

Inside this issue...

Editor's Report

Letters

Edale Weekend

Report

**Bake & Take in
Sheffield**

Dietitian's Report

NEW!! Teen Zone

Fate Recipes

Bake & Take Birthday in Sheffield



In Touch

The Council of Management

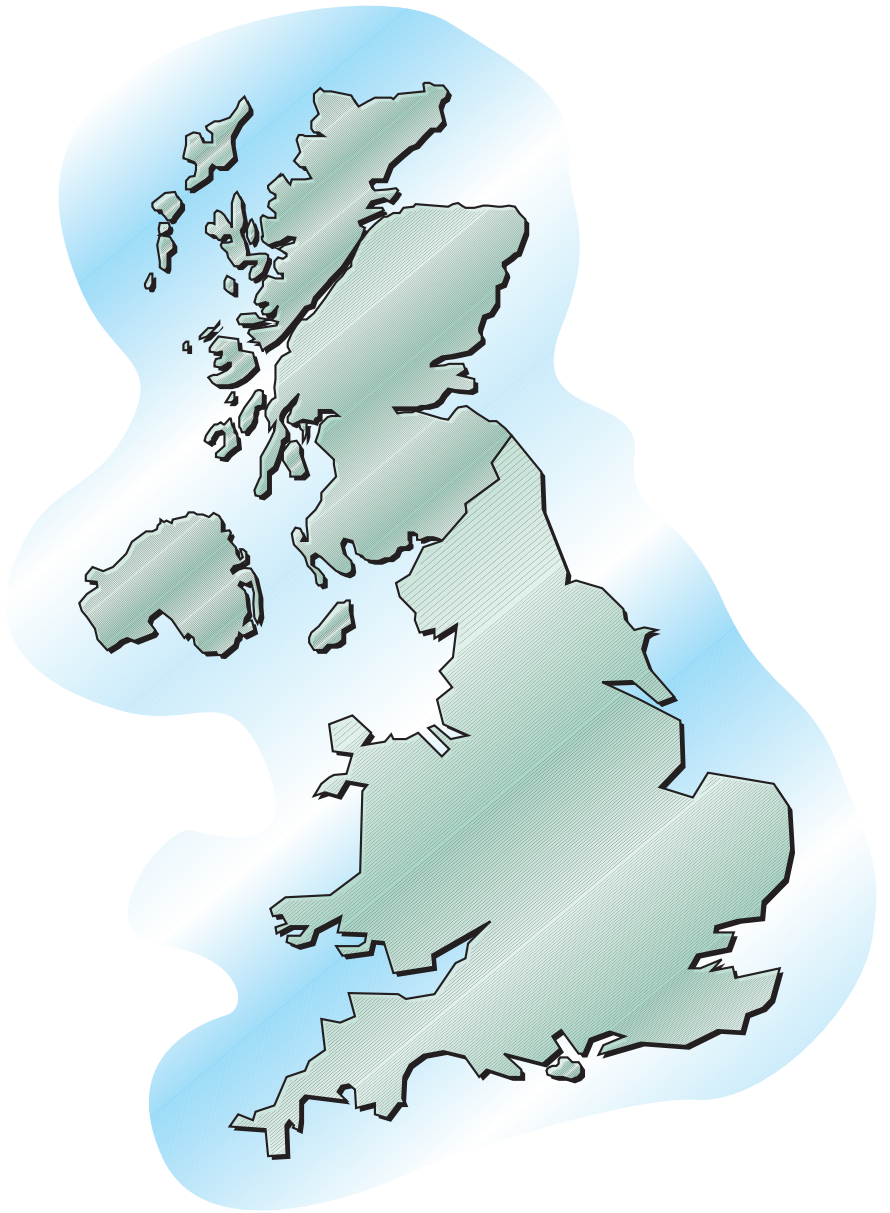
Telephone Helpline: 0208 364 3010

Recorded Information Line: 0207 099 7431

Address: PO Box 26642, London N14 4ZF

E-Mail: info@nspku.org

Internet: www.nspku.org



Contents

- | | | | |
|----|--|----|--|
| 1 | Editor's Report | 14 | Kuvan Works |
| 2 | Bookkeepers Report
Donations | 16 | My Edale PKU Outward Bound
Weekend by Pheobe Wharton (Age 9) |
| 4 | Letters | | From your Dietitian... |
| 7 | Success Stories | 19 | Fun with Cupcakes |
| 8 | Bake & Take in Sheffield | 20 | Deliciously Crispy Battered Veg |
| 11 | Fate Special Foods
– Ifona Welsh Cakes | 21 | Dietary Information for the
Treatment of PKU – June 2010,
Updated list of ACBS items |
| 12 | NEW Teen Zone
– Lucy Goes to Rome
– Trivia Quiz | 22 | The prescription of low protein
foods in PKU |

Editor's Report...

Hi Everyone

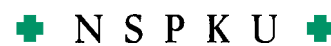
I can't believe we are already half way through the year! Where has the time gone?

We are into the summer and I am sure you are planning your trips away. I look forward to hearing about them for the next issue.

We have a new TEEN ZONE now which is for all our teens and young adults. We will showcase your achievements and stories here, so please send in lots of stuff!

I would like to do a Kids Corner and have some ideas. I am however looking for a budding children's story writer to create a character and write a short story for each edition – if you are interested, please email me and we can work something out.

Regards
Ed



The National Society for Phenylketonuria (United Kingdom) Limited

Please address all correspondence to the Editor, "News & Views",
23 Barnfield Cottages, Arundel Road
Fontwell, West Sussex BN18 0SE
Tel: 01243 544446
Email: editor@nspku.org

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The National Society for
Phenylketonuria
(United Kingdom) Limited,
PO Box 26642,
London N14 4ZF
Company No. 1256124.
Charity No 273670.

Helpline: 0208 364 3010

Email: info@nspku.org
Web Site: www.nspku.org

Registered address:
'Merrywood' Green Road
Wivelsfield Green
West Sussex
RH17 7QD

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Bookkeeper's Report 30.6.10...

I've just returned from a short holiday and thought I would share some of my experiences with you as I know some of you were at the Conference in March.

The first three nights we spent in the Lake District and we added a further two night stay at the Rendezvous Hotel in Skipton. I chose this hotel because I was impressed with the care and quality given at the Conference in March.

The drive from Kendal to Skipton through Hawes and the Yorkshire Dales was excellent, the weather was hot and sunny and we spent the day stopping off at places to browse and have lunch.

At the Rendezvous we had a lovely room overlooking the Leeds-Liverpool canal and the fields and hills beyond.

The canal barges stopped underneath our window whilst someone jumped off the barge and ran to the little side road to take off the chains holding the bridge in place and slowly push it open for the barge to go through, only for them to re-chain the bridge back and then jump back onto the barge and go on their way, fascinating watching.

The wildlife was also abundant, we watched the rabbits playing in the fields and one morning I was awake early and reading by the window when a heron came flying gracefully past on my eye level following the line of the canal upstream – great stuff.

