Liz is Britain’s Best Volunteer!

We’re thrilled to announce that Chief Executive Liz Glenister, who is the founder of Hypopara UK, has been named the winner of Britain’s Best Volunteer award. Liz faced stiff competition from hundreds of nominations for volunteers across Britain and reached the final alongside four other remarkable charity workers.

The finalists were selected by award judges Judith Miller, Trustee of Small Charities Coalition, Andy Partington, the Director of Markel UK and Vicky Browning, Director of CharityComms.

Liz was named the winner following a public vote and was presented with a cheque for £1,250 for Hypopara UK, as well as £1,000 in holiday vouchers for her own personal use.

On finding out she had won the award, Liz said: “I’m absolutely thrilled to have won this award which I see as a fantastic opportunity to raise awareness about the rare condition, hypoparathyroidism, and our small but far-reaching charity, Hypopara UK.

“We are raising funds for vital stem cell research at the moment so this prize will really help. Thank you to everyone who voted, to my committee who nominated me and well done to all the finalists who all work so hard and represent such worthy causes.”


She was inspired to do something to help others after spending many years without support or information about her condition and being told by doctors that she must be “bringing it on herself”.

Today, with over 1600 members, Liz has brought together a team of ten dedicated volunteers and a highly regarded team of medical specialists who work closely to improve the lives of patients living with all types of parathyroid conditions. Patient support is her priority and she has set up telephone helplines, an online forum, Facebook and local groups and is in daily communication with members.

Continued on page 14...

Wednesday 1 June is World Hypopara Awareness Day - join the Facebook campaign by posting your own mug shot! See page 3 for details
Hello everyone,

I am taking this opportunity to thank you all so much for your extraordinary support during the Britain’s Best Volunteer award campaign. I was incredibly moved by all your votes, wonderful messages and kindness which meant so much to me personally and has had a great result – you have helped to raise the profile of hypoparathyroidism and Hypopara UK and made it possible to fund some important research in developing parathyroid stem cells that couldn’t progress otherwise. I also win a much needed break in my beloved Cornwall so thank you for that too! I truly felt part of a supportive family and this result has shown that when we all pull together we really can make a difference. The power of our united voices is having effect in other ways too – the medical world is finally listening to hypopara patients and there has never been more interest in our plight.

Here’s a brief summary of news in the last year and a taste of what you can find inside this newsletter which I hope you enjoy.

Awareness

World Hypopara Awareness Day is upon us again! As well as linking up with groups around the world, we will be running a campaign called “Food Matters”, raising awareness about the importance of diet for hypopara patients, and linking up with the Dairy Council to inform you about calcium. See page 3.

Guidelines

As many of you know, I went to Florence last year for the First International Hypoparathyroidism Conference. Last month the first guidelines, drawn from the contributions of the experts who attended this event, were published. From the UK, the expert involved was our own Professor Thakker and we extend our grateful thanks to him for his involvement and hard work on our behalf. See page 5.

Natpara

No news… we’re still waiting… but we’re working closely with Shire Pharmaceutical, the company that makes it and will eventually distribute it. Ray will be going to the Shire headquarters in Switzerland to give a presentation about hypoparathyroidism at the end of May. Liz, Bill, Isabel and Judith have had several meetings with various personnel in London.

Rare Disease Day

This year Rare Disease Day fell on 29 February. We published an update on Vincent’s Story written by his mum, Christabel who has been a source of helpful information to other parents in the Facebook group (see page 6). We were also delighted to be represented by our dedicated members at the Rare Disease UK parliamentary reception in London (see page 8) and the Genetic Alliance UK conversations in Dundee (see page 9).

Conferences

For the first time, we were invited to the British Association of Endocrine and Thyroid surgeons (BAETS) conference which we were delighted to attend in October. This has led to us being involved in a patient survey carried out by our advisor Radu Mihai and various ongoing pieces of research. We also attended the Society for Endocrinology British Endocrine Societies meeting in Edinburgh in November (where there was, also for the first time, a good buzz about hypoparathyroidism), the Clinical Cases meeting in London in February, and the Clinical Update/Endocrine Nurses meeting in Birmingham in March. (For conference reports and pictures see page 7.)

Money matters

As always we are grateful to the Society for Endocrinology for supporting us, giving us a free exhibition stand at the SfE meetings, and for the SfE travel grant that enables us to attend conferences.

Medical advisors

We are honoured and delighted to welcome two new advisors to our team: consultant endocrine surgeon Fausto Palazzo and consultant anaesthetist Dr Hilary Bridge. Read more about them on page 4.

Committee news

We are very sorry to say goodbye to two long standing committee members and fundraisers, Su Clifton, who has been such a stalwart of the online forum, and Claire Butchers who was our distributor and also one of our representatives at the USA conference in 2014. We will miss them and wish them both well. We are delighted to welcome three new committee members: Aisling Duffy, Jane Compton, and Sarah Tarmaster - see page 4.

Local groups

Many thanks to committee member Lisa Burke who organised the second London group meeting and to Gillian Adams who did the same in Edinburgh. If you’d like to join or organise a group see page 5.

Newsletter

Huge thanks go out to Mandy Mainland for all her hard work and for the many years of late nights, blood, sweat and laughs we shared when she was Editor of this newsletter. She has stepped down as her role as Chief Operations Officer increases and we welcome Judith Taylor who has taken over as our new Editor. Judith has represented us at many external events and conferences as well as being our representative in the international Thyroid Cancer Alliance where she is currently the Secretary and a member of the Board of Directors.

Thank you

As always, the committee and I want to thank you, our members, for your wonderful support during our amazing tenth year and we look forward to your company as we start the next exciting stage of our journey towards improved health and a better quality of life.

