

NSPKU News & Views

The National Society for Phenylketonuria (UK) Ltd

Autumn 2008 – Issue 125

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PKU Highs and Lows, the Kellies' Story

www.nspku.org

In Touch

The Council of Management

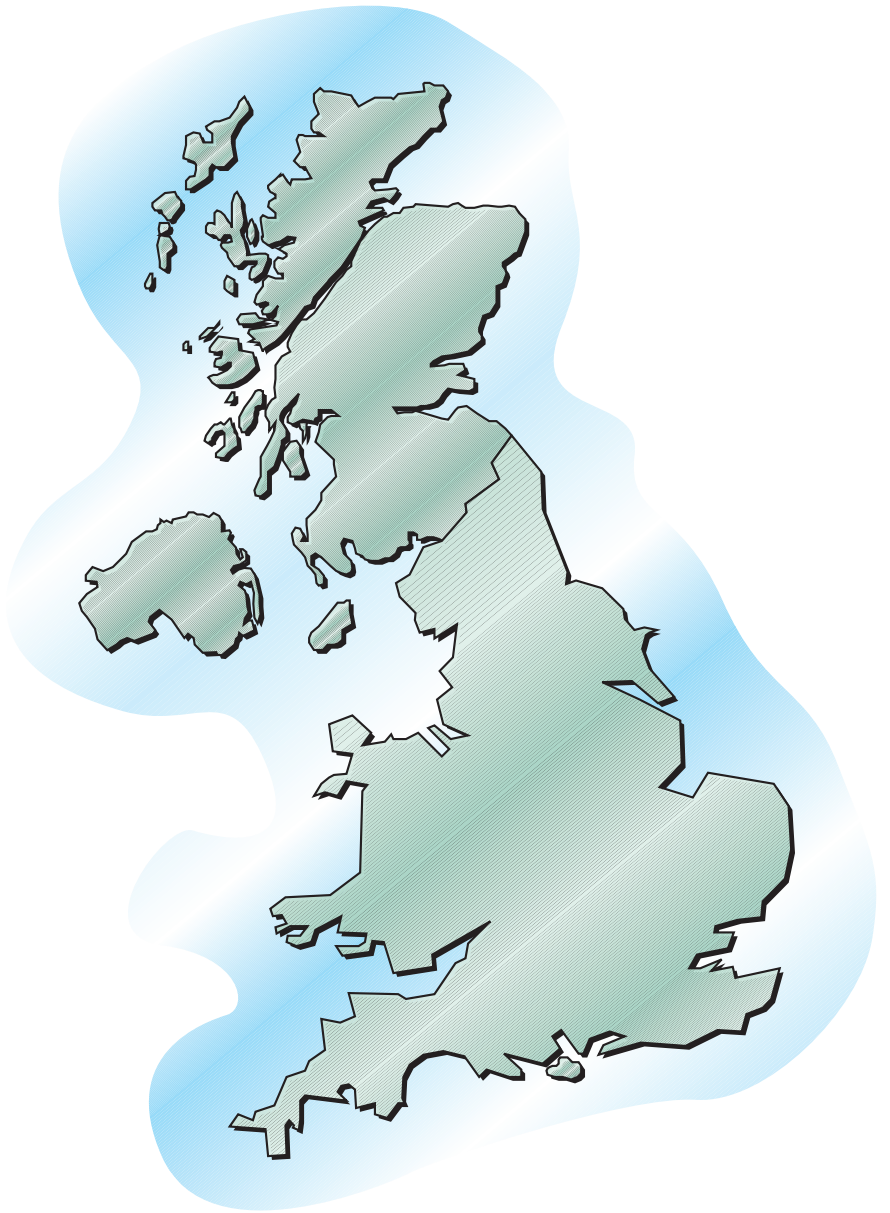
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Editor's Report...