Having not had time previously to use the swimming pool facilities, I made a point of going through and having a swim. Although the changing rooms were out of action due to refurbishment (imminently to be finished), the hotel put on the best alternative and the pool was a happy place to be with people really enjoying themselves.

Dinner was in the smaller Baby Swan restaurant which wasn't in use during the Conference, this also overlooked the canal in an extension similar to a large conservatory, the food was very good. Whilst we were there I bought a piece of jewellery for a friend from the hotel glass cabinet, she was very pleased with it.

Having time to explore Skipton and the surrounding areas, we had a trip out to the Kanban factory shop in Shipley (for anyone interested in making cards and crafts – recommended), also to the Damart factory shop in Bingley, and we went into Skipton on market day which was very busy and thriving.

All too soon our short break has ended and I am now home catching up on work, but, if you're looking for a nice break in the Yorkshire Dales vicinity, then I can only say we were most impressed.

Best wishes.
Vicki King

Donations of over £30 up to 30.6.10

Name	Amount £
Miss K Morgan & Class 3.2 George Heriot's School	94.54
Mrs C Cook - memory of Albert Claude Tufts	172.90
T & P Davies, Llandeilo	60.00
Longlevens Under 8's Tag Rugby Team	500.00
Mr & Mrs F Moore - 50th Wedding Anniversary celebrations	1,000.00
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Mr & Mrs Hobson	40.00
Erin and Caiden Kane, 5k race	270.00

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Letters

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Email: editor@nspku.org

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.



Dear News and Views,

My name is Hannah Pycroft. I am 14 years old and have PKU. I have learnt to manage my diet well and enjoy trying as many new foods as I am allowed using my "PKU calculator" to work out amounts and decide if the foods are worth trying. I have lots of interests mainly dancing. I do 9 different types I enclose a cheque for £225 from my nan's yoga group, run by Mrs Pam Sapey, who organised the fundraising event. I would like to thank them all.

From
Hannah Pycroft



Dear News and Views,

Please find enclosed a cheque for £200 which I have raised after completing the Bodmin Lions Club Ten Tors sponsored walk. This is a 13½ mile walk which I did with my mum, dad and sister on 9 May 2010. We have done this walk over Bodmin Moor for the past 3 years now and although it is hard going, we are proud of completing it once again and wish our sponsor money to go to the NSPKU as I myself have PKU. Many thanks for all the hard work.

Yours faithfully
Lorissa Clemo (age 17)



Dear News and Views,

I enclose a cheque for £410 for the NSPKU. £210 of which is the remainder of the monies collected as a result of Arwyn's "Offa Dyke" walk last May, and £200 collected by a local choir, Sain Teilio, of which Arwyn, myself and Wendy, our daughter, are members. We sang carols at our local town a Saturday before Christmas.

Yours sincerely
Arwyn Davies



Dear News and Views,

Survival Systems International Sweethearts Calendar 2010

Survival systems International (SSI) are a company based in Great Yarmouth, Norfolk, that manufacture and service lifeboats worldwide. One of our field service technicians, Andy Dickson, approached SSI management just before Christmas to ask whether the staff at SSI would get involved in producing a calendar to raise money for the NSPKU. Andy has a 4 year old daughter called Aimee who has PKU.

I am pleased to say that SSI management were

more than happy to fund the production of the calendar and they even took part in one of the pictures. We were able to sell just over 100 calendars, and have the pleasure of enclosing a cheque for £515. With the media coverage we received we hope we have raised the profile and awareness of such a rare disorder as PKU.

Andy hopes to continue his fundraising for NSPKU and is currently looking at doing a parachute jump and also hold a golf day which SSI will continue to support in any which way we can.

Yours sincerely
Claire Gutteridge
(Business development coordinator)



Dear News and Views,

In January we celebrated our 40th wedding anniversary and decided to have an in-house fundraising dinner dance on New Year's eve. We have three grandchildren with PKU and dedicated the funds raised to the NSPKU.

The event was extremely successful and not only did the eighty or so guests have a good time, we also managed to raise £3000 for the charity. A pub quiz held locally also raised £200, making a total of £3200. The cheques are enclosed.

The three grandchildren – the two fathers are our sons, but with two unconnected wives. Ifan, aged 3 years and Awen aged 15 months both live in Llandeilo, whilst Ffion, 17 months, lives in Barnes, London. They are all doing really well and are comfortably ahead of their physical and intellectual milestones. The diet is discipline, but the children's blood Phe levels remain within limits, except when they are ill.

We hope the money raised will contribute to promote the activities of NSPKU, from which we as a family have benefitted considerably.

Yours sincerely
Terry and Pam Davies.



Dear News and Views,

I am writing to tell you about our Easter break we had this year with our 9 year old son Luke, who has PKU. It is the second time we have been to Jersey and we stay at the Merton Hotel in St Helier. It is a large, friendly and helpful hotel. They have a large buffet style restaurant and an A' La carte and dinner menu. They are always helpful at meal times. Breakfast always has plenty of fruits, cereals and juice, they will toast your PKU bread and Luke enjoyed his cooked breakfasts of hash browns, grilled tomatoes and mushrooms.

The hotel also has a small games room, kids club and a swimming pool complex with indoor and outdoor pool. These have slides and a Jacuzzi. Outside is a flo-rider if you fancy learning some surfing skills.

Eating out in Jersey is great! Our favourite place is called "Wildfire Tapas Bar and Grill" (we go upstairs). This last visit, Luke had a fantastic starter of champagne sorbet with fruit followed by a medley of stir-fry vegetables and a side order of fries.

As most of you will be aware, we had the volcanic eruption which caused the flight ban. This happened when we were in Jersey. We were due to leave and fly home to the Isle of Man on the second day of the ban. Having worked in aviation, I knew if our flight was cancelled then we would need a plan B! It was on this occasion that I realised why I always make a list of Luke's products and double it! I also carry a medical note and copy of his prescription. Our flight was cancelled, so we re-booked our room for an extra night, had breakfast and then went straight to the ferry terminal.

The ferry company were only serving people who had turned up due to the emergency. 22 hours later we had tickets to travel the next evening from Jersey to Poole. As there was such a demand to use the computers at the hotel, we phoned home and my sister & partner books us into an hotel in Poole as we would be arriving just after midnight. They also booked our next ferry from Liverpool to the

Isle of Man for the Sunday evening. My brother got in touch and credited our phones as were unable to do this on our network. As we were unable to get through to the car hire companies and trains, we arranged for a friend to collect us and take us to Liverpool. He has a taxi firm in Liverpool and although it was expensive, it saved us time and probably an extra night in Liverpool and it was lovely to see him!

We arrived at Albert docks just after 3.30pm. It was Luke's birthday on that Sunday and he fancied doing some shopping, but we didn't have long enough. The ferry company wished him happy birthday and presented him with a priority boarding pass – he was thrilled and we have promised him we will pop over in the summer for a shopping trip!