Warmest wishes to you all,
WHAD are you doing for World Hypopara Awareness Day?

1 June is fast approaching and it’s an important day in the global Hypopara calendar. The first day of June is World Hypopara Awareness Day (WHAD), when all the hypopara organisations of the world join together to raise awareness of our rare disease, fundraise and celebrate together.

Food matters

The focus of this year’s campaign is food. We all know the old adage “you are what you eat” and many scientific studies have proved this to be true. However, being conscious of what you eat and its effects on the body is even more important when you suffer from hypoparathyroidism.

WHAD 2016 is challenging people to be more food and calcium aware. When you suffer from hypopara, controlling your calcium can be tricky and you can quickly become hypocalcaemic.

Although alfacalcidol/calcitriol can help us to regulate our calcium, what we eat has a direct effect on our body’s levels too. A balanced intake of calcium can help keep levels stable without the need for calcium supplements, which over the long-term can be damaging to the kidneys.

Ask most people what a calcium-rich food stuff looks like and they’ll point you in the direction of dairy. While diary is a good source, it also contains high levels of phosphorus, which we with hypopara have to minimise – so dairy is best eaten in moderation.

Did you know that there are also good non-dairy sources of calcium, such as kale and chickpeas? And food doesn’t just have a positive effect on our calcium levels – rhubarb or spinach will actively block calcium supplements if taken at the same time.

World Milk Day also falls on 1 June and the Dairy Council will be supporting our efforts – visit our website to find out how you can help yourself and download the CALCIUM booklet.

In addition we have created a Food Matters area on the website, where you can download calcium-rich recipes and find out which foods help to keep levels of calcium and phosphorus stable.

Post your mugshot!

Last year’s t-shirt campaign was a huge success and it was truly moving to see so many smiling Hypopara faces popping up from around the world. This year, to tie in with our Food Matters theme, we’re launching the Mug-Shot campaign.

On 1 June we need you to post a mugshot of you and your mug of milk (dairy or plant based) to the World Hypopara Awareness Day page on Facebook.

You can use your own mug, but why not help us even more and buy an exclusive WHAD mug from our shop? (You can buy t-shirts, caps and totes too!). If you prefer you can email your photo to info@hypopara.org.uk as we will also be putting a selection on the World Hypopara Awareness day website – including those from Hypopara organisations around the world.

If anyone wants to tweet on the run-up to the campaign the hashtags are #mugshot #calciumaware and #WHAD2016.

So come on, let’s milk it!

Recipes

Learn more about our new food matters content and see our Bright Cottage Pie recipe on page 6.
[Image 223x717 to 286x792]
[Image 223x320 to 286x394]
[Image 406x536 to 469x610]
[Image 406x248 to 469x323]
[Image 39x371 to 196x524]

**News**

Welcome to our new medical advisors

Hypopara UK is supported by a distinguished team of endocrinologists, surgeons and GPs from around the UK who have a special interest in parathyroid and calcium issues and are recognised experts in their field. We are very grateful for their vital support and for the dedicated work they undertake on our behalf.

We are delighted to welcome the following:

Mr Fausto Palazzo was appointed Consultant Endocrine Surgeon at Hammersmith Hospital, London in 2004 and is an Honorary Senior Lecturer at Imperial College London. He is Clinical Lead for endocrine and thyroid surgery and has one of the largest clinical practices dedicated entirely to thyroid, parathyroid and adrenal surgery in the UK. He is actively involved in quality assurance in all the aspects of endocrine surgery and has a research interest in hyperparathyroidism in pregnancy and miscarriage related to hyperparathyroidism.

Dr Hilary Bridge is a Consultant Anaesthetist at the Oxford University Hospitals Trust and specialises in anaesthesia and ITU.

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

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**Meet our new committee members**

Aisling Duffy is our new Chief Fundraising Officer and is the person to contact if you have an event in mind at aislingduffy@hypopara.org.uk. She writes: “I’m originally from Dublin but now live in London. I was diagnosed with familial hypocalcaemia when I was 13 and then at 18 I was diagnosed with a hyperplastic nodule and a follicular neoplasm (discovered after removal) which led to a partial thyroidectomy. This resulted in the remaining half of my thyroid not actually working and being prescribed levothyroxine for the foreseeable future. Then at 24 a blood test showed I had dangerously low levels of calcium and thus began my treatment for this. Doctors are still unsure whether this is postsurgical or genetic or a mix of both. This is why I looked to volunteer for Hypopara UK. While family and friends are a great support, people who have gone through similar symptoms can be of even greater value to help you through the hard times. I am so happy to be a part of the team here and am looking forward to raising awareness about this rare condition.”

Former nurse Jane Compton joins us to help with patient support in our Facebook group and is our new Awareness Officer. She writes: “I married the love of my life, Steve, in 1984 and we are still happily married 32 years on. We have four children, Jenny 26, Robert 23, Emily 19, and David 17, and one grandson Rory aged four months who is a joy! Steve had a motorbike business until seven years ago, when he decided he’d have a career change and sold it to do The Knowledge, becoming a London Taxi driver aged 50! We love living near London, and I often go up to meet him for lunch or a show or wander round a museum or gallery.” Jane became hypopara in March 2013 following surgery for four-gland hyperplasia. She says: “I decided I’d like to give something back to this wonderful group, having benefited greatly from it myself, so I volunteered to become a moderator on the Facebook site, and have also recently become a committee member.” Read her story on page 11.

