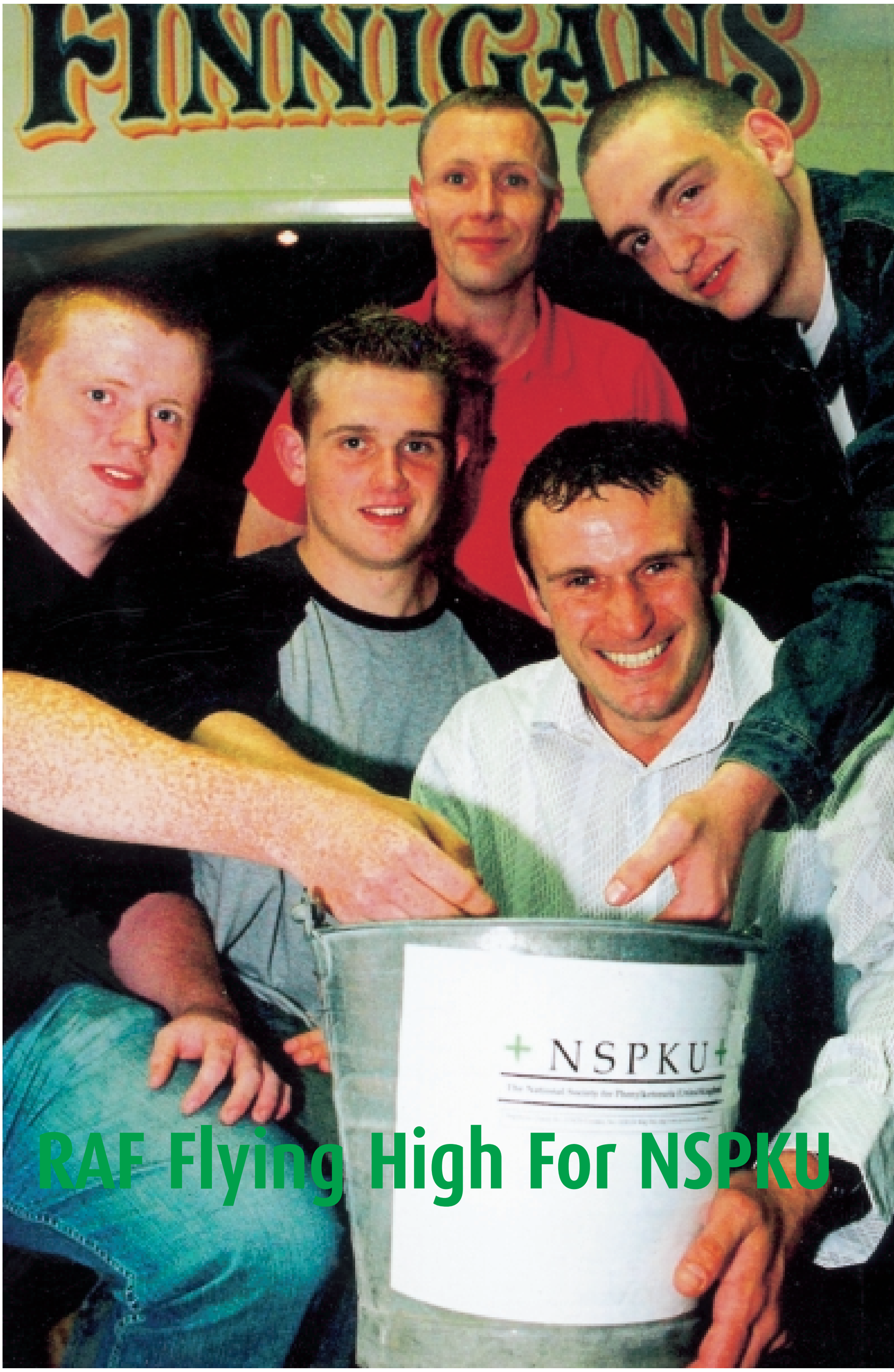
# NSPKU News & Views

The National Society for Phenylketonuria (UK) Ltd

Issue 107

## Inside this issue...



## RAF Flying High For NSPKU

www.nspku.org

# In Touch

## The Council of Management

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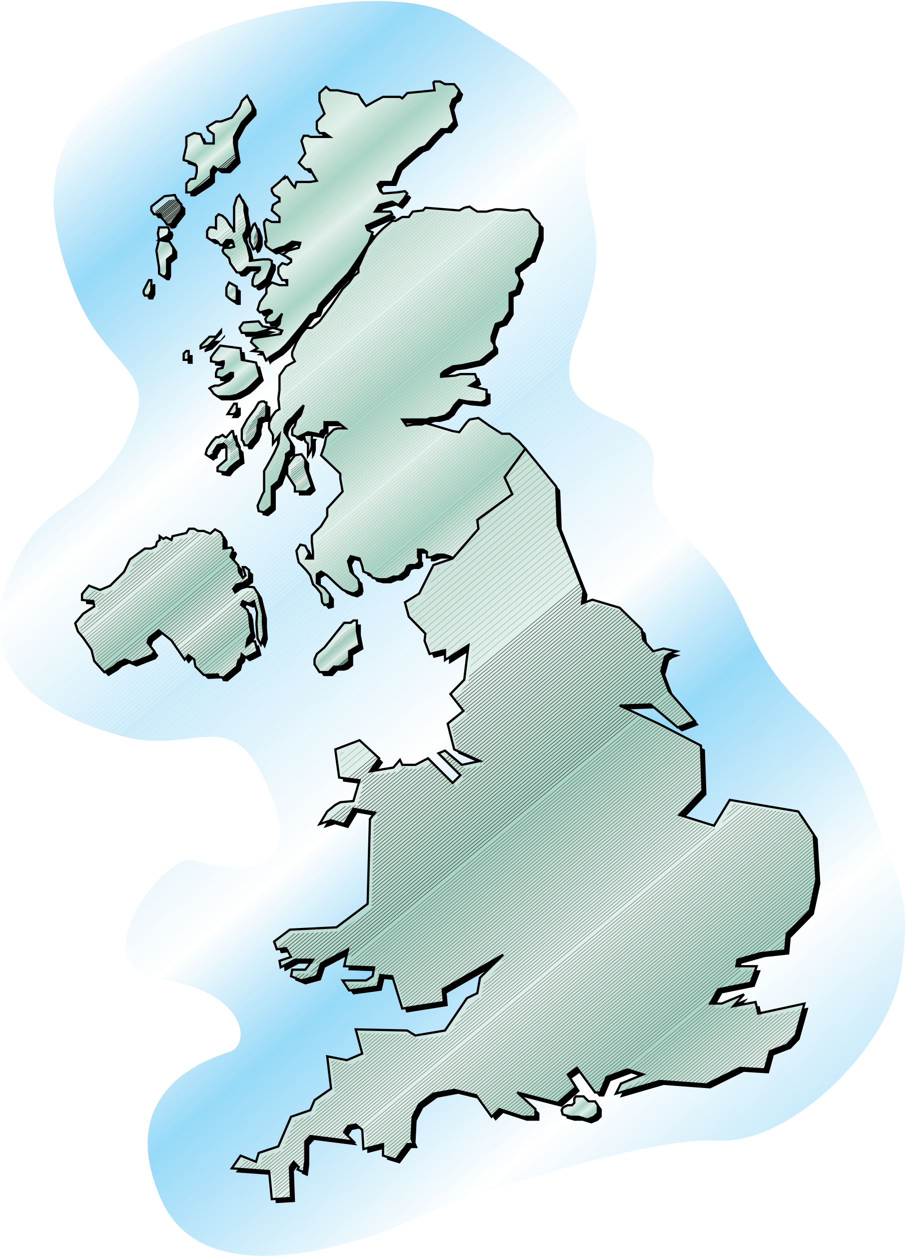