We had a lovely sailing and were glad to be home. We called it our adventure home and Luke loved it!

PS can we just say we loved the article that Stephen Whelan wrote in a previous issue of News and Views – very inspiring, thank you.

Regards
Sarah, Mark and Luke Gell



Dear Tracy,

Thank you for your recent letter and donation totalling £233.33 and for your support of the NSPKU. I hope you all had a lovely time with the charity party at Hurley Village Hall, please thank everyone who took part in and supported the event, and thanks also to the band 'Ashleigh and the Skunks' and DJ Neil Harrington for donating their services to make the evening a huge success.

The money raised will be used wisely by the Society and will help people with PKU and their families.

There will be an acknowledgement of the donation in the Society magazine News and Views in the near future. If you have any photos of the event and would like to send or email them to me for inclusion I will forward on to the editor of News and Views.

With very best wishes.

Yours sincerely
Vicki King (Mrs)
Bookkeeper
On behalf of the NSPKU (UK) Ltd





Sheena Laing 1953-2010

It is with great sadness that I have to tell you of the death of Sheena laing on July 17th, 2010.

Sheena worked as a dietitian in Dundee and Cardiff before being appointed as Chief Dietitian at Edinburgh Sick Children's Hospital. She worked there for 27 years before she took early retirement 4½ years' ago due to ill health.

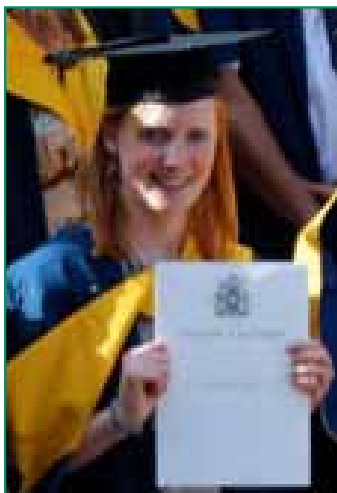
Sheena took a keen interest in metabolic disease and was frequently called upon to write articles for medical journals. She was a member of the Medical Advisory Panel of the NSPKU and a representative of the Society at ESPKU meetings. Sheena was a keen traveller and visited America to help at PKU camps one summer. I know the Americans remember her very fondly. She was also secretary of the Paediatric Group of the British Dietetic Association. Sheena was described to me as "the best boss anyone could have", always making sure that everyone at work was OK and it is her kindness, thoughtfulness and her desire to always put others needs before her own that patients, colleagues and friends will remember her for in her passing.

Sheena was a very private person, totally loyal to her friends and good fun to be around. She had many interests and was always keen to share these others. She was secretary and president of the Soroptimists for Scotland south, she played golf and the piano, loved her garden and the birds which visited (knowing them all), she appreciated art, enjoyed travel, spoke French (although she would say 'not very well mind') and loved cooking and baking. She made and decorated cakes beautifully frequently giving them as presents for special occasions. Giving gave her pleasure.

Although Sheena had no children of her own she took great interest in her two nieces and other family and friends' children, never failing to remember what was the last thing they had done. I took my 3 children to Edinburgh to stay with her for a few days one summer holiday when they were still quite young and Sheena had organised lots of things to do carefully planning what might appeal to them. As we were about to leave for the train to come home she asked the middle one if she had had a nice time to which she replied "I'm well chuffed Sheena". She loved that. She was the same thoughtful dietitian with her young patients.

Even throughout her long battle against cancer she never complained and always looked positively on whatever had to be. She was an inspiration to all who were privileged to know her, either professionally or as their friend, or both, as many of us became.

Eleanor Weetch



Massive Congratulations!!

This is a photo of Sarah Kimpton who has just graduated with a Masters degree in Pharmacy from East Anglia University. She starts her first job on August 2nd at the Norfolk and Norwich Hospital and is looking forward to her first pay cheque!

Many of you will remember Sarah's parents, Simon and Pat, who were great supporters of the Society. Simon was our secretary and got us computerized many years' ago.

Another Huge Success Story!

This is a picture of Purdy Bright, who has recently graduated from basic training with the Royal Air Force. As a child Purdy was always on very low exchange rates never exceeding 6 a day. However with the support of her consultants she came off the diet at the age of 22 suffering no side effects with the exception of fairer hair. Her brother who is also PKU remains on the diet, coming off diet does not suit every PKU.

Purdy had been off diet for 2 years at the time applying for the RAF and after a detailed medical and a bit of extra time for the RAF to look into PKU, she was accepted and able to pursue her career.

After reading an article in a previous issue of "New's and Views" about a young lad with PKU wanting to join the RAF, we thought this would give people like him some hope for the future.

(Thanks to Steve Bright for this)





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BAKE & TAKE IN SHEFFIELD



June 19th was a special day for us in Sheffield. We held a Bake and Take cookery day in the city centre at a very smart hotel in the city centre. However, it was not special for just that reason, it was one little girl's birthday and she was 5 on that day. Her name is Jasmine Green and Jasmine was given the choice of having a party or learning to bake low protein recipes. She wanted to bake!

The day was supported by SHS and Mona Taylor, home economist, demonstrated the recipe and then everyone had a go (or several goes) at doing it for themselves. It was Mona who said at a medical meeting "We remember 10% of what we hear, 50% of what we see but 90% of what we do". There is no doubt that doing something yourself really makes the difference. I would add that doing something regularly is also important for remembering. It may be my age of course but if I leave it too long before practising a skill I'm more likely to have forgotten some important detail which can be the difference between success and failure.



The day was so good for all of us because all worked at their own pace and if anyone lacked confidence in one skill it was practised until it was right. One lady made pastry 4 times. As each item was baked in the hotel kitchen the next skill was begun so we had a steady stream of food coming out onto the display table. How proud everyone was of their baking and what fun it was all learning together. The chef at the hotel really got into the spirit of it all too and offered his own little tips "don't roll those biscuits too thinly - they will burn in my oven".



The leaving comments were encouraging..... can we do it again in 3 months please!



Innovation in Nutrition

Dear All

On behalf of VitaFlo International Ltd I would like to announce that the Company has recently become part of the Nestle group.

As many of you know VitaFlo was founded by Directors Tony Partington, Bill Macnab and myself in 1997 with the main objective of developing an innovative range of specialist products for use in the dietary management of inherited metabolic disorders and disease related malnutrition.

We believe that through our partnership with Nestle, VitaFlo will be able to continue to grow and to expand our product range for infants, children and adults with specific nutritional needs.

VitaFlo will continue to be known by the same name, will still be based in Liverpool and the existing directors and team of employees will stay within the business to ensure that it is 'business as usual'. Please note that there will be no change to the way that you currently order and receive your products.

I would like to take this opportunity to assure you that VitaFlo's commitment to working with you to produce the highest quality products remains the same.

