

NSPKU News & Views

Winter 2009

The National Society for Phenylketonuria (UK) Ltd

Issue 129

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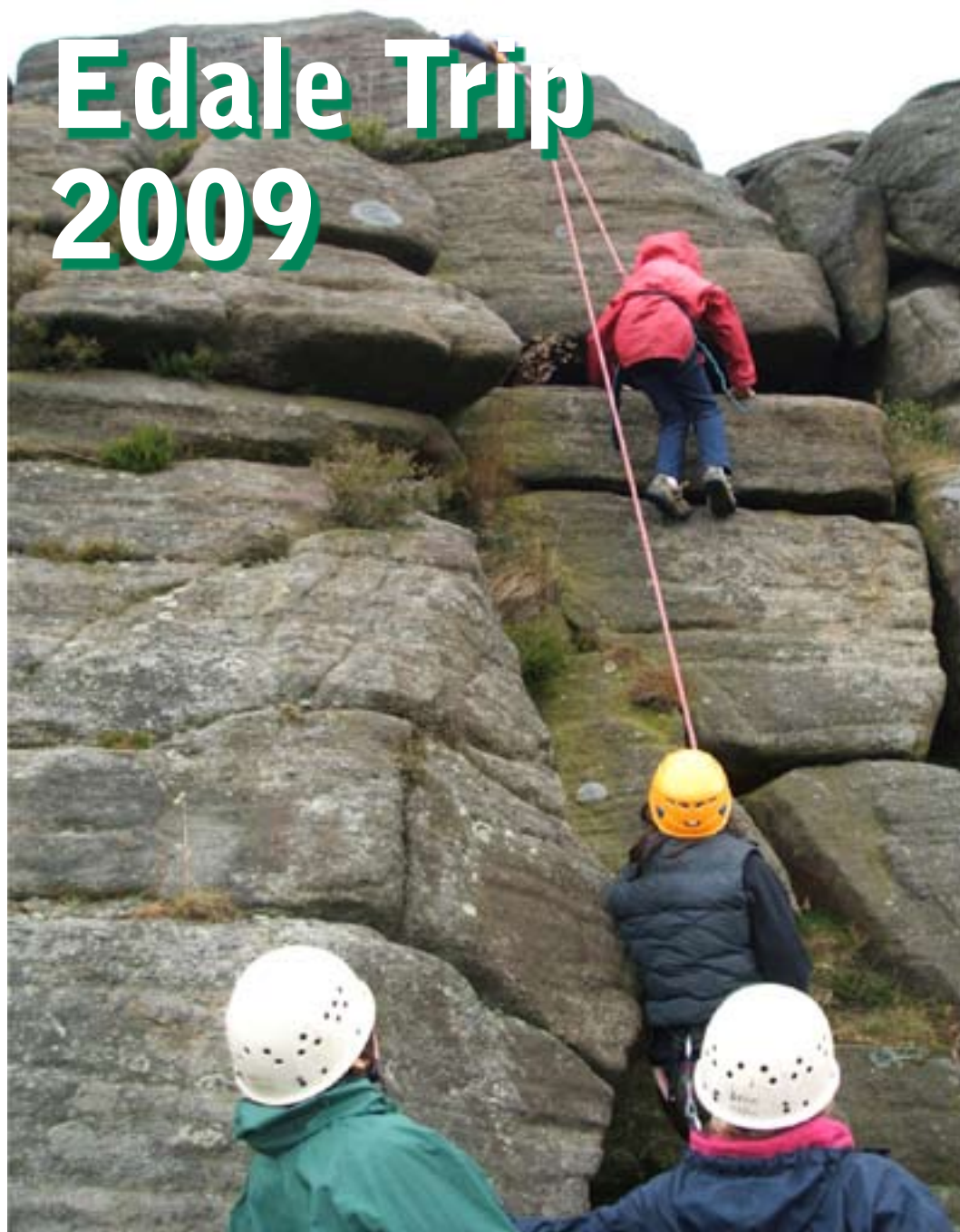
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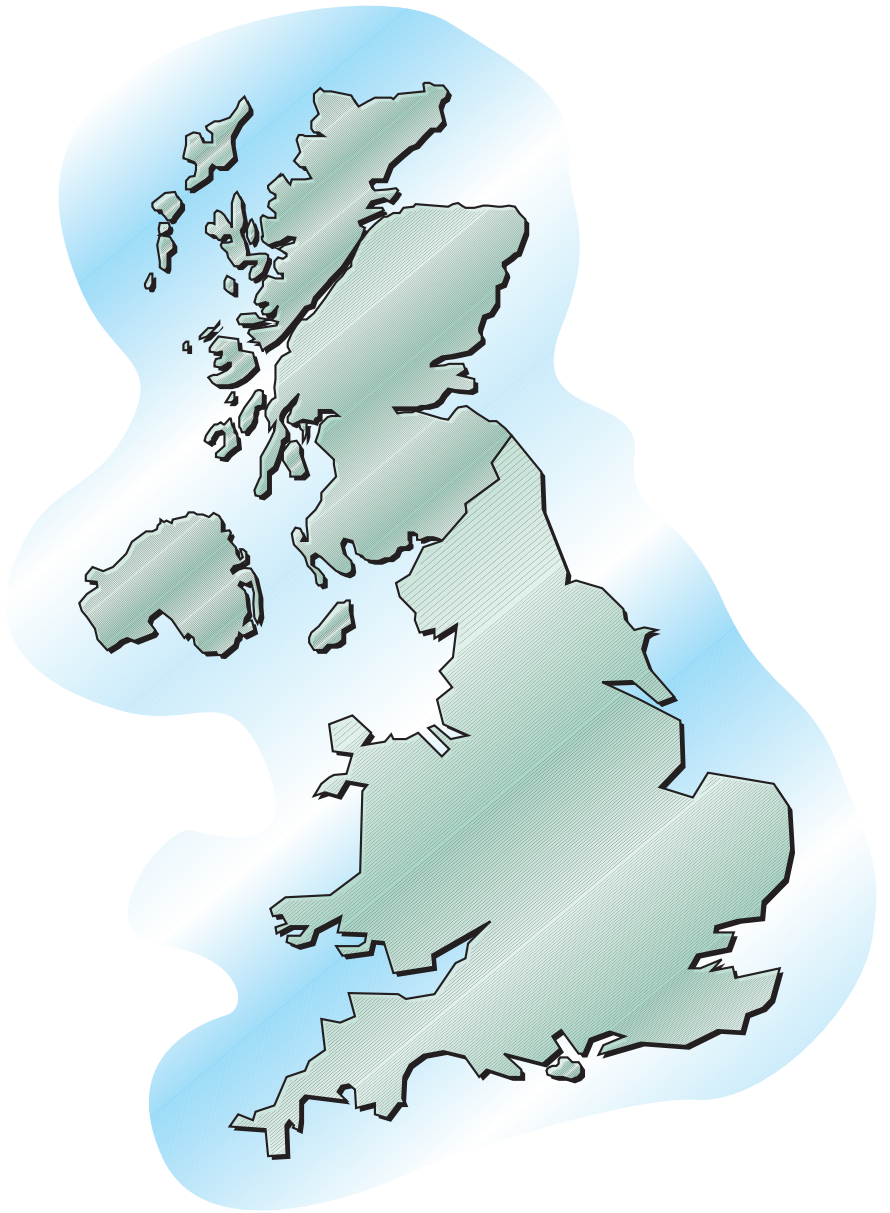
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Editor's Report...