Mmm, not sure the Thomas's will be holidaying in the UK next year. Credit crunch and global warming be damned, we're getting some sun next July! PKU wise however, it's easier to stay near home and travelling anywhere with PKU involves some complicated packing and I must admit I found that a bit of a strain this summer. Wouldn't it be nice to just go on holiday and not have to bring your own bread...and cereal... and milk...and biscuits and, well you know the score. I know I'm being negative but as Viki Kellie points out in her article this issue, PKU really is a pain in the neck some times and there's no point pretending otherwise!

Of course this issue isn't only about the bad times! Eleanor has discovered yet more lovely food suitable for the PKU diet and Eileen Green never lets us down with her ideas either! We've blasted some myths about breastfeeding and PKU and there's yet more recipes to try dotted throughout the magazine.

Next issue however, we'd love to hear from some adults with PKU and we're hoping to have a story about PKU in America. It's fascinating how the exact same condition is handled so differently over there and there may well be ideas for us in their approach. If any readers have any other thoughts or ideas that are in any way related to PKU, we'd love to hear from you!

Kiri Thomas,
Editor



The National Society for Phenylketonuria (United Kingdom) Limited

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Bookkeeper's Report...

My first report for News and Views as the society's Certified Bookkeeper – very nerve racking!

When I look back over the last three years that I've been involved with the NSPKU, I can see how the role has changed and grown – from the first tranche of work to the first meeting with all the COM members, then the first visit to Conference, and so on until now I'm handling a lot of the work that Julia has done for the past eight years or so – quite a daunting task to have such a responsibility.

My grateful thanks to Julia for all the support she has given me over my 'settling in period', it's very comforting to know she's been on the other end of email!

From knowing nothing about PKU previously, I've already learned lots from talking to COM members, lovely people who I've met at Conferences and reading the News and Views magazine. I've also found out that one of my ex-neighbours, now a clinical psychologist in Canada is very much involved with a PKU group out there, and then I find out that a friend of a friend's son has PKU – it's a small world!

Vicki King
Certified Bookkeeper

Donations

Vicki King, Tarkwa, 65 Cromwell Road, Ribbleton, Preston, PR2 6YD

Donations over £30

	£
Margaret Burns and Pat Fordham Charity Group	50.00
W Bro Ben Aspinall, W Master, Lodge of Remembrance 3787	150.00
Colleagues of AM Jeyes, mother of Alicia Jeyes	150.00
In Memory of Winnie Dart	385.00
In memory of Julia Reynolds	50.00
In memory of Angela Kerswill	61.55
In memory of Hannah Lawrenson	175.00
Simon and Vicky Holman - in celebration of their marriage	203.69
Lorissa, Phil, Michaela and Natasha Clemo - Bodmin Ten Tors Walk	285.00
Hannah Rycroft - Nan and Grandpa's party donations	450.00



Letters

News & Views, 10 Silverdale Road, Chorlton M21 0SH
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,

Our second son Chester James was born on January 30th 2008 and was diagnosed with PKU 10 days later. So far he has managed his formula very well and he is still being breastfed.

The Norfolk & Norwich University Hospital have been so supportive and Rachel their dietitian is always available should we have any issues, particularly now Chester is about to be weaned.

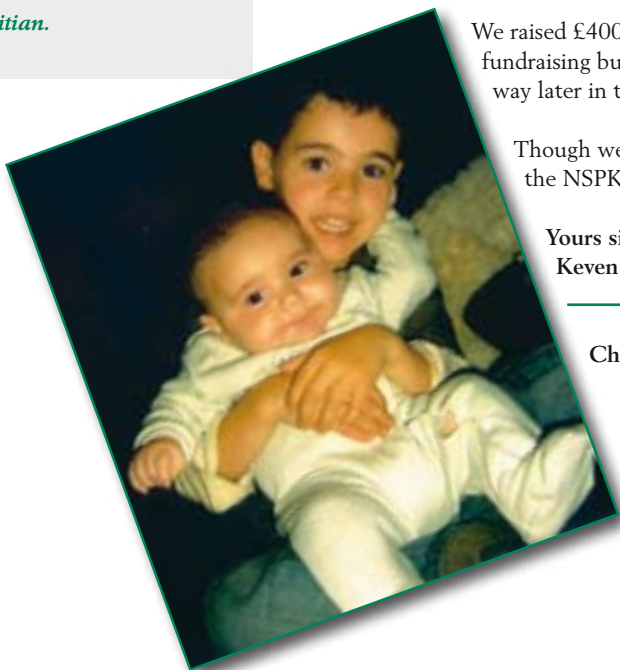
Chester was christened on the 4th May and we decided to hold a raffle for all our family and friends. Carla, Auntie and Godmother to Chester, kindly arranged a splendid prize from her employers, Warner Leisure. This was a luxury 4 day spa break in one of their hotels.