Sarah Tarmaster will be masterminding our PR and social media and as a food blogger will be dreaming up delicious recipes for us too! Sarah is a PR professional and food blogger (http://northwestnosh.co.uk/) who was diagnosed with hypopara in 2013 after a total thyroidectomy (although she wasn’t told she had it until 18 months later). Sarah creates recipes for the Hypopara UK website and supports us in social media and PR. She writes: “My first passion is food and I believe that what we eat directly affects our everyday lives: I particularly like creating healthy recipes that support my hypopara diagnosis. In my spare time I spend a lot of time walking my dog, cycling and knitting. I also really like ships.”

Welcome also to volunteer Heather de Souza who will be taking over distribution so if you need leaflets or newsletters please contact her at distribution@hypopara.org.uk.

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**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
Find your local group

If you would like to meet up with others in your area please go to the Find a group page on the website and click on the regional coordinator's name to send an email, or contact the Local Groups Manager Catherine Smith (catherinesmith@hypopara.org.uk). We are still looking for coordinators in the South West, North West and Wales, and eventually, we hope to have a local organiser in each county to save people having to travel so far so if you’re interested in volunteering please get in touch. We’d love to hear from you!

If you are in Scotland please contact Gillian Adams (gillianadams@hypopara.org.uk).

For Ireland and Northern Ireland please contact Blaithin O’Donnell (blaithinodonnell@hypopara.org.uk).

There is also interest in forming a Primary Hyperparathyroidism group, please contact Judith Taylor (judgethtaylor@hypopara.org.uk)

South East – Lisa Burke
Includes Berkshire, Buckinghamshire, East Sussex, Hampshire, Isle of Wight, Kent, London, Oxfordshire, Surrey, and West Sussex

South West
Includes Avon, Cornwall, Devon, Dorset, Gloucestershire, Isles of Scilly, Somerset, and Wiltshire

North East – Gillian Casson
Includes County Durham, Northumberland, Teeside, Trent, Tyne & Wear, and Yorkshire

North West
Includes Cheshire, Cumbria, Lancashire, Greater Manchester, and Merseyside

Central – Jayne Jackson
Includes Derbyshire, Herefordshire, Leicestershire, Nottinghamshire, Rutland Shropshire Staffordshire, Warwickshire, West Midlands, and Worcestershire

Eastern – Jackie Spicer
Includes Bedfordshire, Cambridgeshire, Essex, Hertfordshire, Lincolnshire, Norfolk,

Guidelines

After years of struggling to get our voices heard, there is now a growing body of reference material to guide specialists and GPs in diagnosing and managing hypoparathyroidism.

Last year, Liz Glenister was invited to contribute to the draft recommendations and the accompanying patient leaflet of the first ever guideline on the treatment of chronic hypoparathyroidism in adults. The guideline has now been published.

The European guidelines were drafted by an international group of authors who are Jens Bollerslev (Norway), Lars Rejnmark (Denmark), Claudio Marroccoli (Italy), Dolores M Shoback (USA), Antonio Sitges-Serra (Spain), Wim van Biesen (Belgium) and Olaf M Dekkers (The Netherlands). The guidelines recommend that all patients with low levels of calcium and parathyroid hormone in their blood should be investigated for chronic hypoparathyroidism. The full guideline can be downloaded for free from: www.eje-online.org/content/173/2/61


In May 2015 Liz and her husband Bill attended the First International Hypoparathyroidism Conference in Florence. A Position Statement arising from the conference, representing the Expert Panel’s synthesis of the conference material, has now been published.

Management of Hypoparathyroidism: Summary Statement and Guidelines,” by Maria Luisa Brandi, John P. Bilezikian, Dolores Shoback, Roger Bouillon, Bart Clarke, Rajesh V. Thakker, Aliya Khan, and John T. Potts Jr, Journal of Clinical Endocrinology and Metabolism

The full paper can be read and downloaded from: http://www.hypopara.org.uk/healthprofessionals.php?id=282

Stem cell research

The £1250 volunteer award (see front page) has been sent to Newcastle University to support parathyroid stem cell research. Dr Kamilla Mahkamova, PhD student and part of the Newcastle team said, “We are very committed to research that can impact on patient health and wellbeing and want to raise awareness about our research.

“We are working together with Newcastle and North Tyneside hospitals to collect parathyroid specimens and as part of the project we had looked at processing parathyroid tissue samples and maintaining them in cultures. We are also looking at different methods of identifying and isolating parathyroid stem cells and growing them. The funds from Hypopara UK will contribute towards running costs such as reagents and use of special equipment for analysing and isolating potential stem cells from parathyroid tissues.”

The team, which includes Dr A. Meeson (a stem cell specialist from Newcastle University) and Mr S Aspinall (Consultant Endocrine Surgeon from North Tyneside General Hospital) is currently involved in making an information video for Hypopara UK which will be on our website soon.
Food Matters

Food blogger and Hypopara UK committee member Sarah, aka North West Nosh, has developed a range of recipes that are high in calcium, magnesium, vitamin D and potassium to support the management of her hypoparathyroidism.

We are very excited that Sarah is now sharing her recipes with us on our new Food Matters page on the Hypopara UK website! Each beautifully designed recipe card includes the recipe, cost, nutrition facts and cook's notes. She has produced this special recipe for cottage pie which we’re sharing with you here.

Most recipes have a dairy, gluten or meat free option, so don’t be put off by the title. If there are any recipes with a certain ingredient or for a certain occasion that you’d like to see, or if you have a recipe to submit then chat to Sarah on the Hypopara UK Facebook group, tweet her on @northwestnosh or email her on noshcreatives@gmail.com.

