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The Council of Management

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The treatment of phenylketonuria varies for each individual patient. No patient should alter their own treatment as a result of reading how another patient manages their diet without first consulting their doctor or dietitian.

While every care is taken in the preparation of News & Views, the Society cannot be held responsible for any information given or views expressed. All articles in News & Views are copyright of the Society, and must not be used without the Council of Management’s authority.

The NSPKU believes, without reservation, that people with Phenylketonuria (PKU) should have access to clinically proven treatments that help them cope with this hereditary condition.

In the UK, people with PKU follow a strict ‘PKU diet’. Whilst this works well for many families and individuals, others have difficulties.

BH4 is a clinically-proven treatment for PKU, available in most European Union countries but not in the UK. The NSPKU welcomes every treatment with proven efficacy that may help people with PKU and their families to manage the condition and will advocate accordingly.

The NSPKU has received enquiries about where it stands in relation to new treatments. Below is the NSPKU’s policy statement which includes BH4:

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Celebrating 40 years of MAP
Formed in 1975 the Medical Advisory Panel continues to play a vital role supporting the NSPKU. Current members Heidi Chan and Cerys Gingell give an insight into MAP’s work.

Editor’s Report

This issue is jam packed! We have exciting news on the conference next year in Cheltenham and details on how to book your place. The Regency town of Cheltenham rose from its humble beginnings as a modest market town to become one of the most fashionable health resorts in the country. Where better to hold the annual NSPKU conference? Chef Stewart from The Cumbernauld in Scotland, who did such a fantastic job cooking for us all in March, will be travelling down to Cheltenham to oversee the menu.

The NSPKU’s Medical Advisory Panel (MAP) celebrates its 40th birthday this year we have two current members of the panel reporting on MAP’s important work with the Society and its members.

And, with a little help from the NSPKU, Lucy Briscoe travelled to Honduras in Central America to undertake zoological research. Lucy shares with us this once-in-a-lifetime adventure.

All this and more – enjoy!

Caroline Bridges

Paula will be back with her dietitian’s report in the next issue.
Dear NSPKU

On the 6th June, a team of my fellow teachers from the John Bentley School, Calne, completed the Welsh 3 Peaks Challenge in aid of the NSPKU. This involved climbing the peaks of Snowdon, Cadair Idris and Pen y Fan in the space of one day. My daughter Ella, 15, who has PKU, is currently in Y10 at the school. An early start saw us summit Snowdon at about 8.00am in gale force winds and heavy cloud, however the weather improved for our second peak, affording us rewarding views as far as the Welsh coastline. Our progress on this peak was so good that we even had time to stretcher an injured member of another group off the mountain. Our last peak, Pen y Fan had been bagged by nightfall, as we were the last team to walk off the mountain. An epic challenge, which saw us raise £780 (via www.givey.com) for the NSPKU. We are still awaiting a couple more donations that will push the total up to over £800. I have attached some photos as proof to our sponsors that the peaks were genuinely “bagged”.

Cheers,

Adrian Roberts, The John Bentley School, Calne, Wiltshire

Dear NSPKU

We have been South Australian members of the NSPKU for many decades and enjoyed meeting the Noble-Nesbitt family in Norwich in 1981. They were very interested in a booklet titled Robin and I Explain PKU which we wrote from the experience of raising our son born with PKU in 1968. The book was revised and made available as an e-book in 2009. It has proved helpful to family and friends and hard copies are given to South Australian babies born with PKU. I like the positive tone of your website and feel our book also has that quality. We are extremely proud of our son’s achievements. He has an honours degree in Economics and occupies a senior position in the Australian Commonwealth Government Treasury. He has remained on his diet for all the last 46½ years – probably a little less strictly since being an adult, but only slightly. He has never missed taking his daily allotment of amino acid supplement. Living in Canberra (though actually currently working part-time in Sydney as well, on a new project) he presents himself for review a couple of times a year to the PKU clinic in Sydney (there not being a PKU clinic in Canberra).

We have valued very much our membership of NSPKU and its journal but have decided to now keep in touch only via your website and somewhat reluctantly to discontinue our membership.

With very best wishes for the wonderful work that you do and our appreciation for all that the Society has meant in the past,

Sincerely,

Robert and Jane Brummitt, Leabrook, South Australia
**Dear News & Views**

We have a 16 month old son with PKU and had recently been discussing ways we could raise money for the NSPKU and raise awareness of PKU in general. We decided to hold a family fun day at our local pub with a bouncy castle, face painting, raffles and an auction. *Freddie’s Fun Day* raised £1,293 – the sun was shining and a great day was had by all!

Many thanks,

*Kelly Lang, Manchester*

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**Dear News & Views**

I have three children; two of them, John, the eldest and David, my youngest, have PKU and Sam, my middle boy, does not. John is now leaving primary school and going on to secondary school.

John class P7 and David class P2 go to a small country school called Bellarena Primary in County Londonderry on the north coast of Northern Ireland. The teaching staff have been totally amazing and very dedicated to the boys and their diets. So, on the 26th June the P7 kids had a 1980s disco and raised £102. This is the most any P7 class has ever raised. The other kids in P7; Ross, Marcus, Marc, Stephen, Tory, Rachel and Lauren decided it would be a nice idea if they could donate this money to the NSPKU. This is all because of John and David.

They are all great friends and have gone through Mum and Tots, Magilligan Community Playgroup and now primary school together. Hopefully you can print this letter in your magazine so that the kids can see for themselves that their fundraising has been acknowledged.

