

# **NSPKU** News & Views

The National Society for Phenylketonuria (UK) Ltd

Issue 106

## Inside this issue...

Maternal PKU

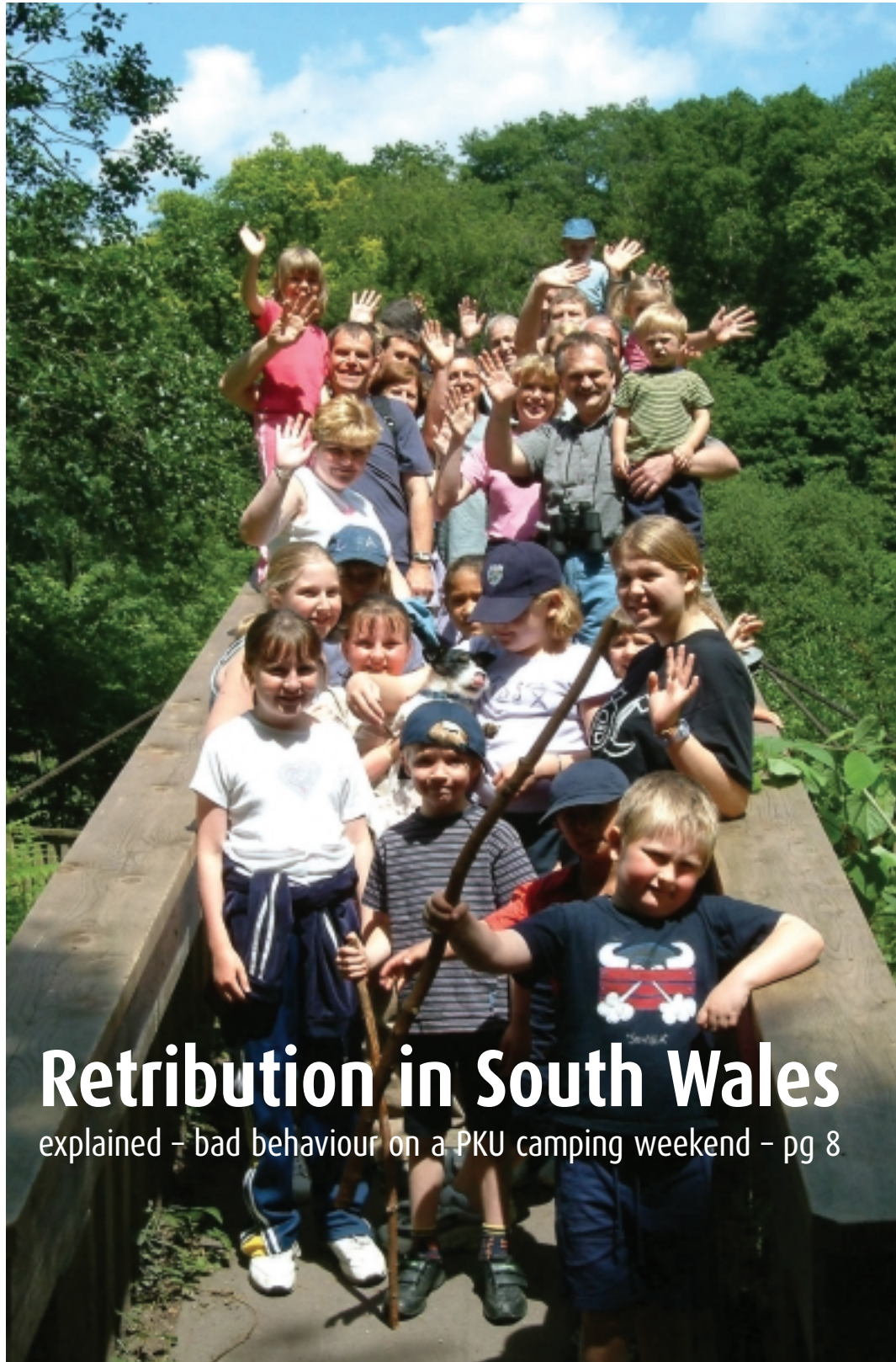
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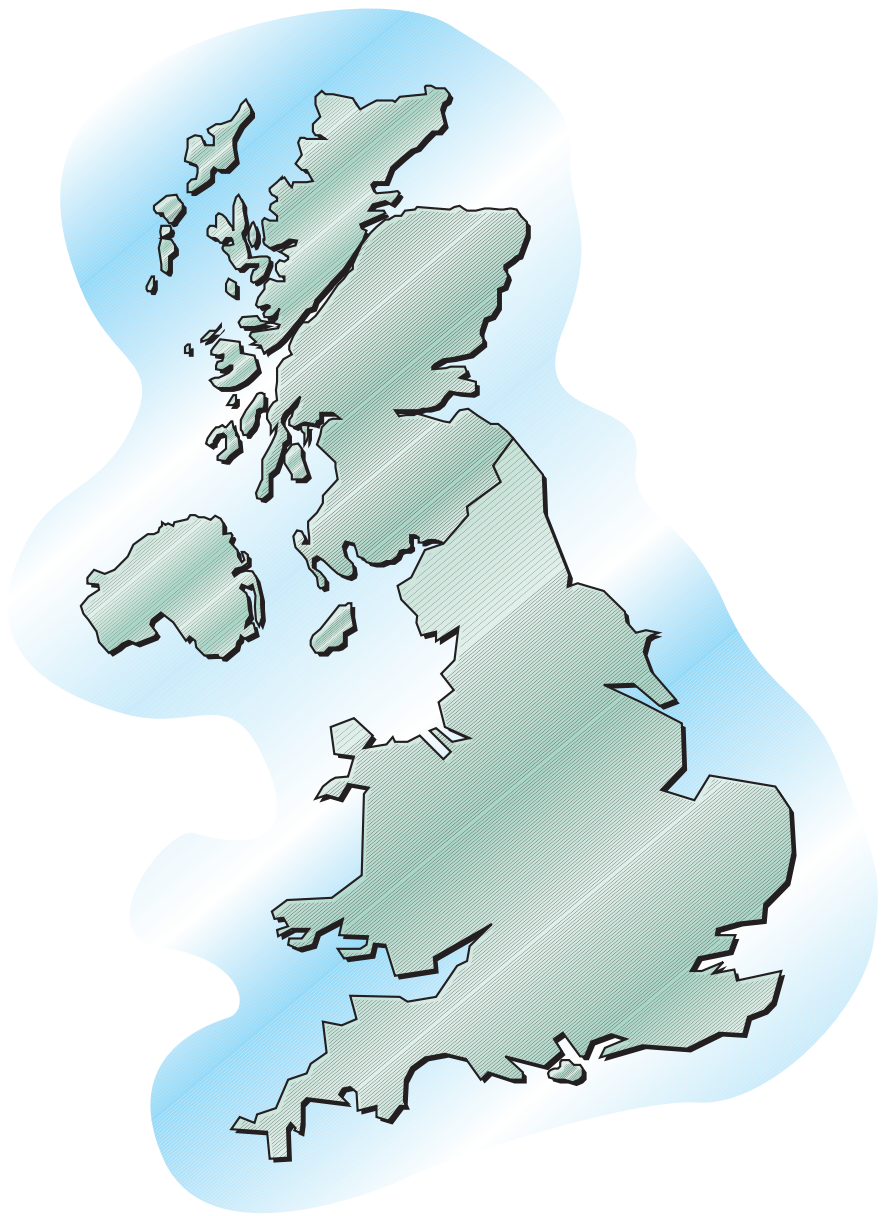
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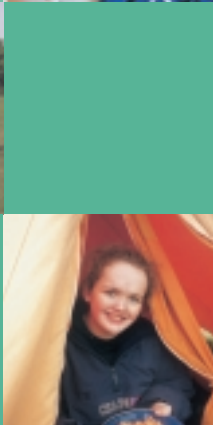
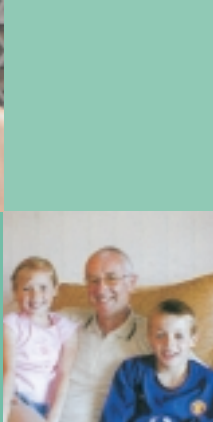
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## Editors Report...