Dear Readers,

We have had an excellent response to the travel articles from the last issue. Readers have written to us with their experiences and I am pleased to say we have even more tips for you in this magazine – a huge thank you to everyone who has sent in their ideas.

With Christmas just around the corner, I thought it might be fun to have a Christmas dinner section. I asked all of our Low Protein suppliers to submit their recipes for the perfect dinner. Three of them took up the challenge – they look amazing so read on and enjoy!!

Anne Verster,
Editor



The National Society for Phenylketonuria (United Kingdom) Limited

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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 Margaret Maksym and I have a son (James), of 14 years who has PKU. James has been in the RAF Cadets for the last 2 years and he thoroughly enjoys it. Can you see where this letter is going? His father and I have always made it quite clear that he will not be able to join the RAF because of his PKU but he lives in hope. We have discussed this with the doctors at the Willink in Manchester and they too have explained this to him.

If my memory serves me correct, I can remember in a past edition of News and Views of another boy who had this same wish of joining the RAF and was refused because of him being PKU. Do you have anymore information about this boy on how he got on ie. did he managed to join or find another route to fulfill his dream?

James is a lovely boy who tries to tackle anything sent his way. He and we do not let him being PKU stand in his way but this is the first problem that we have come across and as yet have not been able to solve.

Hope you can help.

Keep up the good work.

Yours sincerely
Margaret Maksym

Response: We are currently trying to establish the services stance on the issue of acceptance by the armed forces for those with PKU. We have been told of another young man who went through all the selection tests successfully only to be told at the final decision he could not be admitted because he needed a special diet. Another case has been brought to light of a young woman who is applying to be a fitness trainer, and she is being told that the army will not be able to cater for her diet. If anyone with PKU cannot be admitted to the armed forces then this should be included in the services list of conditions which make entry impossible. It could be that a case could be made for admission except on the front line.

It is proving difficult to get an answer from the forces but we are pressing on with this in the hope that we have a definitive answer soon.

Eleanor Weetch
Dietitian Advisor



Dear News and Views,

Please find attached a photo of my daughter Carys Hopkins (pku) aged 10 and her cousin Martyn Lappin (non pku) aged 12 after completing the above race! They managed to raise a total of £244 between them and have decided to split it between the NSPKU and IMD Scotland based at Yorkhill Hospital.

Both ran really good times with Martyn coming in at 17mins 26 seconds and Carys at 17mins 32 seconds! Carys was delighted Martyn did the race with her and she hoping she can get some more of her cousins & friends to run next year! Watch this space!

Regards,
Mrs Hopkins

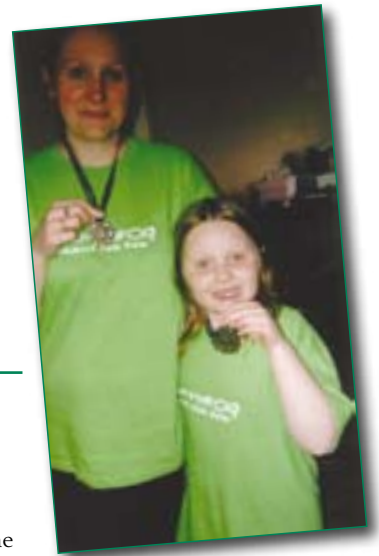




Dear News and Views,

Please find enclosed a cheque for £94. My daughter Effie (7) has PKU. She decided she would like to take part in the Bath half marathon family fun run and ran 1.5 miles to raise money for the NSPKU. Effie was very proud of her success. Both Effie and her sister Lola (3) who also has PKU have enjoyed the PKU events and conferences and Effie was determined to do her bit to help.

Many Thanks
Kath Senior



Dear News and Views,

Please find enclosed a cheque for £250 which was the sum collected after the death of my mom, Teresa Cooking, in lieu of flowers. Mom was very much involved with the baking of biscuits, bread and pizzas for my son Mark and without her support it would have been so much harder. She attended some of the national conferences and in Mark's early years, all the B'ham Childrens Hospital meetings and parties.

Yours sincerely,
Philiamena Farley



Dear News and Views,

Please find enclosed cheques from donations made at the funeral of my mother Hazel Robinson, who died 06/07/09.

Hazel was great grandmother to Joel Stephenson, aged 5, who has PKU. She was always interested to learn about PKU and very proud of my daughter for the way she deals with the very strict diet.

My brother and sister agreed we should have the donations paid to the NSPKU as it was very dear to Hazel's heart.

Keep up the good work

Yours Sincerely
Gill Stephenson (Joels Nannie)



Dear News and Views,

I enclose a cheque for £3900 which is the remaining balance collected as a result of the Arwyn's Offa's dyke walk.

The photo is of Arwyn arriving at his destination after his 13 day trek.

Yours Sincerely,
Jean Davis



Some sad news...

Dr John B. Holton has died, aged 77. John was a founder member of the BIMDG and is best known for his interest in galactosaemia. Prior to retirement he was Top Grade Biochemist at Southmead Hospital, Bristol. He was known to the NSPKU for his writing of the original publication of The Child with PKU.

A service of thanksgiving was held at St Mary's Church, Henbury on Monday 16 November. He is survived by his wife, Ruth and their four children.

Our sympathies go to his family at this difficult time.

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NSPKU trip to Edale 2009





From the Dietitians' point of view

Not only is the Edale weekend a fantastic opportunity to spend time with the children in doing lots of exciting activities it is a good learning opportunity for both the children and the dietitians. As a dietitian and dietetic technician we were able to spend valuable time with the children in our group, building better relationships in a less formal setting. The children responded well to this environment and felt they could be more open about their PKU diet.

It was a pleasure to see the children from Nottingham having their meals and supplements with other PKU children and been able to have the confidence that they were able to eat suitable meals outside of their own houses. For some children it was an opportunity to try new foods and amino acid supplements. The children were able to discuss their diets with the other children at the camp and learn from each other. It was a joy to hear their conversations relating to their diets and to hear their positive attitudes.

We would certainly recommend this weekend for any children of this age group and for their dietitians, we returned the children on the Sunday afternoon to their parents exhausted but delighted that the children had a very enjoyable weekend.

Lindsey Regan

Interview with Susan Nottingham

Did you enjoy the 2009 NSPKU trip to Edale?

Yes I really enjoyed the trip, I had a lot of fun, learnt lots and met some nice friends.

What was your favourite part of the weekend?

I really liked the fun team games, where we had to race the other team to put on lots of different clothes & hats.

Was it nice to meet other children with PKU?

It was great, it was really nice to meet others with PKU and learn from them.