Kind regards,

*Johanna McCurry, Limavady, Northern Ireland*

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**Dear NSPKU**

Please find enclosed a cheque for £200 as a donation for the NSPKU. The money was raised at my cousin Andrew’s wedding on 11th July. Andrew and his fiancée Louise had very generously decided that they would like donations instead of wedding presents. My son Alexander (age 15) has PKU and went to the wedding which was at Nantwich in Cheshire and the bride and groom had arranged for Alex’s food to be specially prepared for the wedding breakfast. They had a lovely day and it was very kind and of them, and we are very grateful for this for Alex and for the NSPKU.

With kind regards,

*Wendy Cheale, Oxted, Surrey*

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**Hi News & Views**

We wanted to let you know that we had a raffle in the Vitaflo office to recognise International PKU Day and raised £300, which we would like to donate to the NSPKU.

Thanks,

*Hannah Cressy, Vitaflo International Ltd, Liverpool*

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**THANK YOU TO ALL FUNDRAISERS**

We know that many people do wonderful fundraising events for the NSPKU via organisations such as JustGiving, Virgin Money Giving and Charities Trust that don’t always get a mention. We would like to say a BIG THANK YOU to all of you. And if you’d like to tell us your story, please do write in!
Your letters and donations

Dear NSPKU
My daughter Katie Griffin aged 6 had a small stall at her school fayre in June. She did an activity that involved people guessing how many sweets in the jar. A local restaurant donated meal vouchers as the prize in support of her efforts. She also sold cupcakes with the blue ribbon on them and gave out information about PKU.
Katie raised £107 with her little stall.
Also, my husband is doing the Great North Run this year and is splitting the proceedings with NSPKU and Myaware my other daughters charity.
Best wishes
Lena Griffin

Dear NSPKU
I am delighted to enclose a cheque donation towards the work of your organisation.
Every new colleague that starts work with our company is given the opportunity to donate £100 to a charity of their choice. This provides them the opportunity to appreciate the values, which are central to our identity as a company.
Thank you for the work you do to make a difference in the lives of those whom you serve.
Yours sincerely
Lauren Szanfranek, Peter Vardy Ltd, Glasgow

Dear NSPKU
Please find enclosed a cheque for £43, which was raised during our recent dress down day. Each month we choose a charity, which has a significant meaning for members of staff. This month it was the NSPKU.
Thank you for providing a wonderful service and we look forward to donating again in the future.
Regards
Shirley Back, Glasgow Contact Centre

A message from the Chair

As 2015 comes to a close it is time to reflect on the year. In brief, we had a great Conference in Scotland; members celebrated International PKU Day; we have moved forward on Advocacy. With respect to the latter, we have met with National Health Service England on the introduction of Kuvan. It was a disappointing meeting but we have requested another. If the next meeting is negative then we have no option but to call on you – the membership together with the wider PKU Community – to properly campaign in getting Kuvan available.
However make no mistake – not all those with PKU will be BH4 responsive. Depending on the article you read anywhere between 20-35%, Still that’s a significant minority!

Many of you will have noticed that Biomarin have bought the rights to Kuvan in Europe. We are meeting with Biomarin in December. This is a prime opportunity to discuss if PegPal can be trialled – not only in the UK but also in Europe.
We’re now busy getting ready for our Conference in March. To be eligible for the full subsidy, the Council of Management unanimously decided that you need to be a fully paid up member. So we urge you all to ensure this is the case by 31st December 2015 to take advantage of this.
I wish you all and your families a Merry Christmas and a Happy New Year.

Eric Lange, Chairman, NSPKU
The Cheltenham Chase Hotel
11th – 13th March 2016

Next year’s NSPKU annual family conference and holiday weekend takes place at the Cheltenham Chase Hotel. Situated close to Gloucester and the spa town of Cheltenham this hotel provides the perfect setting for our 43rd conference with its stylish and contemporary interior, and superb conference facilities.

- 122 spacious bedrooms
- Free wifi throughout the hotel
- Superb spa and leisure facilities
- 1 mile from junction 11A of the M5
- 200 complimentary car parking spaces

Facilities
The Cheltenham Chase Hotel’s 10 conference and meeting rooms for up to 350 delegates make it an ideal venue for our Annual Conference. The facilities are excellent with 122 spacious bedrooms, a fantastic health club and spa plus free internet access.

Supervision of children
The Society employs an independent and accredited Creche Company who will be on site. There will also be a trip for children ages eight and over and a trip for teenagers. Please contact the NSPKU Conference Organiser for further information – contact details at the foot of page.

PKU diet
You will need to bring your own protein substitutes, vitamins and minerals. The PKU diet will otherwise be catered for from Friday evening to Sunday lunchtime inclusively but please note that infant baby foods will not be provided. The PKU diet will not be available on any additional nights.

Getting there
From the North and South (M5)
Take Junction 11a of the M5 and follow the A417 towards Cirencester. Leave at the first exit signposted A46 Cheltenham/Stroud. Turn right onto the A46 signposted Stroud. After a quarter of mile, pass a garden centre on the left – the hotel is approximately 250 yards further on.

From Oxford
Take the A40 towards Cheltenham turning left onto the A436 to Gloucester, which will lead you onto the A417. Exit onto the A46 signposted Stroud/Cheltenham. At the top of the slip road, turn left onto the A46 towards Stroud. After a quarter of mile, pass a garden centre on the left – the hotel is approximately 250 yards further on.

Nearest train stations
Cheltenham Spa – 5 miles
Gloucester – 5 miles

Nearest airports
Birmingham International – 53 miles
Bristol International – 55 miles

Bus routes
There is a bus stop right outside the hotel with regular services to Cheltenham, Gloucester and Stroud.