We raised £400 which we have great pleasure in enclosing. We are also arranging a fundraising buffet/dance for October 3rd so hopefully another cheque will be on the way later in the year.

Though we are still learning how to manage Chester's diet, we would like to thank the NSPKU for the guidance and support we have received.

Yours sincerely,
Keven and Kelly Archer.

Chester and his big brother



Dear News and Views,

Please find enclosed cheques (posted today) totalling £847.25 raised as a result of completing the three peaks challenge on the 11th and 12th of July this year. The challenge was actually organised by the Meningitis trust so the majority of the sponsorship rightly went to them. It is only due to the kindness of friends, family and my colleagues and the students at the John Bentley School, Calne that the remaining sponsorship allocated to the N.S.P.K.U. was so generous.



I have attached two photos, one of me on top of Ben Nevis as evidence that the sponsorship money was genuinely earned! The second is of my daughter Ella, 9, who has P.K.U. She was the reason for my temporary loss of sanity as I dragged myself up three mountains without any sleep!

Yours faithfully
A.Roberts



PKU is not always easy...

Many of us with a 'few years' experience' under our belts, manage to feel positive about the phenomenon that is PKU. Either having PKU ourselves or as parents helping our kids manage the condition, we often find that life is not only tolerable but indeed very close to "normal". That's great and the NSPKU exists solely to assist the PKU community in achieving that stability.

It would be dishonest, not to mention unhelpful however, were we not to talk about the bad times. Not every family finds it easy. In fact, the truth is that PKU is not "normal" and living with it can be painful and difficult. I don't think any of us would choose the condition for ourselves or our children. But there it is, we accept it and work hard to make life with PKU the best we can. Often, we are very successful and live very happy lives despite the condition. Sometimes though, it's important to acknowledge the strains and Vicki Kellie wrote to News and Views because she wanted to share her stressful experience of PKU. Vicki and her husband Roger adore their gorgeous boys but would love to set them free from PKU. I think we can all relate to that. Here, is the Kellies' story.

Reece and Xander were born at 32 weeks, both weighing under 4lbs. Their births were stressful as I was shipped from hospital to hospital and eventually had to have an emergency caesarean section in Margate, miles from where we live in Rye. Not an easy start!

After 3 weeks, the boys were sent to a hospital, still in Special Care as they were not gaining weight. This is where I was told – alone – that they had PKU. Not only this, but I was informed that my babies were likely to have brain damage because of this diagnosis. The rest is a blur and to this day it is unclear to what extent the boys' PKU has hindered their brain development, especially since, as I'll explain, their eating was so erratic in their first year.

The boys came home on New Year's Day 2004. Because of having been fed through N.G tubes, they had real difficulty feeding and very little sucking reflex. Trying to get through their supplement was a struggle and the N.G. tubes were re-introduced. Then, they developed severe reflux

15 times a day each. They started falling behind on the growth charts which was really worrying so the tubes had to go. At this point, the boys would drink liquids and eat pureed fruit and vegetables but this was shortlived. Feeding became a real strain as Roger and I would spend up to 12 hours a day trying to get

them to take their supplement. It was taking over our lives.

By New Year '05 they weren't eating and hardly drinking. They didn't talk, had very little understanding and had only just started walking. Convinced something wasn't right, lots of assessments were started and at 2 ½ they were both diagnosed with ADHD and Autism, the severity of which was unknown until they became older. They were given placements at a Special Needs Nursery which would prove to be amazingly beneficial for them both.

