Royal honour for Professor Anita MacDonald
In touch

The Council of Management

Eric Lange
(Chair)
27 Western Road, Sutton
Surrey SM1 2JE
E mail@nspku.org

Julia Bailey
(Vice Chair)
T 017790 572525
J u.julia Bailey@me.com

Paula Hallam
(Society Dietitian)
65 Shortlands Road
Kingston
Surrey KT2 6HF
T 020 3397 7494
E dietitian@nspku.org

Vicki King
(Bookkeeper and
2016 Spring Draw Officer)
Tarkwa, 65 Cramwell Road
Ribbleton, Preston PR2 6YD
E bookkeeper@nspku.org

Caroline Bridges
(NSPKU Administrator
and Editor: News & Views)
PO Box 3143
Purley CR8 9DD
T 020 3397 7320
E info@nspku.org

Lisa Lee
(Trusseur)
2 Brightstone Close
Banks
Southport PR9 8FH
T 01704 226931
E lisalee@blinternet.com

John Skidmore
(Support Group Co-ordinator)
4 Hall Croft, off High Street
Normanton
West Yorkshire WF6 2DN
T 01924 890991
E supportgroups@nspku.org

Julie Candy
T 07930 452322
E juliekaywilson@gmail.com

Iain Williamson
(Secretary & Teenage/Adult
Co-ordinator)
E secretary@nspku.org
E youngadults@nspku.org
T @pkuteens

Duncan Noble-Nesbitt
(E.S.PKU Representative
& Advocacy)
3 Devonshire Street
Ambergate, Belper
Derbyshire DE5 2GJ
T 01773 853360
E duncanrel@hotmail.com

Paul Candy
(Webmaster)
E webmaster@nspku.org

Niki MacLeod
(2016 Conference Co-ordinator)
E conference@nspku.org

Peter Davies
E peter.d.nspku@outlook.com

Local contacts and support groups

Support Group Co-ordinator: John Skidmore
T 01924 890991 E supportgroups@nspku.org

BRISTOL & BATH
Katherine Senior
20 Eastfield Avenue
Weston BA1 4HQ
T 01225 469878
E kathleen@talktalk.net

EAST ANGLIA
Jo Savage
2 Snowdonia Way
Sunderland
Tyne & Wear NE10 8BR
0191 469 3424

LONDON & HOME COUNTIES
Peter Davies
81 Hotham Road
Putney
London SW15 1QW
T 020 8785 2609
E peter.d.nspku@outlook.com

NEWCASTLE
Ken Dodsworth
7 Lingley Lane, Wardley
Gateshead
T 0191 469 3424

PORTSMOUTH AND DISTRICT
Nigel Martin
79 Strode Road, Stamshaw
Portsmouth, Hants
PO2 8PX
T 01705 644314

READING AND DISTRICT
Nicola Craig
13 Blenheim Dale
Binfield, Bracknell
Berkshire RG42 1YF
T 01344 305312

SCOTLAND
Niki MacLeod
5 Cara Place, Perth
Scotland PH1 3DW
T 01738 626948
E conandbex@yahoo.co.uk

SHEFFIELD
Gillian Race
(Liaison Nursing Officer
– Health Visitor)
Neonatal Screening Laboratory
The Childrens Hospital
Sheffield S10 2ZH
T 0114 271 7415

SOUTH WALES
Ifona Rogers
9 Pant Glas, Penygroch
Cardiff CF4 8TB
T 02920 890065

SUSSEX
Sue Greenhalgh
48 Preehurst, Burgess Hill
West Sussex RH15 0DQ
T 01444 242788
E sue.greenhalgh@arservicesuk.com

Helen Scally
2 Berry View, Huddersfield
West Yorkshire HD4 6LQ
T 01708 101191
E yorkshirepku@gmail.com

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The National Society for Phenylketonuria
(United Kingdom) Limited
PO Box 3143,
Purley CR8 9DD
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Professor Anita MacDonald, OBE
News & Views is proud to celebrate Anita’s richly-deserved award.

NSPKU 2016 Conference review
Sarah Ripley reviews the presentations and workshops from this year’s conference at the Cheltenham Chase Hotel.

Prescriptions: How to get what you need, when you need it
Advice from Barbara Cochrane to help overcome problems that sometimes arise with the dispensing of low protein foods.

Dietitian’s report: Salad days
Great ideas for delicious summer dishes. Plus the latest news from manufacturers.

Perspectives: ‘My sister’s got this condition called PKU’
Amber Oke has PKU. Her sister, Alicia, tells her story of living with the condition from her point of view.

Take the high road
Kylie Doonican travels from Australia to the 2015 conference in Glasgow with her sons.

Editor’s Report
It has been an absolute pleasure working with Paula over the last three years. In that relatively short time Paula has made a lasting impression on the NSPKU by bringing her kindness, knowledge, experience and new ideas to the Society. Paula will still contribute to News & Views when she can and in this issue she brings us some delicious salads and mouth-watering ways to liven up water as well as news from the supermarkets and low protein food manufacturers.

We are fortunate to have so many dietitian’s out there working in the field of PKU who have been very kind and supportive over the past few months. Cerys Gingell and Anne Daly who organise and run Edale each year, Sarah Ripley who organised this years conference and Barbara Cochrane who has provided a report for this issue on prescriptions and who has been so brilliant with her support and advice to people who contact the NSPKU via email and the helpline.

Happy reading.

Caroline Bridges
Dear NSPKU

Prior to Christmas, we asked our customers to select a charity of their choice so we could distribute an amount of money we had to the charity they selected. We are therefore delighted to make a donation of £100 in support of the great work you do.

Best wishes,
Victoria Bates, Axiom Engineering, Stockton-on-Tees

Dear NSPKU

I’m writing to let you know that our friend, Callum Parkinson, ran the Manchester marathon on 10th April 2016 to raise money for the NSPKU. He did really well and ran it in 3:12:29 and raised £606 for the society!

www.justgiving.com/Callum-Parkinson

Many thanks
Kelly Lang, Manchester

Dear NSPKU

Please find enclosed a cheque for £1.30 for the Society. We are very happy to continue our support for all your valuable work connected with those who have experience of PKU. I can confirm that this donation is made within the Gift Aid provisions of the Treasury.

With best wishes.
John & Marina Darby, Edinburgh

Dear NSPKU

Please find enclosed a cheque in the sum of £33.04 for the NSPKU. This is a donation from the staff and parents at the nursery. Instead of sending each other Christmas cards, people were encouraged to write their Christmas messages on our entrance notice board and leave a donation. We chose to donate the money to the NSPKU because we currently have a child at the nursery who has PKU.

Yours faithfully,
Emma Wyer, Leapfrogs Nursery, Crediton

Dear NSPKU

We are delighted to enclose a cheque for £200. My daughter, Caoimhe, is four and has PKU. Her Uncle Shane and fiancée Fiona organised a table quiz and raffle in a local bar, Gribbens. I also donated the rest of the money raised, £350.00, to our local hospital, The Royal Victoria Hospital for Sick Children, Belfast.

Many thanks,
Erin McKenna, County Tyrone

Dear NSPKU

Thank you for the help and support you have given our grandson Joe and his family over the first ten years of his life. We celebrated our Golden Wedding Anniversary recently and suggested a donation to the NSPKU instead of presents. As a result I enclose a donation for £55.50.

Keep up the good work.
Many thanks,
Jane & Mike Willis, Ipswich

Dear NSPKU

We are delighted to enclose a cheque for £150 which once again is instead of sending Christmas cards. Our grandson Hugo (now almost 3 years old) continues to be a very lively and happy little boy and we are very grateful for the help and information from the society.

John and June Fletcher, Aberdeen

Callum Parkinson running the Manchester Marathon in April.

Please send in your photos with letters and donations

It’s always great to show pictures on these pages, so please don’t forget to send in your photos. Digital images are preferable and as long as they are large enough files we’ll do our best to print them alongside your letters.

Email: editor@nspku.org
News & Views, PO Box 3143, Purley, Surrey CR8 9DD
Dear NSPKU

On the 27th December 2015 my wife Kathleen and I celebrated our Diamond Wedding. We had a celebratory dinner but told our guests that we did not want any presents. Instead, if they wished to mark the occasion, we asked that they made a donation to fund research into PKU. Our grandson, Rhys Taylor in Bath, has the condition so it is something of which we are acutely aware.

I enclose cheques to the value of £275 money, which was given directly to my wife and me. I know that several people sent some amounts directly to you so we hope that the Society will have benefitted from a fairly substantial sum of money.

Yours faithfully

H D G Evans, Cheshire

Hi NSPKU

Through an old work colleague I was made aware of your charity as he was doing a fund raising walk...

www.justgiving.com/Colin-Sutcliffe

Persuaded after a couple of beers I added your charity to one of my more popular ebay shop listings.