# Contents

## Editors Report...

Greetings one and all to News & Views 107. I was marvelling at the comparative ease at which my 9 year-old daughter devours her 50 football sized protein substitute tablets per day, and what could I do to help and encourage her when…….POWEE!! it suddenly came to me! An inspirational moment! A vision if you like.

I'll get a sub-editor! It won't help the tablet problem, but it will certainly help me out!

So let me introduce you to the lady on the front cover, Kiri Thomas. Kiri joins us from the West Didsbury Gazette where she was Editor-in-Chief of the "Boot Sale Round up" and part of the editorial team that exposed tax-dodging activities of Bob the Builder. Actually….I'm fibbing, Kiri is a PKU Mum who wants to help out.

Without this sort of help organisations like the NSPKU struggle but with the right input we can continue to produce a superb product that is extremely popular with it's membership (believe me, I'm first to know when someone doesn't get their issue!)

I'm looking forward to working with Kiri to make News and Views even better and particularly look forward to sharing the blame for missed deadlines and ropey editorial (like this)!!

**Pete Bramley**

**Editor**

The 31st Annual General Meeting
for the
National Society for Phenylketonuria
(United Kingdom)
Will be held on
Saturday 20th March 2004
at the
Hanover International Hotel Hinckley,
Leicestershire
Please add this date to your diray
further details will follow…

## Donations

***Donations to 30/06/03 (issue 107)***

**(£30.00 and over)**

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| **In memory of:** | |
| Mrs Emma Gibson | 302.00 |

N S P K U
The National Society for Phenylketonuria (United Kingdom) Limited

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## Chair's Report...

I am sitting down to pen this report early in the morning before the rest of the household is awake. Half-term holidays have just begun and in a matter of hours I must evolve from my role as chair of the society, to my one of taxi driver. My two have a lot to do and see in the short space of a week - all of those things they have been deprived of over the last seven weeks whilst they were working so hard at school. Well, I have a brief opportunity to ponder on what the next few days will bring. The ES.PKU Conference is nearly upon us!

Despite the fact that the NSPKU has been running highly successful conferences for many years now and that Mike has everything running with the military precision he is renowned for, there are still a few flutterings of apprehension in the stomach and a multitude of last-minute queries that need answering. In truth I can't wait to renew old acquaintances and hope to make lots of new ones, and can't wait for the week-end. Don't forget if you are unable to join us, we will be reporting all of the activities and certainly information from the talks in the next edition of News & Views.

Next March our own AGM comes around again and because of the expense of attending, not to mention the work involved in putting on this conference, we are opting to organise another one-day Study Day and AGM, endeavouring to make it as successful as last year's. Again we will be at Hinckley, but as of March 2004 we intend travelling the country again rather than keeping to this central location. Next the north-west, then the south and then the north-east, probably in this order but all will depend on hotel availability and price which is becoming increasingly difficult to keep low, whilst keeping the quality of the hotel high. There is no doubt we have been spoilt at the five star Hinckley International and the excellent rates Mike has been able to negotiate for us.

**Sara Bartlett**
**Chair**

## Sub-Editor's Report...

A few lines to introduce myself to those of you I didn't meet in Leicester at the ESPKU conference! I'm the brand new sub-editor of *News and Views* so please be patient with me! I'm married to Martin and we have two small sons: Seamus is nearly 2 and has classical PKU, Oscar is 6 months old and merely a carrier like his momma and pappa.

In theory, I'm an English teacher but I find mothering two under 2 leaves me with little energy for anything else other than a glass of wine and trashy TV. I'm finding the job of sub-editing *News and Views* really interesting however and it's very uplifting to read all your stories, hints and tips about the challenge of living with PKU.

Martin and I are delighted with both our boys and thrilled that Seamus is doing so well on his diet. We'd love to meet any other PKU families in the Manchester area so please give us a call!

**Kiri Thomas**
**Sub-editor**

## Treasurer's Report...

As I write this we are fast approaching the ESPKU conference but for you reading it now it will be a fading memory, or if you were there, maybe a slightly blurred one!

I (with the not inconsiderable help of Eric Lange my "phone a friend"!) have spent the last few weeks creating, tweaking and fine tuning the budget for this momentous event. I'm sure the cost of an event like this would surprise a few of you (I'll let my husband and the great Mr Bramley drone on about the organisational nightmare). It's not just the cost of food and rooms for which the Society foots the bill for all PKU children and half the bill for the PKU adults. There's also charges for: room hire, the cost of signage and badges, the conference packs and abstracts, the kids' trips, coaches and shuttle buses, the cookery demonstration equipment, the crèche staff and equipment, the speakers' costs, assisted places, the children's party, entertainment, the drinks reception, printing costs, insurance, other equipment hire, sound systems and of course a gratuity for the hardworking staff of the hotel.

Our only method of generating income specifically for the conference is the fee we charge exhibitors for their stand space. Other than this we have to rely on the support of the food manufacturers and suppliers for their sponsorship and the generosity of our members, some of whom make regular donations specifically for conference costs.

I know for many of our members the conference is an invaluable way of meeting other families, discussing experiences, gaining support and of getting new ideas. I personally love it because it's the one time we can go away without having to worry about food and continually thinking ahead to the next mealtime, (although I then worry because I think I've forgotten something!). And for the children, it's a great way of developing friendships with others who share similar experiences to themselves.

Without the assistance we receive these events would soon become a thing of the past so I think we all owe a big thank-you to all who provide the funds to keep this yearly event on the calendar.