However, by now, feeding was once again a big issue and after much consideration, it was decided that they would have gastroscopy tubes inserted. So, in July '07, this went ahead. We were worried that reflux would return as with the N.G. tubes and while it does now and then, not to the level it did before.

Reece and Xander have gained weight and got taller. More importantly, their heads have grown too. Their behaviour is, however, a problem. Their lack of understanding means they don't know they have PKU or understand they should eat. Every now and then, they'll have a chip or a crisp, but only one. They are not toilet trained and have a very set routine which if changed causes real upset. I can't take them out together as it's physically impossible. Other than when they're at at nursery or with respite (every other Saturday for 3 hours), we have no childcare.

Not a day goes by when I don't think it's my fault they have all these "difficulties". We find it hard talking to PKU families due to the ADHD and AUTISM and are not in touch with any families



Reece, Roger and Xander , babies age 11 months

who have Special Needs children. We feel we have been treated awfully by the system from when I was pregnant until now although the dietitians, specialist doctors and nurses we now work with are very supportive. We've had to fight to get respite and fight against other peoples' views about Autism.

The boys are bright, funny and extremely handsome! People always say you'd never know there was anything wrong with them but put them with other 4 ½ year olds and it is obvious.

This is just a short insight into our family life, believe me when I say we could write a book!



Reece, Roger and Xander , boys aged 4 1/2

All PKFoods are now available on prescription

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

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Website: www.pkfoods.co.uk Email: info@glutenfree-foods.co.uk

Five Myths about Breastfeeding and PKU

1. You can't Breastfeed a Baby with PKU

Sure, exclusively breastfeeding is not possible with a PKU baby, but partial breast feeding is possible and is encouraged. It is ready made, at the right temperature and contains important special substances (immunoglobins) which help protect against bacteria and viruses. *Breast feeding helps to bond mother and baby which can be particularly helpful following diagnosis.*

2. Mixing breast and bottle feeding is just too complicated

At first, you will be giving your baby a bottle about every 4 hours and breastfeeding after the bottle feed and also whenever the baby wants. This sounds complicated but really doesn't take long to master. Very quickly, babies can go hours between feeds and you can get more sleep! Remember too that dads can help with the bottle feeding so mothers don't have to do it all!

3. Babies get nipple/teat confusion if you breast and bottle feed

The beauty of human babies is that they are flexible in almost every way you can think. Babies born in a bi-lingual home just learn two languages instead of one. They can sleep in wooden cribs or on their mothers' chests, they thrive on breastmilk from mothers eating a highly spiced diet in India and from mums in France dining on snails and pate de fois gras! PKU, in this country, is diagnosed very early in a baby's life and before they've had a chance to complain, babies with the condition are being offered breast and bottle at every meal. No problem!

4. Breastfeeding means you can never leave your baby with anyone else

Well, at first you probably won't want to leave your baby with anyone else, it's likely you'll be tired and a bit overwhelmed and having a PKU diagnosis will knock any parent initially. However, the silver lining comes when you realise that your PKU baby is absolutely fine with a bottle. This means you can leave a babysitter with some expressed breastmilk or even normal formula along with your baby's special PKU formula. Nana or Grandpa can be confident that your baby, if she or he wakes, will happily take a bottle as they do normally every mealtime!

5. Breastfeeding means eating bland food and never having a glass of wine

First, the bland food issue. Asian food is rarely bland but do you think generations of women there, for example, had special diets when they breastfed? Of course not! Healthy women have, for thousands of years, eaten a varied diet based around what was available and what was culturally normal for them and they didn't stop when they breastfed! But like any physical activity, if you want to do it well, eating chips and pies exclusively won't help your cause! This ties into the old alcohol question. There's no evidence that the occasional drink will harm your baby while you breastfeed but going out on the razzle dazzle probably isn't a good idea whilst in charge of a baby! So, if you fancy a takeaway and a small beer now and again, you can enjoy it! *(Remember however, that it's dangerous to sleep in the same bed as a baby, especially if you've been drinking)*

I'd just like to thank Caroline Hughes here who worked very hard at breastfeeding her PKU baby Sean and who very kindly gave us her time in writing about her experiences. She pointed out lots of the information and tips included above and reminded us how important it is to encourage mothers of PKU babies to give breastfeeding a go! Thanks Caroline!