I donate to several other charities this way and although the amounts are small it will raise £1.50 – £3 per day which adds up over a year. 

All the best

Quentin Turner-Zealey

www.tzlaces.com

Dear NSPKU

I just wanted to let you know that my husband, Gareth, finished his six month hair growing challenge, raising a grand total of £2,510! Hopefully this has already reached the NSPKU. It looked ridiculous by the end (although not as ridiculous as the picture on the JustGiving page which was actually a wig!) because his bald spot remained a bald spot! He was very relieved to have it neatened up on the 29th December (the day after Freddie’s 2nd birthday).

We also produced some novelty calendars using the Manchester City and Manchester United mascots, and sold these to family and friends for £8 each. We sold 150 of them and raised £700.

Best wishes

Kelly Lang, Manchester

Dear NSPKU

I have pleasure in enclosing a cheque for £80 which the Cullingworth Bowling Team raised from a raffle at my late father’s (Cameron Hamer’s grandfather) Memorial Cup Match.

Thank you very much.

Mandy Hamer, Bradford

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!
A message from the Chair

It is with regret that we announce the resignation of our Society Dietitian, Paula Hallam, due to a serious illness in her family. We would like to thank her for the tremendous work she has done in her time as dietitian for the NSPKU; all the families and individuals she has helped; all the publications she has worked on – and those she has proof-read; all the conferences she has attended on behalf of the Society and much more. We wish her and her family all the very best for the future.

Ordinarily we would be looking for one dietitian to replace her. However, our helpline has highlighted increasing issues within the PKU community. These appear to be growing. Consequently we shall be advertising for a paediatric dietitian and an adult dietitian.

After a busy conference in Cheltenham and an excellent exchange of views after the AGM, we have digested what was said and now we need to implement what our members have asked us.

We are pleased to announce that we are going to lobby Parliament on 28th June 2017 – International PKU Day. We – with your help – are going to raise awareness of PKU amongst politicians, NHS administrators and the general public.

If we don’t shout about it nobody will do it for us! Gathering further evidence of the problems you face over the next twelve months will enable us to prepare thoroughly.

Eric Lange, Chair, NSPKU

A message from Paula Hallam

Dear NSPKU members,

It is with great sadness that I need to inform you that I will be stepping down from my role as the NSPKU Dietitian, due to an illness in my family.

Thank you all for your support over the years, since I took over the role from Eleanor in 2013.

I still hope to be involved with the NSPKU in a small way, perhaps writing for News & Views, but I will not be able to manage the full role anymore.

I am very sad to say goodbye to my role as the NSPKU Dietitian, but I know that you will all understand my position.

With very best wishes,

Paula x

NSPKU Charity Tubs

Would you like to promote awareness of PKU and raise money for the NSPKU at the same time?

Our recently upgraded charity donation tubs are now available. The new, eye-catching design will make PKU a real talking point at your workplace, local shop or fundraising event.

Available now. Please contact the NSPKU by email: info@nspku.org or telephone: 030 3040 1090
Looking for adult (18+) patients with PKU to participate in an online survey

My name is Denise Hofman. I’m a Dutch PKU patient, currently doing a PhD at the University of Leeds. My research focusses on the dietary management and impact of PKU in adulthood.

Denise Hofman speaking at the NSPKU Conference 2016 in Cheltenham

We all know that adhering to the strict PKU diet and protein substitutes can be hard. Various metabolic centres have reported decreased adherence to dietary recommendations when patients grow older. Adherence to both the diet and protein substitutes are important for both physical and mental health and low adherence has been shown to lead to deficiencies in vitamins and minerals as well as anxiety, depression and difficulties with cognitive functions like memory or concentration.

With this survey, I hope to contribute to a better understanding of (1) factors leading to low adherence to the PKU diet and protein substitutes and (2) the cognitive functioning in daily life as well as quality of life impacts experienced by adult PKU patients as a result of different levels of adherence. My ultimate aim is to help improve the treatment and quality of life of adult PKU patients.

So far, 65 patients from all over the world have completed the survey. I’m looking for more patients both on and off diet (and anywhere in between!) to participate in my study.

A major thank you to everyone who has participated to date!

If you are an adult (18+) PKU patient and are interested in completing the survey, please contact me via psdlh@leeds.ac.uk and I will send you more information.

Denise Hofman | Postgraduate Research Student | Human Appetite Research Unit | School of Psychology | Faculty of Medicine and Health | University of Leeds

This survey has been granted ethical approval by the School of Psychology Ethical Review Committee, University of Leeds, United Kingdom. Reference number: 15-0398 (07/01/2016)

Investing in the Future

The Society continues to benefit from your excellent support which is now enabling us to invest in a stronger Society to deliver increased benefits.

The Council of Management (COM), after careful contemplation and financial planning, has decided to increase capacity and resource in:

• An additional Society Dietitian
  We will have two dietitians working together and supporting each other – one focussed on support for children and the other focussed on support for adults

• A Conference Organiser

• Communications
  Website and social media

This helps us build on the excellent work to-date, but develop new opportunities and offer enhanced support in the future.

Many of you have been telling us about the opportunities to improve our services and so we are delighted and excited to announce our plans to increase our capacity in these important areas.

We will be advertising for these roles on our website and elsewhere so we can secure the best possible outcomes from this new additional investment.

www.nspku.org

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www.nspku.org
Because...

low protein food should be as good as anyone else's

www.fatespecialfoods.com
Fate Mexican Cheesy Bites

This recipe is so quick and easy to do. It’s a basic recipe that you can change to suit your taste, simply by changing the seasonings. I use fajita spice in the recipe which really goes with the ‘cheese’ flavour, but you can use whatever other suitable spice or herb mixture that you fancy. Even dried onion or garlic granules are good. You could also add different veggies to the mixture; red pepper and spring onion is good, as well as sweetcorn if you have the exchanges!

This recipe makes about 12 bites.

Ingredients

Makes 12 bites

½ tsp yeast
¼ tsp salt
2 tsp fajita spice, (more or less to taste)
2 tsp oil, preferably olive
100mls warm water
A few drops browning
5 slices/100g Violife protein free cheese, any flavour, cut into small pieces.
Spray oil for greasing

Method

Place the Fate Low Protein All Purpose Mix into a bowl. Stir in the yeast, salt and fajita spice. Place the browning and water into a jug, add the 2 tsp oil. Pour onto the dry mixture in the bowl and stir well to make a smooth batter. Stir in the cheese pieces.

Then, place a frying pan onto heat, lightly grease it with a little spray oil. Place dessertspoons of the cheesy mixture into the pan just a few centimetres apart. Use a spoon dipped in water to level the top slightly. Sprinkle with a little extra spice if liked.

Leave to cook for 3-4 minutes until the underside is browned. Turn over and cook for a further 3-4 minutes till cooked through.

They are lovely served with a suitable fresh salad and a squeeze of lime.

They are also good served with a suitable tomato based sauce or dip.

Fate Mexican Cheesy Bites can be frozen, however they are best eaten fresh.

See this recipe step by step on youtube

www.youtube.com/user/fatespecialfoods

Fate Special Foods cookery videos – now on YouTube
Step-by-step recipes, helping you make great low protein food.
Congratulations 
Anita MacDonald, OBE

On 4th February this year Professor Anita MacDonald received her OBE from HRH The Prince of Wales, which was awarded for her services to dietetics. The NSPKU is so proud of Anita and thankful for her years of dedication to PKU.

Anita wanted to be a PKU dietitian from the time of being a student, particularly after she spent time doing some practical training at Alder Hey Children’s Hospital. She was truly inspired by Christine Clothier, a great practical metabolic dietitian.

Anita saw her first patients with PKU in 1979. Initially she only saw a small number of patients with this condition and she had to wait patiently for a metabolic dietetic post to come up in Birmingham in 1987. Within a week or two of starting her new role her first Birmingham baby with PKU was diagnosed.

That little baby is now 29 years old! Anita is also his godmother and he regularly pops in to say hello to her at her clinics.

Anita announced her semi retirement this year but she still intends to keep very active with PKU. She is still caring for her patients with PKU and intends to do more research. Officially she is working three days a week – but in theory only. She intends to keep the ‘BCH Metabolics’ Twitter account very active and watch out for her new PKU blog. The only reason for retirement is so she could have a little more sleep!
A professor at Birmingham Children’s Hospital, whose tireless work has transformed the lives of thousands of young people, has officially received her OBE from HRH The Prince of Wales.

Professor Anita MacDonald, who lives in Sutton Coldfield, picked up the prestigious award from Buckingham Palace yesterday after being included in last year’s Queen’s Birthday Honours.

Since joining Birmingham Children’s Hospital in 1987, Professor MacDonald has led a dedicated team of dieticians that care for children with rare inherited metabolic disorders (IMD).