**Julia Bailey**
**Honorary Treasurer**

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# Letters

*News & Views*, 48 Hazeldell, Watton-at-Stone, Hertford SG14 3SN
Email: nspku.secretary@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 & Views***

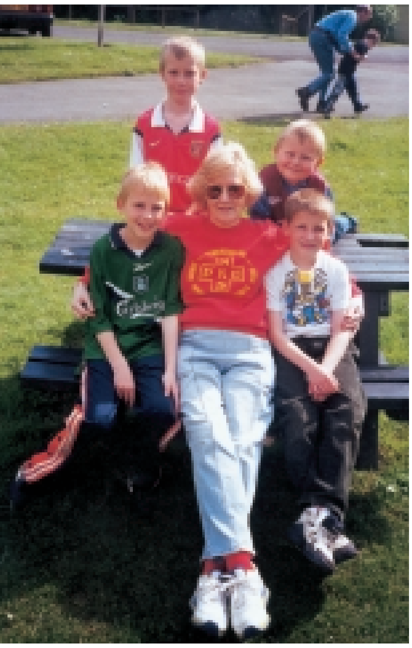
Please find enclosed two cheques totalling £312.30 and a photograph taken at the triathlon at which the money was raised. We have two daughters; Ella (3) has PKU and her younger sister (17 months) who does not have the condition.

The Triathlon took place at the White Horse Leisure Centre in Calne on the 1st June 2003 and was the first Triathlon that I had entered. Cheered on by chants of "Complete not compete" (not that there was any danger of the latter with the former being distinctly unlikely) I began to muddle through the three disciplines. As the only sponsored competitor I felt fairly unique, a feeling that was admittedly heightened by my wearing of garish Bermuda shorts for the swim and by my riding a clapped out mountain bike for the cycle. Braving sniggers and occasional jibes along the theme of "I hope you're raising plenty of money" I "glided" (technical triathlete terminology) past competitors of the 060 class with the consummate ease of one of my more professional colleagues to clinch 75th spot out of 80 competitors.

The enclosed photograph of Ella and myself, which is in fact a reconstruction taken some time after the paramedics had left, nevertheless bears witness to the completion of this ultimate event of endurance. Confined to my bed over the following days I had plenty of time for reflection. As the self-pity gradually subsided it was replaced by a feeling of relief, indeed pride. I realised that on a daily basis my three year old daughter overcomes the challenges of P.K.U. with a good deal less drama and fuss, and for that, as her father, I am truly proud.

Yours faithfully,

***Adrian Roberts.***



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***Dear News & Views***

I would like to share some family news with you. Two weeks ago, we brought our three grandsons, two of whom are PKU, from Bristol for a week's holiday. Christian is aged 14 years, Jack is aged 9 years and Danny who is 12 and non-PKU. To say I was nervous is an understatement! However, we spoke to Anita McDonald the dietitian who supplied the recipes and also some confidence. The low protein foods were at hand a few weeks in advance, and by the time we went to Bristol to fetch the boys, our menu was well and truly set up!

So, I'd like to say to any grandparents, or indeed any member of the family who thinks they can't cope with a PKU diet, to think again because if we can do it, anyone can! The range of food and recipes are so varied. They are simple to make up because of the step-by-step instructions, so that it just takes a bit of effort and a little organisation to prepare meals in advance. Remember three words - Bake, Cook, Freeze - and the rest comes naturally. Mixing the boys' formula each morning in jugs and cups marked with their initials set the day off. One is on Maxamum, the other Maxamaid.

We had some great days out – the boys carried a small backpack with their formula, drink and snacks, and came home to a low protein meal, sometimes fresh, sometimes frozen. Meantime, Mum and Dad were enjoying some free time at home and a well-deserved rest. Let's have a thought for all the Mums and Dads who cater for special diets every day and believe you can do it too if only for a little while. You might surprise yourself – I know we did!

Yours sincerely,

***Shelagh Petterson***

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***Dietitian's Note:***

Well done. The whole family has benefited from the experience. We are currently writing a leaflet for grandparents.

## Contacts

16 year old **Luke Lawson** would love to hear from anyone with PKU in the Nottingham area – especially someone of his age.

Details below.

Luke76@hotmail.com

Address –

118 Ravenswood Road
Arnold
Nottingham
MG5 7FR

*If you wish to make contact with someone else to share your PKU experiences, write to: News & Views Editor, 48 Hazeldell, Watton-on-Stone, Hertford SG14 3SN.*
*Or Email: secretary@nspku.org*

*Dear Sir,*

Please find enclosed a donation for £21.50. This was saved in the family small change pot. We will start again!

Kind regards,

***Paul, Su, Zoe (aged 8) and***
***Toby (aged 5 PKU) Moss.***

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*Dear News & Views*

I write to you with reference to the enclosed cheque for £406.00, which is a donation to your charity.

The funds were raised mainly for family and friends of our staff who attended a barbecue one Sunday afternoon at the end of June. The rest was made up of donations received from people who could not attend on the day. We are hopeful of making this an annual event.

We have enclosed a photo, which was taken in our office as an official hand over of the cheque from myself to Nicole and her granny who is my right hand "man"!

I am sure that you will be able to put this to good use.

Kind regards,

***Mary Fairbairn.***

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*Dear News & Views*

Please find enclosed a cheque for 100 pounds raised for the NSPKU by Richard, Julie and Chloe Saunders, their family and friends by taking part in a 12 mile sponsored walk around Lake Vernwy. Our daughter Chloe who is aged 3 and a half and who has PKU, also took part in fancy dress. We are very grateful for the support and information we receive and would like to show our appreciation.

Yours faithfully,

***Richard, Julie and Chloe Saunders***

---

*Dear News & Views*

Please find enclosed a photograph of my family. My son Jamie (aged 5) has Classical PKU and was recently an usher at his Auntie Carol and Uncle Howard's wedding.

The reception was held at Andover Masonic Lodge where the policy is to raise as much money for charity as possible from functions held at the Lodge. They allowed my sister her choice of charity and she kindly chose the NSPKU on behalf of Jamie. We are therefore very pleased to be sending you a cheque to the value of £350.00.

We would like to thank all of our friends and family for their donations and the Masonic Lodge for their efforts.

PS Jamie is doing extremely well on his diet and I would like to thank his dietitian Judy Wadsworth and Dr. Foote (Royal Hampshire County Hospital) for all of their help.

Yours faithfully,

***Mrs. Angie Haick.***

---

*Dear News & Views*

Please find enclosed cheques totalling 216.09 pounds. Our 3 year old son James, who has PKU, recently lost his much-loved Nan after a sudden heart-attack. Mourners were asked to donate to the NSPKU instead of flowers. We know his Nan would have wanted this and we are grateful she had the chance to see James grow up to be a healthy, happy and very cheeky young man.

Yours sincerely,

***Stephen and Geraldine Smith***

***May we offer our sincere condolences to you and your family regarding your sad loss - NSPKU Council of Management***

## NOTICE

ALL READERS TAKE NOTE
If you wish to continue to receive your "News and Views" please make sure that you return your renewal membership to the Charities Aid Foundation. Anyone who fails to do this will soon be dropped from the mailing list.
(If you have any queries
please contact Julia Bailey)
contact No: 01252 728221

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

# Cover Story - RAF Flying High For NSPKU Once Again!

On Wednesday 3rd September, the junior ranks at RAF Cosford held a charity night in aid of PKU. This isn't the first time the RAF has come up trumps for us so we are especially grateful to them.