Yours sincerely

Maura O'Donnell

Chief Executive Officer

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Fate Special Foods recipes



Hello

This time my recipe is based on one given to me by my friend Ifona. She has a daughter, Heulwen who has PKU. We used to meet at the NSPKU camping weekend every year, and she always used to bring a freshly made batch of them with her to share. I'm sure you will love them as much as we do.

They are useful to have for anytime of the day, Try a couple or three for breakfast, or take them out with you as part of a packed meal, or eat them in the afternoon as a snack with a cup of tea or coffee.

This recipe makes around 20. They freeze well.

Ingredients

250g Fate Low Protein All-Purpose Mix

125g block margarine

75g dried mixed fruit

75g caster sugar

1 tsp baking powder

½ tsp grated nutmeg (grated from a whole nutmeg if possible)

60mls water

Extra Fate Low Protein All -Purpose mix to shape

Little butter or margarine for cooking

Little extra caster sugar to sprinkle

IFONA'S WELSH CAKES



Method

Place the Fate All-purpose Mix and baking powder into a mixing bowl. Rub in the margarine until the mixture resembles breadcrumbs.

Stir in the grated nutmeg, caster sugar and fruit. Pour in the water and stir well until blended well. You might find it easier to use your hands to bring the mixture together.



Lightly dust the work surface with extra Fate All-Purpose Mix, and roll out the mixture to about 1½ cms, (½ inch) thick. Cut into rounds using a 6cms (2½ inch) pastry cutter.

Place a griddle or a thick based frying pan over a low to medium heat.



Grease it with a little butter or margarine. Cook the Welsh cakes, a few at a time, turning each one when they begin to brown.

Leave to cook gently until they are firm, golden and cooked through.



Place on a wire rack to cool. Sprinkle with a little caster sugar.

The Welsh cakes keep for a couple of days in an airtight tin, or store them in the freezer.



Teen ZONE

These pages are for young people to have their say. Send us your stories and we will give them Pride of place here!

LUCY GOES TO ROME!!



Hello World! I'm Lucy and a few weeks ago, I went on a school trip to Rome (TA DA!) Before I start, 2 things. A) If you're in a group tell them about your PKU but to a level that they understand ... B) being to actually learn Italian - things aren't always what they look like! If you can't learn it in time, stick with someone who does. Also teachers may rely on you to get it right!

When flying it is advisable to not go with Ryan-air. They will charge you for a rumble trunk for bread, pasta on all other vacuum packed items. But they do have a good service though. When in Rome I found we could have most the drinks also the fruit and melons are MASSIVE so I didn't go hungry. Also a helpful hint - try to book a hotel with a fridge so medicines can be kept cool - warm medicines make it worse! Letters also help.

When going to restaurants, ask if you could have your pasta or whatever you brought cooked. Unlike Britain, they don't have health and safety laws on heating and cooking food but then again you could always ask for rice and veg. Little recipe hint - rice with spinach drizzled with lemon juice and olive oil.

If you have a high exchange rate try an awesome ice-cream in a wafer cone, 3 different flavours 5 exchanges... only good if you have 10 ex or more.

Rome, the Eternal City is a beautiful place that is well worth visiting and don't be afraid or embarrassed about PKIJ, enjoy it and show off to your friends about YOUR own special Italian pasta

Lucy

Trivia Quiz

1. What sort of creature is a tarantula hawk?
2. Where was Bob Dylan born?
3. In which film did the Rolls Royce have the number plate AU1?
4. What is Homer Simpson's middle name?
5. What fluid ran through the Greek gods instead of blood?
6. How do you Rizzle something?
7. Which country grows the most potatoes?
8. If you landed at Mirabel airport, where would you be?
9. What is the longest river in Italy?
10. According to the proverb which fruit 'tastes sweetest'?

1. Wasp - hunts spiders 2. Duluth, Minnesota 3. Goldfinger 4. Jay 5. Ichor 6. Sun dry 7. Russia 8. Montreal 9. Po 10. Forbidden

Answers

Kuvan Works

Dear NSPKU News,

My 14 year old son has PKU and we have found getting him to social events arranged by both BCH (Birmingham Childrens Hospital) and the NSPKU has always been a challenge through the years, unless of course there was a tenuous link to sport, then he would be happy. So given that he is currently taking Kuvan I wanted him to attend the last NSPKU conference, particularly for the Sunday session when a talk on Kuvan was given by Dr Galloway. I was also hoping to meet with representatives from Merck Serona who market Kuvan in Europe, including the UK. I learned prior to my trip that Merck Serona were not to be represented at the event which for me was hugely disappointing and after listening to comments made about Kuvan as a treatment for PKU from other attendees at the event I feel compelled to write this account of life with Kuvan. For some individuals it may be far more positive then we are led to believe.

My son has rejected virtually every change in his diet that we tried to make from a very early age, only accepting Aminogram Food Supplement but still mixed with the baby formula XP Anamix until well into his primary school years. Even my best efforts of cooking PKU food would be eaten on the first day of baking and never touched again. He is a keen sportsman playing Football, Golf, Tennis, Table tennis, Badminton regularly and last year decided golf was something he would like to take seriously..... Well he did, and within six months he had reduced his handicap to 13 and represented Derbyshire at U14 level twice, more recently gaining a place in the U16 Derbyshire squad and with a target of 7 handicap by the end of the year. For the non-golfers amongst you he's not necessarily the next Tiger Woods but this is a very good standard. In fact he is quite a goal oriented and strong willed young man; very positive traits or so I thought..... It soon became clear to us that his sport was taking a toll, more and more as he got older. At the beginning of last year, we felt he had out grown his coping strategy for PKU. His school work was variable and one day on one of our long trips to BCH we talked about Kuvan; its potential benefits and any possible side effects. I raised the subject of headaches, and to my surprise he said, whats a headache dad? so as I drove along the A38 I tried to explain, he said "I never get headaches but I do get stomach aches" oh! I said when do you get those? "every day" the reply. Well I was horrified, my son, in the 21st century was starving himself daily rather than eat the foods available to him, such was the discipline we had ingrained in him and the strength of his will. It was at the hospital that we realised his height

and weight were diverging and he was in danger of suffering the effects of malnutrition. A lack of food intake was also beginning to affect his school work, and his concentration levels. He was on 10 phenylalanine exchanges per day and since he was a young boy (who disliked most free foods) his exchanges and protein supplement were enough to sustain him. However, as he grew, and increased his sporting activity, his calorie requirements also increased and so his few exchanges were no longer enough to fill him.

Kuvan was licensed in the UK in 2009 and it was thought he may be a responder. He was first trialled with the drug for two days and it looked like he was responsive, but the trial was short and inconclusive. Well, we decided to go for a supported Individual Funding Request to our Primary Care Trust, which was initially rejected, so we appealed. We won the appeal so the request was analysed a second time, only to be rejected again. My son had by now gone back to school in year 9 and we had to trust him to manage his diet. Well he did but not in the way we hoped! Several high blood levels later we established the school canteen had a new customer for 3 rounds of toast at morning break. Perhaps this should not surprise us after the hopes for Kuvan had been dashed - a risk we had to take and his strong will still made him determined not to have the low protein special PKU foods at school.