Did you learn anything about the PKU diet?

I especially liked it when we had time in our rooms and all the girls played a game where we all told each other what exchanges we were on and what protein substitute we take- it was fun to learn about others PKU. I also learnt a lot from meal times weighing out foods.

What was the food like?

It was great, the low protein lasagne was my favourite.

Comments about Edale?

I enjoyed it, met friends, liked all the food and all the activities

Snap shot statements about the weekend?

"I really did enjoy it"

Interview with Nadia

Nadia is on 4 exchanges and it was her first visit to Edale.

Did you like the rooms at Edale?

Yes. They were really nice. We were all talking after lights out and we were the last to get to sleep. I soon made friends with the others.

What was your favourite food at Edale?

I liked the food and my favourite thing was Walker's crisps because I don't get them at home!

From Nadia: Thank you for organising the PKU trip. My favourite activity was the rock climbing outside on real rock!

From Nadia's mother: "Thank you for giving the kids this great opportunity. Nadia had a ball and is keen to come back next year, subject to places! I thanked the Cardiff dietitian but not the others who helped – not sure who they are but please thank them for me. Nadia really enjoyed meeting others with PKU and it was good for her."

Feedback from the children

"They really looked after us"

"Don't worry about the food its awesome, there is lots to choose from" William

Because they really do taste as good as they look...



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Fate Special Foods recipes



*Hello,
I thought of this recipe after the last edition of News and Views when Eleanor, in her Dietitian's report, wrote about Betty Crocker cake icings. The one I was interested in most was the Betty Crocker, ready to spread icing, Buttercream Style, Chocolate. It has just 0.46g protein per 100g which allows you 200g for one exchange. It's well worth trying. It really does have a rich flavour, and can be used as a topping for all kinds of low protein cakes.*

Then, I found it could be used as an ingredient ~ I experimented with it in cooking, and found it made the most delicious chocolate muffins, so rich and crumbly. Thank you Eleanor!

FATE CHOCOLATE MUFFINS

Method

Preheat oven Gas 4. 180°C 350°F

Place the Fate Chocolate Cake mix into a bowl. Stir in the Fate All-Purpose mix.

Add the margarine, and the buttercream style icing. Add the water, and using a wire whisk, mix quickly for about 1 min.

Divide between 12 large paper muffin cases set inside a muffin tin.

Bake in a preheated oven for around 20 mins until risen and firm.

Cool on a wire rack. The muffins freeze well.

*Note:

In this recipe, I use ready to spread icing, made by Betty Crocker, it's the one that is buttercream style, and chocolate flavoured. It gives the muffins a lovely rich flavour and colour. It is available in all large supermarkets.

The amount of protein in the icing is 0.46g per 100g, so it is counted as 200g for 1 exchange.

In this recipe I use 200g of the icing, which is 1 exchange.

The whole recipe makes 12 large muffins, so as long as you eat them in normal amounts, you would not have to count them in your diet.



Do not confuse Betty Crocker Rich and creamy chocolate Fudge with the one to use in this recipe. The packs look very similar. The Fudge type is 2.2g protein per 100g, so you only get only 45g per exchange.



Ingredients

350g Fate Chocolate flavour Cake Mix

80g Fate All-Purpose Mix

90g soft margarine

*200g Betty Crocker ready to spread icing, buttercream style, chocolate

260mls water



Cooking on a Bus!



It looks like a lorry and inside it is like a Tardis! The Cooking Bus came to the Scottish Exhibition Centre, Glasgow in June.

The Dietetic Department and Hospital Education Service of the Royal Hospital for Sick Children, Glasgow, organised the visit by the bus. Groups of young people who attend various clinics e.g PKU and Diabetes, were treated to a session on board.

Helen, the cooking advisor welcomed us aboard to learn about where food comes from, how to hold and chop with a sharp knife. We also had a very special visitor who was attending a Health Service conference at the SECC, Shona Robertson who is the Scottish Public Health minister.

The Scottish Food Standards Agency Cooking Bus has been developed in partnership with Focus on Food Campaign to get across healthy eating and food safety messages to school children in a fun way and it travels all over Scotland and is free to the groups it visits. There are also similar buses in England.

Usually the bus visits schools and community groups and this is the first time a dietetic department in a hospital has been involved, so it was exciting to be on board and hope that it is not the last time it will visit.

Our group of young people who have to follow a low protein diet, had a pure dead brilliant time making smoothies, honey vegetable kebabs and fruit kebabs which were taken home for tea. Most of the children attending the sessions then went back to school to tell the class all about it and hope that their school might ask for a visit in the future.

You can find out more about the cooking bus on: www.focusonfood.org

Barbara Cochrane
Dietitian, Royal Hospital for Sick Children, Glasgow



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PKU and Travelling Abroad

Hi! My name is Julie and I'm married to David and we have 2 sons, Andrew aged 12 and Christopher, 6 who has PKU. I've been a cabin crew member for the last 20 years and can hopefully give you some travel tips if you're planning a flight abroad, particularly if it's your first time. I've met quite a few families that have children with PKU and have decided not to fly abroad due to the worry and planning involved. It does take some thought and definitely some organisation but the rewards are fantastic.

Prior to Christopher being born, we were fortunate enough (due to travel discounts!) to be able to visit many different countries on holiday. However, after Christopher arrived, we had to have a total re-think. All of a sudden, we couldn't just down tools and go off whenever we fancied it. We had to get organised!



Our first point of call was the NSPKU website. They have a fantastic publication regarding travelling abroad and I always use this every time we go away as a check-list as invariably there's something we've forgotten.

Initially, contact your GP/Consultant and ask them to compose a letter outlining PKU and the need to travel with special foodstuffs. I think our letter cost about £25 but when you have it, it'll stand you in

due course for future travel. I have kept mine from when Christopher was a baby and took several copies. It always helps ease the way through airport security!

A good while before your travel date, ensure you have all the food you'll need ordered off prescription for the length of your trip plus some extra in case of unforeseen delays etc.

Unfortunately, airlines do occasionally lose bags so I'd strongly advise that you split your PKU food between your cases. At least if your bag has gone walkabout, you'll have back-up supplies to rely on until your case turns up. In my hand luggage, I always carry at least a 4 day supply of Christopher's protein substitute plus a pack of FATE all purpose mix.

As a general rule, dry food (including pre-prepared rolls/sandwiches) are fine to take through security. It's liquids that are the sticking point, however you can always purchase bottled water airside to make up substitute.

I also carry my trusted scales, a calculator, plus a small container for making up substitute. (the small tupperware 'click' pots that most supermarkets now sell are great for this as they don't leak).

For my hold bags, I decant vegetable/sunflower oil into a couple of baby's bottles rather than carry a large bottle, as this both keeps the weight down and can also be doubled up for measuring out when making bread etc. We've tried taking the pre-made prescription bread with us but because it's vacuum-packed, it doesn't travel well at altitude and we found the whole loaf had disintegrated on arrival!