PKU Pronto!

Carrot soup

This soup is so delicious that everyone will enjoy it, PKU or not. It takes a little over 30 mins and after that you have something fresh and fabulous that will keep for a few days in the fridge or better still, in the freezer. With fresh low-protein bread, it's a gorgeous lunch and you could even take it in a flask to work or school. Here's the recipe:

For 4 (although I would double this and freeze half)
 75g butter
 225 carrots peeled and sliced
 1 medium onion, finely chopped
 Salt and pepper
 25g low-protein rice
 1 sprig of thyme (if you have it lovely otherwise don't fret!)
 700ml water

1. Melt 50g of the butter and stir in the carrots and onions.
2. Season with salt and pepper, cover and cook over a very low heat for 10 minutes. You need to keep an eye here as butter can burn quite easily although the salt should help prevent this.
3. Add rice and thyme and pour in the water. Bring up to the boil then simmer gently for 30 minutes.
4. Remove the thyme and liquidize the soup – I use a stick immersion blender here straight into the saucepan and can recommend that as the easiest and safest way to make soup.
5. Adjust the seasoning and stir in the remaining butter if you'd like an even richer taste.
6. A sprinkle of fresh parsley or chervil would look and taste great on top if you have them.





AVAILABLE ON PRESCRIPTION:

Fate Low Protein All - Purpose Mix

Fate Low Protein Cake Mix

Fate Low Protein Chocolate Flavour Cake Mix



"As a mom with two daughters who both have PKU, I fully understand the low protein way of life. I have developed these mixes and many recipes to help everyone make great low protein food."

Eileen Green



**Ask your Doctor to prescribe Fate mixes,
then ask your chemist to telephone our direct order line : 01215 22 44 33**

Helpline and General Enquiries Tel: 01215 22 44 34

Fate Special Foods recipes



Hello

I didn't really want to call this recipe Christmas Pudding, because it is too good to eat only once a year!

It is very easy to make, using Fate Low Protein Cake Mix, and unlike traditional puddings doesn't take hours to cook, It can be made and eaten straight away, or made and stored in the freezer. Just re-heat them in the microwave or oven when you fancy one.

So why keep them just for Christmas?

The pudding basins I use are bought in Tesco, and hold about 250mls.

FATE CHRISTMAS PUDDINGS

Ingredients

100g finely chopped apple, preferably Cox's orange pippin
 200g currants
 150g mixed dried fruit
 1 tsp ground mixed spice
 2 tsp ground cinnamon
 2-3 large oranges
 1-2 lemons
 250g (1 packet) Fate Low Protein Cake Mix
 50g suitable soft margarine
 few drops gravy browning

Pre-heat the oven Gas 5, 190°C 375°F

Method

Place the finely chopped apple, currants, dried fruit, mixed spice and cinnamon into a mixing bowl. Grate the rind from 2 of the oranges and 1 of the lemons. Add this to the bowl. Squeeze the juice from the oranges, and measure 150 mls of juice. Then squeeze the lemons and measure 50mls of juice. Add this to the bowl. Stir to blend well. Leave to rest for 5 mins.

Add the soft margarine and then add the packet of Fate cake mix. Stir well for about 1 minute until the mixture is all well blended together. Stir in a few drops of browning to give a rich dark colour.

Leave for another 5 mins to rest.

Meanwhile, grease 6 individual pudding basins about 250 mls capacity.

Stir the pudding again, and make a wish. Then place the mixture into the pudding basins. Set them into a deep roasting tin. Pour enough boiling water into the roasting tin to come about a third up the sides of the basins. Bake in a pre-heated oven for about 35 mins for individual ones. When cooked, they should be risen and firm.



