In November several members of Hypopara UK headed to Vienna where they met with other hypopara patients and carers to train as hypoparathyroidism ambassadors.

The newly launched International Hypoparathyroidism Ambassador Programme aims to increase awareness and understanding of hypopara, and to inspire and motivate the international hypopara community. The programme is sponsored and funded by Shire.

Our ambassadors were able to enjoy the fantastic Viennese Christmas market and get into the spirit before immersing themselves in the training sessions.

More news about the ambassador project in our next issue!
Letter from Liz

Hello everyone,
I hope this second newsletter of the year finds you well. I’m just back from the BES conference in Brighton which I think was our most successful yet. I don’t know where the last few months have gone but we are busier than ever, fighting your corner and raising awareness about hypopara and hyperpara. There continues to be interest in hypoparathyroidism from many quarters which is very exciting. Here’s my quick round-up of events since May:

Awareness
Another successful World Hypopara Awareness Day was held on 1 June 2016. To mark the day our committee member and Science Advisor Ray Finlay was invited to the Shire headquarters in Switzerland to give a presentation about hypoparathyroidism. Apparently he packed out the room! We are very grateful to Shire, especially Amy Karrer and Greg Robertson, for arranging such a great event and helping to bring a greater understanding about patients’ lives to those working in the company.

Here at home we ran another successful social media campaign to help raise awareness with hypopara groups around the world. This year, the focus was on the important area of diet which is so often overlooked. If you missed it, here’s our new webpage Food Matters: http://www.hypopara.org.uk/members.php?id=276. Magnesium being added soon!

Conference
Our last conference this year, and on an international scale, is the Society for Endocrinology (SfE) BES 2016 which, this year, was held in Brighton in November. This year our team were Liz and Bill Glenister, Judith Taylor and Aisling Duffy. You can read the scientific programme here http://www.endocrinology.org/events/sfe-bes-conference/sfe-bes-2016/scientific-programme?dayid=0&view=auto and our report and photos are on page 8.

Money matters
We are one of the lucky patient organisations to win an SfE Patient Support Grant this year, to help us produce and distribute patient information leaflets. As always we are indebted to the SfE for supporting us, giving us a free stand at the SfE meetings, and for the SfE travel grant which enables us to attend conferences.

We are over the moon to receive an unrestricted grant from Shire Pharmaceutical to enable us to continue the work we do to benefit patients. This is a fantastic opportunity for us to be able to provide more resources and support patients in more ways while also raising awareness and getting involved in more research to bring about better treatment. If you have a suggestion about what more you need from us as a patient or something you would like to see us make happen please let me know.

Corporate partners
We are now looking for our first corporate partners. If you are a UK company or know a company who may like to benefit from partnering us please follow the link: http://www.hypopara.org.uk/getinvolved.php?id=284.

International news
This has been another very exciting year on the international front. The global hypopara community continues to grow and for the first time the leaders of European hypopara patient groups met together in London. See page 4.

We were sorry to see Tommy Ravlic go from Hypopara Australia this year and wish him well in his new career. I’m delighted to tell you that Hypopara Australia now has a new board in place and will be headed by Shelley Turner who is just in the process of finishing her PhD. I especially want to send love and best wishes for a speedy recovery to Sharon Bassell who is very ill at the moment and has been the rock of this group since the very beginning.

Primary hyperparathyroidism leaflet
We have for some time now, and due to considerable demand, been supporting patients with hyperpara as well as hypopara. Our new leaflet has now been published after extensive review. We launched the leaflet at the SfE BES conference where we also called for a much needed revision of the current guidelines. See page nn.

Research
We are very grateful to the members of our fantastic clinical advisory team who are working so hard to try to improve the lives of hypopara patients. See Research News on page 3.

Distribution
Heather de Souza has done a great job reorganising the distribution side of things so efficiently. If you need leaflets or newsletters please get in touch with her at distribution@hypopara.org.uk

Thank you
As always, the committee and I want to thank you for your wonderful support. We wish everyone the compliments of the season and a very Happy New Year - may 2017 be a good year for you all.