I also now take a hand whisk and a baking sheet for proving bread rolls. It sounds a little bizarre, but we were on a self-catering holiday last year and just presumed there would be a hand whisk amongst the kitchen utensils. We were wrong! And there was no baking sheet either. A run round half of the Costa del Sol ensued trying to find a shop that sold kitchenware!

If you're travelling with a baby with PKU, you are permitted to take your pre made up baby formula through security. This is the only exception to the rule that is normally restricted to 100mls of liquid per container. Take as much as you'll need for your journey length. Do be prepared to taste it at security as this is a BAA requirement.

If you're travelling on a longhaul flight, I'd suggest making up 2-3 bottles of formula and take

additional empty bottles as you require, which you can then have filled with hot water at one of the food outlets airside. By the time you'll need them, the water will have cooled sufficiently to make up your formula on board.

The main problem on board for a person with PKU is the lack of choice of food! I've checked with several major airlines and none now seem to offer a PKU meal. Some offer a low protein meal but these sometimes contain meat! Some offer a 'medical meal' and you'll need to contact your airline in plenty of time (minimum 48 hours) and stipulate your requirements but unfortunately there's no guarantee that they'll be able to provide it.

I had a chat to the catering company that supplies the airline that I work for and asked if they had any suggestions! We came up with a few possible choices. It's possible to order a fruit-plate meal but it's not very filling for a long journey. An alternative is to order a vegan meal which are dairy/meat free. Many of them will be served with rice though, so I always have my scales to hand to weigh out an exchange of the rice (approx 45g). It's a bit fiddly

doing this sitting in an airline seat so don't be afraid to ask the cabin crew if you can use the galley area to weigh out items.

In the past, I've taken with me a couple of slices of bread and some Cheesley (available in most large supermarkets) and made cheese on toast in the oven! Please do ask the crew for their help, that's what we're there for. Also, you could take with you Promin Pasta in sauce pots as they only need hot water adding. I always take a packed meal for Christopher along with plenty of snacks, crispbreads and also Duocal liquid measured up to 100mls to have with cereal.

I hope this is of some help to anyone planning a flight abroad. To date, Christopher has been to Spain, Thailand, Jamaica and South Africa. Not bad for a 6 year old!

Have a great holiday!

Dietitians' note:

Hospital dietitians and consultants would not normally charge for a letter for customs.

Top Tip for travelling with PKU children

RYANAIR come out tops!

We travelled to Sardinia in July with Ryanair. We were allowed to take our son Stan's low protein products as extra baggage, in the hold and were not charged for this.

On Ryanair's website, click on "FAQs", then click on "contact for disability requirements". You will have to make a couple of phonecalls, but they were very helpful. We had to send them a copy of a letter from our hospital confirming that Stan has PKU and a rough idea of what we would be carrying. We also had to let them know the weight of the suitcase.

Well done Ryanair.

Thank you for the article about Clare travelling to South Africa. It's great to know that PKU is no barrier to leading a full and independent life.

Frances Brook

A Top Tip From Sara Bartlett

Just to let you know we have just bought insurance that covers PKU for the first time in years. The company even had details of the condition on their system when we phoned up - we didn't even have to call a special medical screening company. They did ask if she has any behavioural problems, mental retardation or eczema as a result of the condition. I thought the behavioural one was interesting. Would they not have covered her if I said she throws wobbles and has a very bad temper?

Go Travel and its sister company, E Travel insurance 0844 482 0880.

Off to Cape Town for 10 days. We hope to see lots of whales and penguins and visit lots of vineyards.

Sara

All PKFoods are now available on prescription



Chocolate Chip Cookies, Cinnamon Cookies, Orange Cookies, Pasta Specials, White Sliced Bread, Crispbread, Egg Replacer, Flour Mix, Egg Biscuits, Cherry Jelly Mix, Orange Jelly Mix, amine Cookies, amine Biscuits, amine Rusks

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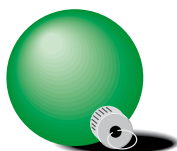
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NSPKU 37th Annual Family Weekend & Conference 2010

The Rendezvous Hotel Skipton

Friday 5th March to Sunday 7th March 2010

Venue:

This year's NSPKU annual family conference and holiday weekend returns to Rendezvous Hotel in Skipton North Yorkshire. This hotel has proved popular with regular attendees and provides us with a delightful location to hold our event.

Escape from the pressures of city life to the picturesque North Yorkshire Dales and Herriot country and enjoy the facilities of one of the most versatile hotels in the area. Stunning views of the Yorkshire Dales from the peaceful waterside setting and lots of real Yorkshire warmth. The Dales offer some of the finest scenery in England; wild, tranquil, timeless landscapes dotted with grand castles, bustling market towns and beautiful gardens. If you simply want to find a quiet country walk it is all here!

The Rendezvous Hotel, Skipton is very accessible from all parts of the country.

Accommodation:

There is a great choice of bedrooms, from executive suites and family rooms to luxurious rooms for two, all offering you what you would expect from a top hotel. Comfortable, spacious bedrooms all with private bathroom, direct dial telephone, TV, hairdryer, trouser press, hospitality tray and individual controlled heating. Add all the hotel's business facilities and function rooms, and you will wonder why you had not enjoyed all the benefits of the Rendezvous Hotel before.

Supervision of Children:

Whilst the children will be supervised in the crèche, the kids' club and outings, it is not possible for the Society or hotel staff to supervise or be in any way responsible for the children at other times or places. It is the responsibility of parents to supervise their children.

Facilities:

80 en-suite bedrooms, training centre, 7 meeting rooms, The Papa Swan Bar, The Baby Swan Restaurant, 120 car parking spaces, indoor swimming pool, children's pool, whirlpool spa, steam room & sauna, solarium, gymnasium. (please note that due to the limited number of bedrooms available, a number of overspill hotels very close by to the Rendezvous Hotel, Skipton will be used to accommodate our guests. In order to maximise your chances of staying in the Rendezvous Hotel, Skipton, early booking is recommended. Guests who stay in other local hotels will conference and take luncheon & dinner in the Rendezvous Hotel, Skipton).

PKU Diet:

You will need to bring your own protein substitutes, vitamins and minerals. The diet will otherwise be catered for. A limited number of baby foods will be available. If however, your infant prefers certain foods we would ask you to bring these along with you. The PKU diet will be catered for from Friday evening to Sunday lunchtime inclusively. It will not be available for any additional nights.



The National Society for Phenylketonuria (United Kingdom) Limited



Location:

Air: Leeds/Bradford airport – 30 minutes.
Manchester airport – 1 hour 15 minutes.

Rail: Skipton station – 1 1/2 miles.

Road: The hotel is situated on the A629 Skipton to Keighley road 1 mile south of Skipton town centre.

Assisted Places:

There is restricted funding available for those who require financial assistance with conference fees. Please enquire in the first instance to the conference organiser who will help you with your enquiry. All applications will be dealt with in the strictest confidence.

