Marie Rodriguez de Killeen. Hypopara UK was represented by Judith Taylor and was also attended by Natalie Holenka (France), Arantxa Sáez (Spain) and Cristina Galligani (Italy).

Judith, Cristina and Natalie each gave a presentation on behalf of their organisations. Judith’s presentation, written with Liz Glenister, was on working with the media, and she gave examples of the campaigns for World Hypopara Day and building the “Living with hypopara” stories on the website, and the two Media Planet supplements published in The Guardian this year."

There was also an interesting talk by Professor Heide Siggelkow (Germany) who presented preliminary results of a quality of life study in Germany. She invited the country representatives to collaborate in gathering questionnaires from hypopara patients in their own countries.

Judith writes: “This was a successful meeting which hopefully will lead towards putting the European network onto a robust footing and working together on activities for next year’s World Hypopara Day.”
BAETS and BES 2018, Glasgow

Joy writes: “It was a great privilege to join Mandy Mainland and work with her on the Hypopara display stand at the BAETS conference. Given the emphasis this year, these sessions were more relevant to our hyperpara members than our hypopara ones. There were several sessions on the thyroid, but parathyroid issues were well to the fore.

The main theme threading through the conference seemed to be imaging and in particular imaging in relation to the localisation of the parathyroid glands. The greatest concern was to balance the need for localisation with a need to minimise the exposure to radiation which scans involve.

Of particular interest to me was a paper entitled ‘Quality of life improvement following parathyroid surgery; a two year review from a single surgical centre’ presented by Nadine Caton. The result was interesting in that both symptomatic and asymptomatic patients reported improved QOL across a range of areas.

This supports the view that surgery should be offered to patients who are ostensibly asymptomatic on the basis of the diagnosis, rather than the severity of their symptoms. This is a recommendation that our group members will be very pleased to hear. Most who came to the stall took a copy of the ‘Living with chronic hypoparathyroidism’ report. This was an excellent opportunity for disseminating such information and increasing awareness of patient’s experiences and of the work of Hypopara UK.”

ECE 2018 Barcelona

Prof Bollerslev and Cristina Galligani with Mari Hartgen. Mari Hartgen attended the 2018 Congress with Cristina Galligani from the Italian Hypopara Association.

Mari writes: I have had the opportunity now of attending and representing Hypopara UK at three ECE’s. Our attendance is crucial, benefiting us and also the medical professionals who we are able to engage with. It is not often that we as patients are given such an opportunity to interact, exchange experiences, learn from as well as impart information to the medical world and this should be valued and encouraged.

Clinical Updates 2018 and 2019

Jane and Steve Compton attended the clinical updates on behalf of Hypopara in Birmingham in 2018 and 2019.

Jane writes: CU 2019 was abuzz with lots of interest in our Hypopara stand. There were no specific workshops on hypopara but it’s always useful to attend and to have a presence at these conferences and engage with endocrinologists. Our Shire patient survey was very popular and all copies were taken!

NCC 2018 and 2019

Jane Compton attended on these occasions based in London.

Jane writes: A fascinating lecture presented by Professor Dae Kim (Consultant ENT and thyroid surgeon at St Georges) on the subject of ‘Lobectomy vs. Total Thyroidectomy’ in an attempt to de-escalate the ‘over-treatment’ of some thyroid cancers and the possibility of partial thyroidectomies which would potentially be less risky for the parathyroids. We had interest from other surgeons in particular Paul Kirkland (ENT clinic, East Sussex) who suggested having patient representatives talking to surgeons about living with hypopara. All in all a fruitful mission!

EMari Hartgen attended the European Congress this year, in Lyon, France and Isabel Wray da Silva was able to join her for part of it. Thank you both!

Mari writes: “These events have enabled me to meet some of the most eminent people in Hypoparathyroidism from across the globe. I have had first-hand experience of the enthusiasm they have in their work and their continued drive to improve their knowledge of Hypoparathyroidism. I have also seen the interest in researching new approaches for dealing with Hypoparathyroidism. From new medications to discussions on Stem cells and parathyroid transplants. All are very exciting and give us hope that (in the not too distant future) those of us living with this condition may have an improved quality of life if not a complete cure.”
Beverley’s Story

The Professor says that my parathyroids have woken up!

Beverley had a total thyroidectomy 24 years ago. She became hypopara immediately after surgery, when she began to suffer with tetany, numbness and Twitches. She has been taking one alpha (alfacalcidol) and calcium since then. At the time of her surgery she was a primary school teacher. Although she loved her job, she found it a struggle to push through the fatigue and was unable to keep up the necessary pace and stamina to do her job justice, so after eight years she gave up teaching.

Beverley’s parathyroids had been reimplanted into her neck during surgery but this didn’t seem to have any effect. Then, 24 years later and after an expert endocrinologist made adjustments to her medication, they started working again!

Beverly writes: “I had a total thyroidectomy due to Graves’ disease which caused me to have an overactive thyroid. My parathyroids were transplanted into my neck during surgery. However, I was told that they were in a mess and there was little hope of them working again. I have had the usual fatigue, pins and needles, cramps and reduced quality of life over the years, due to this condition.

“After feeling very unwell from May 2016 I asked for a referral to an endocrinologist. My vitamin D3 was low, serum calcium was unstable and urine calcium was very high. Unfortunately this made matters worse as my urine calcium was increasing as the endocrinologist juggled with the one alpha doses, going up and down trying to balance serum calcium and urine calcium. In January this year, I asked for a referral to another endocrinologist who is an expert in hypopara. He is amazing! His aim was to reduce my medication as I have kidney stones and calcification.