Warmest wishes,
Liz Glenister

lizglenister@hypopara.org.uk
Welcome to our new medical advisors

**Professor Karim Meeran** BSc, MBBS, MD, FRCP, FRCPath is Professor of Endocrinology, Deputy Director of Medical Education and Lead Clinician for Endocrinology at Imperial College, London. After qualifying from the Royal Free Hospital, London in 1988 he trained in Endocrinology at Hammersmith Hospital and St Bartholomew’s Hospital. His clinical focus is in all aspects of endocrinology and diabetes including thyroid, adrenal, prolactin and pituitary diseases, parathyroid, calcium, vitamin D and bone metabolism and neuroendocrine tumours.

**Professor Graham Leese** BMSc (Hons), MBChB, MD, FRCP, FRCPE is Consultant and Honorary Professor in Diabetes and Endocrinology at Dundee University. He undertook his training in Diabetes and Endocrinology in Dundee and Liverpool, before returning to Dundee as an NHS Consultant in January 1996. He is Associate Postgraduate Dean at Dundee University and is a member of the Chief Scientist ETMR Committee of Scotland.

For the full list of our medical advisors please see the back page of this newsletter.

New hyperpara leaflet published!

Our new leaflet on primary hyperparathyroidism has now been published and was launched at the SfE BES annual meeting in Brighton in November. It has been written by **Judith Taylor** and **Liz Glenister** and extensively reviewed by members of our Medical Advisory Team, and has been endorsed by the Society for Endocrinology Clinical Committee of the Bone and Calcium Network.

The leaflet has been produced by **Isabel Wray da Silva** with help from **Pete Hambling** and **James Wilson** and printed by **Steve Fry** at Creatiff Solutions, Bristol. Many thanks to **Debbie Willis**, Policy and Professional Affairs Manager at the SfE for her help too.

The leaflet can be downloaded from our website [http://hypopara.org.uk/resources.php?id=19](http://hypopara.org.uk/resources.php?id=19) or ordered from distribution@hypopara.org.uk. Hospitals may order bulk copies of this and our other leaflets free of charge for display in their clinics.

This leaflet was made possible thanks to a Patient Support Grant from the Society for Endocrinology.
New European hypoparaha patient network

Until this year, most of the leaders of the European hypoparaha organisations had only communicated online. On 8 July a historic event took place as the leaders of seven European hypoparaha organisations from the UK, Ireland, France, Italy, Norway, Sweden and Denmark were brought together in London by Shire Pharmaceutical to advise the company about patient needs.

Liz Glenister, Bill Glenister, Isabel Wray da Silva and Blaithin O’Donnell attended on behalf of Hypoparaha UK.

Liz writes: ‘As you can imagine, it was an emotional occasion for us all. I had never expected this event could take place so I was very excited to see familiar faces again and to meet new ones at the welcome dinner. The following day we were taken to the Bioscience Communications offices in Victoria where an intensive but fascinating day of workshops and fruitful discussion took place. We shared our varied yet similar experiences of living with hypoparaha in different countries, collaborated to produce a consensus on effects of the condition and discussed our perceptions of unmet need in Europe. I’m extremely grateful to everyone for making the journey to London and to Shire for bringing us all together at last.

Greg Robertson and Amy Karrer of Shire International were wonderful hosts and we hope that through their feedback Shire came to better understand the limitations which such a rare disease can impose. We thank them and the excellent Bioscience Communications for facilitating such a productive and insightful meeting.

Since then, we have kept the communication going. Our first teleconference was kindly hosted by Natalie Grosset-Holenka of Hypoparaha France and thanks to an online forum we continue to work together as a team. We hope that this informal but effective network will one day grow into a European Hypoparaha Alliance. We also hope to attend, as a group, the European Society of Endocrinology meeting in Lisbon in May 2017 and we will be working together on a theme for the next World Hypoparaha Awareness Day on 1 June.

Together we have a louder voice.

Christmas Cards

Living with a parathyroid condition can affect the whole family not just the patient. To highlight the needs of families, we’re delighted to bring you two beautiful Christmas cards made by children whose mothers have hypoparathyroidism. We love that they’ve both used our butterfly too!

Winter Landscape by Heather Adams, age 12

Christmas Tree by Kai Worthington, age 8

Many thanks to Heather and Kai and to all the other children who submitted designs. Unfortunately, our printer was not able to use them all for technical reasons but they were ALL lovely!

Inside each card reads...
Season’s Greetings to suit all uses.
Size A5 (5.83” x 8.27”/14.8cm x 21cm)
Pack of 5 cards £3.75 plus p&p £1.25

The cards can be ordered from our online Hypoparaha UK shop

http://www.hypoparaha.org.uk/getinvolved.php?id=264
Help wanted!