Family Weekend / Conference Fees:

Non-PKU Adult (18 years & over)	£180.00
PKU Adult (18 years & over)	£90.00
Non PKU Child (11 - 17)	£90.00
Non PKU Child (4 - 10)	£45.00
PKU Child (4 - 17)	Free
All under 4's	Free

Day Visitor Fees:

Non PKU Adults (18 years & over)	£35.00
PKU Adults (18 years & over)	£17.50
Children (0-17 years)	£10.00

Additional Nights:

If you wish to stay an extra night before or after the conference, please contact the hotel & book direct. We have negotiated a special rate of £30.00 per adult (£15.00 per child under the age of 12 years) with a £15.00 single occupancy supplement. This rate is for Thursday or Sunday night.



Christmas Dinners

FATE LEEK AND SWEET POTATO SOUP

This soup is light but full of flavour, perfect as a starter. The recipe makes just over 3 litres of soup, so there's plenty for a large family, or for freezing. Try to get the red skinned, white fleshed sweet potato, as these have a firmer texture. You will usually find them in markets and asian grocers, although they are sometimes found in the major supermarkets.

There are a couple of very good suitable brands of vegetable stock cubes, but if you prefer, you can make your own vegetable stock to use in the soup. Serve the soup with fresh warm Fate bread or star croutons ~ they really look good especially at Christmas.



Method

Place a large pan onto a high heat, and add the oil and butter. When hot and melted, add the onion and leek. Cook for about 10 – 15 mins until soft and slightly browned. Add the sweet potato and stock cubes and the water. (There is no need to dissolve the cubes in water beforehand, they will dissolve in the soup as it cooks.



Season with salt and pepper, grated nutmeg and stir in the bay leaves.

Put a lid on the pan and bring to the boil, then turn the heat down and simmer for about 20-25 mins until the vegetables are cooked.

Leave to cool a little. Discard the bay leaves, and then either place into a liquidiser until smooth, or use an electric hand blender to blend until smooth. Place back into the pan and simmer until really hot again.



Place into warm soup bowls, and add thinly sliced spring onion and a sprinkling of chopped parsley.

Serve with warm Fate bread, or Fate star croutons.

Ingredients

- 1 tbsp butter
- 2 tbsp oil
- 250g onion, roughly chopped
- 750g leek, roughly chopped
- 1kg sweet potatoes, roughly chopped
- 2 litres water
- 4 suitable vegetable stock cubes
- salt and pepper to season
- ¼ tsp grated nutmeg
- 4 bay leaves
- For a garnish:
- Sliced spring onion
- Chopped fresh parsley

FATE SAGE AND ONION PARSNIP BAKE with CHESTNUTS

*This recipe has all the savoury flavours of winter, so its perfect for Christmas dinner.
Served with suitable vegetables and the family gravy, who needs Turkey?*



Method

Pre-heat the oven Gas 5. 190°C. 375°F.

Use a sharp knife to cut the chestnuts into small rough pieces. Place a frying pan over a medium heat and add the chestnuts. Do not add any oil. Cook for about 10-15 mins until quite dry and crunchy. They will darken in colour, but they shouldn't burn. Leave to cool.



Place the Fate All-Purpose Mix into a mixing bowl. Stir in the salt and season with pepper. Rub in the butter or margarine until the mixture resembles fine breadcrumbs. Stir in the baking powder.

Add the grated parsnips (when grating the parsnips, discard the hard core that is sometimes down through the middle of larger parsnips, as this tends to be very tough)



Add the finely chopped onion, oregano and sage. Stir well.

Measure the water and pour into the mixture. Stir well until blended together well.

Grease a baking dish or round cake tin about 8or 9inches (20cms) in diameter.



Spread the mixture to the edge of the tin, but do not smooth the top, leave it rough.

Spoon on the chestnuts onto the top and press down lightly so that they stay in place.

Bake in a pre-heated oven for 30-40 mins. It should be slightly risen and firm. A metal skewer pushed into the centre should come out clean when cooked through.



Leave in the tin for 5 mins before turning out. (cover the top with kitchen paper when you turn it out to catch any loose chestnut pieces)

Serve hot with family gravy and suitable vegetables.

The bake can be frozen. It's a good idea to cut it into portions and wrap individually before placing in the freezer.