Find more recipes at:
hypopara.org.uk/resources.php?id=277
Out and About

During the past year Hypopara UK has been out and about at several scientific conferences and events around the UK and further afield, including these.

BAETS 2015

This marked the first year that Hypopara UK was invited to participate in the annual conference of the British Association of Endocrine and Thyroid Surgeons, a welcome opportunity to meet with surgeons from around the country in Henley. “There was much interest in our stand, requests for information and news of exciting research,” says Liz.

Bes 2015

The Society for Endocrinology’s British Endocrine Societies meeting crossed the border into Scotland last November, where it was held in the Edinburgh International Conference Centre (EICC), in the heart of the historic city of Edinburgh.

Hypopara UK was represented in Edinburgh by Mandy Mainland, Gillian Adams and Erika Glenday with Liz and Bill Glenister. Pictured below, left, are Erika and Gillian with Christine Kirk our new organiser from Hull.

Our lead medical advisor, Professor Bill Fraser, chaired a session on “Frontiers in the management of hypoparathyroidism”. Dr Karen Winer from the National Institutes of Health (NIH), Bethesda, MD, USA was the featured speaker. Dr Winer, who has had a special interest in hypoparathyroidism for many years, is the Director of the paediatric endocrinology program which focuses on bone health, disorders of growth and puberty, metabolic syndrome, malnutrition, obesity, and diabetes. Her other areas of interest include studies related to the determinants of peak bone mass and muscle-bone interactions during infancy and childhood.

There is a summary/abstract of Dr Winer’s Edinburgh talk at www.endocrine-abstracts.org/ea/0038/ea0038MTE6.htm

International Thyroid Congress, Orlando, FL, 2015

Yes, Hypopara UK materials also travelled to Orlando, Florida for the International Thyroid Congress, which was opened by Donald, Mickey, and friends. Judith Taylor displayed the materials on the Thyroid Cancer Alliance stand at the meeting. Once again the patient information leaflets proved very popular with physicians from other parts of the world.

Clinical Update, Birmingham, 2016

Christine Kirk and Jane Compton represented Hypopara UK at the Society for Endocrinology’s Clinical Update and Endocrine Nurses Update meetings in Birmingham in March.


Liz Glenister and Aisling Duffy planning during a break at the Clinical Cases meeting in London, February 2016.
Rare Disease Day 2016

29 February 2016 marked the ninth international Rare Disease Day coordinated by EURORDIS. On and around this day hundreds of patient organisations from countries and regions all over the world held awareness-raising activities based on the slogan “Join us in making the voice of rare diseases heard”.

Rare Disease Day takes place on the last day of February each year. The main objective is to raise awareness amongst the general public and decision-makers about rare diseases and their impact on patients’ lives. The campaign targets primarily the general public and also seeks to raise awareness amongst policy makers, public authorities, industry representatives, researchers, health professionals and anyone who has a genuine interest in rare diseases. Since Rare Disease Day was first launched by EURORDIS and its Council of National Alliances in 2008, thousands of events have taken place throughout the world reaching hundreds of thousands of people and resulting in a great deal of media coverage. It has progressively become a world phenomenon, with the USA joining in 2009 and participation in over 80 countries throughout the world in 2015.

This year, three of our members represented Hypopara UK at a reception in the Houses of Parliament, London. We also featured an update of Vincent’s story on our website.

Jane Compton writes: I enjoyed an inspirational afternoon at the Rare Diseases reception at the Houses of Parliament with Isabel Wray, Nat Usai Fonnesu, and Steve Compton.

The main idea of the day was to highlight the plight of patients with rare diseases and to hear what work is being done to help those patients.

There were some very interesting speakers, some doctors, some ministers, but my personal favourite speaker was Lord John Walton, (he’s been a Lord for the past 27 years) at the grand old age of 93, who talked about his long and distinguished career as first a neurologist, then a researcher with The Medical Research Council, and a lifelong champion of rare diseases. He has done a lot of work helping to identify genes, leading to treatment options. He was amazing, and sharp as a tack!

Elizabeth Kendall MP spoke about the importance of getting the patient’s voice heard, and emphasized the importance of doctors and health care professionals being trained properly to LISTEN to patients and their families.

Dr Gina Radford, Deputy Chief Medical Officer, spoke about the need for helping those with rare diseases who have no actual diagnosis.

Alistair Kent OBE from Genetic Alliance UK spoke of the Genome Project which is helping patients get a diagnosis. In doing so, this mapping of genes will provide a database that will help others in the future.

It was great to meet Isabel and Nat for the first time too, and find out about their personal struggles. We had wine and delectable canapés whilst enjoying the view across the river.

On a funny note, on the way in going through security, Nat was asked if she had an egg in her bag! To which she replied “Yes! It’s my snack!” The policeman laughed and said she could take it in as it was boiled! He was worried it was a rotten egg to hurl at an unsuspecting MP!!

All in all a it was a very rewarding and informative afternoon, and it’s just great to know that our struggles are being taken seriously by these people, and that we are not alone.
Meet Vincent – one year on!

Vincent, whose story we featured in the previous issue of the newsletter, is now more than a year old! Vincent has a very rare disease indeed; a rare form of a rare disease, in fact. He has a genetic form of hypoparathyroidism caused by a calcium receptor mutation of which there are over 300 types. His type is only the second reported case in the world.

Vincent is doing very well on his PTH pump. He is being well managed between his specialist paediatric endocrinologists at Great Ormond Street Hospital and the Royal London every three months, his local hospital for two-weekly blood tests and his parents, day and night.