Well finally we have managed to get Kuvan, but only because we pay for it. The benefits are far greater than I could imagine. He now has 20 exchanges per day and I suspect with a higher dose he could increase this further probably 25 or even more. He eats toast with his friends in the morning and chooses his lunch from the school cafeteria. He doesn't starve himself daily now and he is a far happier young man. The arguments we had about food have subsided and our home is a happier place to be, not just for him but his siblings (both non-PKU) and my wife and I. We have also carried out a quality of life survey both before and after Kuvan. I already knew the answer; our lives had changed for the better and the report concurred. Kuvan is not a solution for all, some people don't respond, but when it does work it can have a major impact on life for a PKU sufferer. Neither is it a complete cure but I've got a 14 year old boy who is prepared to move to Spain to try and obtain Kuvan rather than not have Kuvan - it's provided by some hospitals in Spain at no cost to the family, and is also available in 16 other countries in Europe.

The cost of Kuvan is high but not as high as you might think; my son is 45kg and is taking only 9

mg per Kg. That works out around £29,000 per year but his diet is far more relaxed, and his true character is revealed to us. He is still a typical 14 year old and is most definitely a teenager, but the changes are amazing, no longer an angry young man but a cheerful joker who I hope will fill a positive role in society.

So I call on the NSPKU to take action on behalf of those individuals who could benefit from the treatment of PKU with Kuvan. It is not acceptable that an organisation supports only a treatment that is accepted because it is the only treatment we know. Kuvan has been through extensive clinical trials, the current diet has never been subjected

to that level of assessment so none of us really know which is better! Each individual and family that suffer from PKU is different, no two cases are exactly the same, alternative treatments like Kuvan are available, can be prescribed and in my view should be made available on the NHS, as they are in Spain. I think the organisation has a responsibility to campaign for alternative treatments as well as providing fantastic support for the development of an ever widening variety of low protein food.

Max Lee

(contact Max on max.lee@gmx.co.uk)

A response from Eleanor Weetch

I would like to respond to the several points raised in your letter to the Society. First of all the NSPKU is a charity established by parents to help and support those with PKU (and their families and carers) either on or off diet and those born before national screening. Its aim is to promote awareness of the condition, provide information and support and encourage research and new treatments.

As such, at our annual conference we always try to include a speaker on potential new treatments and the role of Kuvan® has been included in the 2003 meeting and then at every annual meeting from 2007 onwards. The NSPKU also sent a senior representative to support your appeal for funding of Kuvan® for your son recently. In addition, a number of patients in the UK took part in clinical trials for Kuvan® and many others will have been updated on its development by their clinician or metabolic dietitian. We feel therefore that the Society has done its utmost to keep members informed of progress in this field.

It is important to understand the different classifications of the low protein foods, amino acid supplements and drugs such as Kuvan®. Low protein foods and amino acid supplements are classified as 'borderline substances' and as such are approved by the Advisory Committee on Borderline Substances (ACBS). Kuvan® is classed as a 'drug' and has passed through very stringent approval processes by regulatory authorities in various countries worldwide. In the UK, the use of trade stands to advertise/promote prescription only drugs is not permitted at patient conferences (often referred to as 'direct patient marketing') and pharmaceutical companies have to adhere to the ABPI (Association of British Pharmaceutical Industry) code of practice revised in 2008. Hence Merck Serono did not have a stand at the recent NSPKU meeting. This policy is similar for all medical conditions treated with approved drugs, although it is permissible for company representatives to register for and attend patient meetings. They are allowed to display information in the form of posters which must be factual, balanced and must not contain statements encouraging patients to ask health care professionals to prescribe specific drugs.

Obviously, the approval of Kuvan® is a relatively recent addition to the potential treatments for PKU and so the Society plan to develop a written policy for manufacturers of foods, amino acid supplements and drugs, observing the ABPI Code of Practice, so that everyone is clear about what is permissible at conferences in the future.

In the next issue of News and Views there will be an article about the current situation with Kuvan®. Our medical advisors are also meeting with relevant Government bodies at the end of May and drawing up guidelines for its use in individuals with PKU. Similar to all new drugs that have only been studied for a relatively short time, we should also be cautious and mindful of possible long term side effects that might emerge as more individuals are treated.

Finally I am pleased your son is doing so well and please be assured the NSPKU is working at promoting the use of recognised safe treatments for its members.

My Weekend at the Edale PKU Outward Bound Weekend

by Phoebe Wharton (Age 9)

FRIDAY

We arrived at the Centre in Edale at 2:30 and I was the second person there in my dormitory with Hannah (10), Nadia (10) and Madison 9.



We had a nice welcome from Eleanor who I know from the PKU conference and Ann who was the overall leader

When we got there we had to put our sheets on and unpack all our things and put things

in a drawer under the bed. There were bunk beds and I slept on the top.

At 3 o'clock there was an introduction in the lounge and they talked about how you weigh out your exchanges.

Then we played some games like Splat and a few others and this helped to get to know the names of all the other children and leaders.

There were 19 children altogether including boys (12 of them) and girls (7 of them) I think!

Once we had played games our first activity was to solve Word puzzles indoors because it was raining outside.



The instructors for the activities were Beth, Neil, Lis and Pete. Beth was my favourite one because she was very funny and gave us all nicknames (she called me Midget!)

Once it stopped raining we went outside in a van to another part of Edale where there was a big bridge which was as high as 4 of Beth on top of each other and we went down it on an abseiling rope.

Before that we had dinner and I had baked potato with carrots broccoli and some Fate sausages. I am on 3 exchanges - the same as Madison and Hayley - and we chatted about it was a bit hard to have low amount of exchanges.

In the evening we got back and went to the games room and stayed there playing ping pong and watching TV until late.

SATURDAY

On Saturday morning they woke us up at 7:20 by knocking on the door and coming into our room.

We are all a bit tired from the 1st day but we go up and got dressed and went to breakfast. I had 1 exchange of cornflakes (15g) and 2 pancakes with golden syrup cooked by the chef. They were free and were very yummy!

Our first activity was caving and we had to climb into a pitch black cave which got deeper and deeper whilst we walked through it. Each of us



had a big suit and big helmet with a torch on it. At one stage we turned all the lights off and it was pitch black in the cave for 10 minutes.

We came back for lunch which was pasta with tomato sauce and orange juice to drink and apple for pudding.



In the afternoon I did the high ropes and the 'Leap of Faith'. With the high ropes you were attached to a harness and you had to climb up a stack of black crates whilst other people were building it. I got up as high as 14 crates and when I fell off,

then it was Madison and Susan's go and Susan won it when she climbed 14 crates and stayed on for longest.