No. 10 Cheltenham – Gloucester
No. 46 Cheltenham – Stroud
A park and ride scheme also operates in both Cheltenham and Gloucester.

Weekend conference fees

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<tr>
<td>Adult with PKU (16 yrs+)</td>
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<td>Child with PKU (0-4 yrs)</td>
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Day visitor fees – Sat 12 March 2016

<table>
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<tbody>
<tr>
<td>Adult with PKU (16 yrs+)</td>
<td>£10</td>
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<tr>
<td>Adult (16 yrs+)</td>
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</tr>
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</tr>
<tr>
<td>Child (0-15 yrs)</td>
<td>£15</td>
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</tbody>
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*Does not include evening meal and entertainment.

Additional nights
Please book directly with the hotel if you require additional nights. Per night – £80 B&B, dinner – £21, based on two adults sharing.

Assisted places
There is restricted funding available for those who require financial assistance with conference fees. Please enquire in the first instance to the conference organiser who will help you with your enquiry. All applications will be dealt with in the strictest confidence.
Firstplay Dietary Foods have teamed up with Dialachemist to provide a **FREE** Home Delivery Service, so you can receive your Firstplay Dietary Foods products including Promin, Taranis and XPhe Jump direct to your home or chosen delivery address.

**ASK YOUR DIETITIAN FOR MORE DETAILS**
THE NEW ADDITIONS TO THE FAMILY
AVAILABLE IN EARLY 2016

Strawberry Biscuits - Pack Of 120g
Chocolate Biscuits - Pack Of 120g
Dalia Milk - 200ml Serving
Shortbread Biscuits - Pack Of 120g
French Toast - Pack Of 250g
Chocolate Cookies - Pack Of 135g
Caramel Shards - Pack Of 130g

BE CREATIVE

Apricot Cake - Pack Of 240g
Lemon Cake - Pack Of 240g
Hazelnut Spread - 230g Tub
Pear Cake - Pack Of 240g

For further information contact:
Tel: 0161 480 4602 Email: info@firstplaydf.com
Firstplay Dietary Foods Ltd, Unit 4 Avondale Industrial Estate, Stockport, SK3 0UD
www.prominpku.com www.facebook.com/promin.metabolics
During July this year, I undertook a wonderful experience that I would do again in a heartbeat. I carried out zoological research in the small Central American country of Honduras in the Cusuco National Park. To do this I fundraised over £2,000 which included a contribution from the NSPKU for which I am so very grateful. However, whilst most people on the expedition had to deal with the terrain and the local wildlife, I had the extra challenge of having PKU! Thankfully the Honduran diet (mainly rice, potatoes, plantain, salad and tropical fruits) is very similar to my own and the food was superb!

My travels started very early in the morning with a flight to JFK, New York – a nine hour flight on my own and at 18 years old it was a very daunting prospect. I was lucky in that I made friends very quickly and I had a very talkative journey. The next leg led me to Chicago for a twelve hour overnight flight; needless to say I didn’t actually get any sleep. The next morning I flew to Miami and then finally on to San Pedro Sula, Honduras. I was met at the airport and taken to the hotel before my real adventure began.

Early Wednesday morning, I was introduced to the people I would be with for the next two weeks and I got to know them as we journeyed up the mountain on the back of 4x4 pickup trucks. We all came off battered and bruised and we were very grateful for the lunch that greeted us. However, our joy was short lived and we went straight on Jungle Training; a fun three days surviving in the jungle but mostly walking around in deep jungle, learning how to sleep in hammocks and cook for ourselves. The latter was not exactly the height of luxury and the food was, well, basic and consisted mainly of rice. At the end of the three days we were treated to jungle soup – a soup full of vegetables with Hunters Dough (a very basic dough of corn flour and water slowly roasted over an open fire and served with honey).
Back at Base Camp, things were more relaxed and more varied as Research Assistants (RA’s) we were awarded the opportunity to work. I was able to help in many fields recording bats, inverts, amphibians and reptiles (herpetology). I even helped discover a new species of moth to Cusuco because it flew in my face and I discovered a new morph of snake and loads of Plectrohyla dasypus (a species of frog). The ornithology (study of birds) was great but it required a very early start and we were rewarded with a lot of very cute hummingbirds! We also measured tree health and habitats. This was done over transects – a path along which one counts and records occurrences of the species of study. The food here was gorgeous however being mobbed by bees for having honey or jam in the mornings was not the best of experiences especially as tea had to be sacrificed!

During my second week I was based in the satellite camp of Cantiles, with a very arduous walk up and down. After three hours of walking we made it in time for lunch and set up our hammocks and tents. The next day I spent a full day on a herpetology walk into a dwarf forest where the highlight was me falling down a massive hole! The forest was amazing as it hardly grew higher than the top of my head and although we didn’t actually find anything, it was still a great experience.

The following day I spent with ornithology where we caught ten birds then again with herpetology in the evening where we caught three Plectrohyla exquisite (a species of frog), which we tested for the Chytrid fungus, the most significant threat to the world’s amphibian populations.

We then had a day off, which was spent at a waterfall where we relaxed and were able to enjoy the jungle without fear of being bitten by mozzies and in the evening I was able to observe the bat team processing fruit bats. The next morning was another bird mist netting session where we caught some very cool birds such as wood creepers, grey collared solitaires and more hummingbirds. In the afternoon I helped the herpetology team process the three snakes we had on the base, a Timbo (Wilson’s Pit Viper – airlift out if bitten), Steve the Palm Pit Viper (another airlift and possible death) and Sammy a cute little frog eater. The next day was our last as we headed back to base camp to prepare for leaving the next morning. During this time we were able to reflect on what we had seen and just enjoy the walk back. When we did leave Cusuco the ride back was very bumpy and I swear I got even more bruises than on the way up. In base camp we found two male Norops Cusuco (lizards) fighting which we caught and processed and the results of which have gone towards the diversity in this endemic species.