Vincent’s mum Christabel says: “We have had no issues with the pump and his calcium levels are stable with two-weekly blood tests at the local hospital and a minor adjustment to the dosage when necessary. His kidneys were healthy with no stones at the most recent scan and the nephrocalcinosis identified from the original scan has gone. Apart from the Forsteo (PTH), Vincent has also recently started a thiazide which has normalized his urinary calcium. He also takes vitamin D, vitamin K2 and magnesium faithfully every day. He is walking well now and is very active and strong. His eye sight is measuring in the normal range now with the help of the glasses.”

Genetic Alliance conversations, Dundee

Allison Sharp attended an event organised by the Genetic Alliance UK in Dundee on 11 March, on behalf of Hypopara UK. Here is a summary of the key issues and highlights of the day:

Allison Sharp writes:

We set off for this event just a little bit nervous and very unsure of what to expect. On arrival we found a small conference room, seven attendees, and Natalie Frankish - a Development Officer from Genetic Alliance UK.

This was an opinion and fact-finding exercise. Genetic Alliance UK is the umbrella organisation that represents those with genetic, rare and unnamed diseases, as well as care providers and support organisations. By gathering opinions and ideas at small events like this, as well as through social media, it can pass on our thoughts and concerns to others.

Since 2005 the Genetic Alliance has had a Development Officer for Scotland recognising the fact that health is one of the devolved powers. However within Scotland there has been slow progress with many agencies being slow to react and evolve.

The meeting was a free-flowing discussion centred round three key areas:

- What support is needed to live healthier lives?
- What areas of health and social care matter most?
- Thinking about future health and social care, where should our focus be?

We put across the list of questions and concerns furnished by ourselves, Liz and others.

It became apparent that many of our issues have been raised at other meetings, being common to other rare disease groups throughout the country, including: how to get information to doctors and GPs; how to get tests done when they are needed; how to access the results in a timely manner; how to get doctors and GPs to use guidelines to diagnose and treat; the care provided in Scotland is not consistent from area to area; tests requested by GP but denied by the laboratory because they have been done already within a set time frame; accessibility to orphan drugs; the use by chemists of various generic medicines as opposed to a particular brand as they are cheaper (for example to keep calcium levels consistent the variations between brands means that one particular brand needs to be specified on the prescription); and the lack of a specific hormone replacement for hypopara available on the NHS. The discussions also highlighted issues such as the lack of knowledge by GPs about specific rare/genetic diseases, which leads to delays in the correct diagnosis (or misdiagnosis) of rare diseases, leading to potentially inappropriate treatment or dismissal of patient concerns (“it’s all in the mind”); and the lack of understanding of rare/genetic diseases by consultants.

There was a proposal for surgeries or groups of surgeries to have access to a specialist GP for rare/genetic diseases and/or a coordinator who would be able to help GPs deal with affected patients regarding treatment and appropriate referrals.
Other proposals included the idea of a single point of care coordinator, coordinated appointments so with one visit a patient could see several specialists as required, for the establishment of a rare/genetic disease centre in Scotland, and an idea for promoting awareness through events such as a Rare Disease Week in schools along the lines of Red Nose Day, for example Kidney Day or Rare Disease Day.

I also raised the issue of how new drugs and treatments are accepted for use by the NHS. Once licensed by the EU they are passed to the Scottish Medicines Consortium which decides whether or not they are cost effective and are an improvement over existing treatment. Until recently there was a cap of £30,000, if it went over that the treatment was denied. Natalie related instances of the intransigence of this committee. However recently there has been a significant change with the price cap being removed and extra funding put in place resulting in a 40% increase in medicines available.

If a treatment is denied by this committee then there is still the option of an Individual Treatment Request, although this would appear to be a rather long drawn out bureaucratic procedure. This is an area where I feel that the Genetic Alliance can be of great use to hypopara sufferers. When (or if) pump-delivered PTH is licensed for use by the EU then they can help with the intensive lobbying that will be required to persuade the SMC to accept this for use by NHS Scotland.

Overall this was a very productive meeting with lots of ideas, problems and concerns raised.

For a copy of Allison's full report please contact the Hypopara UK office.

More information about the Genetic Alliance can be found at its web site: www.raredisease.org.uk

Information was provided regarding the Patient's Rights Act which can be found here: www.raredisease.org.uk/documents/ukrarediseaseforum-progress-report-2016.pdf

Although Hypopara UK was set up mainly to help patients with hyPOparathyroidism we also support people with other parathyroid disorders. Primary hyperparathyroidism is the third most common endocrine condition and more and more patients are finding their way to us through the website, helpline and Hypopara UK Facebook group.

The following has been adapted from the draft text of our revised leaflet on Primary Hyperparathyroidism which has been written and edited by Judith and Liz and is now being reviewed by our medical advisors.

**What is PHPT?**

Primary hyperparathyroidism (PHPT) is a disorder of the parathyroid glands which is caused by an excess of parathyroid hormone (PTH) in the blood caused by overactivity of one or more parathyroid glands. As a result, calcium levels in the blood may be increased.

When the parathyroid glands sense that the calcium in the blood is low, they release PTH. PTH increases the rate of transfer of calcium from the bones, kidneys and intestines to the blood, bringing the blood calcium level back to normal. When the calcium level is normal, the parathyroid glands normally stop releasing PTH.

In PHPT, one or more parathyroids keep producing PTH irrespective of the blood calcium level, as the control mechanisms do not work effectively. This results in calcium being removed from the bones and increasing the calcium levels in the blood, which might cause problems and make you feel unwell.