The NSPKU is involved with the young daughter of Cpl Micky Doyle of the Station Regiment Flight. £640 was raised for PKU and the junior ranks usual Wednesday night bop saw a great night had by all with performances from the scantily clad girls and funky guys from tribute band "Five Steps to Abba".

The NSPKU really appreciates *all* the effort that our supporters go to in raising much-needed funds for our charity. PKU is usually so well treated that it's easy to forget how much patients and their families rely on resources such as the dietary booklets – all paid for by the society. Without these publications and other help given, the diet would be extremely difficult to follow, offering a lot less variety, and becoming very inconvenient. Nobody could say that the PKU diet makes life easy, but with your fundraising support, we go a long way to fitting it into normal, modern, busy lives. So, well done RAF Cosford and everyone else who raises money for us and keep it up – we need it!

# The Clinical Psychologist

## By Claire Rowlands

In January this year, our daughter Tesni who was then approaching three, decided that she wasn't going to "do" Maxamaid anymore. It had been hard work to persuade her to drink her supplement for several months up to this point and tears, complaints and downright refusal always greeted its appearance. I could spend two or three hours a day trying to persuade her to drink it, and one five-ounce bottle could take over an hour to drink. However, after a nasty bout of flu in December (when she did not take any Maxamaid at all for six days) and a Christmas holiday at Grandma and Grandpa's house, her routine had become so disrupted that she seemed to think that Maxamaid was an option she could refuse! She was only drinking about half the required amount and even that was accompanied by more protests and upset and endless hours with Mummy in front of Ceebeebies *pretending* to drink her Maxamaid from a bottle. We tried various flavourings and other supplements, pink cups, straws and sneaky ways of slipping the bottle into her mouth while she slept, all to no avail.

It's not always easy to ask for help, especially when you want the medical team to think that you're doing a good job, and when you don't want to admit that this thing is beyond you, but we couldn't hide the truth from Tesni's dietitian, Sheila Dawson! When she regularly saw Tesni's level going not just off the scale but off the sheet of paper, she stepped in and asked us how we would feel about being referred to Anna Brazier, a clinical psychologist. I had mixed feelings at this point. To begin with, I was hugely relieved that help was available and that somehow, we might just be able to persuade Tesni to drink her supplement without the accompanying drama. At the same time though, I was apprehensive about sharing what I saw as my failure as a mother with anyone – and what is a clinical psychologist anyway?

I needn't have worried. With Tesni happily settled at nursery, her Dad and I went to see Anna.

To begin with, we discussed the problems that we had been experiencing not only at Maxamaid time, but also with other aspects of Tesni's behaviour such as the battle of the seat belt and the toothbrush wars. We came to realise that we felt unable to control or change her behaviour and that if she refused to do something, it wasn't worth fighting about because we could never win. She had us all wrapped around her little finger because as every parent reading this knows, getting the child to drink the supplement is all that matters – you will do anything to get them to drink it and they know it!

Anna suggested that we keep a note of three things: who did what, when and how we reacted for the next few days. A typical entry would read something like:

| | |
|---|---|
| 12.30 | Mum told Tesni to come for lunch. Tesni declined. Mum ignored. |
| 2.00pm | Tesni refused afternoon Maxamaid. Mum spent an hour trying to persuade her while Tesni played. |

When we returned to Anna with reams of notes, a few things soon became glaringly obvious. Firstly, only Mum administered the Maxamaid (not Dad or anyone else), secondly, Tesni got lots of attention for *refusing* to take her Maxamaid, and thirdly, once she had decided to drink it, it was accompanied by a long cuddle and a session in front of the video with Mum. Interestingly, there was never a problem with taking her bedtime drink, which she had in bed while we read stories.

Having identified this behaviour, Anna could then suggest some strategies to help to change things around. She suggested that there should be some ground rules – one or two things in Tesni's routine that were equally as non-negotiable as her milk. We also decided that, if she refused to take her milk, I should remove myself and go and do something else instead of giving her the attention she was used to – in a calm and pleasant manner of course! Finally, Tesni should know that if she drank up all her milk quickly, there would be time for a favourite activity such as gluing and glittering, going to soft play or even wearing her best stripy tights to nursery! You could call it bribery, or you could call it positive consequences, but the point is that it WORKED!

The first time I tried this, when I said, "OK, we'll have your milk later, I'm going to wash up," Tesni followed me out the door shouting "BUT I WANT TO DRINK IT NOW!" And she did. Wow. I think that the combination of simple, invariable ground rules and ensuring that she gets the positive consequences and attention she loves when she drinks her Maxamaid and not when she doesn't are the keys to our success. She now drinks most of her Maxamaid on most days and there is rarely a fuss. Because she has something to look forward to, she

# and Me

tends to drink more quickly too. A couple of weeks ago she surprised us all by suggesting that Daddy should give her her milk, so progress is being made there too. The next thing is to wean her off the bottle and to persuade her to drink independently. These are proving more difficult, but we are making slow progress (using positive consequences again!) and, of course, the important thing is that she is taking her Maxamaid and in doing so is not ruining family life anymore!

This is what happened in our family. Every child and every family is different so what worked for us might not work for everyone, but the most valuable things that I found were these:

> Keep a chart over a few days of who does what and when and the consequences. You might see a pattern or be able to identify behaviour that could be turned around. *Make sure you record when things go well as this may give you clues for which steps to take next. Remember to take into account your child's age and developmental stage when looking at making changes.*
>
> The child should know that positive consequences will follow when the supplement has been taken – even if this is just praise. *Make a point of working out what your child really likes, look at consequences that fit with your child and your family and are simple to put into place. Tesni's stripy tights are a good example – when she takes her milk she gets to wear her favourite tights.*
>
> The child should be given attention for "good behaviour" (i.e. complying!) and not for refusing to comply. *Remember attention includes lots of persuasion and even shouting! Make sure you are not "rewarding" the behaviour you don't want by mistake.*
>
> Establish some simple ground rules that are non-negotiable, and stick to them! *Choose something realistic and if there are other adults around, choose something you can all agree about*

I hope this is useful. To quote that great philosopher Pete Bramley: "The diet takes some doing, the administering of the diet is even harder for the younger ones and even harder for the older ones and even harder on us all. If we don't help each other, it gets even harder. Just one bit of help can make it much easier." Yeah.