After leaving San Pedro Sula, I arrived in Miami for a day’s stop over. This was an amazing experience in itself and I had a brilliant adventure after going on the obligatory shopping trip in Miami Beach. I had lunch in a very cute bookshop restaurant – a massive helping of fresh ratatouille! In the hotel I finally had wifi and tried to catch up and just say that I’d survived. No matter how much I do in my life I will always remember this adventure and my new favourite food of Pastelitos (corn flour and water dough wrapped around diced vegetables, plantain and potatoes then fried).

Lucy Briscoe

“Thankfully the Honduran diet is very similar to my own and the food was superb!”
If you’re under 10 and have PKU,

I’m on a low protein diet just like you! Let’s share stories!

I’m in charge of sending you our special adventure storybooks!

Will you join our club?

There’s always something to look forward to in your letter box every month when you join the Anamix 6 Fan Club! Sign up for free to learn more about your low protein diet by visiting www.anamix6.com or asking your dietitian.

The gang can’t wait to hear from you!
we’ve got something for you!

Have you signed up yet?

I’m hungry!
We’ve got lots of lovely recipes for you!

I’ve made a brilliant website for us all!

We’ll have so much fun!

Something for the older ones...

Visit www.pkuconnect.co.uk
to download our new Christmas Recipes made easy book!
For 15 years the NSPKU has supported two outward bounds weekends – Edale in Derbyshire and Derwent near Keswick in the Lake District. These glorious locations offer children with PKU the opportunity to enjoy the great outdoors with activities that would challenge even the toughest celebrity in the jungle! They are so popular that people who went as children often volunteer years later to come back as helpers! Dietitians Barbara Cochrane and Cerys Gingell, Keswick and Edale stalwarts, tell us about this year’s events...

It didn’t seem a year since we were heading down the M74 on our way to Derwent Hill, an outward bound activity centre situated in Portinscale just outside Keswick in the Lake District. But there we were on our coach heading off again with a group of young people aged between 9 and 17 years to meet up with others from Newcastle and Leeds for a weekend of fun and activity. It is always a relief to be on the road, after weeks of getting the final details sorted out, food ordered and consent forms chased up.

Many of the young people had been with us before with some coming for many years – why do they keep wanting to come back! We must be doing something right, it can’t be because we get them up at 7 am, nag them to go to sleep or send them back to finish their protein supplement when they think they can get a nearly finished pouch past me!

We arrive after a brief stop for lunch and there is a hive of activity as we unload the coaches, there are squeals of delight as friends meet up again and then we meet with our instructors for the weekend. We see some well-known faces of the staff that have been around on our previous visits over the past 13 years. The youngsters are split into groups for the dormitories and also activity groups and the first task is to get the right luggage in the right rooms and then down again to get information on the afternoon activity. We introduced an activity on the first afternoon a few years ago to enable the young people to be settled in to the centre earlier with a view to them sleeping better on the first night. This has been quite effective as we don’t tend to have to stay up until 2 or 3 am trying to get them to sleep. It also means that the staff don’t end up too grumpy from lack of sleep!!

When we return it is back to the dormitory to unpack, make up the beds and then down again for the protein substitute. We have this all laid out so that the young people can quickly identify their own, make it up and then be ready for their meal. A transformation we have seen over the years is the huge difference changes to the formulation of the protein substitutes has made to the way the young people accept their supplement. During the early years we would spend a lot of time before meals encouraging the young people to make up their drinks, stand with them while they often struggled to take it. sick bucket on hand! Nowadays with the liquid supplements, it is often a matter of a few minutes to get it drunk and signed off and away to have fun. The weekend also provides the young people with the opportunity to try out a different protein substitute without being under pressure and often we have children who arrive on one type and go home on something completely different. It is amazing that the young people will listen to their new friends and try something new, when their dietitian has been trying for months.

Then it is off for the evening meal, exchanges to be weighed, the noise is loud with everyone catching up with all their news from the past year. The afternoon activity also helps to build up an appetite and we are very fortunate that the chefs are always so willing to try new recipes and are now well used to the low protein foods and come up with some interesting dishes for us.

An evening activity may consist of an orientation exercise or a night line – this is a hilarious activity whereby the young people are put into teams, blindfolded and have to guide their team around ropes put round trees in the wooded area around the centre. The aim is to build trust in the team,
for the onlookers it is hilarious watching the children manoeuvre round trees, crawl along the ground and have lots of fun.

Bedtime is a challenge! However, this year all was quiet by 11pm, a miracle; there might have been quiet talking going on, but most slept well.

The mornings bring another round of protein supplement, rooms tidied and inspected, breakfast and then back into groups to get instructions for the morning activity. There is always a brief meeting of the instructors and staff to see how the overnight was, any issues and discussing any particular needs of the group.

This year, over the weekend we had the usual activities such as kayaking, gorge walking and the high ropes including the famous “death swing”, but also had a new activity – bush-craft. We learnt how to make a fire in the grounds around Derwent Hill and then made low protein bread. One of our adult helpers this year is a scout leader and suggested we try cake in an orange. The centre of the orange is removed, half filled with low protein cake mix, top put back on, covered in tin foil and cooked on the open fire. It was delicious. It just goes to show that being on a low protein diet doesn’t stop you doing anything!