**What causes PHPT?**

The most common cause is a benign (non-cancerous) growth in one parathyroid gland. In other cases, the condition may affect more than one gland and occasionally, all four glands may be affected (which is sometimes called hyperplasia). There are other causes of high blood calcium; in these cases, though, the PTH is usually low. PHPT does not usually run in families. However, there are rare inherited conditions such as, familial isolated hyperparathyroidism (FIH) and hyperparathyroidism-jaw tumour syndrome (HPT-JT), and multiple endocrine neoplasia (MEN) types 1 and 2A.

Doctors usually diagnose PHPT after finding a high level of calcium (hypercalcaemia) on a blood test along with a high or “inappropriate” level of PTH. Sometimes this is discovered incidentally during a routine blood test.

If there are symptoms, these may include loss of energy, tiredness, feeling thirsty, frequent urination, stomach pain, constipation, and bone pain. Some patients also report having mood changes, confusion, memory issues, or depression. In severe cases people may suffer from nausea and vomiting, heart rhythm disturbances, high blood pressure, pancreatitis, kidney stones, or osteoporosis (low bone density). However, some patients have only mild symptoms or no symptoms at all.
Meet three of our members who have been diagnosed with PHPT with different treatment and outcomes. Jane, Mary, and Judith.

Jane’s story

Jane had four-gland disease and has permanent hypopara following surgery. After difficulties managing her hypopara with alfacalcidol, calcium, and Sandocal she is now taking the injectable form of PTH (Forsteo) to control her blood calcium

“Since starting the injections my quality of life is hugely improved”

Jane writes: I first became aware that I was not feeling “right” in 2010 aged 50. I was tired all the time, irritable, forgetful, and wasn’t sleeping well largely due to having to get up to pass urine at least twice a night. I lost my appetite and lost lots of weight. My muscles ached terribly and I just had no energy or lust for life. This was not like me at all. Previously, I had always been energetic and kept very busy with my four children and busy job as a nurse.

I saw my GP, and she thought I was just menopausal. I continued to feel dreadful and continued to see my GP feeling that something was very wrong.

After some months, eventually a blood test revealed a high calcium level and I was referred to an endocrinologist. I spent the next two years being “watched” to see if my calcium went up any more. Scans and ultrasounds failed to identify any problem which was very demoralising and frustrating for me. I asked for a second opinion, and eventually one of my parathyroid glands looked “odd” on an ultrasound and I was referred to a very experienced endocrine surgeon who operated in March 2013. By this time I had been ill for almost three years, felt very depressed and had not been able to do my job or function properly as a wife and mother for much of that time.

At the operation all four of my parathyroid glands were found to be hyperplastic, and so were all enlarged. The surgeon removed 3 1/2 glands, along with half my thyroid, thymus gland and all the lymph nodes in my neck as they too were all found to be hyperplastic.

Sadly, the remaining half parathyroid gland never worked and I was very unwell post-operatively with crashing levels of calcium. I was left with permanent hypoparathyroidism.

My doctors tried to control my calcium level with alfacalcidol, calcium, and Sandocal, but I was one of those patients who was very hard to manage with these drugs as my calcium levels would swing violently up high, then come crashing down. My quality of life was just awful as I needed to attend the hospital for frequent blood tests and dose adjustments. I found I would rarely be able to do things I had planned and became increasingly more unsociable as my health deteriorated.

Something had to change. I didn’t feel as though I could go on living like this. I had read that some patients did much better on the injectable form of parathyroid hormone (PTH), but that it was difficult to get funding for this drug (Forsteo) as it is currently off-label for hypoparathyroidism. I decided to try and get this drug, and my doctors applied on my behalf.

In April last year I was lucky enough to get funding to try this drug as I was so difficult to manage on the other drugs. I am happy to say that since starting the injections my quality of life is hugely improved. My calcium level is much more stable, and as a consequence I can do much more of what I have planned. Sadly, PTH has not helped my muscle weakness/aches/memory or general fatigue, but I feel so much better in myself without my calcium swinging around, and feel I can manage these problems by pacing myself.

Two years ago the doctors also discovered I had a pituitary tumour (non-functioning). This, in conjunction with parathyroid hyperplasia, and pancreas disease can sometimes be due to a syndrome known as MEN1. (Multiple endocrine neoplasia). As I have two out of three organs affected for this disease I am currently undergoing full sequenced genetic testing through the Genome research programme and should receive results in the next few months confirming whether I carry the gene for MEN1 or not.

Mary’s story

Mary was 64 when she was diagnosed. She writes: In 2011, I had a blood test for vague symptoms, when my doctor noticed my calcium was slightly high, although tests failed to localise an enlarged parathyroid gland. She is now on a trial with cinacalcet to control the symptoms

“Surgery isn’t the number one option, so I am on a trial of cinacalcet”

Mary was diagnosed with primary hyperparathyroidism after her doctor noticed her blood calcium was slightly high, although tests failed to localise an enlarged parathyroid gland. She is now on a trial with cinacalcet to control the symptoms

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Judith’s story

After months of unexplained symptoms and taking sick leave, Judith was referred back to the clinic where she had been treated for thyroid cancer, and was diagnosed with primary hyperparathyroidism and osteoporosis.

“I had surgery to remove a parathyroid adenoma and immediately the lights came back on and I was soon back at work”.

Judith writes: I was diagnosed with thyroid cancer back in 1965 when I was 15. I had a lobectomy and neck dissection to remove an affected lymph node in the Middlesex Hospital, London, and woke up in the men’s ward because they said it was the easiest place to monitor me closely. For the following years, my calcium and phosphates were monitored regularly and I was exhorted to drink more milk, and was prescribed calcium during my first pregnancy, but it was decades before I learned that one parathyroid had been removed and that I was mildly hypocalcaemic.