The main form of treatment for many of these conditions is a therapeutic diet. They are caused by a gene fault, which leads to a reduction or complete lack of an enzyme involved in the many complex chemical reactions causing a build-up of harmful chemicals or reduction in those chemicals needed for the body to work properly.

If left untreated imbalances occur that could lead to serious and sometimes fatal complications.

Over the last 29 years the hospital’s Inherited Metabolic Disorders Clinical Team has grown from having just three members to now more than 30 and have treated more than 1,000 children across the country.

Professor MacDonald, the UK’s first Consultant Paediatric Dietician and only Consultant Metabolic Dietician, has been at the forefront of ground-breaking research, education and training and is a respected global voice on improving treatment in this area.

Her work on improving treatment for children with Phenylketonuria (PKU) is particularly renowned.

Oral medicine protein substitutes are essential to prevent brain damage in patients with his specific IMD.

Previously these were bitter and unpalatable but Professor MacDonald led a revolutionary project to develop a more attractive range of substitutes, which are now available across the world.

Although she has received international acclaim for her innovations in the field, caring for her patients and families is at the heart of everything she does.

To improve the quality of life for the children Professor MacDonald and her team introduced the UK’s first and only home care service in 2000 and a 24/7 on-call dietetic service is also available.

A highlight of the year for her IMD patients is an annual party for children and their loved ones.

The fun event, which gives families the chance to enjoy themselves and meet those with similar conditions, began with just a handful of party goers more than 25 years ago but last month’s celebration played host to more than 100.

“When I first received the news that I’d been awarded an OBE I was in shock.

It didn’t really sink in until I had the honour of visiting Buckingham Palace to meet his HRH The Prince of Wales yesterday - It was a fantastic and humbling experience.

It’s not only recognition of my work but of the whole team at Birmingham Children’s Hospital. Everyone works so hard to deliver the best quality of care to our children and young people.

Dietetics is not always the most high-profile so it’s pleasing the profession has also been recognised.”

Professor MacDonald

“Professor MacDonald’s commitment to improving treatment and care for children and young people has had a huge impact, not only for patients here at our hospital, but also across the world.

Everyone here is immensely proud of her and the well-deserved recognition of her tireless work and passion that’s been evident day in, day out, for more than 25 years.”

David Melbourne, interim Chief Executive at Birmingham Children’s Hospital

- Conducted over 40 studies on PKU
- Published 90 articles and research papers on PKU
- Been involved in all the UK Kuvan studies and networks with PKU researchers around the world.
- Obtained her PHD in 1999
- Awarded an honorary membership of the NSPKU in 2012
- Chair of ENEP, a European group of expert dietitians working on PKU
- Advised on the composition of many of the protein substitutes that we have available today
- Played an active part in the eagerly awaited European PKU guidelines

Anita MacDonald Fact File

ITV News reported on Anita’s big day and published this article below on their website…
Vitabite, ProZero and Mini Crackers are foods for special medical purposes and must be used under medical supervision.

Vitaflo International Ltd, Suite 1.11, South Harrington Building, 182 Sefton Street, Brunswick Business Park, Liverpool, L3 4BQ
Web: www.vitafriendsPKU.co.uk

Chef Neil - Here to help you create delicious low protein snacks and meals. Recipes available at www.vitafriendsPKU.co.uk

PKU Ambassadors – Keep up to date at www.natboyson.co.uk & www.emmaharbage.co.uk

Join us online at www.facebook.com/VitafriendsPKU

Follow us @vitafriendsPKU

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Sign up for our newsletter at www.vitafriendsPKU.co.uk

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Millionaire's Shortbread

### Ingredients

**Shortbread**
- 25g Butter
- 25g Hard margarine
- 25g Caster sugar
- 90g Fate Low Protein All Purpose Mix
- 1-2 tsp Cold water

**Caramel Sauce**
- 100g Light brown sugar
- 100g Butter
- 100ml PROZERO

**Topping**
- 5 x 25g Vitabite bars, broken into chunks
- 50g Butter

### Method

1. Pre-heat oven to 200°C/180°C fan/gas mark 6.
2. Place butter, hard margarine and caster sugar into a mixing bowl and beat until light in colour and texture.
3. Fold in Fate Low Protein All Purpose Mix.
4. Using your hands, mix and squeeze the mixture until it binds together (add water as needed to form a manageable dough).
5. Transfer to a surface lightly dusted with Fate Low Protein All Purpose Mix and continue to knead the dough for approximately 30 seconds or until smooth.
6. Roll out the dough to a thickness of ½ a centimetre and place onto a lightly greased 8” x 11” baking tray.
7. Place into pre-heated oven for 20-25 minutes, until pale golden in colour.
8. Remove from oven and cool on a wire rack.
9. Place butter and brown sugar into a saucepan over a low heat until butter has melted and sugar has dissolved.
10. Add PROZERO to mixture and simmer for 5-10 minutes, stirring continuously until the mixture has reduced down by approximately a quarter.
11. Transfer to a bowl or jug and place in the refrigerator for 10 minutes to cool but not set.
12. Pour caramel sauce over shortbread and place into the refrigerator for approximately 30 minutes, or until set.
13. Add Vitabite chunks and butter to a heatproof bowl. Melt by placing bowl over simmering boiling water, stirring occasionally or melt in the microwave on a low heat.
14. Spread over top of set caramel sauce and place into refrigerator for approximately 30 minutes, or until set.
15. Once set, remove from baking tray and cut into squares.

Recipe makes: 24 bite sized pieces

Preparation Time: 40 mins
Cooking Time: 20-25 mins
Chilling Time: 70 mins

ProZero and Vitabite are foods for special medical purposes and must only be used under strict medical supervision.
This was my first experience of planning and organising an NSPKU conference and it was definitely a labour of love. Over 200 emails were sent and received during the four months prior to the event and the programme underwent 14 revisions before it was finalised! The members of the NSPKU ‘Council of Management’ were all very supportive and work extremely hard in their mostly voluntary roles. The staff at the hotel had no previous knowledge of PKU or the strict diet followed by most of the delegates and this had to be fully explained to the staff and the Chef. The menus were carefully planned in conjunction with the nutrition companies and each company sponsored a meal. The hotel Chef, Mark, and his team did a fantastic job of preparing the low protein meals using unfamiliar products and a matching menu was provided for the delegates who didn’t have PKU.

The conference started with dinner on the Friday night and a magician was on hand to entertain everyone.

SATURDAY

Eric Lange, NSPKU Chairman welcomed everyone to the conference and the first two speakers were adults with PKU who described their experiences.

Living with PKU:
Adherence to Dietary Management

Denise Hofman, Postgraduate Research Student, Human Appetite Research Unit, School of Psychology, Faculty of Medicine and Health, University of Leeds

Denise Hofman is a patient with PKU from the Netherlands who is currently doing a PhD on the dietary management of adults with PKU at the University of Leeds. Denise talked about her experiences growing up, travelling and studying abroad with PKU and she believes living with PKU has directly influenced her study choices. Her qualifications include an undergraduate degree in Biomedical Sciences, a Masters in Health Food Management and she is now studying for a PhD at the University of Leeds. As part of her doctorate, Denise has chosen PKU as her research topic and her research is focussed on issues with adherence to (i.e. how well someone sticks to) the PKU diet and protein substitutes.

Poor adherence to the supplements can cause significant nutritional deficiencies and this theme was continued in the presentations given on Sunday. Her study will assess the self-reported level of adherence of adult PKU patients, factors affecting adherence, quality of life and executive functioning (attention, working memory, adapting new and unexpected conditions in the environment, as well as reasoning, problem solving and planning). Research of this nature is vital to help healthcare professionals understand more fully the difficulties faced by patients with PKU, especially in adults, as most research has been carried out in the paediatric setting. (See advert on page 7.)
Diet for Life: Weighing up the Evidence

John Bassett

John Bassett is a final year medical student with PKU who has stayed on diet, his presentation covered the advantages of staying on diet, problems with staying on diet, his tips on how to stay on diet and enjoy a social life and his own story with regards to the PKU diet. John described the neurological changes in the brain caused by high phenylalanine levels which in turn can be detrimental to executive function, verbal fluency, memory, processing, inhibition and motor control. These changes have been shown to improve after treatment in children. John also shared the ‘Dopamine Hypothesis’ - going off the PKU diet can cause a reduction in dopamine in the brain. Dopamine has an effect on concentration, memory and mood and may be responsible for anxiety, depression, decreased social maturity and isolation seen in adults with PKU who are off diet.

In his presentation he compared the published evidence in the literature regarding adults with PKU staying on diet and his own personal experiences; looking at the drawbacks, benefits and challenges he faced staying on diet as an adult. One of the problems discussed included stress/embarrassment when eating in restaurants. John had very strict control until about age 16, when he started to look after his own diet more. As his diet relaxed, he noticed problems concentrating, his mood fluctuated and he was underperforming slightly at school. This led him to be stricter at university (phe levels <500µmol/l) where he achieved a 2:1 in Biochemistry and a place at medical school. He has recently graduated and will soon be starting work as a junior doctor.