Comment from Anna Brazier: *Although I have worked with children and families who are facing all kinds of medical conditions, I had not previously worked with a family where a child had PKU. When I had done some homework about PKU prior to meeting Tesni and her family, I was thinking about how difficult it must be to try to keep calm about something as important as Maxamaid. It struck me how quickly children must learn that parents would probably do anything to make sure that they have their special milk. As it turned out, Tesni had learned that lesson very well. I wonder if that rings bells for other parents?*

*Claire's initial reaction to the referral was one which many parents describe to me once they know me better. No one wants to feel that they might be criticised as a parent and I think these feelings run particularly high when a child has a medical condition. Her second comment "what is a clinical psychologist anyway?" reflects the fact that there are not many of us about.*

*Clinical Child Psychologists have a psychology degree and a postgraduate degree in Clinical Psychology. This means that they take a psychological approach to whatever difficulties are brought to them. In practice that means talking about behaviour (who does what when), talking about a child's development, temperament and relationships, and about the particular challenges of the child's medical condition. Naturally, the talking will focus on different aspects of family life depending on the difficulties encountered. Usually some time is spent trying to understand the difficulty and the context in which it happens (and doesn't happen). Very often a discussion together with taking time to think, allows parents to come up with ideas, after all, it is they that know the child best. Our training helps us to ask the right questions to get the discussion going in a problem solving way. We also have time to consider the emotional impact of having a child with a medical condition. Sometimes in busy outpatients clinics it can seem as if everyone is just getting on with it without a problem and parents can feel quite isolated.*

*Even if there are no clinical psychologists attached to your unit, many dietitians have access to one. Sometimes someone might be available to run a one off discussion group, or to problem solve with the dietitian if you've got a bit stuck about what to try next. The important thing to remember is that most parents encounter this kind of difficulty at some point and that there is usually someone in the team who can help if you take the initially difficult step of asking.*

***Claire Rowlands***

# Jonathan Trace Runs London Marathon in Aid of Birmingham Children's Hospital

Jonathan Trace ran his first London Marathon and raised a staggering £5,600 for PKU. Jonathan, aged 43, ran the exhausting 26 miles of London's cobbled streets in a time of 3 hours and 54 minutes.

Jonathan from Tapestry Productions said, "It was an extremely tough event but I kept going knowing the money I would raise would be to help children with metabolic disorders. One of our staff has a daughter who attends the PKU clinic at Birmingham Children's Hospital."

Anita McDonald Head of Dietetics said, "This is a very generous donation from Mr. Trace which we will use to set up a metabolic disorder database to assist us to look at trends with children with PKU."

The 31st Annual General Meeting
for the
National Society for Phenylketonuria
(United Kingdom)
Will be held on
Saturday 20th March 2004
at the
Hanover International Hotel Hinckley,
Leicestershire
Please add this date to your diray
further details will follow…

# Wild Wild West (Yorkshire)

Glorious August sunshine set the scene for the annual PKU day conducted and orchestrated by John & Sharon Skidmore in Normanton, West Yorkshire.
Stalls Included:
Tombola stall
Raffle
Draw
Kids entertainer
Toiletries stall
Calendar – stationery
Plants / flowers
Card stall

The seclusion of a private cul-de-sac provided the perfect setting for a congenial afternoon of fun, festivity and fundraising in aid of the NSPKU, an annual soiree hosted by John Skidmore and wife Sharon in Normanton, West Yorkshire. The gods were kind and bestowed glorious weather for a perfect fun day.

John, regaled in a western Stetson greeted all comers with a cheery, cheeky Yorkshire grin. Each was pointed in the general direction of Graham and Mary who issued fantastic culinary fare and refreshments and then sent out in the "market place" to have their pockets, wallets and purses summarily emptied. The method of emptying said pockets included Tombola, Raffle and host of stalls.

Families of children with PKU from across the region attended and well over 100 people attended throughout the day.

The raffle was drawn towards the end of the day, when the twelve lucky winners were announced. Donations received before, during and after the event helped the total amount raised reach a staggering £1050. Who said those Yorkshire folk were tight!

John and Sharon aim to help families support each other by coming together to share experiences, have fun and raise funds for NSPKU. They truly appreciate all the help and support they received so freely from everyone to make this event such a huge success.

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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 over 120 ready meals and snacks all suitable for PKU sufferers.

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 sufferers in the UK with the opportunity to purchase ready made meals, breads, cakes and sweet and savoury snacks at supermarket prices.

*Available now in Scotland, Manchester, Newcastle, Birmingham, Leeds, Liverpool – Available shortly in the rest of England, Wales and Ireland.

**Phone Leanora or Pauline on 07773 342594**
24 hour answering machine 0141 616 3350
Fax 0141 639 7624 e-mail sales@yeswecookthat.com
7 Capel Avenue, Newton Mearns, Glasgow, G77 6EL

# The Italian Job

**New Loprofin Lasagne sheets are just the 'Italian' job and are an addition to the authentic low protein Italian pasta range from SHS. Ideal for cannelloni as well as lasagne they do not need to be pre-soaked before cooking.**

**Each 75g portion contains:**
**Energy 148kJ, 270kcal and Protein 0.3g**
**of which phenylalanine 7.5mg.**
**Available on prescription in 12 x 250g boxes.**

**For more information on Loprofin Lasagne sheets please contact Nutrition Services on 0151 228 1992**

SHS

SHS International Ltd, 100 Wavertree Boulevard, Liverpool L7 9PT, United Kingdom. Tel: +44 (0) 151 228 8161 Fax: +44 (0) 151 228 2650 Internet: www.shsweb.co.uk

# SHS recipes

## French Style Lasagne

**Ingredients**

- 390g can Ratatouille
- 4 x 15mlsp (4tbsp) homemade vegetable stock or water

**Sauce:**

- 1 x 200ml cartons **Snopro Low Protein Drink**
- 15g (½ oz) butter
- 15g ( ½ oz) **Loprofin Low Protein Mix**
- 1 x 5mlsp (1tsp) French wholegrain mustard, optional
- Salt and pepper to taste
- 6 sheets **Loprofin Low Protein Lasagne**
- 2 x 12.5cm x 10cm (5inch x 4inch) ovenproof dishes or foil containers
- Oven temperature: 200 C/400 F/Gas Mark 6

### Method

❶ Combine the ratatouille and stock in a medium sized bowl
❷ Pour the **Sno-Pro** into a pan, add the butter and heat gently until melted. Whisk in the **Loprofin Low Protein Mix**.
❸ Bring to the boil, stirring briskly to achieve a smooth sauce. Stir in the mustard and adjust seasoning to taste.
❹ Spoon about a third of the ratatouille mixture over the base of the two ovenproof dishes. Cover each with a layer of **Loprofin Lasagne sheets,** breaking the sheets to fit the dishes.
❺ Repeat the layers, finishing with lasagne sheets, then cover with the sauce.
❻ Place the Lasagne in a preheated oven for 25 minutes, until the top is golden brown. If desired serve with a crisp salad
❼ Serves 2

### Tip

Keep the lasagne sheets in a single layer, so that they will cook evenly, in contact with the sauce.