NEW
NOW AVAILABLE ON PRESCRIPTION



Family favourites for the Barbeque

Promin burgers are now available in two flavours, Original and Lamb & Mint and Promin sausages in three flavours, Original, Apple & Sage, and Tomato and Basil so all the family can enjoy the barbeque

Firstplay Dietary Foods was formed in 1993 to produce Promin Low Protein products from a small factory in Stockport, where we only produce low protein products which is great for people on a restricted diet as it minimises the risk of contamination. Our original low protein and gluten free pasta range, includes Promin Pasta and Promin Tri-Colour Pasta, now a well established brand and are available on prescription. The range also includes Imitation Rice, Pasta meal, Cous Cous and

Lasagna Sheets. By talking with PKU patients, parents and Dietitians a great range of tasty products have been developed.

Hot Breakfast - Original, Apple and Cinnamon, Chocolate, and tasty Banana flavours.

For lunch or an evening meal: Pasta Shells in Tomato, Pepper and Herb sauce, or Pasta elbows in Cheese and Broccoli sauce and now Spirals in a spicy Moroccan sauce

A recent addition is our great tasting Burger Mix, you can easily shape it into burgers,

meatballs or even dinosaurs for the kids! - they taste great with chips or mixed with some of our pasta. Finish with Rice pudding - 3 flavours available or a Chocolate and banana dessert, there's a strawberry and vanilla one too. Please call us or visit the website for more information and keep sending your recipe and meal suggestions.

Firstplay Dietary Foods produce low protein foods especially for your diet.



Always consult your dietitian before trying something new.

ALPHABET, ELBOWS, SHELLS, MACARONI, COUS COUS, RICE, PASTA MEAL, SPIRALS, SPAGHETTI, LASAGNA SHEETS

To order telephone or fax: **0161 474 7576**, E-MAIL: firstplaydf@smartone.co.uk WEB: www.promin-pku.com

Dietitian's Report

What's for afters?

This month I've been looking at what's around in jelly puddings on the supermarket shelves. In the past most jellies were made using gelatine as the setting agent. Gelatine is high in protein and therefore not suitable in the PKU diet.

But things have changed and recently there have been some lovely new jelly puddings which are set with gums e.g gellan, carob, xanthan and locust bean gums and carrageenan. These are all very low in protein so that's good news for us.

I am featuring a few of these but do have a look in the shops yourself. You do not need to automatically discount jelly in the shops. Check the labels of jellies for protein content and anything with a protein of 0.3g protein per 100g is suitable. As a double check look to see what the gelling agent is.

Marks and Spencer

These jelly bricks found in the chilled section contain fresh fruits – pineapple, mango, cherries and blackcurrants and make a very attractive pudding. You could serve it in slices with some sorbet or some of the new SHS dessert ice cream or fresh or tinned fruit. The jelly is free.

Individual Jellies

Also in Marks are individual Raspberry and cherry Jelly with fruits. Good for the lunch box or as a special treat. They are also free.

Morrisons

Do individual jellies on the shelves (not in the chilled section) and the flavours are Peach and Pear in Tropical flavour jelly and Diced peach in Strawberry flavour jelly. They are free.

Asda

Great Stuff Jellies
– no added sugar.

These individual jellies contain no sugar and are sweetened with just fruit juice.

They come in the following flavours:

Apple in Blackcurrant Jelly
Pears in Strawberry Jelly
Mandarins in Orange Jelly
Peaches in Raspberry Jelly

They cost £1.28 for 4 little pots. You can find them on the shelves (not in the chilled section). They are free.

Asda also do some jelly crystals in orange and Strawberry flavour. You simply add a sachet to 500ml of boiled water, stir and leave the jelly to set in 2 hours. I added some tinned peaches to little dishes to make individual jellies. It made 6 pots of jelly so good value at 28p for 2 sachets. That's only about 2p per jelly.

For a party you could make the 2 flavours and set in layers. Make them using slightly less water so that it is a little firmer and add some fruit. Let that set and then make the second colour and pour over the first when it has cooled a bit. Two-toned jelly looks lovely and very clever! They are free.