His tips were as follows:- find out where the good vegetarian/vegan restaurants are in your town. Health food shops are a really good source of low protein diary/meat alternatives, start cooking and learn how to adapt recipes. Finally, make sure your friends know about your PKU and roughly what your diet is as this helps in social situations where food is often central.

Both presentations generated many questions from the audience and clearly demonstrated PKU does not prevent academic success.

The Destiny of Late Diagnosis

A film on late treated and late diagnosed PKU. The film was made by the German PKU Association and the NSPKU paid for translation into English with subtitles where necessary. The film was thought provoking and well received. There was an interesting discussion afterwards and while it could be claimed the film was “political” it clearly re-enforced the benefits of Newborn Screening. It would be interesting to know how many people there are late diagnosed and untreated in the UK.

The Edale Experience

Cerys Gingell, Metabolic Dietitian, Nottingham

Anne Daly, Metabolic Dietitian, Birmingham Children’s Hospital

Anne Daly and Cerys Gingell gave a short presentation on the Edale activity weekend in Derbyshire, which they help run annually for the NSPKU. These weekends are an excellent opportunity for children from the ages of 8-11 to meet other children who have PKU in a fun and interactive weekend. They are so popular that people who went as children often volunteer years later to be helpers! The instructors get to know the children over the weekend and learn how they cope with new challenges and are adept at knowing how far to push them, as well as knowing when someone has reached their limit! The weekend also helps children prepare for school trips by giving them confidence to manage their own diet away from home. The children who attend love meeting other children with PKU.

Edale and Me

Faith Sheridan

Faith Sheridan is an 8 year old girl with PKU and she very confidently shared her action packed experience of Edale. She enjoyed a range of activities including abseiling, canoeing, caving, limbo and the ‘great leap of faith’.

Research in PKU

Professor Anita MacDonald, OBE, Birmingham Children’s Hospital

Anne Daly, Metabolic Dietitian, Birmingham Children’s Hospital

Professor Anita MacDonald discussed two new studies that have been conducted at Birmingham Children’s Hospital.

Glycomacropeptide (GMP) - a relatively new protein substitute and Sapropterin (Kuvan). GMP is the only naturally occurring protein that does not contain Phe, and is of interest as a source of protein for dietary management of PKU. Nutritional complete foods and drinks can be made with GMP to increase the variety of protein sources for the PKU diet. As an intact protein, GMP improves protein use and increases satiety compared with amino acids and it is hoped it will also improve bone density.

Kuvan is a synthetic version of Biopterin which is a co-factor for Phenylalanine Hydroxylase (PAH), the enzyme that is affected in PKU. People with PKU do not have a deficiency of Biopterin, but in about 20% of patients (about 1 in 5), there is enhancement in the PAH enzyme function when given Biopterin. Therefore, potentially more Phenylalanine (Phe) exchanges could be tolerated in the diet.

There are several facts to consider while discussing treatment with Kuvan

• Only a small minority of patients may benefit from Kuvan
• Kuvan is more likely to benefit those with milder forms of PKU who are already taking a more relaxed diet
• Kuvan is several times more expensive than dietary treatment alone (£14,000 – £58,000 depending on body weight).
• There are still several ‘unknowns’ regarding the role of Kuvan in the management of PKU. It has been, therefore, very difficult even for professionals to understand and agree regarding the potential role in the treatment of PKU or Kuvan in the UK.
**Workshops**

Well-attended Saturday afternoon workshops covered a variety of topics.

**WORKSHOP 1: PKU Menu Planning doesn’t have to be a Nightmare**

Francine Freeman. Metabolic Dietetic Assistant, National Hospital for Neurology, Charles Dent Metabolic Unit, London

Tiziana Midolo. Metabolic Dietitian, National Hospital for Neurology, Charles Dent Metabolic Unit, London

From wonky veg to jack fruit, time-saving tips to food budgeting – Francine and Tiziana shared ideas on how to keep the PKU diet varied, interesting and healthy.

**WORKSHOP 2: Snack in Seconds**

Cerys Gingell. Metabolic Dietitian, Nottingham. Anne Daly. Metabolic Dietitian, Birmingham Children’s Hospital

Cerys and Anne presented a fun and interactive workshop for children where they examined food labels and discussed how they used their exchanges. The children were also shown how to make low protein snacks as an alternative to shop bought items.

**WORKSHOP 3: The Blood Spot**

Elaine Salmons. Senior Specialist Nurse, Birmingham

Elaine’s blood spot workshop turned into a very relaxed and open drop in session with Elaine fielding a wide variety of blood spot queries from all ages.

**WORKSHOP 4: Healthy Eating and the PKU Diet**

Sarah Howe & Louise Robertson. Senior IMD Dietitians, Queen Elizabeth Hospital, Birmingham

This focussed on where sugar is found in the low protein diet by counting out sugar cubes to show how much sugar is in certain foods and drinks, how to increase fibre, working out the fat content of foods and label reading (looking at packages and seeing what is healthy!)

**Keeping Track of Me: Living with PKU**

Shauna Kearney. Consultant Clinical Psychologist/Paediatric Neuropsychologist, Birmingham Children’s Hospital

Covering the developmental stages of growing through adolescence into adulthood, Shauna Kearney tackled the psychological issues of living with PKU and how psychological interventions may help.

**Cookery demonstrations**

Chef Neil Palliser-Bosomworth (Vitallo) & Mona Taylor (Nutricia) both gave excellent low protein cookery workshops. Neil focussed on using foods naturally low in protein and Mona used a variety of low protein foods available on prescription.

**Transition and Transfer to Adult Services**

Sarah Ripley. Metabolic Dietitian, Mark Holland Metabolic Unit, Salford Royal NHS Foundation Trust, Manchester

My presentation ‘PKU and Transition’ looked at the reason for transfer to adult services and the importance of successful transition. Until 8 -9 years ago, adults on diet were looked after at the children’s hospitals as numbers were low. As ‘diet for life’ is now recommended, more adults are staying on a low phe diet and adult services are increasing in size year on year. Adult physicians are experts in conditions that progress with age, paediatric physicians are experts in childhood development. Transition is defined as ‘The purposeful, planned movement of adolescents and young adults from child centred to adult orientated health care systems’ Blum et al. Journal of Adolescent Health 1993: 14:570-6. During transition the aim is to gradually develop the skills and knowledge of the young person to empower them to manage their condition independently. Each young person will need to undertake transition at their own pace. There are differences between adult and paediatric services, e.g. new products, new staff, new environment – maybe a new hospital. Poor transition can lead to disastrous health outcomes for both physical and mental health... at its worst, poor transition leads to dropout from medical care for those with a long term condition, and deterioration in those with disabilities.

In my second presentation ‘A Tale of Two Pregnancies’, I highlighted the importance of good phenylalanine control during pregnancy. This showed the differences in the outcome of a baby born to a mum with PKU who planned her pregnancy and was on a strict diet before conceiving compared to a mum with PKU whose pregnancy was unplanned and poorly controlled due to non-compliance and compounding social issues. Baby number one was born at full term, was a healthy weight and his length and head circumference were in proportion. Baby number two was born early by caesarean section due to poor growth and had a small head with incomplete brain and lung development. His future development will therefore be delayed and he will require specialist medical input for the rest of his life.
Healthy Lifestyles with PKU

**Suzanne Ford**, Metabolic Specialist Dietitian, North Bristol Trust, Bristol

Suzanne highlighted the importance of healthy and cardio protective lifestyles with PKU. Adults with PKU are at risk of developing raised blood fats (hyperlipidaemia) as the adult PKU population ages and managing the risks of diseases associated with raised blood fats will be different to adults without PKU. Food companies, government targets, policies, regulations, the media – ALL have interests in manipulating our food and nutrient intake. Whether a person with PKU is on or off diet, their weight and other cardiovascular risk factors such as lipid profile have an influence on the level of risk. Suzanne discussed saturated fat and coronary heart disease in addition to the protective role of plant stanols; which reduce the absorption of cholesterol in the gut so more is lost in the faeces. This in turn helps to lower total cholesterol and LDL-cholesterol (the bad type of cholesterol) in the blood. Products with added plant stanols and sterols are now available, e.g. two teaspoons fortified spread can provide at least 0.8g of plant sterol per day would be needed e.g. two teaspoons fortified spread (both branded and own-label products are available). Other types of fortified foods are on the PKU Red List (fortified yoghurt, yoghurt type drinks and milk).