“Think Research”
Rare Diseases Patient Day

Statistically, it is not unusual to be affected by a rare disease: there are between 5,000 and 8,000 different rare diseases and together they affect the lives of three million people in the UK (Department of Health, 2013)

Aisling Duffy recently attended a patient day organised by Rare Diseases UK to help patient advocates get to grips with the research world.

Aisling writes:
It was a very interesting day and I was so happy to attend to represent Hypopara UK.

The day started with a few presentations from Professor John Bradley, Professor William H Ouwehand, Dr Robert Semple and Professor Lucy Wedderburn. They spoke about ‘Rare Diseases and the Future’, ‘The Diagnostic Odyssey and what we can do about it’, ‘Metabolism and Endocrine RD theme’ and also ‘Childhood Myositis’.

Professor Ouwehand discussed the 100,000 Genomes Project which aims to sequence 100,000 whole genomes from NHS patients (and their relatives) by 2017. This will help put genomic medicine in place for the NHS and to develop new treatments. Below is a statement taken from the 100,000 Genomes Project’s website:

“It is estimated that one in seventeen people are born with or develop a rare disease during their lifetime. At least 80% of rare diseases have an identified genetic component, with 50% of new cases of rare diseases being identified in children. However, it can take considerable time and expense between a patient first presenting at a doctor and receiving an accurate diagnosis. The time taken to sequence a whole human genome has been dramatically reduced and will become more affordable for routine use as the price continues to fall.”

For all people with genetic hypoparathyroidism this will help greatly to family members and a quicker overall diagnosis.

The training sessions I attended were ‘How to Read Study Protocols’ and ‘Running a Successful Patient Group’. We received a copy of the book ‘A Pocket Guide to Good Clinical Practice, Including the Declaration of Helsinki’ by the NHS. The NIHR (National Institute for Health Research) also included a ‘Jargon Buster’ in our info packs of terms used in research papers.

The Charissa Atkin Fund

We were so shocked and saddened to learn of the sudden death of Charissa Atkin, a member of Hypopara UK for many years. Our thoughts are with Charissa’s mother, Angela Beckenham, and her husband Steven Atkin who is still an active member of our Facebook group.

Charissa's family very kindly asked for donations instead of flowers at her funeral and raised nearly £500 for Hypopara UK. This is going to be used to set up a fund in Charissa's name to support the education of young endocrinologists in the South West of England, where she lived.

Steven writes: Charissa had an emergency operation for a multinodular goitre which was strangling her trachea and had a thyroidectomy. Her parathyroids were taken out by mistake at the same time. She was discharged but then immediately re-admitted after being unwell. She spent three to six months in hospital while they tried to stabilise her condition. Charissa was actually in the middle of her university training to become an operating department practitioner to work in hospital in theatres. Because of her new illness and the time she missed she was made to repeat the year she had missed.

Charissa was keen to help raise awareness about hypoparathyroidism and fundraise for the cause so if you would like to add a donation to Hypopara UK in her name we will add it to the Charissa Atkin Fund.

Help wanted!

Hypopara UK is run entirely by volunteers. We have no paid staff at all, and most of us are coping with hypopara too. If you can help out in any way, or would like to find out more about volunteering, then please get in touch with Liz - lizglenister@hypopara.org.uk
There is increasing interest in rare diseases and in hypo and hyperparathyroidism as areas of research and we are extremely grateful to our medical advisors, in particular, for continuing their efforts to achieve funding and to investigate areas of need.

**Oral PTH trial**
Entera Bio’s oral PTH 1-34 drug for the treatment of hypoparathyroidism was approved as an orphan drug by the European Medicines Agency (EMA) in May and is now being manufactured in the UK. Our lead advisor, Professor Bill Fraser, expects the study to start in summer 2017 at the latest. It will be a multinational trial including the UK. Unlike the last clinical trial this will be run from several centres around the UK for ease of access and participants will be able to remain on the tablets after the trial is completed. Please do not get in touch with us yet - we will contact all members by email when registration is open.

**Natpar**
Natpar is still waiting for EMA approval but progress is being made. It is now expected in early 2017. Last week, a NICE Scientific Advice meeting was held for Shire Pharmaceutical to seek advice on trialling the product and setting up a patient registry. Professor Neil Gittoes was present to give the clinician view and Liz Glenister and Ray Finlay were pleased to be invited to attend as patient experts to explain about living with the condition and the existing treatment. Ray was also able to describe his experience of taking part in the REPLACE trial in 2010 which was very useful. We will keep you posted!