I am always impressed by the way the instructors get to know the young people and become very tuned into how youngsters cope with new challenges and are adept at knowing how far to push them, know when someone has reached their limit, but also know who can push themselves just that bit further. The instructors are always keen to understand how the children cope with their diet and have been known to try out the supplements and low protein foods!

We have seen over the years many of the young people challenge themselves and achieve goals that they and their parents may have thought not possible. The weekend also helps to prepare the young people for their school trips by giving them confidence to manage their diet away from home on their own.

The young people who come along, when asked what they enjoy about the weekend, always say that it is about meeting others who have PKU, they do not feel so alone. The older ones also say it is about getting back on track with their diet and meeting up with friends they have made.

Sunday afternoon sees the last activity and packing for home. The drying room is emptied of all the wet gear and unclaimed wet clothes piled into a black bag and taken home by the leaders, buses are loaded up, goodbyes said and it is off home again for another year.

We are grateful for both the support from the companies who supply the low protein foods, spare protein supplement and helpers. The reps are always keen to come along to help and they benefit from seeing their products in action and the honest comments from the young people!

We are also very grateful for the support from the NSPKU and hope that our weekend is seen as a valuable part of the support given to the families.

If you are interested in finding out more about next year’s weekend, ask your metabolic dietitian to contact Barbara Cochrane. barbara.cochrane@ggc.scot.nhs.uk
Edale Youth Hostel is based in the beautiful countryside of the Hope Valley in Derbyshire. Since 1999 a group of dietitians and helpers have attended this event in June on behalf of the NSPKU to offer a fun and exciting weekend for children between the ages of 8–11 who all have PKU in common. Paula, the society dietitian, is the main organiser of the weekend; liaising with the staff and catering services to ensure superb low protein food and snacks for the children and challenging activities to keep them busy.

For many years I have volunteered to attend with Anne Daly, dietitian, from Birmingham Children’s Hospital and although it’s very tiring it is a very enjoyable and rewarding weekend. The children have a great time meeting other children with PKU and sharing ideas on low protein foods and protein substitutes and clearly gain more confidence about discussing and managing their own diet. Although food is an important part of the weekend the children get the chance to try many outdoor experiences such as abseiling, caving, canoeing, archery, high ropes and much, much more.

With the fantastic facilities, knowledgeable staff and lovely location Edale is perfect for offering incredible adventures in the great outdoors. The children enjoy it so much we are now starting to see some of them come back for more the following year!

Cerys Gingell, Specialist Paediatric Dietitian, Nottingham

The dates for the the next Edale weekend are 24–26 June 2016.
If you’d like to register your interest please contact Society Dietitian Paula Hallam on 020 3397 7494 or email dietitian@nspku.org
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Taste, our secret ingredient.
The NSPKU was a founder member of the European Society for Phenylketonuria back in 1987 and the first meeting was held in Aalter, Belgium. This year was Berlin’s turn to host the conference. Adult Metabolic Dietitian, Sarah Ripley and Duncan Noble-Nesbitt, NSPKU COM report on the important new guidelines and much, much more...

As a Dietitian working with over 250 adult PKU patients, I was honoured to be asked to represent the NSPKU on behalf of Paula Hallam NSPKU Dietitian at the recent E.S.PKU conference in Berlin.

The aim of the conference was to build bridges between east and west, from the past to the future and between different cultures and treatment strategies. Most delegates arrived on Thursday and the Manchester flight arrived at 9am to a chilly, overcast Berlin. The shuttle bus took us to the hotel and we were able to check into our rooms straight away, leaving time to see some of Berlin in the afternoon.

At each meal time a tasty and beautifully presented ‘PKU Buffet’ was provided in addition to a non-PKU buffet. This not only catered for the low protein diet but also showed how appetising low protein food can be.

Friday

The conference was opened by The Chairman of the German PKU association (DiG) Tobias Hagedorn. The association is celebrating its 40th Birthday this year and he reminded us that late diagnosed patients are not a minority population as approximately 4000 patients were born before screening was started.

European PKU Guidelines

Professor Francjan van Spronsen and Annemiek van Wegberg (Dietitian) introduced the new guidelines described as ‘a statement built on the past for the future’. The guidelines aim to standardise PKU treatment as much as possible and are designed to be used by doctors, dietitians, obstetricians, psychologists and other professionals involved in the treatment of patients with PKU. All available literature on PKU was reviewed and critically appraised to create the guidelines and each guideline had to be agreed by 100% of the group. The guidelines were revised following input from external patients from Europe and professionals from the whole world. It was recognised that much of the available data is from children and little data is available for adolescents and adults, further research is needed in these areas.

Main points

• There is no evidence showing it is safe to stop the PKU diet at any age
• On diagnosis babies with blood phenylalanine level 360-600µmol/l will be treated
• 0-12 years aim blood phenylalanine level 100-360µmol/l
• >12 years aim blood phenylalanine level 120-600µmol/l
• Pregnancy aim blood phenylalanine level 120-360µmol/l

The guidelines will not be widely available until after they have been submitted and accepted for publication in a medical journal – this is a difficult process and the paper would be unlikely to be accepted if the information is already available on the internet. It may take a few years before the full guidelines are available. Discussion took place as to the best method for dissemination of the information and this has yet to be finalised.
Differences between the European and the USA Guidelines

Annemiek van Wegburg (Dietitian) explored the difference between the guidelines published in the USA in 2014. The 2 working groups in the USA used different methods to the 5 European working groups and recommend target phe levels for all patients should be <360µmol/l due to a lack of published evidence on the long term effect of higher phenylalanine levels in adults. There are also differences in healthcare provision and financing of treatment with the USA being more focussed on medicine / new treatment options rather than diet.