Activity is another important factor and there are UK Recommendations for Activity for 19-64 year olds

- All adults aged 19 years and over should aim to be active daily
- Over a week, this should add up to at least 150 minutes (2.5 hours) of moderate intensity exercise in bouts of 10 minutes or more
- Alternatively, comparable benefits can be achieved through 75 minutes of vigorous intensity activity spread across the week or combinations of moderate and vigorous intensity activity
- All adults should undertake physical activity to improve muscle strength on at least 2 days a week
- They should minimise the amount of time spent being sedentary (sitting) for extended periods

These messages are important as patients with PKU are just as likely as their counterparts to be overweight and at risk of heart disease/stroke/diabetes in later life.

Micronutrients in PKU

**Dr Gisela Wilcox**, Consultant in Metabolic Medicine, The Mark Holland Metabolic Unit, Salford Royal Foundation NHS Trust, Manchester

Dr Gisela Wilcox discussed the risk of micronutrient deficiencies in PKU. Her presentation highlighted the frequency of these deficiencies where compliance with amino acid substitutes is problematic, mostly in the adult PKU population. Many patients struggle to consume all their prescribed dose of these due to known issues with taste, smell, etc. If these are discontinued / reduced for any reason, it is important to consume sufficient quantities of good quality protein (high biological value) which are provided by animal sources of protein, such as meat, poultry, fish, eggs, milk, cheese and yogurt. Low biological value proteins are found in plants, legumes, grains, nuts, seeds and vegetables. When a protein contains the essential amino acids in a proportion similar to that required by the body, it has a high biological value. When one or more of the essential amino acids are missing or present in low numbers, the protein is has a low biological value. These foods also provide essential vitamins and minerals. Many patients on a ‘normal diet’ do not consume sufficient protein as they either dislike the high protein foods or feel guilty for eating them, this is very dangerous and over time can lead to irreversible health problems from deficiencies in nutrients such as vitamin B12, calcium, vitamin D. Dr Wilcox emphasised all patients with PKU should continue to attend a specialist metabolic centre at least annually to enable their diet to be assessed by a dietician and blood taken to check for micronutrient deficiencies.

Dental Management of Children with PKU

**Dr Susan Parekh**, Clinical Lecturer/Honorary Consultant, UCL Eastman Dental Institute, London

The impact of dental disease can be far reaching, from pain caused by infection, the psychological impact of appearance and halitosis, damage to adult teeth and loss of weight due to poor dentition. In a study done in Australia in 1999, the teeth of 40 children with PKU were compared to control:-

- 35% of children with PKU had never seen a dentist
- 75% were caries free (no difference between groups)
- 33% of children with PKU had tooth wear (erosion) compared to 24% of control children

Acidity of the flavoured protein substitutes was higher than unflavoured protein substitutes AND Coca Cola.

Statistics for erosion of teeth (irreversible loss of tooth tissue by acid, but not involving bacteria) showed 50% of children have erosion by five years of age and 44% ofteenagers have erosion.

**How to avoid erosion**

- Limit acidic foods/drinks/supplements to meal times
- Avoid acidic substances last thing at night, rinse with water after protein supplements, avoid tooth brushing straight after acidic substance. Prevention is the key!
- All children should be registered with a dentist
- Brush teeth twice a day as soon as teeth erupt (supervised)
- Use toothpaste containing no less than 1000ppm fluoride

**Dietary advice**

- Do not let your baby fall asleep with a bottle
- Use a straw with protein supplements
- Do not use mouthwash immediately after brushing as this negates the protective effect of fluoride

**SUMMARY**

The weekend was a great success and I would like to thank all the speakers for their excellent talks and giving up their time at a weekend; the hotel staff for all their help and in particular Chef Mark for the provision of excellent low protein meals; the NSPKU for offering me the opportunity to plan and facilitate their annual conference; the nutrition companies for providing their low protein foods and last but not least all the patients and families who attended.
The evening’s entertainment was brought to the conference this year by local band ‘The Hip Kicks’ some of their own great tracks saw people flock to the dance floor and keeping with the flow, some classic tracks from Queen, Stevie Wonder and The Proclaimers set off rounds of air-drumming, air guitars, dance-offs and even break dancing! The music was enjoyed by all ages with the bright lights and full band layout bringing the young and old(er!) together! If they could have played for longer, some people may still be there!

There was plenty on offer for the children this year at the hotel; a superslide was installed in the garden and the UK’s first interactive mobile caving system rocked up and provided hours of fun. There was a games room where children (and adults) got very competitive over table tennis, pool and air hockey. And when everyone needed to relax and cool down the swimming pool was available with a qualified lifeguard to keep an eye on everyone.
CONGRATULATIONS TO OUR 2016 SPRING DRAW WINNERS

On behalf of the NSPKU thank you to everyone who sold tickets for our Spring Draw this year which raised over £2,200. And of course thanks to all those who bought tickets as well. The draw was made on the Saturday night at this year’s conference in March at the Cheltenham Chase Hotel.

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Prize for the person selling the most tickets Tracy Critchley

Thank you to Vitaflo Ltd, Mevalia Ltd, YesWeCookThat.com and Fate Special Foods Ltd for their generous prize donations.

Yes We Cook That.com
Specialist Dietary Foods

Freshly prepared PKU ready meals
Now available by post to all UK and Northern Ireland addresses

Would you like...
To open the fridge to a freshly cooked PKU meal, labelled with the ingredients and exchanges waiting for you?

Yes We Cook That!
To open the freezer and find Spaghetti ‘Meat’ balls and Fishless Fingers and Chickless Nuggets, all with 0 exchanges?

Yes We Cook That!
To know that we really understand PKU, really understand your diet and really know what exchanges are?

Yes... we do!

Working closely with PKU dietitians and PKU patients Leanora Munn and Pauline Young of Yes We Cook That.com now have a menu of 180 ready meals and snacks all suitable for PKU diets. All meals are clearly labelled with the ingredients and any exchanges and are made using only prescriptive flours, egg replacers, milks and pastas.

Our menus are available through your dietician in some parts of the country or directly from Yes We Cook That.com. Our aim is to supply all PKU people with the opportunity to purchase ready made meals, breads, cakes and sweet and savoury snacks at supermarket prices.

Phone Leanora or Pauline on 07773 342594
24 hour answering machine 01290 332 949
e-mail sales@yeswecookthat.com
Yes We Cook That.com, 39 Leggate, New Cumnock, Ayrshire, KA18 4NG
The Juvela Low Protein Range

The Juvela Low Protein range is available from your pharmacy

For further product information and delicious recipe ideas:

☎ 0800 783 1992
@ lowprotein@juvela.co.uk
✈️ www.lowproteinfood.co.uk
.panelControl

Juvela Low Protein Foods
Outward Bound Activity weekend – Keswick

Are you between 9 and 22 years of age and want to meet up with other people with PKU?

Do you attend a PKU clinic in Scotland or the North of England?

We are organising our annual Outward Bound Activity Weekend at Derwent Hill Outdoor Centre, Portinscale, Keswick, from the **28th – 30th October 2016**.

This weekend is organised by the dietitians from Glasgow, Leeds and Newcastle. It is open to all young people aged from 9 years old under the care of these centres and from all centres in Scotland.

This year we are also taking a group of young adults – aged approx from 14 to 22 years – in addition to the younger group. If you would like to join us and have not yet had any information, please ask your dietitian to send you the information.

The cost for the weekend – Friday lunchtime to Sunday afternoon – is £60. Please contact your dietitian if you would need help with this cost.

Check out the website for more information on the centre: [www.derwenthill.co.uk](http://www.derwenthill.co.uk)
Low protein foods used in the management of PKU have been around since the very early days when the diet was first used. The low protein prescription foods are specially manufactured alternatives to natural basic foods such as bread, pasta, biscuits and milk, eaten by the general population with the aim being to improve convenience for patients on a restricted diet.

Around 1955, the first low protein food reported was a biscuit made from wheat starch, sugar and fat. Later on, bread became available in tins (many of you of a certain vintage will remember the tinned bread!). In Glasgow, a special low phenylalanine loaf and also biscuits were made by a local bakery and was reported as being a boon to patients! Over the years the low protein foods have improved considerably in the variety, palatability and ease of use and many commonly used convenience foods have low protein alternatives such as cup a soups, pasta pots and pizza bases.

With the increase in range, number of foods available on prescription and scrutiny of GP budgets, come associated problems for patients in obtaining sufficient supplies to meet their needs.

A survey of Scottish patients and parents* asked questions about how acceptable the foods were, why the foods were used and any issues in obtaining supplies. We also asked if anyone had comments made to them from primary care health professionals regarding dispensing and prescription. This is a common complaint from parents and adults who attend our clinics.

When we received the questionnaires back we found that most of the people who replied acknowledged that the low protein prescription foods were useful for the management of their diet, helped to control their phenylalanine levels and recognised that they were needed to help satisfy the appetite and provide variety in the diet. We found that the most commonly ordered foods were the pasta/rice/cous cous, flour, biscuits and bread. However, around 25% of those who returned the questionnaire had an unhelpful or disapproving comment from either the GP surgery staff or their pharmacy regarding their prescriptions. This in turn led to parents and adults with PKU being reluctant to ask for new products or extra foods being added to the list. I am sure many of you are familiar with this type of problem.