**Pre-operative vitamin D study**
Consultant endocrine surgeon Saba Balasubramanian is passionate about hypoparathyroidism and has been working continuously for many years to bring about research to help improve surgical procedures. Sadly his application for a study on prophylactic vitamin D to reduce incidence of post-thyroidectomy hypocalcaemia which was reviewed and supported by Hypopara UK was turned down but he is currently working on a study on intraoperative imaging.

**Intra-operative fluorescent imaging**
This is another study by Saba Balasubramian on an imaging device that has the potential to identify parathyroid glands and avoid parathyroid injury in thyroid and parathyroid surgery. Phase 1 was completed in May and there have been very good results. The spectroscopy study began in July. The phase II study will involve patients who are undergoing both thyroid and parathyroid surgery. The aim is to develop a clinical protocol that can then be tested in a randomised clinical trial before being put to routine clinical use. Saba says, “All this will take time, but I am optimistic that we will find technology to reduce the burden of this disease in a few years”.

**Patient Survey**
We will be contacting you in January to ask you to take part in an online patient survey about living with hypoparathyroidism. We hope as many members as possible will take part in this which will be the first of its kind on this condition in the UK. It will be sponsored and run by Shire in conjunction with Hypopara UK and we will announce details as soon as possible. Please keep an eye on your inboxes for an email from us! Thank you in advance for your support.
Parathyroid stem cell video

In Newcastle, a research team headed up by Consultant Endocrine Surgeon Simon Aspinall and Dr Annette Meeson are looking at how stem cell transplants may help people with hypoparathyroidism. They have been working on an educational video to explain the process to patients. Hypopara UK member Gillian Casson volunteered to take part and you’ll be able to see her tell her story and find out more about stem cell therapy when the video is released.

Gillian writes: When I got the call to represent Hypopara UK, I was thrilled and excited especially as it meant appearing in a short video!

Newcastle University is looking at research around stem cells for sufferers of hypoparathyroidism. The project is still in the early stages but I was asked to talk about the daily challenges we face, what it is like to live with this disease, and how Hypopara UK has helped me. I also talked a little about new treatments and what this means to us.

The day arrived for my ‘big scene’, Lights were erected and camera was rolling ... and the nerves set in! After a couple of takes I managed to give a comprehensive list of issues that we all face every day and how this impacts on our lives. At times I think the amount and severity of our challenges raised a few eyebrows.

I’m no Dame Judy Dench but I gave it my best, and hopefully although stem cell research is still in its infancy, it can used in the future to improve quality of lives for those suffering from hypopara.

Parathyroid transplant survey

Last year, consultant surgeon Radu Mihai asked members of Hypopara UK and surgeon members of BAETS and ENT-UK for their views on possible research projects of interest in the field of thyroid-parathyroid-adrenal-NET pancreatic surgery. Our request about parathyroid transplant surgery made the cut so and as a result of this Mr Mihai this year surveyed our members to find out their views on the subject. He will be presenting his findings at the British Association of Endocrine & Thyroid Surgeons (BAETS) meeting in Berlin in November. The poster, if published, will be available on our website but here is a sneak preview.

Mr Mihai is very grateful for your support and sends a big THANK YOU to everyone who took the time and trouble to take part. He says ‘I think these are very interesting data that would have been impossible to collect without the generous involvement of the Hypopara UK members’
Out and About

Brighton

In November, Hypopara UK had a stand at the Society for Endocrinology BES meeting in Brighton. Liz and Bill Glenister, Judith Taylor and Aisling Duffy manned the stand and were able to meet some of our medical advisors and to introduce our patient materials to delegates, including our Hypoparathyroidism patient leaflet and the new Primary Hyperparathyroidism leaflet.

Pictured above - Aisling handing out leaflets as people arrived; and below - Dr Kronenberg (left) receiving the SfE’s Transatlantic Medal from Professor Simon Pearce, the scientific chair and a member of Hypopara UK’s medical advisory team.

We are very grateful to the Society for Endocrinology for its support in making it possible to attend the meeting.

Do it for Hypopara UK

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: “Following an operation in September 2013 I was left with a very complicated (and very rare) side effect called hypoparathyroidism, which means the body cannot regulate calcium levels within the blood. This can lead to very frightening muscle spasms through the entire body, and if not treated quickly could even cause heart failure.