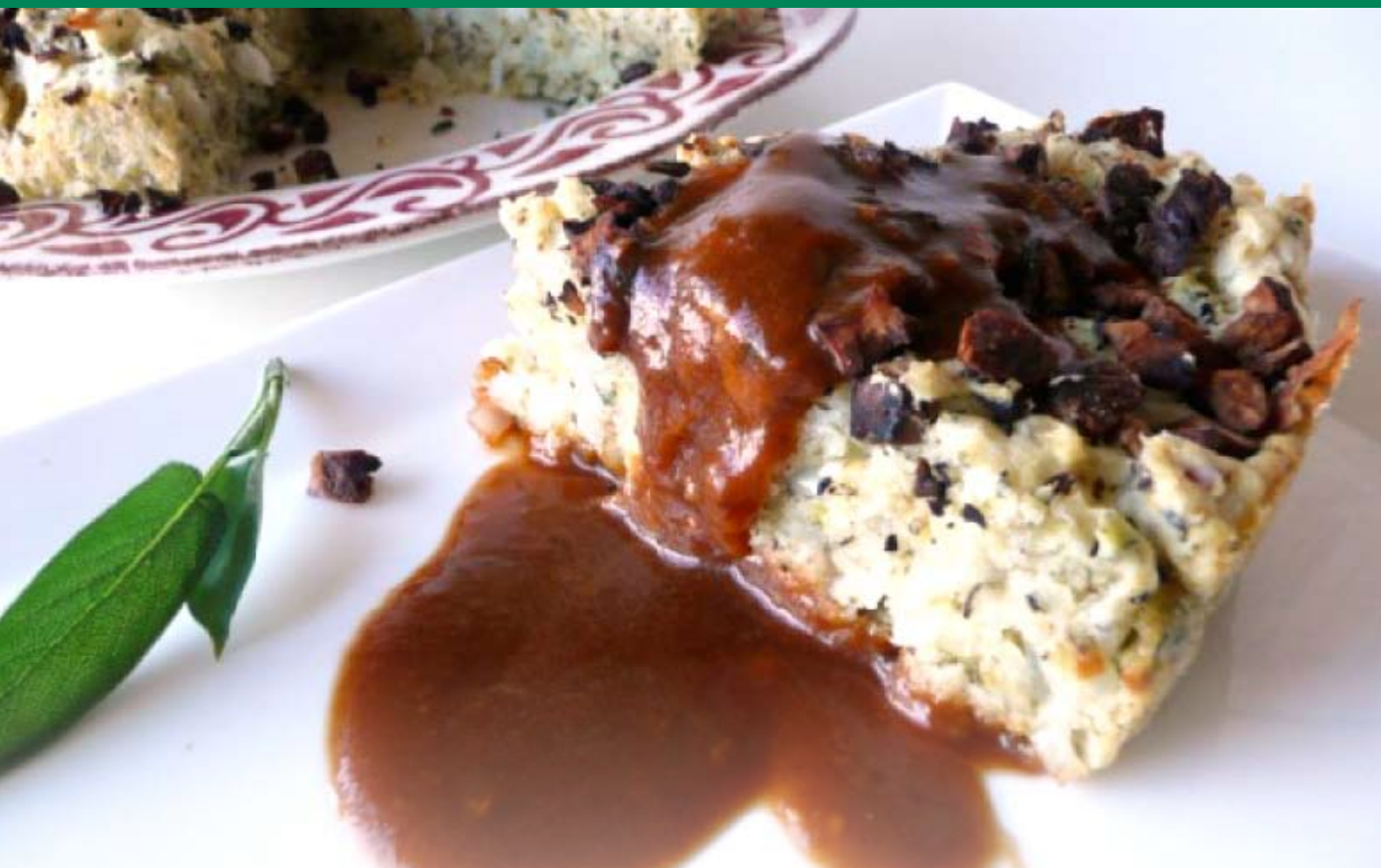
Ingredients

- 100g chestnuts
- 300g Fate Low Protein All-purpose Mix
- 1 tsp salt
- Pepper to season
- 150g butter or block margarine
- 1 tsp baking powder
- 100g parsnips, grated
- 200g onion, finely chopped
- 3 tsp dried oregano
- 3 tsp dried sage, or 6tsp fresh, chopped
- 180mls water



A note about the chestnuts:

I used the 'Merchant Gourmet' vacuum packed ones available in large supermarkets. They are allowed freely in moderation, if you are unsure, please ask your dietitian. I used 100g for the whole recipe, which is enough to give the dish a good flavour and a crunch topping.



Instead of cooking the sage & onion bake in a cake tin, you could just spoon the mixture onto a greased baking tray, aiming for something like 20cms x 12cms (8ins x 5ins) and press the chestnuts on the top. Bake Gas 5 190°C. 375°F for 30-40 mins until firm and a metal skewer pushed into the middle comes out clean.

Leave to cool for about 10 mins before slicing.

FATE YULE LOG ~ 2

In this recipe I use Betty Crocker ready to spread icing, buttercream style, Chocolate. You get 200g for 1 exchange which is more than you will need to decorate the Yule log. (I think about 150g is about right) Measured and used in this way, it is freely allowed.

The Yule Log doesn't take long at all to make and decorate, but if you prefer, you can make it in advance, and store it in the freezer until you need it. The Yule log will keep well in a cool place for a few days. A perfect cut and come again cake during Christmas.

Method

Pre-heat the oven, Gas 5/190°C/375°F

First make the cake:



Place the Fate Chocolate flavour Cake Mix into a mixing bowl. Add the margarine and the water. Mix well for 1 minute and pour it into a greased and lined Swiss Roll tin measuring 32mm x 22 cms. Bake for 12 - 15 mins until risen and firm. Take out of the oven, and immediately turn it out onto a piece of greaseproof paper. The paper that was used to line the tin will probably still be on the cake, so remove it and throw it away.

Spread the cake with jam, and whilst the cake is still hot, gently roll it up, starting at the longest side, using the greaseproof paper to help you. Roll it up quite tightly and place it on a wire rack or plate to cool.

Next, put the Yule Log together:



Measure 150g (3/4 exchange) of the Betty Crocker buttercream style icing. Trim both ends of the cooled Swiss roll to neaten. About 6 cms from the end of the cake, cut a piece off at a sharp angle and place it on the side of the main piece of cake. Use a little buttercream to stick it in place. This represents a small branch on the side of the log.

Carefully place the cake onto a pretty plate or Christmas cake board.

Gently spread the rest of the Betty Crocker buttercream style icing over the whole of the cake to cover. Then use a fork to mark the surface to look like wood bark.

Decorate the top with suitable decorations, ie, festive jelly lollipops, sprigs of holly, Merry Christmas motto etc.

Then use a sieve to sprinkle a little icing sugar over the log.



Note: Ask your dietitian if you are unsure about using the Chocolate buttercream in your diet.



Ingredients

250g Fate Low Protein
Chocolate flavour cake mix.
65g soft margarine
125 mls water
2-3 tbsp jam, preferably
raspberry
150g Betty Cocker ready to
spread icing, buttercream style,
Chocolate at room temperature.
Little icing sugar to sprinkle



STUFFED PASTA ROLLS WITH A GINGERED WINE SAUCE

Method

Preparation: Preheat oven to 400° F

Using a potato peeler pare 8 slices, lengthways, from the zucchini (courgette). Repeat the process with the carrot (do not use the first two slices as they will be narrow.) Reserve the 8 slices of the zucchini (courgette) and carrot.

Finely chop the onion or leek with the remaining zucchini (courgette) and carrot.

Heat the oil in a saucepan. Add the chopped vegetables, and cover and cook over medium to low heat for 4-5 minutes, until just softening. Stir occasionally during cooking. Next, stir in the ginger and seasoning to taste. Set aside until required.

To prepare the pasta: Fill a large pan three-quarters with water. Add 1 Tbsp oil and 1 tsp salt, and bring to a boil. Individually place 4 Loprofin Lasagne sheets in the boiling water and cook for 5 minutes, over medium heat. (Check during cooking to ensure the pasta sheets do not stick to each other.)

Carefully remove each lasagne sheet from the pan onto a flat surface. Repeat the cooking process with the remaining lasagne sheets. Meanwhile, blanch the zucchini (courgette) and carrot strips in boiling salted water for 2 minutes. Drain and cover with cold water.

To prepare the sauce: melt the butter in a clean saucepan. Stir in the Loprofin Baking Mix, broth, white wine and ginger. Bring to a boil while stirring.

To assemble the rolls: place a slice of zucchini (courgette) and carrot next to each other on a flat surface, and cover with a sheet of lasagne. Spread 1/8 of the chopped vegetables over the center of the pasta and carefully roll up to form a tube. Repeat with remaining vegetable strips, pasta and chopped vegetables to give 8 rolls.

Pour a thin layer of sauce into the baking dish and arrange the stuffed pasta rolls on the top. Pour the remaining sauce over the rolls and cover the dish with aluminum foil.

Bake for 25 minutes in preheated oven. Serve immediately.

Serves 4

Ingredients

100 g (4 oz) zucchini (courgette)
100 g (4 oz) carrot
125 g (5 oz) onion or leek
1 Tbsp cooking oil
2 Tbsp ginger, minced
Salt and pepper

8 sheets Loprofin Lasagne
1 Tbsp cooking oil
1 tsp salt

Sauce
7 g (1/2 Tbsp) butter
7 g (1 Tbsp) Loprofin Baking

Mix
225 mL (8 fl oz) clear vegetable broth
50 mL (2 fl oz) dry white wine
1 Tbsp ginger, minced

The Best in Low Protein...
www.lowproteinliving.co.uk





VEGETABLE GOULASH WITH COURGETTE DUMPLINGS

Ingredients

150g (6oz) onions, sliced
1 x 15mlsp (1tbsp) vegetable oil
75g (3oz) carrots, sliced
75g (3oz) swede, diced
75g (3oz) green pepper, sliced
100g (4oz) cauliflower, broken into small florettes
3 x 5mlsp (3tsp) paprika pepper
Pinch of ground nutmeg
2 x 15mlsp (2tbsp) tomato puree
1 bouquet garni
250ml (½ pint) vegetable stock
125ml (¼ pint) beer (or stock if pref.)
1 beef tomato (approx 150g/6oz)
Salt and pepper to taste

Dumplings:

100g (4oz) Loprofin Low Protein Mix
2 x 5mlsp (2tsp) baking powder
50g (2oz) vegetable suet
50g (2oz) courgette, grated

Method

Place the onions and oil in a large saucepan, over a moderate heat, cover and cook for 1 minute.