The Leap of Faith was my favourite. You had to climb up a pole with stumps on and there was a



small platform on top where you had to jump off it with a rope and harness on you. As you jumped you floated in the air like a feather!

After that we had a free play time and it was sunny and we played outside in the gardens of the centre with all the girls and boys.

For dinner I had chips and salad and water to drink. I had to weigh the chips and they were 45g for an exchange and I had 2 exchanges. There were pancakes again for pudding and I had 2 with golden syrup – they were my favourite!

In the evening we did problem solving – we were in our groups from the rooms and we had to find posters that had writing to take you to different rooms in the centre and the first group back won prizes.

Later on we had a pyjama party. Everyone brought their sweets and we went into one room and all chatted about how the weekend was going and other things.

SUNDAY

We were woken up again at 7:20 and after breakfast we went out in a van to go canoeing.

There was 3 people in a canoe and we went on a canal with 2 canoes tied together. We went under a bridge and there was a wide open water area where we played games like throwing a ball in each other's canoe, and throwing the balls and having to paddle and bring it back.



After the canoeing we got out, me, Nadia and Morgan and Hayley all jumped into the freezing water – it was great fun but then we had to sit in the van in our wet clothes till we got back!

We had lunch, then we all had to bring our bags to the lounge and store them until our parents came for us.

We said goodbye to everyone that was leaving early in the van and then I said good bye to Nadia, Hannah and Madison then I left with my dad who came to collect me.

Overall it was a FANTASTIC TIME AT THE OUTWARD BOUND WEEKEND!

Outward Bound Rocks!!!!

Phoebe,

What a fabulous report. I love it and it will be great for News and Views to encourage other children to go on the weekend.

I am so pleased you had such a good time and the pictures are amazing – especially the one on top of the crates.

Thank you very much for taking the time to send all of this to me. It was a delight to receive.

Eleanor



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enjoy!

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SHS 100 Wavertree Boulevard Liverpool L7 9PT tel: 0151 228 8161

Fun With Cup Cakes

These little cakes are very fashionable at the moment and Eileen Green from Fate Special Foods had an eye-catching display at the conference which was featured on the last front cover of News and Views. They are very easy to make using either Eileen's Cake Mix or SHS's Cake Mix. The cake mixes come in Vanilla, Lemon and Chocolate but the real fun starts with the fancy topping. Butter cream icing is quick to make as follows:

175g soft butter

350g sifted icing sugar

Beat these 2 ingredients together either using an electric hand whisk or a wooden spoon until it is all well blended. It is important to have the butter really soft.

For coffee flavour – add a teaspoon or 2 of coffee essence (Camp Chicory and coffee essence) or a heaped teaspoon of coffee granules dissolved in 1-2 teaspoons of hot water

For orange and lemon – add a little finely grated rind of the fruit – 1-2 teaspoons

Colours – use green for a mint colour, red for pink. You only need a few drops.

Decorate with grated low protein chocolate, jelly diamonds or slices, hundreds and thousands, sparkle spray etc.

There are so many really lovely decorations in the supermarket now. Betty Crocker icings are excellent – Buttercream Style Vanilla and Rich and Creamy Vanilla are completely free and the Buttercream Style Chocolate used over many cakes can also be counted freely.

I found that Morrisons do 3 flavours of buttercream frostings – Vanilla, Strawberry and Chocolate.

Protein contents were:

Vanilla 1.4g per 100g

Strawberry 1.4g per 100g

So 70 g = 1 exchange

Chocolate 2.4g per 100g

So 45 g = 1 exchange

I was attracted to the strawberry flavour as I hadn't seen this flavour before and it's a really good cup cake flavour and look. I think that 35g of vanilla or strawberry frosting would be right for 1 cup cake. So that would be ½ an exchange per cake.



The Morrisons chocolate frosting is not as good value as the Betty Crocker as the protein is higher. I would suggest 25g of chocolate frosting for 1 cup cake = ½ exchange per cake.

The Jelly Diamonds and Orange and Lemon slices are free and I found these particular ones in Morrisons and Tesco.

They all look wonderful on a 3 tiered cake stand and make a modern alternative to the big birthday cake. They are often used at weddings now – but we don't have to wait 'til then!



Delicious Crispy Battered Vegetables

There are so many vegetables around at the moment and sometimes it can be hard to think of something different to do with them. Anyone who has grown courgettes will know this – they just keep on coming. The following 2 recipes are really good for using with onion rings, small mushrooms, courgettes, cauliflower florets, red pepper strips, asparagus. Once you have dipped in batter you can also sprinkle a few breadcrumbs over them before frying, this give a nice texture. They can also be served with a squeeze of lemon juice.

This recipe was sent to me by John Cardy. It is very popular in his house so he is sharing it with us.

Batter mix for PKU Onion Rings

Ingredients

80g Loprofin Low Protein Flour
2tsp Egg Replacer
1tsp Baking powder
2tsp Sugar
½ tsp Season All (Swartz or supermarket own brand)
Chinese 5 spice if available. (small pinch only)

Method

1. Mix all together dry in container.
2. Add small amount of water and stir well to make a paste
3. Then add water slowly while stirring the mix until a smooth mixture is obtained which will only just run off of spoon.
4. Allow mixture to thicken for approx. 5 mins. Then add small amount of water to bring back to original thickness as above. (If it becomes too thin slowly add flour until correct)
5. Dip onion rings into mix until well covered.
6. Drop into hot oil. (approx. 170c)

Cook until golden and crisp turning the onion ring two or three times while they are cooking.



Eileen Green's recipe

Ingredients

150g Fate Low Protein All-Purpose Mix
1 tsp Baking Powder
1½ tsp suitable spice, such as Cajun spice mixture or paprika
½ tsp Salt
250ml Water
Pan of hot deep oil for frying

Method

1. Place the Fate All-Purpose Mix into a bowl. Stir in the baking powder, spices and salt. Add all the water and quickly mix with a large fork or metal spoon, until a smooth batter is made.
2. Take the prepared vegetables, a few at a time, and dip them into the batter so that they are thoroughly coated, then carefully place them into a pan of hot oil.
3. Leave to cook for 1-2 minutes until brown and crisp.
4. Drain well and serve with a suitable dipping sauce such as garlic mayonnaise

There have been a number of changes recently to the PKU foods available on prescription – some additions, but rather more deletions. I understand this has been due to lack of demand for some items (biscuits and pasta) and difficulty with quality control resulting in unreliable availability for others (Snack Pot: Tomato and Basil). I have also been told that the strength of the Euro has made it not economically viable to import certain ranges (Aproten and Harifen).

This is the list of the deletions and additions and following on is the full list including these changes.