PKU in the next decade

Professor Harvey Levy looked into his crystal ball to predict how PKU will be treated in 2025. He believes the low phenylalanine diet will still be used, however, there are other future treatments:

1. Kuvan. This has limitations as not all patients will respond and those who do may still require dietary restriction.
2. PEG-PAL. This is an alternative enzyme therapy using the naturally occurring Phenylalanine Lyase administered by injection. Clinical trials are ongoing in the USA and it is hoped this may replace the diet in many – this is not currently being trialled in Europe.
3. Direct Enzyme Replacement Therapy (ERT). This would use synthesized or genetically expressed Phenylalanine Hydroxylase (PAH). Currently the enzyme PAH is not stable outside the body and work is ongoing with this.
4. Gene editing. A method to ‘normalise’ the faulty gene is being trialled in another metabolic condition Tyrosinaemia Type I and hopefully this will be expanded to other conditions in the future.

Professor Levy concluded “In my almost 50 years of research in PKU, I have never known a more exciting time.”

E.S.PKU & PKU Board present: PKU Travel Network

E.S.PKU have partnered with PKUBoard. PKUBoard is a free online platform founded by PKU patients Alexander Hennig and Gregor Hammerschmidt in 2004. It offers a message board, blood level tracking, a recipe database, and more. Users can find help or ask new friends for advice while traveling to a foreign country. Within the travel network users can decide what kind of offer to make e.g. accommodation and review what is being offered easily. Registration within the network, as the whole PKUBoard platform, is free. http://www.pkuboard.info/travel/index.php/Overview/

Out and about in Berlin

Berlin is the capital of Germany and one of its 16 states with a population of 3.5 million people.

Buddy Bears

Buddy Bears are a series of painted, life-size fibreglass bear sculptures originally developed in Berlin. The bear is Berlin’s heraldic animal with a high level of public appeal and the buddy bears capture the hearts of Berliners and visitors in various different designs.

“In my almost 50 years of research in PKU, I have never known a more exciting time.”

Professor Harvey Levy
Berlin wall memorial tour

The Berlin Wall enclosed West Berlin from August 13, 1961 to November 9, 1989, cutting a line through the entire city centre. The Berlin Wall Memorial is the central memorial site of German division, it extends along 1.4 km of the former border strip in the centre of the city. The memorial contains the last piece of Berlin Wall with the preserved grounds behind it and gives an impression of how the border fortifications developed until the end of the 1980s. The preserved historical remnants and traces of border obstacles on display help to make the history of Germany’s division comprehensible.

A very moving short film on the history of the Berlin Wall began with the political situation after World War II and showed the events leading from the construction to the fall of the Berlin Wall.

The Window of Remembrance honours the 130 people who are known to have died at the Wall in connection with the border regime – for example during an attempted escape. This commemorative “window” presents pictures of the people who died. Their names and birth and death dates are also shown. This allows each victim to be remembered individually here. Not every niche has a photo, some were intentionally left empty since additional victims may be discovered and added in the future.

Conference Close

A closing speech was given by Tobias Hagedorn, conference host DIG PKU and also Eric Lange E.S.PKU president. The flag was handed over to the representatives from Turkey where E.S.PKU conference 2016 is scheduled.

The afternoon outings were then followed by the formal dinner and dancing, which was a lovely informal end to a fabulous conference.

Sarah Ripley
Adult Metabolic Dietitian
Salford Royal NHS Foundation Trust
Guideline news, and the forgotten children

This year’s conference was held at the Holiday Inn Berlin Airport – Conference Centre Schönefeld Berlin. As expected it proved to be an efficient and effectively run conference. With this being the German Society for Phenylketonuria’s (DIG-PKU) 40th anniversary, the host nation was keen to put on a first class event.

The conference was a “sell-out” with over 300 people having to be turned away. There were 450 attendees, 150 with PKU or an allied disorder representing 40+ countries.

The opening speeches concentrated on the European Guidelines, late treated and untreated people with PKU and emphasised the need to ensure that the management of the condition remains robust.

The meeting then split into the three streams:- the scientists and professionals, patients and families and the delegates. As the E.S.PKU representative for the UK my attendance at the delegates meeting was required. The first session returned to the new European Guidelines focussing on interpretation and dissemination. Work has already begun in this area and as the publication will be in English the dissemination will be more straightforward in the UK.

The meeting also considered an update on the issue of European food labelling which had been highlighted earlier in the year as a potentially serious change set to affect the labelling of specialist foods such as low protein dietary products. Following a meeting between the E.S.PKU and the European Commission, confirmation was provided that the changes planned for July 2016 would not affect low protein foods for PKU.

Presentation of the European Guidelines

This discussion presented the process and methodology for writing the new Guidelines: how many experts were involved and what their specialisms were. In addition, the process included external reviewers, implementation and future research. Key recommendations were outlined.

In summary...

• Lifelong treatment is recommended as there is no evidence to suggest it is OK to stop diet.

• Lifelong follow-up of adults with PKU is recommended whether on treatment or not as the nutritional balance was indicated and potentially not normal off diet. Often those off diet follow a “vegan-like” diet with decreased micro nutrition.

• Nutritional follow-up is recommended with consideration of bone density indicated.

• Other recommendations include neurocognitive follow up in adolescence or on demand.