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

Or better still, sign up for the ride yourself!
Patient stories
Overcoming challenges

Hannah’s story

Hannah was diagnosed with hypoparathyroidism in her teens and needs weekly calcium infusions. Alongside working hard as a student nurse, she took part in the physically demanding Colour Obstacle Rush in Aintree last May (see Hypopara UK News Spring 2016). She also manages to travel to faraway places – this year she went to Florida! Here she explains how she manages.

Hannah writes: I was diagnosed with hypoparathyroidism when I was 16 years old and since then I have received weekly calcium infusions.

I was told I wouldn’t be able to travel, but I have now worked out a regime with the help of my consultant which allows me to go on one holiday each year for up to two weeks which has made a huge difference!!

The first holiday I tried was Spain five years ago. Since then I have been to Disneyland Paris, Vienna (Austria), New York and Florida. Being able to go on holiday has given me the chance to have a normal life for a couple of weeks and feeling well! I have been able to see places I never thought I would and I am too busy enjoying myself to worry if my levels are going to suddenly drop - but if levels do drop I just take it as it comes and manage it myself and go to the hospital if I need to (that’s why you get good travel insurance!)

Getting travel insurance has never been a problem for me, although I do pay more due to my other health problems. The company I regularly use is called OK To Travel. It covers pre-existing conditions and is reasonably priced and reliable.

I am a student nurse currently doing 37.5 hours a week on placement (including nights) plus two days at the hospital per week so knowing I have a holiday to look forward to gives me the motivation to carry on.

I would urge everyone to try and go away when they can even if it’s just for a short break. A stress-free environment for a short while really does make a difference. You only have one life - see everything you want to and don’t let this condition take over!

“You only have one life - don’t let this condition take over!”
Gillian had a baby in 2013 and felt better than she had done for very long time since her surgery, but she put on a lot of weight too. After walking and exercising to lose weight she went all the way, completing Tough Mudder to raise funds for charity and then qualifying to be a fitness instructor. And she has also succeeded in gradually cutting down her calcium meds to zero!

Gillian writes: I was very fed up being overweight after having a baby, so after about six months I decided to start walking about four miles a day with the baby in his pram. After a couple of months I’d lost a stone in weight and my calcium levels didn’t seem to be too badly affected by the exercise... in fact if anything I noticed my symptoms less.

I was enjoying being slimmer and getting some exercise, so, on my next appointment at the endo clinic, I went armed with information from Hypopara UK and the world-wide web and asked if my calcium tablets could be reduced, alfacalcidol increased and could I have some prescription vitamin D3 please? (If I cut my calcichew down, I’d be cutting out prescription strength vitamin D and I thought it was very important to keep that the same.)

To my delight, my endo was very happy to comply. He gave me a prescription for Fultium D3, reduced my calcichew to one tablet a day and increased my alfacalcidol from 1.00mcg to 1.5mcg per day.

I reduced my calcium to one tablet a day very slowly and found I felt ok.

One day I saw an advert for an all ladies Boot(y) Camp, which was exercise classes done outside and it sounded like a great fun. So, wanting to lose more weight, I filled out the health screening form, explained my medical conditions and went along at 6.30 am the next day! Yes...6.30 AM!

We were running, jumping, skipping, slamming a battle rope, doing something that almost resembled press ups and it was fantastic! I went home after 30 minutes of this crazy exercise class, tired but buzzing and feeling great. I took a little extra calcium, but I was fine and there were no crashes.

I continued with these classes for another 12 weeks and lost another stone in weight. Many inches of fat disappeared and lo and behold ... I had some muscles appearing. The instructor, Louise, asked the class one day if anyone fancied joining her and some others in completing Tough Mudder to raise funds for Children In Poverty. I signed up and started extra training with her. I also joined the local authority gyms and was exercising quite intensely four to five times a week. All the while my calcium supplement was just one tablet a day. I gradually reduced it for a year and one day decided I didn’t need it at all. So, didn’t take it ... and I was fine. I was still exercising every day for at least 30 mins at high intensity and I was fine!

We completed Tough Mudder on 26 June this year and, although I was concerned about my calcium levels and had taken medication with me in a waterproof (and mudproof) bag, I had again been fine! I hadn’t had any emergencies, no crashes. The worst was cramps in my calves towards the end, when we had started to slow down around about Mile 11 or so, but even that was manageable. And I wasn’t the only one, many participants were starting to cramp up, so it was normal.