## Christmas Window Biscuits

**Ingredients**

- 100g (4oz) hard margarine, at room temperature
- 50g (2oz) caster sugar
- 160g (6 ½ oz) Loprofin Low Protein Mix
- 15g ( ½ oz) custard powder *
- 3-4 x 5mlsp (3-4tsp) **Loprofin PKU Milk Drink**
- Approx. 16 boiled sweets, broken into small pieces *
- Oven temperature: 150 C/300 F/Gas Mark 2

### Method

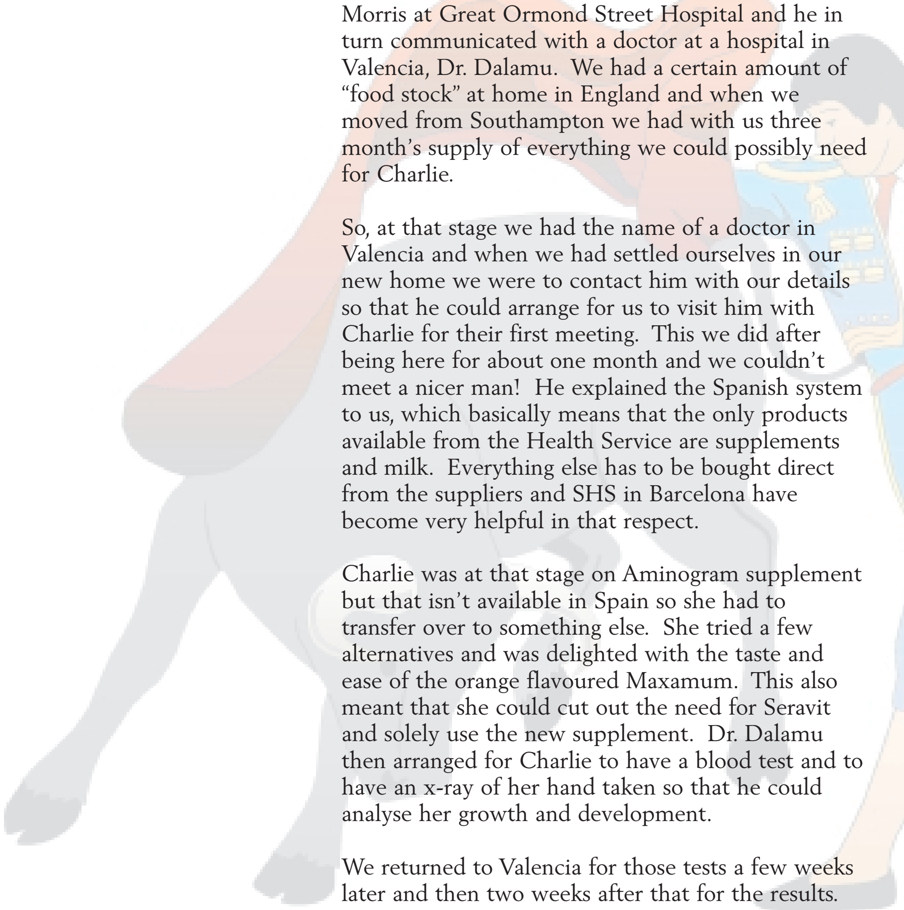
❶ Place the margarine and sugar in a mixing bowl and beat well, until light in colour and texture.
❷ Stir in the **Loprofin Mix** and custard powder.
❸ Using one hand, stir and squeeze the mixture until it comes together, adding sufficient **Loprofin PKU Milk Drink** to give a manageable dough.
❹ Transfer to a surface lightly dusted with **Loprofin Mix** and knead the dough for about 30 seconds, until smooth.
❺ Roll out the dough to about ½ cm ( ¼ inch) thickness, on a surface lightly dusted with **Loprofin Mix.**
❻ Cut out shapes, using a 7.5cm (3inch) star or heart cutter and using a 3.5cm (1 ½ inch) cutter, cut a smaller star or heart from the centre of each biscuit.
❼ Re-roll the trimmings and carry on cutting out the shapes, until all the dough is used.
❽ Transfer the biscuits to lightly greased non-stick baking trays and bake in a preheated oven for 15 minutes, until pale golden in colour.
❾ Remove from the oven and spoon broken boiled sweets into the centre hole of each biscuit, return to the oven for a further 5 minutes.
Allow the biscuits to cool slightly on the baking trays, carefully remove from the trays and complete cooling on a wire rack.
Makes approximately 20 biscuits

### Tip

**NB**: The biscuits can be used as 'tree decorations' – make a small hole in the biscuits, before cooking. Thread a piece of ribbon through the hole in the cooked biscuits, which can then be used to hang them on the Christmas Tree.

***Check with NSPKU Food List re. suitable brand.**

# Hola PKU!



Myself, my husband, our 13 year old daughter Charlotte and our family Labrador, Toby moved form Southampton to Spain in June 2002 for a completely different lifestyle and I'd like to tell you a bit about our experiences so far during the 12 months that we have lived here.

Charlie has PKU and when we first decided to move here, she was our first priority. We spoke to Dr. Morris at Great Ormond Street Hospital and he in turn communicated with a doctor at a hospital in Valencia, Dr. Dalamu. We had a certain amount of "food stock" at home in England and when we moved from Southampton we had with us three month's supply of everything we could possibly need for Charlie.

So, at that stage we had the name of a doctor in Valencia and when we had settled ourselves in our new home we were to contact him with our details so that he could arrange for us to visit him with Charlie for their first meeting. This we did after being here for about one month and we couldn't meet a nicer man! He explained the Spanish system to us, which basically means that the only products available from the Health Service are supplements and milk. Everything else has to be bought direct from the suppliers and SHS in Barcelona have become very helpful in that respect.

Charlie was at that stage on Aminogram supplement but that isn't available in Spain so she had to transfer over to something else. She tried a few alternatives and was delighted with the taste and ease of the orange flavoured Maxamum. This also meant that she could cut out the need for Seravit and solely use the new supplement. Dr. Dalamu then arranged for Charlie to have a blood test and to have an x-ray of her hand taken so that he could analyse her growth and development.

We returned to Valencia for those tests a few weeks later and then two weeks after that for the results. He was delighted with the results and confirmed that we are doing everything correctly. It was during that visit that I asked about other low protein products and he invited the dietitian to join us. She in turn escorted us to the hospital storeroom and filled several boxes with biscuits, flour, bread, and Duocal, which was extremely kind of them.

So that was our last visit to the hospital but we keep in touch with Dr. Dalamu by email and phone and he advises us when we should take blood tests. Initially we took one after one month but now he is happy for us to wait two months. With each blood test we have to provide a complete list of everything that Charlie has eaten that day, the first one I did in English but since then the Spanish has improved so now we do it in Spanish!

All in all the experience so far has been interesting and relatively straightforward. There are little things which are awkward such as the bread that Charlie liked now being unavailable to us. She always enjoyed the Rite Diet bread but we just cannot get that here. So, I make bread instead which according to Charlie isn't as nice but is OK! We also use the Ener G low protein cheese for pizzas. So far I have managed to bring it over with me when visiting parents in England but I did speak to the company in England recently and they are more than happy to send some to us.