My Father’s Journey to Screening

The session ended with a talk by Robert Guthrie’s daughter, Patricia S Guthrie, and she spoke about her brother who had untreated PKU. She told us her father liaised with Horst Bickel with his idea to measure phe levels. He used blotting paper and a microbiotical approach. She outlined how hard he pushed for mandatory testing in the 1960s. Patricia shared her memories of travelling a lot in her early years to promote screening and to prevent retardation. A screening method was developed and her father became a public health champion, advocating screening by the government. Their travels took the family to Australia to set up the screening programme there. She has been amazed over the years that so many people with PKU have hugged her and said: ‘I love your father’.

Newborn screening

The next session outlined the current screening situation in southeast Europe – not all countries have screening. A survey to assess the current state of PKU screening, indicated that Macedonia and Moldova for instance have low incidence of PKU. These are also poor countries with few metabolic centres and varying levels of patient organisations. The future of newborn screening is changing, new technologies are changing the scope of screening. Can we expect genetic testing alongside screening of newborn?

This session ended with the screening of the DIG/NSPKU video The Forgotten Children which powerfully outlined the plight of those with untreated and late diagnosed PKU. The stunned silence that followed this video gave plenty of food for thought and focussed minds on the wider implications of PKU and the need to ensure that the management of the condition remains robust.

E.S.PKU Review

The society becomes ever stronger. At the general meeting the committee voted to accept the membership applications from both Israel and Gazza Palestine signalling a historic moment for the E.S.PKU.

International PKU day was also discussed and each of the delegate members outlined the events that had happened in their own country on 28th June 2015.

Many left the Conference feeling empowered. When nations come together, great work can be done.

Duncan Noble-Nesbitt

For more information and videos of some of the talks please visit www.espku.org/conferences/e-s-pku-conference-2015/
Because...

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Ingredients

Makes 12 mince pies

250g Fate All-Purpose Mix
140g block margarine
30g soft light brown sugar
60mls pure orange juice
About 300g suitable mincemeat (see above)
A little icing sugar to sprinkle

Method

Preheat the oven, Gas 6 200°C

First make the pastry:

Place the All-Purpose Mix and margarine into a mixing bowl. Rub in the margarine until the mixture resembles fine breadcrumbs, then continue until it resembles coarse breadcrumbs.

Place the soft brown sugar into a small dish and add the orange juice. Give it a stir (the sugar does not need to be dissolved). Add this to the rubbed in mixture and stir quickly with a metal spoon until smooth. Do not worry if you think it is very soft, just leave it to rest for a couple of minutes.

Lightly dust the work surface with a little Fate All-Purpose Mix, and knead the pastry for a couple of minutes until it is smooth.

Roll out the Fate Rich Pastry to about 5mm thick.

Then using a cutter about 7½cm diameter, cut out 12 circles of pastry and put into a 12 hole patty tin. Fill each one with between 1½ – 2 tsp mincemeat. Roll out the remainder of the pastry and cut smaller circles, about 6½cm diameter, or star shapes. Lightly moisten the edge with a little water and press down on the top of the mincemeat. Use a small fork or knife to pierce a hole in the top to let steam escape during cooking.

Bake in a preheated oven for about 15 mins until cooked and golden brown.

Remove from the oven and place on to a cooling rack to cool.

Lightly sprinkle with icing sugar if liked before serving.

They are lovely served warm on their own, with brandy butter, low protein custard, or low protein cream.

See this recipe step by step on youtube

www.youtube.com/user/fatespecialfoods

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Step-by-step recipes, helping you make great low protein food.
The Medical Advisory Panel (MAP) of the NSPKU exists to support and advise the NSPKU main Council of Management (COM). It consists of Clinicians, Dietitians, Psychologists and Nurse Specialists, as well as representatives from the NSPKU COM.

The first MAP meeting was held on 20th June 1975 at Alder Hey Hospital in Liverpool. Its members included the physician and dietitian from the clinics in Liverpool:- Dr Freddie Hudson and Miss Christine Clotthier, in London:- Professor Otto Wolff, Miss Dorothy Francis from Manchester:- Dr George Komrower, Miss Jennifer Coutts and members of the NSPKU COM:- Mr Brian Smith, Dr John Noble Nesbitt and Mr Brian Talbot.

The term for each member of the panel is four years and the group meets twice per year to discuss items such as publications (reviewing, updating or suggesting new publications), research opportunities, suggestions for conference speakers and/or topics, the NSPKU website, outward bound weekends and International PKU Day. Members of MAP also help with external helpline or email queries when a more medical opinion is required.

Current members Cerys Gingell and Heidi Chan have offered their perspective on the work of the panel.

I have worked as a metabolic dietitian in Nottingham for 17 years. During this time I have looked after children with PKU and maternal PKU patients in Nottinghamshire. I was asked to join the NSPKU Medical Advisory Panel in May 2012 and I was delighted to accept the opportunity. This has been an excellent opportunity for me to meet with dietitians, specialist nurses and clinicians working within the field of PKU and be able to share some of my own experiences and gain from others in the group during the two meetings per year and of course emails in between the meetings. I have been involved in the reviewing of the dietary management guidelines for PKU and to be able to produce information sheets for example on Travelling with PKU. I have helped to run workshops for children with PKU at the NSPKU conferences and have thoroughly enjoyed working and developing some games to play with the children. I have helped with the running of Edale activity camp for many years and again have learnt a wealth of information from the children that attend and how they manage with the challenges of a low protein diet.

In October 2013 I was able to attend The E.S.PKU conference in Antwerp representing the society in Paula’s absence. This was a great learning opportunity and I wrote a summary article for News & Views on my return.