One of the most common problems is the confusion with the gluten free prescribable foods. Pharmacists and GP’s may be under the impression that the foods and the amount needed are similar. The amount of gluten free foods allowed each month is based on recommendations by the National Prescribing Guidelines, but is a lot less than for a low protein diet. Consequently, many GP’s and pharmacists think that people on a low protein diet are getting too much when they ask for their prescriptions. In addition, many of the “luxury” gluten free foods not allowed on prescription can be bought over the counter in supermarkets, but for low protein diets this is not possible and the foods must come on prescription, thereby patients have prescriptions questioned as to why someone with PKU needs cakes and biscuits on prescription and these may be refused or adjusted.

Why do we need the low protein foods?

• They are vital to provide sufficient energy in the diet. If someone with PKU does not have sufficient energy in their diet, they will use their own stores to provide energy, releasing phenylalanine (phe) and thereby increasing their phenylalanine levels, which will be detrimental to their health.

• They are needed to provide variety in the diet, so that a range of foods should be used to stop the diet becoming boring. This will be why you need the six different types of pasta and not just one or two.

• If there is not enough bulk in the diet – i.e. you don’t fill up sufficiently – then you will be hungry and consequently be tempted to take extra of the restricted foods, again increasing the phe levels.
What can you do if you are having problems with the supply of your low protein foods:

• Try and organise your supplies so that you order monthly. GP’s like monthly prescriptions. This will also help you to rotate stock and use up foods before they become out of date.

• Print off the prescription information from the NSPKU website and hand into your GP and pharmacist, this might help to give them more information on your condition. www.nspku.org/publications/publication/information-pharmacists

• Take advantage of the home delivery service from the specialist companies. They will help manage your prescriptions, the foods should have a better date and will help you get the foods you need and in the amount you require.

• Always make sure you do your monthly stock check with the company, this will help overstocking of product and wastage. These foods are expensive.

• If you order from your local chemist, ask for a copy of your repeat prescription list on a regular basis – at least yearly – and delete any foods you do not use and foods that have multiple entries

• Hand a copy of your request to your chemist at the same time as putting in your request to the GP. This will mean that your chemist can check what is prescribed and may save time and wrong orders.

• Check your order against the NSPKU unit recommendations. We found that the majority of people did not request the number of units they needed for their age. This will help if you are questioned about why you need so much. www.nspku.org/publications/publication/prescription-guidelines

• Do check what you order – are you ordering 35 packets of biscuits, cakes and snacks and hardly any pasta or bread? This would be hard for your dietitian to justify that you need this amount of “luxury” low protein foods.

• Speak to the practice manager if you are having problems getting what you need. They can often be invaluable in helping manage your prescriptions if you are having difficulty.

• Change your chemist. Many people stick with the same chemist even though they are having problems – shop around. By having a chat with the pharmacist when they are not too busy, you can get a feel for how helpful they are.

• Are there any other people in your area with PKU, find out from your dietitian and use the same chemist.

• Ask your dietitian for more help if you continue to have problems with your prescription requests. They will be able to speak to the practice manager or receptionist who deals with the prescriptions to help you sort out the problem.

The low protein prescription foods are a vital part of your diet and without them, you will not be able to have the energy you need and your diet will become boring through lack of variety. Managed properly, your low protein food prescriptions should not be a cause of stress for you. You should have enough of what you want, when you need it and in sufficient variety.

Barbara Cochrane, Metabolic Dietitian, Royal Hospital for Children, Queen Elizabeth University Hospital, Glasgow

* A questionnaire survey on the usage of low protein staple foods by people with phenylketonuria in Scotland. B Cochrane; B Schwahn; P Galloway; P Robinson & K Gerasimidis.

“Over the years the low protein foods have improved considerably in the variety, palatability and ease of use.”
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CARAMEL SURPRISE

For further information contact:
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PIP Code 401-5764

Shortbread Biscuits - Pack Of 120g
PIP Code 401-5749

Rusks - Pack Of 250g
PIP Code 401-5723

Caramel Shards - Pack Of 130g
PIP Code 401-7531

Chocolate Cookies - Pack Of 135g
PIP Code 401-5772

Fish Substitute - Pack Of 248g
PIP Code 401-7695

Caramel Dessert - Pack Of 500g
PIP Code 401-7687

Strawberry Dessert - Pack Of 500g
PIP Code 401-7679

For further information contact:
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Fruity water
Top summer tip... why not try 'fruity water'? Add strawberries / cucumber and mint / slice of lemon and lime / pomegranate seeds to water to add a touch of colour and taste to your water jug. It is a delicious way to keep hydrated, super healthy – and it’s PKU-friendly!

Try these ideas from Jamie Oliver:
• Add a few slices of fresh lemon or lime.
• Quarter an orange, squeeze in all of the juice, then toss in the squeezed quarters for colour and extra flavour.
• Mash up a handful of strawberries or raspberries with a fork then add to the jug and stir through.
• Scrunch a handful of fresh mint in your hands to get the flavour going then add that to the jug with a squeeze of lemon or lime juice. If you’re feeling a bit adventurous, add a few slices of cucumber too. It might sound strange, but it is seriously refreshing.

Cucumber, avocado and dill salad
adapted from Waitrose summer recipes 2014
Preparation time: 15mins
Serves: 4
Ingredients
1 cucumber
2 ripe avocados, diced
½ x 20g pack fresh dill
1 tbsp extra virgin olive oil
1 tbsp balsamic vinegar
1 tsp honey & mustard dressing (see NSPKU booklet for suitable brands)
250g Violife cream cheese (or other suitable vegan cheese)

Method
1. Halve the cucumber lengthways and deseed using a teaspoon. Cut into 1cm slices and place on a serving platter with the avocado and half the dill.
2. Whisk together the oil, vinegar and mustard dressing and drizzle over the salad.
3. Chop the remaining dill and add to the Violife cream cheese, season and spoon on top of the salad.
4. Delicious served with some toasted low protein rolls or bread.

Summer slaw
adapted from Waitrose summer recipes 2015
Preparation time: 20mins
Serves: 6-8 as a side
Ingredients
½ small white cabbage
½ small celeriac
2 small red onions, finely sliced
3 carrots, peeled and coarsely grated
100g radishes, quartered
100g Violife plain cream cheese
1 tsp honey & mustard dressing (see NSPKU booklet for suitable brands)
1 tsp cider vinegar
1 tsp caster sugar
25g fresh flat-leaf parsley, finely chopped

Method
1. Using a sharp knife, finely shred the cabbage, removing the tough stem and core. Peel and cut the celeriac into matchstick size. Toss into a large bowl with the other vegetables, season and set aside.
2. In a small bowl, whisk the Violife cream cheese, mustard dressing, vinegar and caster sugar.
3. Spoon the dressing over the vegetables and toss gently to coat. Check the seasoning again, then scatter with the chopped parsley to serve.
Raw beetroot, pear, carrot and ginger salad adapted from Karen Dudley’s cookbook ‘A Week in the Kitchen’

Serves: 8

**Ingredients**
- 6 medium beetroots
- 8 carrots
- 3 ripe pears (you could also use apples)
- ½ cup vinaigrette
- A thumb of fresh ginger (about 4cm), peeled and finely grated
- Zest of 1 orange

**Method**
1. Peel and thinly slice the beetroots and the carrots (cut lengthways), like matchsticks.
2. Peel and core the pears and cut into thin slices.
3. In a small bowl mix the vinaigrette and fresh ginger together, then pour over the vegetables and pears.
4. Arrange in your chosen platter and garnish with the orange zest.
Prescription low protein foods – NEWS

Low protein products discontinued from Nutricia

There are a number of Loprofin low protein products that either have been discontinued already or are about to be discontinued:

- Loprofin Lemon Cake Mix
- Loprofin Strawberry Dessert Mix
- Loprofin Vanilla Dessert Mix
- Loprofin Chocolate Dessert Mix
- Loprofin Flakes Apple & Honey*  
- Loprofin Chocolate Wafers

*Still available until the end of August 2016

Nutricia Metabolics have said the following, about the discontinuation of these low protein products:

“At Nutricia Metabolics, we are committed to supporting the greatest number of people with the largest and most comprehensive range of metabolic products and services. In doing so, we look to assure the quality of all products, and are continually reviewing and upgrading our Loprofin range as part of this process.

Unfortunately this sometimes results in the need to discontinue supply of certain products. With a wider offering of foods low in protein now available in supermarkets, it is no longer sustainable to continue to produce the products listed above. Therefore we have made the decision to discontinue these products from the dates highlighted in the table above.