I moved to Holland and was working for a large international scientific publisher when I was diagnosed with a recurrence of thyroid cancer in 1982. After surgery I found myself in the intensive care unit because it was a long and extensive op, and I was on a calcium drip, but my blood calcium returned to normal within days.

Once the children were older I went back to work full time and had a busy active life, until I came back from a trip to the USA feeling inexplicably tired and lacking in energy. When I thought about it, the symptoms had been there for months or more. My GP took me seriously and tested me for all sorts of things, we even considered Lyme's disease as I'd been to a part of the USA with Lyme-bearing ticks. Nothing showed up, but I became sicker and weaker, with some pretty strange symptoms. My memory let me down, I couldn't concentrate, I had muscle and bone pain, and I went to the loo a lot. I also had mood swings and was mildly depressed too; it felt as if someone had thrown me into a deep pit and switched off the sun. To cheer myself up I went on again and the sun came out. My energy returned, I carried on working and waking up in the men's ward because they said it was the easiest place to monitor me closely. For the following years, my calcium and phosphates were monitored regularly and I was exhorted to drink more milk, and was prescribed calcium during my first pregnancy, but it was decades before I learned that one parathyroid had been removed and that I was mildly hypocalcaemic.

I moved to Holland and was working for my own money and also seen endos and spoken to surgeons from Harley Street, travelled to Hammersmith and finally at the Royal Victoria Infirmary, Newcastle. Interestingly, some have agreed I have primary hyperparathyroidism, others insist I haven’t. Luckily the endocrinologist I am seeing at the RVI agrees that I have, but because the adenoma isn’t showing on scans and I have other health problems, surgery isn’t the number one option, so I am on a trial of cinacalcet. I am on to my 15th day, and I know it’s only early days,

but my left side bone pain has been considerably less the last couple of days, so fingers crossed!!!!

This has anything to do with the calcium, but I have seen various specialists from neurologists to rheumatologists to endocrinologists to heart specialists. I have had every test going and no cause found, but my body was telling me I was ill and I wasn’t going to go away and live like this. Some days the tiredness has been so overwhelming, that I have fallen asleep whilst eating. I have had palpitations so bad, I thought I was going to pass out.... stomach upsets, depression, ringing in ears, bone pain 24/7, that kept me from sleeping, no way was I imagining this!

It’s been a long five years. I’ve spent my line reading. And he also ordered a blood calcium test. Well ... a few days later he phoned, and told me my calcium was high and that I had primary hyperparathyroidism and osteoporosis. My GP just said “eureka!”

Although I was at the magic age of 50, surgery was immediately recommended, no question. From diagnosis to surgery took less than six weeks. My neck had already been opened up several times which meant there was a lot of scar tissue, and there wasn’t a suitably specialised reoperative parathyroid surgeon in Holland, so I went to London. Scans and ultrasound were negative, so I had a special procedure at the Hammersmith Hospital called parathyroid venous sampling to find out where the affected parathyroid was as it was not easy to locate in all the scar tissue, and when it was found I was operated on within weeks, and went back to work soon after. The lights came on again and the sun came out. My energy returned, I carried on working for ten years, had several promotions, ended up running a department of 20 people, and spent much of my time travelling on business between the USA, the UK, and Holland.

I have been luckier than many, and I have had excellent surgeons and doctors, but my experiences opened my eyes to the lack of patient information out there about parathyroid disorders. I joined the US Hypoparathyroidism Association and when I read that Liz was setting up a similar organisation in the UK ten years ago I offered to help. And here I am!

PS we still have the bright yellow sofa looking shabbier now but I could not bear to part with it!
Pregnant with hypopara - again!
Stephanie’s story

Congratulations to Stephanie on the birth of her son Noah!

Stephanie wrote earlier this year to tell us that she was expecting her fourth child – this article was written a few weeks before the birth.

“I hope my experience will inform others and make them more aware. Never be afraid to ask and voice your concerns about being pregnant and having hypoparathyroidism.”

Stephanie writes: I’m a 32-year-old mother of three children with number four on the way very soon. First two children before my diagnosis of thyroid cancer in 2008 and my last two with my condition hypoparathyroidism.

My story started when I was 24. I had two healthy children aged six months and two. The day after my son’s second birthday I was diagnosed with papillary thyroid cancer. This came as a huge shock to my whole family and I was faced with how aggressive the surgery and treatment would be. I was informed that not only would I need a total thyroidectomy but a complete radical neck dissection taking away the muscle in my neck, my left jugular vein and lymph nodes and much more. Not only that but more surgery might follow involving taking away my voice box and oesophagus. Having to deal with being told you have cancer is one thing but to have your children living with a mum who can’t sing or talk in a normal way was heart-breaking. However to my huge relief I recovered from a thirteen-hour surgery to be told that my surgeon managed to save my voice box and oesophagus. I felt so blessed and eternally grateful to my surgeon.

My recovery was very bumpy. I spent the first couple of years in and out of hospital being treated for hypocalcaemia as during surgery my parathyroids were removed. Little did I know that these tiny pea-like glands have such an important role in your body’s function and now I had to take medication to help with the condition. My career as a nurse has also helped me understand my condition even more and I’m in a fortunate position that if I’m ever unwell I’m in the best possible place. Also I have a fantastic support network around me and without my family I wouldn’t have got through it with two young babies at the time.

Fast forward six years and I’m now blessed with my third child Gabriel. I chose this name as it means God is my strength and I truly believe my baby is a miracle.