ACBS Items June 2010

Discontinued

Nutricia Ltd (SHS)

Loprofin Orange Wafers
Loprofin Chocolate Chip Cookies
Loprofin Sweet Biscuits
Snack Pot Tomato and Basil

Gluten Free Foods Ltd

PK Foods Low Protein Pasta Spirals

Ultrapharm Ltd

All Ultrapharm items are deleted except
Ultra PKU Fresh Bread
Ultra PKU Fresh Pizza Base

Juvela

The Juvela company have taken their range back into their own control, but they are still being delivered via Homeward and will continue to be so if that is the method of receiving them.

Additions – New to list

FirstPlay Dietary Foods Ltd

Flat Noodles (pasta) 500g
Ready to Eat Low Protein Snax – 4 flavours (12x25g)-ready salted, salt and vinegar, Jalapeno and cheese and onion
Taranis Low Protein Apricot Cake
Taranis Low Protein Pear Cake

VitaFlo Ltd

ProZero Drink 250ml and 1 litre cartons

Dietary Information for the Treatment of PHENYLKETONURIA

Up-dated list of ACBS items

SEPTEMBER 2010

There are several deletions and additions to this list

SPECIAL LOW PROTEIN/PHENYLALANINE PRESCRIBABLE PRODUCTS ALLOWED FREELY

(except where indicated)

These foods can be used without counting in the diet (except where indicated); check that the name on the packet or tin exactly matches the name listed below and the brand specified. The items are as supplied and many need special preparation and additional ingredients added must be selected appropriately for your low phenylalanine diet. The pack weights and number of packs in a box have been included where supplied by the manufacturer.

BISCUITS

GLUTEN FREE FOODS LTD

PK Foods Aminex Low Protein Rusk 200g
PK Foods Aminex Low Protein Biscuits 200g
PK Foods Aminex Low Protein Cookies 150g
PK Foods Low Protein Crispbread 75g
PK Foods Low Protein Chocolate Chip Cookies 150g
PK Foods Low Protein Orange Cookies 150g
PK Foods Low Protein Cinnamon Cookies 150g

NUTRICIA LTD (SHS)

Loprofin Low Protein Vanilla Cream Wafers 100g
Loprofin Low Protein Chocolate Cream Wafers 100g
Loprofin Low Protein Crackers (savory) 150g
Loprofin Low Protein Herb Crackers 150g

JUVELA

Juvela Low Protein Cinnamon Cookies 125g
Juvela Low protein Orange Flavour Cookies 125g
Juvela Low Protein Chocolate Chip Cookies 110g

PASTA

NUTRICIA LTD (SHS)

Loprofin Low Protein Rice 500g
Loprofin Low Protein Pasta Spirals (Fusilli) 500g
Loprofin Low Protein Macaroni 250g
Loprofin Low Protein Penne 500g
Loprofin Low Protein Vermicelli 250g
Loprofin Low Protein Spaghetti 500g
Loprofin Low Protein Lasagne 250g
Loprofin Low Protein Tagliatelle 250g
Loprofin Low Protein Gnocchetti Sardi (small shells) 500g
Loprofin Low Protein Conchiglie (large Shells) 500g
Loprofin Low Protein Animal Pasta 500g

Loprofin Low Protein Snack Pot 47g – 8 pots/case
Flavours: Curry
Curry Snack Pot 1 pot = ½ exchange

FIRSTPLAY DIETARY FOODS LTD.

Promin Low Protein Pasta (seven shapes) – Macaroni
All in 500g pack

Short Cut Spaghetti
Shells
Spirals
Alphabets
Elbows
Flat Noodles

Promin Low protein Tricolor Pasta (four shapes) - Shells
All in 500g packs.

Spirals
Alphabets
Elbows

Promin Lasagne Sheets 200g pack

Promin Low Protein Pastameal – 500g
Promin Low Protein Couscous – 500g pack
Promin Low Protein Imitation Rice – 500g pack
*Promin Pasta in Sauce:
Tomato, Pepper and Herb) 4 sachets in a box
Cheese and Broccoli) 1 sachet = 1 exchange
Pasta in Sauce Moroccan Flavour – 1 sachet = ½ Exchange

Available from: FirstPlay Dietary Foods Ltd., 338, Turncroft Lane, Offerton, Stockport,
SK1 4BP Tel: 0161-474-7576

BREAD, FLOUR and MIXES**FATE SPECIAL FOODS**

Fate Low Protein All-Purpose Mix 500g
Fate Low Protein Cake Mix 2x 250g
Fate Low Protein Chocolate Flavour Cake Mix 2 x 250g
N.B. Fate low protein products can only be obtained directly from Fate Special Foods.
Please ask your chemist to telephone 01215-22-44-33 to arrange direct delivery to your chemist.

GENERAL DIETARY LTD

Ener-G Low Protein Rice Bread – sliced 600g

GLUTEN FREE FOODS LTD

PK Foods Low Protein White Sliced Bread 550g
PK Foods Low Protein Flour Mix 750g

NUTRICIA LTD (SHS)

Loprofin Low Protein Loaf – sliced and unsliced 400g
Loprofin Bread Low Protein White Rolls 4 rolls in a pack
Loprofin Low Protein Part-Baked Rolls 4 rolls in a pack
Loprofin Low Protein Mix 500g
Loprofin Low Protein Lemon Cake Mix 500g
Loprofin Low Protein Chocolate Cake Mix 500g

JUVELA

Juvela Low Protein Loaf unsliced 400g
Juvela Low Protein Bread Rolls 5 rolls in a pack
Juvela Low Protein Pizza Bases 2 x 180g

Juvela Low Protein Mix 500g

ULTRAPHARM LTD.

Ultra PKU Fresh Bread 400g
Ultra PKU Fresh Pizza Base 5 x 80g
(For this bread and pizza base your chemist needs to contact Ultrapharm directly to obtain these products. Not available through wholesalers. Telephone: 01491-570000)

BREAKFAST CEREALS**NUTRICIA LTD (SHS)**

Loprofin Low Protein Breakfast Cereal Loops 375g
Loprofin Flakes – Apple Flavour 375g
Loprofin Flakes – Chocolate Flavour 375g
Loprofin Flakes – Strawberry Flavour 375g

FIRSTPLAY LTD

Hot Breakfast – Original)
Apple and Cinnamon Flavour) 6 sachets
Chocolate Flavour) per box
Banana Flavour)

PUDDINGS AND DESSERTS**GLUTEN FREE FOODS LTD**

PK Foods Low Protein Orange Jelly Mix (4 x 80g) carton
PK Foods Low Protein Cherry Jelly Mix (4 x 80g) carton

FIRSTPLAY DIETARY FOODS LTD

Promin Low Protein Rice Pudding Mix – Flavours: Original, Apple, Banana, Strawberry – 4 sachets per box
Promin Low Protein Chocolate and Banana Dessert
Promin Low Protein Strawberry and Vanilla Dessert
Promin Low Protein Caramel Dessert
Promin Low Protein Custard Dessert

Taranis Low Protein Apricot Cake 6x40g bars
Taranis Low Protein Pear Cake 6x40g bars
Taranis Low Protein Lemon Cake 6x40g bars

NUTRICIA LTD (SHS)

Loprofin Dessert Mix Vanilla 500g
Loprofin Dessert Mix Strawberry 500g
Loprofin Dessert Mix Chocolate 500g

All above are free if made with Duocal or Calogen but if chocolate flavour is made with Loprofin milk or SnoPro count as ½ exchange per serve.