Tesco

Fruity Jelly- Flavours are:

Mandarin segments in mandarin jelly
Peach in strawberry jelly
Pineapple in pineapple jelly

Also Just Jelly in little tubs

Orange
Blackcurrant

Value Range

Orange Flavour Jelly



Dietitian's Report continued...

(Under Other Jelly things!)

Dole also do individual jellies and a Fruit Parfait. These are free.

Hartley's are well known for their individual jellies (but make sure you don't pick up the sugar free ones). They are free.

Greens do an Orange and Red Quick Jel. This is good in a low protein pastry case with some fruit. These are free.



SPC

Fruit n' Jelly Splits are just what they say they are, jelly on the bottom and fruit on the top. Flavours are:



Peach in layered
Mango and
Pineapple Jelly

Mandarin in
layered Pineapple
and Orange Jelly

Pear in layered
Apple and
Raspberry Jelly

SPC

Also do a Fruit sorbet which you freeze at home. You can find these with the jellies and little tubs of fruits on the shelves, not the freezer, and the flavours are mango, Strawberry and Mandarin.



Other Useful Little Puddings

Barbara McGovern told me about some little mousses in Marks and Spencer. These come in 2 flavours:

Strawberry and Raspberry 1 pot = 1 Exchange
Lemon 1 pot = 1½ Exchanges

Barbara also told me about a good store cupboard pudding which is easy to make.

Angel Delight

1 packet Angel Delight powder

180ml Rice Milk or low protein milk

Pour chilled milk into a bowl and whisk in the Angel Delight until light and creamy.

Put in the fridge to thicken for 2 to 3 hours.

80g of this pudding = ½ Exchange

Asda's Great Stuff. Irresistible Flavour Delight (all except Chocolate) (You may need a little more particularly with vanilla flavour)

1 packet of Great Stuff

300ml of cold Rice Milk or Low Protein Milk.
(You may need a little more particularly with vanilla flavour)

Pour the cold milk into a bowl. Add the packet of Great Stuff powder.

Whisk thoroughly for 1 minute until light and creamy. Put in the fridge to set for 10 minutes.

90g of this pudding = ½ Exchange

Branded Foods containing all free ingredients

Jo Jamieson, mother of a little boy with PKU found a tinned soup at a local organic food fair which was very low in protein. It was a Suma Carrot and Coriander soup.

Listed Ingredients:

Water, carrots, onions, sunflower oil, coriander leaf, garlic, sea salt, black pepper.

All of the ingredients are free so this soup could be taken without counting as an exchange.

This applies to other foods like tinned tomatoes with herbs and onions.

If you are unsure about the listed ingredients take the food along to your dietitian to ask or you can send the wrapper to me. The added advantage of sending the wrapper to me is that I can then feature the food in News and Views and everyone can look out for your find!

Coming Soon!

Up-date sections of the Pictorial Guide

Many of you will have copies of the pictorial guide to the PKU diet. Photographs are so much help when choosing the correct foods and are useful to show the pharmacist, grandparents, schools and friends.

Two sections have been up-dated:

ACBS Prescribed Foods

There have been a number of new foods passed for prescription and many have been re-packaged. The guide includes all of these new and 'changed look' foods. You can see at a glance what's available. Make use of them in your diet to add variety and energy.



Crisp and Snack Section

This has been totally re-vamped too. There is a vast choice of crisps and snacks and many come in handy packs providing one exchange. There are also included some free crisps and snacks made from cassava or tapioca. The ones which are free only contain free ingredients so if you find a cassava or tapioca crisp which contains Whey powder or egg or prawn for example it will not be free.

You will also see from the guide which are good value for giving the most for your exchange.



Look out on our web site for the launch of these 2 sections or ask your dietitian who will be alerted to availability.

Yes We Cook That.com

Specialist Dietary Foods

Freshly prepared PKU ready meals

Available near you*

Would you like...

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

Yes We Cook That!