Living in Spain is fantastic. PKU isn't a problem for us, it never has been. We have never treated PKU as an illness and it has never stopped us travelling over the world. Charlie is a very adaptable young person and the lifestyle and climate here along with the abundance of fresh fruit and vegetables make it a perfect place for the family to live and a teenager to grow up.

I shall include my email address if anyone has any comments or questions but to anyone out there wishing to do something similar, it can be done and there are always alternatives to anything that you or your child is used to.

***Debbie, Stuart and Charlotte Eason***
***debsandstu@hotmail.com***

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Special Foods ™

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**MIXED IN ONE MINUTE**
**OMELETTES AND SAUSAGES THAT LOOK LIKE THE REAL THING**
**EASY TO ROLL PASTRY**

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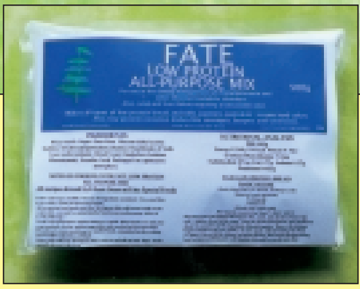
only 1.6mg phe per 100g



**FATE LOW PROTEIN ALL-PURPOSE MIX**
only 5.2mg phe per 100g

**FATE LOW PROTEIN CHOCOLATE FLAVOUR CAKE MIX**
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***EVERY PACK CONTAINS EASY TO FOLLOW RECIPES DEVELOPED BY EILEEN GREEN***

> *“As a mum with two daughters who both have PKU, I fully understand the low protein way of life. We all know that low protein food is different, but just because it is different it doesn't mean that it can't be as good. I have developed these new mixes so that everyone can make great low protein food”*
>
> Eileen Green

***Just ask your Doctor to prescribe these new products 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 ~ SPECIAL FOODS FOR SPECIAL PEOPLE**

# Appeal For Information

**Dear News & Views**

I have a 7 year old daughter, Holly, who has PKU and is currently allowed 8/9 exchanges per day.

Holly takes a packed lunch to school, but rarely eats her sandwiches. She is fed up with the usual fillings, ie Jam, Lemon Curd, Enger-G Cheese, Choc Spread, Heinz Sandwich Spread, Banana or Cheese Spread. I have tried other things such as Honey, Mushroom Pate and Salad, but she doesn't like them.

I would love to hear from other families who have experienced similar problems and who may be able to offer some different ideas for sandwich fillings.

Can you please help.

**Regards**

**Lisa Chambers**

**lisaanddavechambers@hotmail.com**

# 2004 Spring Draw

First prize : **£500.00**
Second Prize: **Microsoft X-BOX**
Third Prize: **Personal CD Player**
Plus many other **valuable** prizes

**Dear Member**
This is our major fundraising activity of the year -all proceeds going towards those with P.K.U .
We are enclosing Raffle Tickets to the value of **£15** for you to buy or sell on our behalf.

**The prize for selling the most tickets is a free place at the NSPKU Conference in March 2004….**

* WIN A FREE JUICER IF YOU SELL MORE THAN £75 WORTH OF TICKETS *

HAVE A GO AND RAISE AS MUCH AS YOU CAN

NOTE
All counterfoils, money and unsold tickets should be returned no later than **29th February 2004**.
Any cheques should be made payable to **NSPKU**. **DO NOT SEND CASH**.
If you feel you are unable to take part on moral or religious grounds, please return the tickets to the Spring Draw Officer, but please consider making a donation to the Society.
The Prize Draw will take place at the Annual Conference on

**Saturday 6th March 2004 at The Hanover International Hotel, Hinckley , Leicestershire**

**Eric Lange**
NSPKU Spring Draw
27 Western Road
Sutton Surrey SM1 2TE

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REQUEST FOR FURTHER BOOKS - send your request to the above address

Please send me a further …………………….. books .

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# Fate Special Foods recipes

## FATE THIN AND CRISPY PIZZA

***Hello,***

This time my recipe is a Thin and Crispy Pizza. I hope you enjoy it as much as we do!
*This pizza uses the recipe for Fate flat breads, to make the bases. They are very easy and quick to prepare. The pizzas look good if you make them about 10 – 12 inches in diameter, so it is best if you have a frying pan this big.*

*I've written the recipe so you can make two large pizzas, this way you can have one to bake and eat, and one to freeze for another day.*

*For the tomato topping we use Tesco's original Pasta sauce, (the stuff that comes in a jar) and then a sprinkling of any vegetable we have such as sliced onions, peppers, mushrooms, olives, etc.*

*Just a note~ the one thing you can't forget is oregano. A pizza is not a pizza without Oregano! It's good with basil as well, but oregano is* ***the*** *taste of pizza. You can also add a sprinkling of dried chilli flakes if you like a spicy kick to your pizza.*

### Ingredients

**For the topping:**

Jar of Tesco's Tomato Original Pasta sauce or similarly allowed sauce.
1-2 tsps dried oregano
1-2 tsps dried Basil
1 medium onion, sliced
few slices red or green pepper
few mushrooms, sliced
12 ~ 16 black olives
Dried chilli flakes (optional)

**For The Bases:**

150g Fate Low Protein All-Purpose Mix
1 tsp salt
½ tsp baking powder
50 mls oil
100 mls water
Extra Fate All-Purpose Mix for shaping.

### Method

First of all, prepare the vegetables for the topping, they have to be lightly cooked. This is best done in a microwave oven ~ Place the sliced onion, peppers, and mushrooms onto a microwaveable plate and cook in the microwave on high for a couple of minutes until just soft. The time of cooking will vary for different microwaves, but the vegetables should be lightly cooked and not too soft. Leave to cool.

*Then make the thin and crispy base:*
Pre ~ heat the oven Gas 6. 200°C 400°F

Place the Fate All-Purpose Mix into a mixing bowl, and add the salt and baking powder. Stir well. Add all the water and all the oil. Use a large metal spoon to quickly stir the mixture until it is smooth and blended well. Leave to rest for a couple of minutes. Place a large frying pan over a gentle heat. (Do not add any oil).

Place a piece of cling film onto the work surface and sprinkle with a little extra Fate All-Purpose Mix. Take about half the mixture and roll it into a ball in your hands. Place the ball onto the cling film, and using a rolling pin, roll out the dough large enough to fit your frying pan. (Remember there is enough mixture to make 2 x 12 inch pizzas)

Carefully take the rolled out base and using the cling film to help you, gently lift the pizza base onto your hand, and transfer it into the hot frying pan. Leave it to cook for about 30 seconds, and then turn it over to finish cooking. (The pan should be hot enough to give the base a bubbly, speckled brown appearance on both sides) Do not over-cook. Repeat with the remaining dough to make another pizza base.