MISCELLANEOUS FOODS**FIRSTPLAY DIETARY FOODS LTD**

*Promin Low Protein Burger Mix Original Flavour (2 x 62g sachets)
*Promin Low Protein Burger Mix Lamb and Mint Flavour (2x62g sachets)
*Count as 1 sachet = 1 Exchange

Promin Low Protein Sausage Mix – Original, Tomato and Basil, Apple and Sage. All flavours 1 sachet = ½ Exchange

Promin Low Protein Snax 12x25g bags
4 Flavours: Ready Salted, Salt and Vinegar, Jalapeno and Cheese and Onion

Promin Low Protein Chocolate and Hazelnut Flavour Spread

FAT and FAT and CARBOHYDRATE PRODUCTS**NUTRICIA LTD (SHS)**

Calogen LCT Emulsion – Neutral, Banana, Strawberry 200mls and 500mls bottles.
Duocal – Liquid 250mls
Duocal –super soluble 400g can.

EGG REPLACERS

GENERAL DIETARY LTD

Ener-G Egg Replacer 454g

GLUTEN FREE FOODS LTD

PK Foods Low Protein Egg Replacer 350g

NUTRICIA LTD (SHS)

Loprofin Egg Replacer 2 x 250g

Loprofin Egg White Replacer 100g

MILUPA

*Milupa lpd 400g

250ml = half an exchange when made as instructions

NUTRICIA LTD (SHS)

*Loprofin PKU Long Life Milk Drink 200ml cartons

Contains approx. half an exchange per carton

*Sno-Pro Drink 200ml cartons

Contains half an exchange per carton.

VITAFLO LTD

ProZero Protein Free Drink 250ml and 1 litre cartons

PROTEIN FREE HIGH ENERGY BAR

NUTRICIA LTD (SHS)

Duobar available in Neutral, Toffee and Strawberry 8 x 45g bars

Loprofin Low Protein Crunch Bar 8 x 41g

VITAFLO INTERNATIONAL LTD

Vitabite 7 x 25g bars per box

LOW PROTEIN DRINKS

* These products contain some phenylalanine. Check with your dietitian how much of these drinks you can have.

LOW PROTEIN FOOD MANUFACTURERS' CONTACT NUMBERS

Useful if there is a query.

Fate Special Foods	01215-224433
General Dietary Ltd	0208-336-2323
Gluten Free Foods	0208-953-4444
NUTRICIA LTD (SHS)	01225-751-098
Ultraparm Ltd	0845-2701200
VitaFlo Ltd	0800-515174
Juvela	0151-432-5300 or
	Freephone 0800-7831992

The prescription of low protein foods in PKU

People with PKU can only eat a very limited diet. They are unable to eat many nutritious and staple foods: e.g. meat, fish, eggs, cheese, milk, nuts, ordinary bread, pasta and other cereal products. There are few normal foods they can eat in unlimited quantities and these mainly include free fruits and vegetables which have a low calorie density. Therefore, the diet requires supplementation with many low protein foods that are available on ACBS prescription.

This is for 3 important reasons:

1. Low protein foods provide an essential source of calories to support growth and prevent catabolism which may lead to metabolic instability in PKU.
2. Low protein foods provide bulk in the diet to prevent hunger and consequently people eating higher protein forbidden foods. The latter would also increase blood phenylalanine concentrations.
3. Low protein foods provide variety in a very limited diet.

None of the ACBS foods can be considered as luxury items. There are over 100 items available on prescription, and it is difficult to define how much to prescribe of each item.

In order to give some you some guidance on this, a table is included on page 2 indicating maximum numbers of units of low protein foods to prescribe for different age groups of patients. This has been calculated on energy requirements and in general, low protein special foods are expected to provide between 50% of estimated daily energy requirements in patients with PKU. Some patients eat a variety of different low protein items, but there are many who will eat only a small number of items and eat only low protein bread or crackers as their main energy source. It is therefore not unusual to find that a patient or carer request only flour or biscuits on prescription. Therefore, rather than specify that patients have a maximum quantity of each food item each month; a maximum number of food units per month for all low protein foods (*except milk replacements and glucose polymer supplements*) depending on the age of the patient is recommended, so that patients can have the necessary variety in their diets. The definition of a unit is given on the next page:

ACBS prescribeable foods	Definition of one unit
Pasta	1 box (500g)
Bread/bread rolls	1 packet
Flour mix/cake mix	1 packet (500g)
Breakfast cereals	1 packet
Pasta snack pots	4 snack pots
Ready to eat Pasta Snacks	12 x 25g
Pizza bases	2 pizza bases
Sausage/burger mixes	4 sachets
Biscuits	1 packet (150g)
Energy supplements e.g. Duobar, Vitabite	1 packet
Cakes	6 x 40g
Egg replacer	1 packet
Dessert mixes	6 sachets
Low protein spreads	1 tub

The table does not include milk replacements such as Calogen, Duocal, Loprofin drink, Prozero and Sno Pro or glucose polymer supplements. The amount prescribed will vary from patient to patient, so will be determined on an individual basis.

Table indicating recommended maximum number of units of low protein foods for each age group.

Age of patient with PKU	Recommended maximum number of low protein items to prescribe each month
4 months -3 years	15 units
4-6 years	25 units
7-10 years	30 units
11-18 years	50 units
Adults	50 units
Pre-pregnancy/Pregnancy	50 units

NB: this excludes low protein milk replacements: Calogen, Duocal, Loprofin drink, Prozero and Sno Pro. It also does not include protein substitutes e.g. PKU Lophlex LQ, PKU Anamix Junior, PKU Gel or glucose polymer supplements.

NSPKU Conference and Holiday Weekend 2011

will be in Liverpool from Friday 18th to Sunday 20th March

The Britannia Adelphi Hotel is our venue for the NSPKU Conference and Holiday Weekend. This is a beautiful historic hotel in the centre of Liverpool, 5 minutes walk from the station and easy access from John Lennon Airport.

The costs below include VAT and are for full board from Friday evening to the Sunday lunchtime including all meals, tea/coffee at break times and conference talks and trips out for the children and young people.

£210 adults, those with PKU half price

£105 children aged 5-15, those with PKU are free

£ 50 children aged 0-4, those with PKU are free

Full details and booking form will be in the next edition and will be posted on the NSPKU website, meanwhile, the hotel website is <http://www.britanniahotels.com/hotels/liverpool>

All PKFoods are now available on prescription



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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 dietitian 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

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&



Homecare

...because life is complicated enough!

*Holiday destinations within the UK. Homecare is not available in Northern Ireland or the Republic of Ireland