Add the carrots, swede, pepper and cauliflower, cook for 2-3 minutes.

Stir in the paprika and nutmeg, cook for a further 1 minute, stirring.

Stir in the tomato puree, bouquet garni, stock and beer, bring to the boil. Reduce the heat, cover and simmer for 10 minutes.

Skin the tomato and cut into bite-sized pieces, add to the goulash with salt and pepper to taste, cover and cook for a further 5 minutes.

Prepare the dumplings – combine all the ingredients in a large bowl, stir in sufficient water to bind the mixture, to give a soft, not sticky dough.

Shape the dough into 6 rounds and place gently in the simmering goulash, cover and cook for 15 minutes.

Remove the bouquet garni and serve portions of the hot goulash with the courgette dumplings.

Serves 2

CRANBERRY AND PEAR TARTS

(These festive pies make a nice alternative to mince pies)

Ingredients

1 crisp pear (approx 125g/5oz), peeled and cored
6 x 15mlsp (6tbsp) cranberry sauce
150g (6oz) Loprofin Low Protein Mix
40g (1½ oz) hard margarine
40g (1½ oz) butter
2.5mlsp (½ tsp) caster sugar
Large pinch ground cinnamon or mixed spice

Oven temperature:
200 C/400 F/Gas Mark 6

Method

Coarsely grate the pear into a small bowl, add the cranberry sauce, stir well until evenly mixed, set aside until required.

Place the Loprofin Low Protein Mix in a large bowl, cut the fats into small pieces and rub into the mix until the texture resembles coarse breadcrumbs.

Gradually stir in 2-3 x 15mlsp (2-3 tbsp) water, sufficient to bind the crumbs and give a manageable dough.

Transfer the dough to a surface dusted with Loprofin Mix and lightly knead, for 30 seconds, until smooth.

Roll out just over half the pastry and use to line 12 tartlet tins.

Divide the pear and cranberry filling evenly between the pastry cases.

Roll out remaining dough and cut into rounds for lids, cut a small star shape out of the centre of each. Place the lids over the pear and cranberry filling, gently pressing to seal the pastry to the base.

Lightly brush the pastry tops with water. Mix together the caster sugar and spice, sprinkle evenly over the moistened pastry.

Bake in a preheated oven for approximately 15 minutes, until the edges are lightly browned.

CUSTARD SAUCE

Ingredients

15g (½ oz) custard powder
1-2 x 5mlsp (1-2tsp) caster sugar
Approx. 1 x 200ml carton Sno-Pro Low Protein Drink*
Few drops vanilla essence

Method

Place the custard powder, 1 x 5mlsp (1tsp) caster sugar and 1 x 200ml carton Sno-Pro in a ½ litre (1 pint) microwave proof bowl, whisk/stir briskly, until the ingredients are thoroughly blended.

Cover and microwave on Full Power for approx. 2 ½ minutes, whisking/stirring every 30-40 seconds, until the custard is smooth, thickened and boiling.

Stir in vanilla essence to taste, extra sugar if desired and adjust the consistency if required, by stirring in a little extra Sno-Pro or water.

Makes approx. 200ml (7floz)

* 1 x 200ml carton Sno-Pro Low Protein Drink = ½ exchange

NB: An 800watt microwave with a turntable was used when testing this recipe, check your manufacturers instructions for appropriate cooking times, if you have a microwave with a different wattage.

A Special Christmas Dinner from Yes We Cook That.com

Yes We Cook That's Sausage Rolls

Makes 8 large or 16 small sausage rolls. 0 exchanges

Ingredients

1 portion of low protein pastry
(We make it using the ratio of 50 grams vegetable fat, plus 50 grams butter, to each 200 grams low protein all purpose mix. Rub the butter and fat into the all purpose mix, then add water (a very small amount at a time), until you have a pliable dough. This may be made well in advance, and can also be frozen raw for using later.)

1 portion of Yes We Cook That Beefless Sausages

Small Permitted gravy browning and vegetable oil for brushing over the tops.

Method

Roll out your pastry a small amount at time (about an eighth of the pastry), between two sheets of cling film, or similar type of plastic paper. Cut the pastry into an oblong 10 cm (long enough to take 1 sausage) x 15 cm, and put the trimmings back into the main ball of pastry.

If you have taken the pastry off the paper, put it back on, as this helps you to roll it.

Lay the sausage along one side of the pastry oblong, not too near the edge.

Brush the other edge with warm water, then lift the paper at the edge where the sausage is, and begin to roll the pastry so the sausage is inside it (remembering not to leave the paper inside too).

The wet side of the pastry will then stick to the dry pastry, sealing it.

Place the sausage rolls on a baking sheet, with the sealed side downwards.

Repeat the above steps until you have as many as you require.

Brush the sausage rolls with mixed up permitted gravy browning, mixed with a little vegetable oil, to give the 'shiny' effect.

Score a few neat lines sideways to let the air circulate when baking, and as a guide for cutting the sausage rolls up if you want small ones.

Bake in a preheated oven (Gas mark 4) until the pastry is firm to the touch (about 15 minutes). Our sausages are precooked, so you don't need to worry about cooking them.

Let them cool a little when they come out of the oven, as they'll be quite hot for little mouths, and cut them in half if you want small ones.



Yes We Cook That's Cream of Golden Carrot & Parsnip Soup

2 good portions. (Exchanges 0, unless you count one carton of low protein milk.)

Ingredients

1 permitted vegetable stock cube
2 peeled and chopped carrots
2 parsnips
2 shallots
A knob of butter
A pinch of nutmeg
1 small carton (200ml) of low protein Loprofin or SnoPro milk
1 pint of water
Parsley to garnish
Salt & freshly ground pepper to taste.

Method

Melt the butter, a little salt and pepper and the nutmeg in a heavy saucepan. Add the carrots, shallot and parsnips and fry gently, until the vegetables are browned, but not burnt. Add the water, and simmer the carrots and parsnip and shallot, along with the stock cube, until the carrot is soft (about an hour). Take care to make sure the water hasn't dried up before the carrot is soft (if it gets very low, add more water).

Once the carrot is soft, reduce the liquid in the saucepan until about a quarter pint remains (this doesn't have to be exact). Allow to cool a little, then put everything into a blender, along with the carton of low protein milk and the parsley, and whiz until thick and creamy.

Adjust the seasoning to suit your taste, garnish with parsley, and enjoy.