“I had a very tough few months, feeling absolutely dreadful, as he gradually decreased my one alpha and calcium and increased my cholecalciferol (D3), in the hope that this would encourage the parathyroids to produce more PTH. When I first saw him my PTH was 0.8 (1.1-6.8). In late April I had another PTH blood test before and after lunch and my PTH had risen to 2.1 and 2.5 (1.1-6.8). Since the beginning of April I had not had any one alpha, as the Professor didn’t want the blood test to be contaminated with alfalcaldiol, as this suppresses PTH. Also, I had not taken any calcium since the end of April. My bone profile, thyroid function and urine calcium were carefully monitored throughout this process to ensure that I stayed safe.

“This was a very scary time but worth it, as my bloods show that my adjusted calcium and inorganic phosphate levels are now stable and normal and urine calcium has dropped from 14.64 to 4.72 (2.5-7.5). The Professor says that my parathyroids have woken up!

I’m keeping my fingers crossed that my PTH continues to be controlled by my parathyroids! I still take cholecalciferol (D3) drops three times a day with meals, to help with the absorption of dietary calcium in the intestines. Although having been hypopara has caused some irreversible effects on my body, I just find it incredible that my parathyroids are actually working again after so long and that this could give hope to other surgical hypopara patients. My body is still adjusting to this radical change but I feel much better, less fatigued and more in control of my body, instead of the hypopara being in control of me. Long may it last!”

Beverly’s message is, “I hope that more endocrinologists become experts in hypopara, as although it is a rare condition, it has a huge impact on the quality of life of such patients, due to symptoms caused by fluctuating calcium levels and also that patients can be monitored and treated more appropriately for the condition. I feel that I am very fortunate after 24 years, to have had such good care and support from an endocrinologist who is an expert in hypopara and hope other surgical hypopara patients will be given hope by my experience.”
Committee News

Welcome to our new volunteers! A very special welcome to Fiona who will be taking over from Liz as our CEO next year

Fiona Smith – Deputy CEO

Fiona Smith has been announced as Deputy CEO and will be shadowing Liz to ease the transition until she formally takes over in October 2020. Fiona is already involved in a wide variety of activities for Parathyroid UK and she has taken on these challenges with calm efficiency and humour. She is a qualified accountant with experience as Executive Director for a large charity. She has just taken early retirement so is well placed to give the charity the time and energy it needs. As a recovering patient, she understands the compassionate vision we have for Parathyroid UK and is committed to leading us safely forward. We are delighted to welcome Fiona aboard and wish her all the best as she begins her new role.

‘After a total thyroidectomy in 2012 for cancer, I was readmitted for low calcium within twelve hours. Three calcium infusions later I was sent home and told to take 9 calcium tablets a day. It was months before I was referred to an endocrinologist. Through Hypopara UK I was able to get the right treatment and find an endocrinologist with a specialism in calcium. I have been fortunate enough, after 7 years, to regain some parathyroid function, and I am slowly being weaned off Alfacalcidol.’

Farewells

A few sad goodbyes have to be said with the departure of Ray Finlay, Judith Taylor and Aisling Duffy over the last two years – a big thank you to all of them for their time, effort and commitment.

Ray joins the Support Team and will remain as our Science Advisor and occasional public speaker.

Joy Foster and Lyn Smith move to the new Hyperpara committee as part of our reorganisation and both remain Facebook admins.

Blaithin O’Donnell has left us due to the demands of her job and Fiona O’Shea has stepped in as Hypopara Ireland Coordinator to replace her. Good luck Blaithin, keep in touch!

Jane Compton and Gillian Adams have also relinquished Committee duties but both continue to volunteer in the Support Team and have attended conferences this year – thank you!

Mari Hartgen
Europe Representative

Mari has represented us at several European conferences with considerable expertise and flair and you may know her from our Facebook groups.

‘I was diagnosed with Graves’ disease at the age of 16. I am now 57 and living with Hypoparathyroidism and other complications due to my thyroid surgery. I am passionate about educating others on Hypoparathyroidism. It’s the only way we will get the medical community to understand our day to day living with this rare and sometimes complicated disease.’

Janette Langdell
Shop Manager

Janette is a caring admin in our UK Facebook group & we’re very grateful for her excellent organisational skills in our shop.

‘I am excited and honoured to have taken on the role of Shop Manager for Parathyroid UK. I’ve been busy organising new stock bearing our new name and logo. Exciting times ahead! Having had hypopara myself for many years, I’ve gratefully received years of valued support from Hypopara UK.’

Hasmeeta Mahandru
Newsletter Editor

Hasmeeta is our newest committee member and has jumped straight in at the deep end by taking on the newsletter which she has done brilliantly!

‘I was diagnosed with thyroid cancer in 2016 and following a total thyroidectomy and removal of my parathyroids, I was diagnosed with hypoparathyroidism. Then followed a long battle to try to get me onto teriparatide. Unfortunately, this was not successful through NHS which is when my firm stepped in and offered to pay for it! I have been on teriparatide for just over a month so it’s too early to tell if it’s working or not. I cannot stress enough how valuable the support from Hypopara UK has been.’

Sophie Worthington
Regional Groups Co-ordinator, Support Team

‘I’m Sophie, I’m 44 years old married to Dean and have two dogs. I’m a Devonian living in Wales. I’ve had Hypopara for 4 years. I’ve been a member of this group for over 3 years now and find it very informative and there’s always someone around to help! I’m looking forward to my new role and to meeting you all.’
Parathyroid 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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Parathyroid UK is endorsed by:
British Thyroid Association (BTA)
British Association of Endocrine & Thyroid Surgeons (BAETS)
Society for Endocrinology (SfE)
European Society for Endocrinology (ESE)
British Medical Association (BMA)

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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.

Please send articles for consideration to the newsletter editor, Hasmeeta Mahandru by April 5th 2020
hasmeetamahandru@parathyroiduk.org

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