Gillian’s story

Boosted by my success in completing Tough Mudder, and finding I could do all this exercise with very little in the way of symptoms or side effects, I decided I wanted to do more and become a fitness instructor. So, with the help of my Instructor, Louise, I found a course and went for it. I accomplished my goal and qualified as a Level 2 Fitness Instructor in July this year.

However, I wanted more, so I started College in September and am now studying HNC Health, Fitness and Exercise. Once I have completed that next year, I will do an 18-week HNC Personal Trainer Course. I’ve also passed a course to become an instructor of classes in a maximal intensity exercise programme called Fatburn Extreme.

I thought when I had my thyroid removed and ended up with hypopara, that life would never be the same again ... and it hasn’t! With help and support from Hypopara UK, and an understanding endocrinologist, I have managed to hop, skip and jump, (literally) back into life.
Fiona’s story

Fiona has had hypopara since 2003 following a total thyroidectomy. She was very well maintained and had two children without any problems and felt like she was leading a normal life, until she moved home and changed doctors, when things went horribly wrong. Here she explains how high calcium and inappropriate health care nearly ruined her and her family life – and how she came back again to good health.

Fiona writes: In April 2015 I went to my new GP for the first time after moving house with tingling. The GP never met anyone with hypopara before so sent me to the acute assessment unit of my local hospital to get bloods done as we both felt it was my calcium. As it happens my calcium was exactly where it was meant to be, but my new endo decided my calcium was too low and increased my Adcal from four to six tablets a day. I questioned her at the time but at this point I knew very little about hypopara because I was so well maintained on Adcal and when I was first diagnosed there was no info on it.

After increasing the Adcal I started feeling unwell, it was nothing specific, I just wasn’t coping at work and with life in general. In August I broke down at work to a colleague and said I felt I was having some sort of a mental breakdown. A few weeks later we went on our annual holiday where I started to anxiety and ended up in hospital in Spain with terrible heart arrhythmias. I was diagnosed with anxiety.

Back home my GP sent me for tests which all came back normal. By this stage I was unable to work and on sick leave. One evening I was home alone with the children when I started to feel faint and had a rapid heartbeat. I rang dad and while on the phone to him I passed out. He came very quickly and found me slumped on the ground with my two children aged three and five asleep upstairs.

I had several further hospital visits, and at one time, multiple sclerosis was suspected. But I was discharged with no diagnosis of anything. Within 24 hours I took ill again, this time with full-blown tetany, I had rigors, I thought I was going to die, and so did my husband. I went to hospital by ambulance. My blood calcium was extremely high, but again the endo said it was ‘fine’. A few days later her registrar came to me, pulled the curtains round, diagnosed me with anxiety and asked my permission for a psychiatric referral as I needed to be admitted there. I knew then that if I stayed any longer with this team that I’d perish so I found a private endo.

On the day I discharged myself the endo came round with her team and said she didn’t know what was wrong with me and actually diagnosed me with fibromyalgia. I was humiliated and broken sitting in my pyjamas in a six-bedded unit in front of six professionals.

When I finally saw the private endo she was horrified at the state of me and my bloods. She immediately put me down to two Adcal and started to wean me off calcium permanently. Some weeks later I ended up in hospital gravely unwell with a reading of 3.33 as I was started on one alpha too soon. At this point I was also diagnosed with acute kidney failure. I was a mess, my family was a mess, the children thought I was going to die and I was broken, physically, financially and mentally.

Fast forward a full year later and I’m me again, off calcium altogether, kidney nearly resolved, mentally well and loving life. One group of people got me through all of this and that was you all at Hypopara UK. I found you a few months ago and I might as well have won the lottery. You gave me hope.

Please don’t suffer, don’t allow yourself to be wrongly diagnosed, trust your gut feeling and never accept ‘normal’.
Sarah writes: This is a tale of two halves. In the first half I'm a fighter, a survivor and I'm proud that my body has been strong enough to get through a serious illness. But on the flip side, I tell a tale of mistrusting the very vessel I am so proud has survived.

In 2013, I became the proud owner of a lot of extra scarves. Now, this is not a bad thing as, in my opinion, scarves are a great addition to any outfit.

So why did 2013 see such an exponential growth in my personal scarf collection? It was a reaction by friends and family to my diagnosis of well-defined, papillary thyroid cancer, just before my 31st birthday. Guess when I got those scarves?