Yes We Cook That's Turkless Dinner

Recipe serves 2. (Exchanges depend entirely on the amount of potato)

The Turkless and stuffing balls are free of exchanges, and we have used 2 exchanges for the below, to serve 2 people with 1 exchange each of roast potatoes

Method

Prepare the oil and butter as above, and allow it to cool while you're getting the potatoes ready.

Peel the potatoes, and boil them in a saucepan of lightly salted water for 5 minutes only.

Drain them, cool them, cut them in half, and rub them with the mixture of vegetable oil and butter. Lightly sprinkle with salt, and roast in an open oven proof dish for an hour, or until a skewer can go through them without resistance.

Peel and slice the carrots, and simmer them in a pot of water until tender.

(Do this while the potatoes are roasting, as carrots take a while to go soft.)

When the carrots are soft, and the potatoes are almost ready, put your Yes We Cook That 'Turkless and Stuffing Balls' into the microwave. Lift the corner of the carton with the tab, so the carton is slightly open, and microwave for three minutes on high. Check the contents are warmed through, as all microwaves vary in power.

Arrange the turkless and roast potatoes and carrots on a plate and serve.



Ingredients

1 portion of Yes We Cook That
Turkless and Stuffing Balls

2 x 80 gram potatoes

2 medium sized sliced carrots

4 tbs vegetable oil & a Knob of
butter (melted together in the
microwave for a few seconds
only)

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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

find
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the
web
at:

www.nspku.org



Bookkeeper's Report for News and Views

I would like to say a special thank you to everyone who organises fund raising events for the NSPKU. The amount of time and energy needed to organise events needs special dedication, but I also know that, having read through your letters, how enjoyable you find them. I always love reading about what you have been up to and the varied and sometimes novel events that you think of always surprise me.

One such event held earlier this year was by Welsh farmer Arwyn Davies who walked the 177 miles of Offa's Dyke over a 13 day period. Arwyn was joined by his family and friends at different stages. You will be able to read more about him in this magazine.

As well as the walk itself a Summer Ball was held and with special assistance from Ann Griffiths and the staff at the Nat West Bank in Llandeilo and gift aid the total amount raised was £7000.

Also a special thanks to Vicky Ellis from Huddersfield who places a collecting box in the chemist Cohens where she works and regularly sends a cheque when it gets full, always quickly re-labelling it and placing it out again for people to pop their change into it.

Vicki King,
Bookkeeper

Donations of over £30 up to 30.09.09

Name	Amount £
Judith Blincow - Mermaid Inn, Rye,	850.00
Arywn Davies, Offas Dyke Walk	520.00*
Vincent O'Neill, Manchester 10k run	650.00
Ann Griffiths, Offas Dyke Walk with Arwyn Davies	550.00
Kath and Effie - Bath 1/2 Marathon	94.00
Memory of Mrs Alice Emily Hurton	97.00
Computershare - Casual Clothes Day	174.48
Howard Worth Chartered Accountants - Dress Down Day	50.00
Ms Fairlie Carter	50.00
Caroline Kelly - 2009 London Flora Marathon	252.00
Jean Davies - Summer Ball	750.00
A & J Davies - Sponsorship Forms	3,900.00
Mrs P Farley - in memory of Teresa Cooling	250.00
Mrs G Stephenson - in memory of Hazel Robinson	200.00

*more to follow

NSPKU MERCHANDISE



NSPKU will be selling two designs of Christmas cards this year

Each packet contains 10 cards with envelopes and will retail for £3.00 per packet.

This message inside reads:

*With Best Wishes for Christmas
and the New Year*

For more information please contact Mike Bailey, see inside front cover for contact details.

Dietitian's Report

Ultrapharm Ltd

Ultrapharm are distributors for the Harifen Low Protein Crispbreads and Harifen White Chip Cookies. These 2 items are currently unavailable on prescription. I have been informed that because the pound has dropped alarmingly against the euro imported products have become very expensive so the company have been forced into the decision not to import.

Useful foods in the supermarket

I recently received the following 2 message from mothers about some pretzels they had found in the supermarket.



“I have recently come across gluten free pretzels in Morrisons and ASDA free from sections which are low in protein. They are only 0.5gr of protein per 100gr and my son loves them. Please find attached the front and back covers for information. I hope other parents of PKU children can benefit from using those as they are really tasty.”

As enjoyed by Matthew Sheridan and approved by Eleanor!!



I have been in touch with the company about the protein content and they have double checked with their quality control that the protein content is 0.5g protein per 100g. There are some old stock bags on the shelves which have been incorrectly labelled as containing 2.4g protein per 100g. The nutrition information is being changed to 0.5g per 100g but this will take a little time to filter through.

A single 60g bag contains 0.3g protein. This is quite an awkward protein content as it is not free (0.3g per 100g is regarded as free). You should count a bag as ½ exchange to be within the rules. Normal pretzels are much higher in protein so this is a great find.

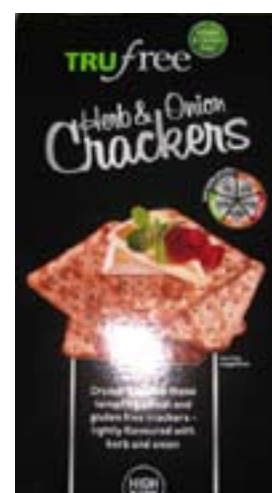
I bought the pretzels in Morrisons and they were 86p per bag.

Trufree Herb and Onion Crackers

Also by the same company are these crackers which could be useful for picnics, dips, and savoury spread or pate or low protein cheese.

5 crackers = 1 exchange.

I bought these in Sainsbury's and they were £1.78 per box



The following foods were found by Barbara McGovern, mother of Archie.

Ambrosia Jelly Puds



These puddings come in 2 flavours . strawberry and raspberry, and have jelly on one side and custard on the other.

Each pudding gives 1 exchange per pot.

In Sainsbury's they were 79p each

Innocent Pure Fruit Squeezies



These squeezies can be found in the refrigerated section of the supermarket. I bought Strawberries and raspberries. These are free fruits and can be included as a free item in the diet. There are several flavours so please do check that all the fruits are free in the ones you pick up.

They cost £2.19 for 6 tubes. I bought them in Sainsbury's

Innocent Smoothies for kids



These are presented in small cartons with a straw. Some of the flavours have a higher protein content

than others because they contained passion fruit but I found the apples and blackcurrant were low and would be suitable as a free item.

They cost £1.44 in Morrisons for a box of 3 cartons.

Drinks at the Showcase Cinemas

Michelle Smith rang and told me about Tango Ice Burst and Slush Puppies which are available at Showcase cinemas by dispenser. Her son Nathaniel asked many times if he could have one but because Michelle did not know what was in them she said 'no'. She then decided to ask the manager if he could tell her the ingredients and he took her to see the boxes but no detail was given on these but there was a number to ring to find out. Michelle did this and went through all the ingredients and they are all free, even the sugar free Slush Puppy which is sweetened with Ascesulfame K.

So Nathaniel is very happy he can have his drinks at the cinema like his friends and Michelle let me know so that I can pass it on to you all.

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