Place the cooked bases onto a large baking sheet, (there is no need to grease) Spread about 3 tbsp of pasta sauce on each. Sprinkle with dried Oregano and Basil. Add a few chilli flakes if liked. Then arrange the cooked onion, peppers, and mushrooms on top, and add a few black olives.

If you are only cooking one pizza, place it into a pre ~ heated oven for about 10 – 15 mins until really hot and crispy. Meanwhile, place the one for freezing in the freezer and wrap it well when it is frozen. Defrost before cooking in a pre ~ heated oven

Best wishes,
Eileen Green - Fate Special Foods

# Dietitian's Report

## COCONUT MILK

In the last food analysis for phenylalanine we had fresh coconut milk analysed. Please note this was for **fresh** coconut milk and **not** tinned coconut milk. The tinned milk frequently contains the pressed coconut kernel and so has a higher protein content. If you use tinned coconut milk you must go by the protein information on the tin. Tinned coconut milk is not free. Fresh coconut milk is free.

## AMINO ACID ANALYSIS

The next group of 10 foods

*Are there any foods which you think would be useful to include in our list for analysis? Is there a fruit or vegetable which you would like to use but it isn't in the lists and so you avoid it? Please get in touch with me and I will put it down as a possibility and then we will analyse the most popular suggestions. Each analysis costs us around £120 so if you are thinking of doing some fundraising this yearly project might be something you would like to help with so that we can keep on introducing new foods to the diet.*

## SAINSBURY'S FREE FROM RANGE

**Gluten, wheat and dairy free savoury biscuits**

*These biscuits, which were mentioned as a useful product in the last issue (number 106) of News and Views have been incorrectly labelled as containing 0.2grams protein per biscuit. They should be avoided until the correct information is available and their suitability can be re-assessed.*

## SHS INTERNATIONAL LTD

**Low protein Snack Pot Curry Flavour**

***One of our members packed the low protein curry pots in their suitcase which went in the hold of the plane. Unfortunately because of the low pressure in the hold the pots burst open and the father of the family smelt of curry all holiday!***

I have spoken to SHS about this and they confirm that it has happened to them when transporting the pots in the hold (around one in five pots burst). They advise that the pots be taken in hand luggage only and because the pots and lid seals are fragile to bubble wrap put in a plastic bag for safety.

## ANYONE FROM WALES?

*A pharmacist from Mold in North Wales contacted me recently after reading our information on the web site. In Wales all prescriptions for age 24 and under are free.*
*Well done Wales!*

# Dietitian's Report

## LILT FIZZY DRINK

*The grandmother of a child with PKU sent me an email about Lilt. Lilt (made by the Coca-Cola Company) now contains aspartame.*

*Lilt used to be OK in the PKU diet but the recipe has changed.*

*Please take care to always read the labels on foods and drinks very carefully as recipes do change. You always need to be a food inspector!*

*A 330ml can of fizzy drink sweetened with aspartame will provide 2 exchanges (100mg of phenylalanine)*

*That's a lot!*

## ASPARTAME FINDS A PARTNER

*Aspartame-acesulfame K*

*There is a new sweetener available which is a chemical combination of aspartame and acesulfame K. These two sweeteners are combined in the ratio of 1:1*

*The salt of aspartame-acesulfame has been given what is known as 'temporary national authorisation' in the UK. This came into force on May 27th 2003. This type of authorisation is permitted for a maximum of two years. During this time the manufacturer of the new additive is required to seek the necessary changes to European legislation. The European Commission must publish a proposal to amend the relevant existing laws to include the new additive on the positive list. The Member State must also ensure that foodstuffs containing the additive are officially monitored.*

*With regard to labelling, the salt of aspartame-acesulfame must adhere to the labelling requirements of its two parts. Therefore, a food containing the sweetener salt of aspartame-acesulfame must be marked with the indication "contains a source of phenylalanine"*

## NEW AND USEFUL MANUFACTURED FOODS AVAILABLE IN SUPERMARKETS MORNING FARMS BREAKFAST STRIPS

*By the time you read this many of you will have tried these look alike 'bacon' strips. The strips can be found in the frozen vegetarian section of the major supermarkets. It looks like streaky bacon and one strip provides one exchange of protein. (There is no meat in this food) So now the PKU diet can provide a 'bacon' sandwich using streaky strips!*

## THORNTON'S SWEETS

*Thornton's have now started to include nutrition information on their packs where there is room to do so. There are a number of sweets which are suitable, some I mentioned in last month's issue. Check the labels and anything with a protein content of 0.3g protein per 100g or less does not have to be counted. Please make sure that the protein content you are looking at is the figure for 100g of the product* and not *for the item. This is important. Please ask your dietitian if you are unsure about this rule or the suitability of a food.*

Eleanor Weetch
Society Dietitian

The 31st Annual General Meeting
for the
National Society for Phenylketonuria
(United Kingdom)
Will be held on
Saturday 20th March 2004
at the
Hanover International Hotel Hinckley,
Leicestershire
Please add this date to your diray
further details will follow…

NEW

# Fasta Pasta

Available on Prescription for Phenyketonuria

## at lasta...

Ideal for modern day living the unique new Loprofin low protein Snack Pot from SHS is a quick and simple to use convenience food.

Just add boiling water and you have savoury curry flavour pasta in only a few minutes, ideal as a snack or as a part of a main meal.

## ... low protein snack pot

Each 47g pot contains: Energy 694kJ, 165kcal, Protein 0.9g of which phenylalanine 23mg (½ an exchange per pot).

**For more information on the Loprofin Snack Pot, please contact our Nutrition Services Department on 0151 228 1992.**

SHS

SHS International Ltd, 100 Wavertree Boulevard, Liverpool L7 9PT, United Kingdom. Tel: +44 (0) 151 228 8161 Fax: +44 (0) 151 228 2650 Internet: www.shsweb.co.uk

# NSPKU *Direct*

## Help support NSPKU!

We now sell a wide range of merchandise, please use the form below remembering to state the size and colour (state a 1st and 2nd choice) where applicable. For postage and packing prices, see table below. Please fill in the form below and return to Sara Bartlett at the address shown.

**Sara Bartlett**
*(Merchandise)*
16 kempton Drive
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Notts, NG5 8EU
Tel: 01159 202089

## Order Form NSPKU *Direct*

| Product | Size | Colour | Price | Quantity | TOTAL |
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| Adult Poloshirts *(Red, White, Navy, Jade, Grey, Wine)*<br>*S. M. L. XL. XXL* | | 1ST CHOICE:<br>2ND CHOICE: | £9.00 | | |
| Children's Sweatshirts *(Red, Black, Grey, Navy, Wine)*<br>*3-4, 5-6. 7-8, 9-11 years* | | 1ST CHOICE:<br>2ND CHOICE: | £8.00 | | |
| Children's Poloshirts *(Red, White, Navy, Jade, Black, Dk Green)*<br>*3-4, 5-6. 7-8, 9-11 years* | | 1ST CHOICE:<br>2ND CHOICE: | £6.00 | | |
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