We would like to apologise for any inconvenience caused by this decision. We are committed to our low protein range of products and we have a plan in place to optimise our current portfolio and to develop innovation within the Loprofin range.

If you have any questions or would like any further information or assistance in this transition, please do not hesitate to contact our Resource Centre on 01225 751098”

NEW products available on prescription from Taranis (distributed by Promin Firstplay Dietary Foods)

- Taranis Chocolate Chip Cookies
  PIP Code 401-5772 135g
- Taranis Chocolate Chip Biscuits
  PIP Code 401-5764 120g
- Taranis Raspberry Shortbread Biscuits 120g
  PIP Code 401-5756 120g
- Taranis Biscuits with Caramel Shards 130g
  PIP Code 401-7531 130g
- Taranis Shortbread biscuits
  PIP Code 401-5749 120g
- Taranis Rusks
  PIP Code 401-5723 250g
- Taranis Dalia liquid (milk substitute)
  PIP Code 401-5780 200ml carton
- Taranis Pause Dessert – Strawberry Flavour
  PIP Code 401-7679 500g pack
- Taranis Pause Dessert – Caramel Flavour
  PIP Code 401-7687 500g pack
- Taranis Fish Substitute*
  PIP Code 401-7695 248g pack (4 x 62g)

* The Fish substitute – 30g portion contains 30mg phenylalanine (50mg phe = 1 exchange) 1 portion (30g) = ½ exchange 2 portions (60g) = 1 exchange

Please discuss with your Dietitian before introducing this product to your diet.

Update from Promin Firstplay Dietary Foods

Low protein ‘Snax’ now available in individual flavours:

- Promin have received an approval from ACBS to supply Promin Snax as 1 flavour of 12 sachets.
- Patients can still order a variety pack of Snax if they prefer to have a mix of flavours.
- The PIP Code for the Snax remains the same (356-1586), however Promin will be applying for PIP Codes for separate flavours.
- Please tell your chemist which flavour you prefer unless you are ordering a mixed pack of Snax, as the prescriptions will still say ‘Snax Mixed Flavour’ unless you specify which flavour you would like.
- If you receive Promin products on home delivery from ‘Dial a Chemist’, they will be contacting all patients requesting Snax to specify which flavour you would like to receive.

Remember to follow @NSPKU on Twitter for updates on low protein foods, ideas and recipes!
Low protein supermarket foods

Koko coconut yogurts

Koko Dairy Free has launched an exciting range of low protein and dairy free yogurt alternatives. The range is dairy free and low in protein and is made with freshly pressed coconut cream for a silky smooth creamy texture, and fermented with live dairy free yogurt cultures for the true taste of yogurt. Koko Dairy Free says, “You’ll be surprised just how much like dairy yogurts they taste”.

The range
- Original Plain 500g
- Strawberry 2 x 125g
- Raspberry 2 x 125g
- Peach & Passion fruit 2 x 125g
- Coconut & Lemon 2 x 125g

Prices
- £1.85 for 500g Original Plain
- £1.25 per 2 x 125g

Stockists
Available from Morrisons, Asda and Ocado

Protein content/exchanges
They all contain 0.6g protein per 100g, except the Coconut & Lemon flavour, which has 0.7g protein per 100g.
- 1 pot (125g) = 1 exchange
- 165g (original) = 1 exchange

Further information and recipes visit www.kokodairyfree.com

Update from Mevalia

New products from Mevalia low protein:
- Low Protein Rice 399-1106 (400g pack size)
- Low Protein Ditali Pasta 399-1114 (500g pack size)
- Low Protein Burger Mix 399-1098 (400g pack size)

Basic hamburger recipe

35g Burger Mix, 45ml water, 1 teaspoon olive oil, salt and pepper according to taste and dietary allowance.

Mix the Burger Mix, water, oil, salt and pepper with a spoon to form a smooth mixture.

Shape into flat burgers. Heat sunflower oil in a pan and fry the burger for about 30 seconds on each side.

Further information and recipes visit www.mevalia.com

Serving suggestions:
- Add steamed vegetables to bring more variety to the recipe
- Serve with a side salad
- Herbs and spices can be added to the burger mix to change the flavour, such as Cajun spice, Thai 7 spice mix or Mixed herbs.
- Burgers can be served with condiments such as suitable mayonnaise, sweet chilli sauce, tomato ketchup and tomato salsa or chutney (see the NSPKU dietary information booklet for suitable brands)

Feel Free Foods gluten free donuts

Shirley Osborne wrote to me to tell me about these gluten free mini donuts: Feel Free Foods – mini gluten free donuts (sold frozen)

Protein content/exchanges
Protein = 1.3g/100g or 0.5g per donut (half an exchange per donut)

Stockists
Available to buy in Tesco’s (in the freezer section) and online.

www.feelfreefoods.co.uk

www.kokodairyfree.com
We’ll have so much fun!

We’ve got lots of lovely recipes to share!

We can share stories about being on a low protein diet!

I’ll send you our special adventure story books!

There’s a brilliant website!

HAVE YOU JOINED OUR ANAMIX 6 CHILDREN’S CLUB?

As a member of the Anamix 6 club you always have something to look forward to in your letter box every month. Sign up for free and learn all about your low protein diet™ as well as receive brilliant story books and lots more!

You can join online at www.anamix6.com

The Gang can’t wait to hear from you!

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™Recommended for children 10 years and younger
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FROM NUTRICIA METABOLICS

LowProteinConnect.com

- provides support and advice
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- stay updated on the latest news and share your experiences
- can be accessed across a range of devices
- offers practical advice on cooking low protein meals
- information on upcoming events and educational sessions
Alicia Oke has lived with PKU all her life, but she doesn’t have the condition – her older sister, Amber, has. Alicia’s story provides a fascinating insight into living with PKU from a sister’s perspective.

‘My sister’s got this condition called PKU’

People always commented how similar my sister, Amber, and I looked. We shared the family nose, our wonky fringes and late nineties haircuts were mirrors of one another and our mum even dressed us in the same busy floral t-shirts when we went to weddings. But what passers-by on the street and other children hogging the swings couldn’t see were our genes: and they were very different.

Amber was born on the 15th December 1991 with ten fingers and ten toes, a beautiful giggle and classic PKU. Instead of putting the roast potatoes in the oven and checking the turkey, my parents were in and out of hospital and checking Amber’s blood levels that Christmas. PKU was unheard of in my family and in our small town; Amber was the only case of classic PKU in the Torridge area. With the help and support of Amber’s dietitian, my mum and dad coped exceptionally well with the condition, both as first time parents, and first time parents of a child with PKU.

Four and a half years later, I was born in the summer of 1996. The doctors confirmed I had a thick head of hair, a chubby face and that I didn’t have PKU. My parents decided on the name Alicia for me fairly quickly, as it went so well with Amber, but there were far bigger challenges ahead. They had to continue raising a child with PKU alongside one without.

I can’t remember not knowing about PKU; it was a well-established part of my family before I was born, so I simply had to live alongside it. My parents didn’t sit me down at the dining room table, lecture me about the complexity of PKU and conduct a quiz afterwards. We just talked about PKU like we talked about the Teletubbies and in that way, I just seemed to understand that Amber couldn’t eat some of the foods that I ate. However, my mum did tell my exactly what PKU was and what it did to my sister. She didn’t sugar coat a definition with silly words or rhymes, she told me that PKU meant that one of Amber’s enzymes couldn’t break down protein, and that she drank a supplement to replace what she couldn’t have naturally. And that is exactly what I told my friends at school when I talked about my sister. Just after I said how annoying she was. I may not have fully understood it when I was six, but it meant that I had all the correct information, so when I got older, I could effectively and concisely inform my friends why my sister wasn’t “just a vegetarian.”

I didn’t really notice the difference most of the time. Amber always had the same meal as I did, but just a version appropriate for her diet, so I never questioned why she had something different to what I had. If we got invited to the same birthday party, we had what looked like same food, on the same plates. Little did I know that my mum had bought the same Toy Story themed paper plate and filled it with things...
for Amber. This just made it seem like we were both catered for at the party; we worried about how the magician made the rabbit appear rather than how we were going to magic up some food for Amber. In fact, I was so obsessed with Amber’s low protein pink wafers that my mum bought me equivalent pink wafers. Everything was equal, just like any parent of any child had to achieve, regardless of a metabolic condition.

Instead of getting mountains of chocolate eggs at Easter, Amber and I received one egg each and small toys instead. This was because Amber could only have a little bit of chocolate each day. I enjoyed my egg but got far more pleasure out of the Barbie dolls.

I also went along to all of Amber’s consultant appointments and helped my mum prepare Amber’s food. I loved playing on the rocking horses in the doctors’ waiting room (and got stuck in one once!) and using the special flour to make cakes. I was as involved in that side of Amber’s life, and it that sense it became my life too.