My third pregnancy actually went rather smoothly. My condition was very well-controlled and my medication never required to be changed however after Gabriel was born I breastfeed him for 13 weeks and I began to feel suddenly unwell. I decided to stop breastfeeding and with no warning my calcium crashed requiring me to be admitted to hospital for treatment.

Unfortunately this was a huge mistake made on the endocrine side of things as they had failed to monitor my bloods or warn me of the effect of weaning off the breast and the implications that can have if you have hypopara. This was a very difficult time for me as my treatment had to change in regards to my alfacalcidol and calcium being increased.

Things began to improve and then to our absolute surprise my husband and I discovered I was pregnant again!! This pregnancy has been the hardest as my calcium and alfacalcidol have been increased twice so far. I attend a medical obstetrics clinic every three weeks where I have my calcium and thyroxine levels and urine checked.

Between 20 and 30 weeks pregnant was the most difficult as my calcium was low despite increasing my medication. However, the last few weeks things seem to have settled more and I’m having less tingling and numbness and other symptoms associated with hypoparathyroidism.

This time round I have made sure that in my birthing plan I require my bloods to be checked on admission when in labour and throughout and that I’m monitored closely post-natal to avoid any calcium crashes.
The soul of common things

Congratulations to Dede Leydorf who has had hypoparathyroidism from childhood and who developed a photojournalism project for her Master’s degree at the London College of Communication - for which she deservedly gained a distinction.

Dede wrote: “Since my childhood, autoimmune disease has been my companion. Emotion and surrealism drive my images that depict the subconscious of my illness experience.

“I aim to take the viewer into moments of seizure disorientation and back again to clarity, filtered through the distorted lens of memory. I integrate my memories of pain, confusion, embarrassment and fear through the camera, reliving the time when I walked down the halls of my former middle school, where I had daily episodes of seizure and the severe spasms of tetany. I also psychologically depict my childhood neighbourhood and the horseback riding stable where I found strength and escapism. These photographic projections, fused with my present day acceptance, speak to the soul and my experience.

“Ultimately, The Soul of Common Things illustrates the universal human experience of finding meaning through suffering.”

Dede’s work was featured at this year’s final show by students on the MA Documentary Photography and Photojournalism course at the LCC in January. You can view it on her website:

www.deborah.atavist.com/the-soul-of-common-things

Liz is Britain’s Best Volunteer! continued from front page...

Committed to providing reliable and accessible information, Liz wrote the website content in 2005 (and still a work in progress), followed by the first ever patient information leaflet on hypoparathyroidism in 2008, which was later published by the Society for Endocrinology. Liz’s tireless campaigning sparked an interest in the condition which helped to bring about clinical trials and new research including the first clinical guideline on hypoparathyroidism to which she contributed.

Liz placed equally high importance on raising awareness about the condition and over the years this has gradually influenced the way in which this rare condition is now regarded. Determined to shout out loud for those with no voice, she has also set up new organisations as well as founding World Hypopara Awareness day, celebrated on 1 June.

Aisling Duffy, who nominated Liz alongside Isabel Wray da Silva, said “This charity has changed my life and I owe it all to Liz – without her all hypoparathyroidism sufferers would still be unaware of the help and information out there.”

Well done Liz, from all of us in Hypopara UK!
We were shocked and saddened to learn of the sudden death of Jenny Dixon who had been a member of Hypopara UK since the outset and had recently taken on the role of organiser of the local group in York. Jenny was due to get married in April to her soulmate, John Watts and had been sharing her plans and her excitement with other Hypopara UK members through our Facebook group. Our deepest condolences to John and to Jenny’s family and friends.

Jenny’s parents, Jane & Steve Dixon, who very kindly sent us a donation, wrote: “We are so pleased that Jenny had support from organisations like yours and would like to thank you for that. If you would also pass on our thanks to others within Hypopara UK who knew Jenny, that would be appreciated as we know groups and friendships were very important to her. Thank you.”

Our sincere condolences to David Coates, a former committee member, whose lovely wife Patricia died recently after a short, brave fight with liver cancer. David and Tricia attended the first ever AGM of Hypopara UK in Harrogate in 2011 and immediately threw themselves into fundraising for us which they have been doing ever since, with typical humour and warmth. Our thoughts are with David and their son Niall at this difficult time.

Colourful fundraising

On 15 May Hannah Mullen and Becky Mitchell and friends took part in the Color Obstacle Rush at Aintree Racecourse, Liverpool to raise money for Hypopara UK. It is described by the organisers as “The biggest run in the world that combines the fun of colour and obstacles”.

Hannah writes: “As everyone knows I suffer from hypoparathyroidism and they know how hard it can be to get through the day! We want to raise awareness for this sometimes debilitating condition so a cure or better way to manage it can be found. Since I was diagnosed, the support has been amazing and we want to ensure that they can continue to give others the same support I have received."

At the time of going to press they had already raised £600 (including Gift Aid). Donations can still be accepted, see www.mydonate.bt.com/fundraisers/hannahmullen1

Massive thanks to Hannah and Becky, and to ALL of our fundraisers!

Raise money for Hypopara UK

If you, or anyone you know, would like to take up a challenge as a fundraising event then do let us know!

Not feeling that energetic? How about hosting a coffee morning, movie night or pampering session? Be creative! It’s a great excuse to get your friends together and have fun......all for a good cause!

Contact our Fundraising Officer Aisling Duffy aislingduffy@hypopara.org.uk

In memoriam

Hannah and Becky (left and centre left) with friends on their “colourful” Hypopara UK tee-shirts
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:
Genetic Alliance UK
Rare Disease UK
National Voices
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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If you would like to set up a standing order we would be very grateful.

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Our sort code: 09 – 06 – 66
Our account number: 42582811

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