To them, the news that I'd be left with a big scar across the front and left side of my neck after a full thyroidectomy and left neck dissection (taking out the cancer which had spread up the lymph nodes in the left side of my neck), was concerning. They were worried as to what effect the scar would have on my body image.

But they needn't have worried, I love my scar. I purposely cut my hair short so you can see it in all its keloid lumpiness. My scar is my talking point, my war wound, my trump card and my party piece. My scar is my survival story.

My scar represents my story to date, a scary, sometimes sad journey that I have travelled over the past three years. It's a time that has made me who I am now – a more confident, happier with her body image, determined and focused-self.

I never wanted to have cancer, but it's made me value life and put myself first for once. Going through cancer I've grown confident enough to challenge roles that are created for me by society, media and unwittingly by family and friends. I question more and care less what other people think about how I look and what I do. It's been a positive outcome from a negative experience.

So what's the other side of this story? It's a story of another scar that cancer has left on me. An unseen scar, the one that's in my head.

Cancer didn't make me hate my body image, but has actually helped refocus my negative body image – it'll never be fully positive, but I'm getting better at it. What cancer did is it made me hate myself. My actual, physical shell of a body.

After I had been through a frenetic five months of ultrasounds, biopsies, diagnosis, more scans, operations and radiotherapy I stopped. Treatment stopped, weekly consultations with my oncology team stopped and at this moment, my brain started.
Quietly at first – the distrust, the questioning, the disbelief that my body could let myself down in such a monumental way. I hated her with a passion, how dare she let me down? How dare she multiply too much, poison me from the inside? How could I trust her that she wouldn't do it again?

When you have thyroid cancer, after your thyroidectomy and radioiodine treatment, you're popped onto levothyroxine (replacement thyroid hormone). And to supress the cancer returning, you're popped on a higher than normal amount, which means you can eat what you want but you don't sleep well and you can be a little bit anxious.

Or in the case of someone like me, who suffers from anxiety and depression, it can make you very, very anxious.

Mix this with a negative appraisal of your actual body and you get an onslaught of worry, dread and tears. Every twinge, lump, bump, noise, creak or flutter and I was down to the doctor. I've had a barium swallow, two extra MRIs, an x-ray, about six ultrasounds and finally, a lot of counselling.

People focus on what they can see – the operation, the scar, the isolation suite for radiotherapy. What they don't prepare you for, what no one talks about is the mistrust and hatred of your body. I don't trust her not to mess up again, I distrust what she is capable of, and I limit myself.

Outwardly I am easy going, I laugh, joke and go to work, just like you. But inside I question myself incessantly – having been left with a post-cancer condition, will I be able to stay out without falling asleep in front of a date? With nerve and muscle damage in my shoulder will I be able to take part in things that my friends do? With hypoparathyroidism, will I ever be able to carry children? With a low immune system should I go and stand at a gig and enjoy myself? I keep myself in, I make excuses and I control what I eat. I sometimes want to punish her for everything she has done.

But I'm getting better. Day by day I push myself a little further. There are days when I don't talk to my body; we walk around in silence, me barely acknowledging her and she aching, hurting, feeling like she's falling apart around me.

It will be a long journey that we take together, my body and I. She will be with me to wherever I end my journey. And we shouldn't walk through life in silence, mistrusting one another.

So I need to look at my scar and what it represents and I see that fragile vessel, cell upon cell spreading out from that thin, lumpy, keloid line. And I know I have to look after her and I have to trust her. When my lymph nodes are up I have to trust it's a cold and not cancer returned, when I ache all over I need to stop, rest and look after her. Together, hand in hand, we'll be there for each other and we'll be positive that we can support each other.

When we speak about 'body positivity' we generally use it to describe being positive about our body image – looking like how we want to look like and not being shamed into feeling we have to look and act in a certain way.

But body positivity is more than that. It goes deeper. It's not only our body image we need to be positive about, but how we feel about this amazing, unique bag of cells that fights so hard to keep you alive each day. Body positivity is about being positive about what your body can achieve, what your body can do, what your body does for you.