However, there were some days where I wished I didn’t have to deal with PKU. The times where I had my coat zipped up and boots on, ready to leave the house for a family day out, but we couldn’t because Amber hadn’t finished her supplement yet. And I always ran upstairs and closed my bedroom door whenever Amber was having her blood tested as I couldn’t bear to watch the needle or PKU hurt my sister. Those days were the hardest to have a sibling with PKU. But I loved my sister and she and PKU were a package deal, so I had to love PKU too.

Even now at university, one hundred and twenty miles away from Amber, I search each restaurant menu for something that Amber could eat before I order my meal. It’s just an instinct. I seek comfort in knowing that I could come back to the same restaurant and spend some quality time with my sister without PKU being an issue. And sometimes the low protein options are far more tempting than the rest of the menu! Even though I don’t have PKU myself, I live with PKU every day. But it doesn’t punish me, or Amber at that; I believe it makes me who I am. Having a sibling with PKU has given me such a sense of understanding and respect that I truly believe I wouldn’t have gained anywhere else.

“Alicia Oke”

“Having a sibling with PKU has given me such a sense of understanding and respect that I truly believe I wouldn’t have gained anywhere else”

1. **Treat each child as an individual.** Let your child without PKU explore the condition, let it teach them respect, not restrict them to a similar diet. Both children need to learn to be around other different children, so restricting your child without PKU to a low protein diet will merely isolate your child with PKU in the outside world.

2. **Explore PKU with both children.** Get both children involved with preparing the low protein foods and consultant visits/doctor’s visits. This will help both children understand the condition and avoid jealousy or resentment.

3. **Explain the condition correctly.** Inform your child without PKU exactly what PKU is and what it does, in simple, but correct language. This will give your child the information they need to begin to understand PKU, and allows them to educate and make others aware.

4. **Make the same meal for each child.** If your child without PKU is eating a cottage pie, but your child with PKU is eating roasted vegetables, then you will make PKU a bigger issue than it should be. Create the same meal, but a variation for your child with PKU, so only the ingredients of the meal are different, not the meal itself. This will normalise PKU in general, and especially at meal times.

5. **Substitute where unfair situations may occur.** During Christmas and Easter, your child with PKU may receive toys or money as a substitute for holiday chocolate. This may upset your child without PKU, so substitute copious chocolate with alternatives for both children. Children usually prefer toys over chocolate anyway.
The 2015 NSPKU Conference outside Glasgow, Scotland was an eye-opener for my 12 year old PKU son Lachlan. As if the food buffets full of beautifully presented low protein foods weren’t exciting enough, he couldn’t believe the lineup of PKU people reaching outside the conference room each meal! He was spoilt for choice and spent the next three days with a feeling he’d never properly had before – the feeling of being stuffed full of such a variety of foods he couldn’t stop eating!

Lachlan has attended various PKU events, met other PKU children and adults and eaten foods from PKU buffets before, but never on this scale. Although he knows his condition is rare and understands the basic science of hereditary conditions, it is still a difficult concept for a child to comprehend. He has asked if there will ever be another PKU child at his school or in his soccer team, or even living nearby. He wondered at the idea of never randomly meeting other PKUs. And then he walked into a hotel conference with more PKU people than he had ever seen! That moment of realisation, knowing he is not alone, meant so much to him. He wondered at the numbers for days afterwards, reminiscing about “the Westerwood” and all the people who “know about PKU”.

Lachlan and I were very fortunate in receiving the Vitaflo Travel Grant from the MDDA for travel to the NSPKU Conference in March. We were looking for a variety of information and experiences for Lachlan as he enters his teens and this conference had several child and teen sessions aimed at helping PKUs to understand the components of food, healthy eating, food selection and the options available both in supermarkets and from Low-Protein food providers. There were guest speakers from the NSPKU community discussing study, sports and friendships with examples of managing all of these in your PKU life. There were also several sessions reporting on scientific research and progress with trials so we felt this conference could be very beneficial in moving Lachlan into the next phase of his PKU management with confidence.

Confirmation of our success in receiving the grant caused a great flurry of excitement and activity in our house – we had just ten days before the conference began! It was a crazy week of planning and preparing but when our departure time arrived we were confident we were well prepared for the journey. We had made a last minute order to Nutricia for par-baked bread rolls and wafers plus had a prescription for Vitallo’s Express 20s filled and sent ready for the trip. I also pre-selected the fruit platter and vegetable platter options for the flight to ensure Lachlan would be served foods at meal times. We were able to supplement these with some individually wrapped crackers, biscuits and cakes we had brought with us. While we knew the first few days of PKU food would be supplied at the conference we needed to be prepared for our sightseeing days afterwards. We needn’t have worried as the food samples we were given at the conference more than fed Lachlan for the rest of the trip and stocked our pantry for the foreseeable future! We used an entire large suitcase to lug it all around the UK and bring back into Australia – all declared and accepted by customs.

On the first evening we were overwhelmed by the number of companies displaying their products for the conference. We spent time trying foods and discussing the options available from these companies each day, learning something new or discovering new products each time we ventured into the room. Lachlan took part in some R&D product sampling for Vitallo’s new cooler flavours and felt very excited to have the opportunity to rate future flavor options for his preferred formula. Some new products from the Cambrooke range also gained his tick of approval. I was very interested to learn that this company was named after the owners two PKU children “Cameron” and “Brooke”. I knew Fate Special Foods was named after Eileen’s PKU daughters Faye and Kate but I had no idea Cambrooke foods was also a family run, PKU inspired business in the USA!

The lovely ladies from Mevalia introduced Lachlan to their range with some product sampling topped with supermarket guacamole squeeze, something...
we’d never thought to try before. We’ve since bought some here in Australia for a quick addition to crackers and sandwiches. Mevalia also stock a range of sliced bread which Lachlan thoroughly enjoyed and proceeded to eat all around Scotland and London after the Conference!

With so many companies providing low protein options in the UK, the NSPKU were able to organize each meal to be designed and provided by a different company and the Westerwood Hotel Chef did a wonderful job following the recipes and instructions for the food preparation! Recipe cards and booklets were provided with each meal, giving some creative ideas and new takes on old favourites. It was handy to test the texture and taste of the various pastas and breads over the course of the conference. The meals also provided an excellent opportunity to meet new people and share ideas and stories of our PKU experiences around a table of your own choosing each meal.

I was impressed with the attendance of families and children to many of the sessions available. It was obvious the annual NSPKU Conference is an opportunity for families to connect each year and strong bonds had formed over the years of attendance. Whole families came for the fun of the holiday (especially at the inaugural Conference hosted in Scotland – considered quite a coup to the local Scottish families).

Although the UK is much smaller than Australia they have never previously held a Conference in Scotland, preferring instead to alternate between the South and the North of England only. Our own MDDA has addressed this issue for many years now and held Conferences and Retreats in cities all over Australia and deserve recognition for this tremendous effort.

Smaller children were able to attend some special outings to a local zoo and the resort facilities throughout the day, allowing their parents the freedom to select those activities and sessions most appropriate to their needs and current situations. The PKU sessions for young people were run by psychologists, dietitians and PKU young adults, providing informative and realistic information on the management of PKU in a young person’s life. Lachlan thoroughly enjoyed the dietitian’s session on food components, recognising the fat and salt content of a variety of products for a greater understanding of maintaining a healthy diet while choosing low-protein foods. He was also interested to hear the scientific reports on the laboratory trials for BH4. While he is a classic PKU and doesn’t have much hope for these products being of use to him in the near future, he was interested to hear about the procedures and tests, the research pathways and potential for breakthroughs at some point. I think he found the notion of a mouse with PKU quite interesting!

Eileen Green’s Fate stall was abuzz throughout the conference. She had a variety of her recipes prepared for everyone to try, along with recipe sheets and free booklets to complement her original recipe book.

Lachlan enjoyed all of her foods but especially loved her pancakes with fresh blueberries on the Sunday morning! The foods she had planned for her buffet night were also a hit and the hotel chef had great success in following her directions to prepare the recipes she’d left.

Most of us have heard that UK residents are able to order their low protein food products for free through their health system and this routinely makes us all green with envy. My conversations with families and young adults at the Conference confirmed the positive impact this has on their ability to stay on diet. Families are able to experiment with recipes without the cost of each cup of flour or pasta hanging over their heads.

The variety of low protein suppliers in the UK is also enviable. While there appeared to be some favourites, the continuing existence of this number of companies, alongside newer companies and products breaking into the market, shows individual tastes require more than one option to be satisfied. I can only dream of this in Australia, at this stage, but hope to see an increase in suppliers and products in the future.

Our experience in Scotland at the NSPKU Conference has made an impact on both my son and me in many ways. From information gathered to a feeling of comradery, this trip was beneficial in ways we are still discovering. I cannot thank the MDDA and Vitaflo enough for this wonderful opportunity.

Kylie Doonican

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