Being part of the NSPKU Medical Advisory Panel (MAP) has given me an insight as to how the charity operates. The meetings are very well organised and the set agenda gives opportunity for everyone to discuss ideas and bring their experience to the table. I have been involved in the updating of resources for pregnancy, and to increase GP’s awareness of PKU. My experience is within adolescents and adults, and there are so many aspects that require addressing within this growing population so it is always so valuable to have the support of Paula! I try to return the favour by assisting with any external queries. I am always trying to source low protein alternatives in the supermarket and at food festivals, the most recent one being a vegan festival. I am very active in forwarding ideas to the metabolic nutrition companies and suggesting healthy eating low protein options aimed at the busy lifestyles of adolescents and adults. In addition, promoting the NSPKU resources to those wishing to return to diet, and need further support as part of my one to one dietary education session, and outpatient settings has been an eye opener for those who have become members.

Last year, I attended the E.S.PKU conference in Croatia for the first time since working within the field of PKU. It was a fantastic event for networking with European peers and an eye opener to see what products were available outside of the UK. I hope for the remaining time as a MAP member that I serve in the best interests of the patient, family and carer.
Hi I’m Emma Harbage. Ex England under 20s player & have aspirations of being in the elite England women’s rugby squad. I’m currently studying Sports Science and Sports Nutrition at Leeds Trinity University and used to attend the elite sports collage Hartpury as a scholarship student. In the little free time I have... I work as a Gym Instructor and I volunteer as a Strength and Conditioning coach, working with a range of athletes within different sports.

Hi, I’m Nat Boyson my blog is intended to inform, entertain and perhaps even educate. I am a fairly ordinary guy with a fairly ordinary life. I will be sharing information on the products that I use and giving tips and suggestions based on my own discoveries and things shared with me. So get in touch if you have a suggestion.

Follow the VitafriendsPKU Facebook page today for the latest PKU news.

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- Tasty low protein recipes
- Top tips
- Latest low protein supermarket buys

www.facebook.com/VitafriendsPKU.uk
PKU – Not
A light-hearted view of a parent bringing up a PKU child

Travelling with PKU
It doesn’t matter how far you go with a PKU child or as someone with PKU. It could be to TESCO. It could be to the Far East. Doesn’t matter. Only one thing is for certain – PKU comes nailed on. You can be 1 or 31 but as the world gets smaller through the benefit of air travel (notwithstanding volcanic ash) you can bet your bottom dollar that you may be in Row 38 Seat B on the aircraft but in Row 38 Seat C is your mate PKU and a shed load of Pasta/Analogue/Tablets etc etc. And how about short-haul? Ryan-Air case in point. Charge for bags! That’s us out then because we’ll have to get the Ferry to Ireland if it doesn’t sink under the weight of dietary paraphernalia.

I always remember when my little one was really little. When she was swamped by a car seat and having to stop on a long road trip every so often to feed her. I remember having to mix Analogue at the side of the road off the M6 and marvelling at the way that the powder and the water could stay apart for so long whilst my child shattered the car windows with shrill screaming in demand for her fill – deep joy.

That’s another cramming exercise too. If you are going by car with a baby you have enough stuff to take anyhow, without trying to get a Pharmacy in too – I felt like one of those guards on the Japanese underground stuffing commuters into a train. Foreign travel despite being loaded up is no problem though. You are on holiday and there’s a little bit of you that wants a break from the diet – we all do. And that’s why God invented CHIPS. Don’t tell your Dietitian tho’ – it’s naughty. But don’t let PKU hold you back from travelling anywhere. We’ve been out to the Far East and came back and she got on fine – plenty of veg and a much healthier PKU diet than the UK eating establishments can provide – did go to McDonalds a couple of times I admit. However as they cook food from fresh in the Far East you can have what you want, just ask – and they smile at you too – all the time, no I mean all the time.

It’s not as easy travelling with PKU, but it’s not hard enough to stop you.

Christopher Columbus – Hertfordshire.
Are you the parent of a child with Phenylketonuria?

We are conducting some research with parents of children with PKU. It will look at the experience of parenting and parental wellbeing. There are two components. Part 1 looks at parental wellbeing and what can help with this. It will also look at things that can make it easier for parents and children to stick to a low protein diet. Part 2 looks at the experience of parenting a child with PKU.

If your child is currently being seen at Liverpool, Bradford or Manchester PKU clinics, and you would like to find out more about this study, you can contact the researchers using the following contact details:

Email: pku@manchester.ac.uk
Phone: 07555 350386

If your child attends clinics at Alder Hey, Manchester and St Luke’s, Bradford you will receive information in the post about the studies along with details of how to take part.

Disability Living Allowance

Important information if you get a Disability Living Allowance

Disability Living Allowance (DLA) is ending for most people. A new benefit called Personal Independence Payment (PIP) has been introduced to help with extra costs if you have a long-term health condition or disability. The Department for Work and Pensions (DWP) will write to everyone who was aged 16 to 64 on 8 April 2013, to tell them that their DLA is ending. Look out for a letter from DWP. You’ll continue to get DLA until DWP writes to you about when it will end.
The Juvela Low Protein Range

Bread & Rolls

A selection of Cookies

All-Purpose Flour Mix

Part-baked Pizza Bases

The Juvela Low Protein range is available from your pharmacy

For further product information and delicious recipe ideas, visit our website www.lowproteinfood.co.uk and join us on Facebook: juvelalowprotein

For lots of delicious recipe ideas over the festive period visit: www.lowproteinfood.co.uk/recipes or ring us on 0800 783 1992 and we will pop a copy of our fabulous recipe booklet in the post!