This article first appeared in Ladyfest Manchester and we are grateful for their permission to reproduce it. Ladyfest Manchester is a collective which creates events that combine music, art and ideas with a feminist ethos. https://ladyfestmanc.wordpress.com

**“Be positive about what your body can achieve, what your body can do, what your body does for you.”**

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**Share your story...**

Sarah is building up a stock of patient stories to make available to the press. If you have an unusual story to tell and would like to contribute please contact her at sarah@hypopara.org.uk
**Butternut, sage and pancetta spaghetti**

*Serves 4 • Prep 10 mins • Cook 35 mins • Cost per portion: £1.00*

Sometimes a warming pasta dish is just what you need, however many pasta sauces are either full of calories or full of tomatoes (which can interfere with calcium supplements). This spaghetti dish is easy to make, but tastes great.

**Ingredients:**

- 1 medium butternut squash, cut into 2cm dice
- 2 tblsp light olive oil* and extra to fry
- 1 pack of smoked pancetta
- 1 medium brown onion, sliced fine
- 300g spaghetti
- 2 cloves of garlic, sliced fine
- 3 tblsp extra virgin olive oil
- Juice of half a lemon
- Salt and freshly ground black pepper
- One supermarket packet of fresh sage, leaves picked off stems**
- 100g fresh rocket or watercress
- Gruyere cheese to grate over

**You will need:**

- 1 large roasting tin
- 1 medium frying pan
- 1 large saucepan

**Method:**

1. Turn the oven on to 200c and whilst it’s coming up to heat peel and dice the squash. You can leave the peel on if you like, but I think it tastes better without. Put the squash into the roasting tin, pour over the olive oil and season with salt and pepper. Pop into the oven and roast for 30 mins.

2. After 15 minutes put a full kettle on to boil and whilst it’s coming to the boil, put the frying pan on a medium/low heat. Add the pancetta to the frying pan, once it has released some of its fat add the onion and stir. You will need to stir this regularly, your aim is to soften the onions and keep them sweet, not brown them.

3. Place the saucepan on a high heat and add the water, wait for it to come to a rolling boil and then add the spaghetti. As soon as it has become malleable, stir to stop it sticking together. Always keep the pasta at a rolling boil, only turn down if it looks like it will boil over.

4. Check the squash, if it’s catching at the edges and soft, take out of the oven, if not then turn up the heat to 220c and continue cooking.

5. Add the garlic to the frying pan, turn the heat to low and keep stirring regularly.

6. Once the pasta is done, drain, then return the saucepan and add the extra virgin olive oil and stir.

7. Take the squash out of the oven and add to the spaghetti pan, discarding the oil in the roasting tin. Tip the contents of the frying pan into the spaghetti and season with lemon juice, salt and pepper. Snip over the all the sage leaves. Mix together and once combined, taste (add more seasoning if required), divide between four bowls and top with the rocket or watercress and a little bit of grated Gruyere.

- To make this vegan: omit the pancetta and Gruyere, grate a quarter of a nutmeg over the spaghetti before mixing.
- To make this gluten free: use gluten free pasta.
- Butternut squash is a good source of: Vitamins A, B6, C and E, copper, iron, magnesium, calcium and potassium.
- Rocket is a good source of: Vitamins A, C and K, folate, calcium, iron, magnesium, manganese and potassium.
- Watercress is a good source of: Vitamins A, B2, C and K, calcium and manganese.

**NB** Government advice suggests limiting cured meats to 50g portion per person

* Recent studies have shown that oils high in poly-unsaturated fats such as sunflower and vegetable oil can cause high levels of toxic chemicals to be created when cooked with. I use coconut or refined olive oil (not virgin cold-pressed) to cook with, but butter and lard have also be shown to keep levels of toxic compound low (but maybe not the calories).

**If you don’t have any fresh sage, substitute 1 tblsp dried sage and add to the frying pan with the onions.
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.

Liz Glenister set this group up in October 2007 and it’s the oldest hypopara group on Facebook.

Liz writes: We have been educating each other in the group for a long time now about ways to manage calcium levels and passing on the tips that we have gleaned over the years, many of which are now recognised and supported in the guidelines and by our specialist advisors. We welcome our hyperpara members as well.

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 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:

“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 hypopara 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

“Since 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

To join us on Facebook search for Hypopara UK Group or follow the link: https://www.facebook.com/groups/hpthuk/
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 is recognised by:
British Thyroid Association (BTA)
British Association of Endocrine & Thyroid Surgeons (BAETS)
Society for Endocrinology
NHS Choices

Members of:
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Thyroid Cancer Alliance

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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, Judith Taylor, judithtaylor@hypopara.org.uk

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