To open the freezer and find Spaghetti 'Meat'balls and Fishless Fingers and Chickless Nuggets, all with 0 exchanges?

Yes We Cook That!

To have a birthday cake and know that you can eat it all?

Yes We Cook That!

To have all this at Supermarket prices?

Yes... it is!

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.

*Available now in most of the UK and Ireland.

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

NSPKU 36th Annual Family Weekend & Conference 2009

The Rainbow Hotel Torquay

Friday 20th March to Sunday 22nd March 2009



Venue:

This year's NSPKU annual family conference and holiday weekend will be held at the Rainbow Hotel, Torquay. This hotel provides us with a delightful location to hold our annual event. Our conference is slightly later this year and the weather on the 'English Riviera' by late March is usually very mild and extremely pleasant.

The hotel is located just 5 minutes walk from the sea front and 10 minutes from the town and harbour.

Accommodation:

All rooms are en suite, with TV and hospitality trays. Many have trouser press / ironing board and hairdryers. There are a variety of bedrooms at the Rainbow, including family rooms for up to 5 people. Some family rooms have a door leading on to a private terrace, overlooking the outdoor pool and garden area. Please bear in mind the rooms that are available will be allocated on a 'first come, first served' basis so early booking is recommended! If interconnecting rooms are required, please state whilst booking. Also please let us know if you have any special requirements (other than the PKU diet).

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:

Keep fit in the indoor health club, swim in the heated pool, make use of the mini-gym or relax in the steam room. The evening entertainment takes place in Club Rainbow, which is the hotel's very own nightclub, and available exclusively for the NSPKU.

Meals are served in the attractive Garden Restaurant overlooking the adjacent park and garden.

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.



Location:

Torquay is located 30 minutes from the end of the M5 and is well served by public transport. The station with regular trains from Birmingham and London is just 5 minutes walk away. National Express coaches run a regular service to Torquay. Plymouth and Exeter airports are also within easy reach.

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 (17 yrs and over) £170.00

PKU Adult (17 yrs and over) £85.00

Non PKU Child (5 - 16) £50.00

PKU Child (5 - 16) Free

All under 5's Free

Day Visitor Fees:

Non PKU Adults (17 yrs & over) £35.00

PKU Adults (17 yrs & over) £17.50

Children (0-16) £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 £25 per adult (£12.50 child) for Thursday night and £15 per adult (£7.50 child) for Sunday night including cabaret. Rates include breakfast.

The NSPKU Conference Organiser is Dave Stening chair@nspku.org Tel 0207 099 7431 www.nspku.org

NSPKU MERCHANDISE



NSPKU will be selling two NEW 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.



Fruit Tart

Ingredients:

Pastry
115g (4oz) Loprofin Mix
60g (2oz) Butter
25g (1 oz) Icing Sugar
30ml (2 tbsp) Water

Makes 1 portion
Preparation time: 10 minutes
Cooking Time: 15-20 minutes
Xchange FREE

Filling

45ml (3tbsp) Bramley apple sauce
6-8 segments canned mandarin oranges
Or slices of fresh orange
1 x 4 Yorkshire pudding tin

Serving suggestions:
This tart can either be served on it own
or with a portion of cream or yoghurt.
Chef' Tip:
Remaining pastry can be frozen and used as casing for an
assortment of fillings.

Method:

- 1) Preheat the oven 200° / Gas mark 6.
- 2) To make the pastry: In a medium bowl rub the fat into flour until it resembles breadcrumbs, make a well in the centre and add the water, mix with your hands to combine together.
- 3) Sprinkle the work surface with **Loprofin mix**, and place on the pastry, kneed for 1 minute. Divide into 4 and roll out each portion to fit the Yorkshire pudding section in the tin. Slightly prick the base and bake blind in the preheated oven for 5 minutes before removing to a cooling tray.
- 4) Spoon the apple sauce into the pastry case.
- 5) Decorate with mandarin orange segments or slices of fresh orange.

For more great tasting recipes, visit

www.lowproteinliving.co.uk



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