*Check out John Skidmore's report on his PKU experiences at sea as regards the diet. Very interesting. I don't think for 1 minute that everybody can afford a cruise (and there is absolutely no chance of getting one on prescription) but the article serves to highlight three important issues.*

Number 1 – Boats can make you uncontrollably sick and sink when they hit hard objects.

Number 2 – Boats are extremely slow. So if you want to get somewhere fast, walking is much quicker (obviously walking on water is much harder unless you are a politician)

Number 3 – The Head Chef on board of the boat was not just accommodating but was obviously quite a nice guy. He was representing his company also. (Fred.Olsen Cruise Lines, you are now officially the preferred supplier for holiday cruises for the PKU community – our thanks to your accommodating staff)

Now this is where I take issue with the non-PKU population. If we, as an established PKU community can “get on with it”, what is the problem with the people who aren't interested or see that it is below them to cater for the diet? To make that slight adjustment to their sacrosanct regime.

I'm on my political podium now and it's going to take some shifting to get me off it.

I know of a family who went to a holiday resort in Europe. It was near Paris. There was a mouse there with big black ears and other such characters. This family stayed in a hotel, which

was on site. They ate there. The waiters wouldn't even let the family put their PKU bread through the restaurant toasters. The child went without.

You see. When it comes to customer care the two holiday venues are not comparable when it comes to PKU.

The difference is outstanding. On one hand all the help and support you need for the diet and the other.....unprintable.

Me? I'm going for swimming and walking on water lessons and (given the heavy plug) a discounted cruise courtesy of Fred. Olsen.

And in true legal style, I'm sure that this body of text will not prejudice any future court proceedings brought against the Society (NSPKU) or myself.

**Pete Bramley**

Editor

**NSPKU**  
The National Society for Phenylketonuria (United Kingdom) Limited

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the  
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at:

www.nspku.org

## Chair's Report...

I just can't believe how fast the year is flying past. No sooner is the AGM over than preparations for the ES.PKU conference begin in earnest. Later in July the COM are having a big meeting to finalise arrangements. In fairness to Mike, Pete B and Eleanor, work has been going on for some time already, as you would expect.

The Hanover Hinckley has shown us what it can do at the AGM, and now we are encouraging them to go that little bit further and help us put on the biggest, and hopefully the best, conference we have ever had.

Families are booking from all over Europe so for those of us who think, 'I'll do it tomorrow', I suggest you think about booking today. Especially families who wish to be roomed together because as with all hotels, family rooms are limited and will go on a first come first served basis.

We are looking forward to showing other countries the level of care provided for people with PKU here. Don't forget, many countries look upon the care given to PKU's in Great Britain as an ideal to strive towards. Add to this the enthusiasm of our medical profession to take part in research and the continual re-assessment and improvement of the diet that is ongoing, and you can see why so many are keen to come and see what we do first hand.

Don't be shy about coming and mixing - the family next to you may be more concerned than you, and be grateful for your interest and conversation. Try to come, if only for a day, and talk to the families there, exchange ideas, support and make new friends, or even pen-friends.

Remember, if you cannot afford the whole cost of attending then contact Mike Bailey for an application for sponsorship for the amount you are unable to pay. As usual the funds set aside by the society for this purpose are limited and although given to those whose need is considered the greatest, will also be awarded to those whose application is prompt.

See you in October!

**Sara Bartlett**  
Chair

## Treasurer's Report...

The collection of membership fees via the Charities Aid Foundation (CAF) has proved to be a fairly painless process. However there are a few of our members both literary and family who have continued their standing orders and direct debits into the Societies account. This creates needless extra work for both CAF and ourselves. It may also result in those members not appearing on our membership list and therefore not receiving future publications. I would therefore ask that all members ensure that they return their renewal forms to CAF and that all future payments are made to them. I have also noticed that a sizeable proportion of the membership have not yet renewed their membership this year. If you have misplaced your renewal form or have any questions about the process please feel free to contact either me or Lucy Welch. On a brighter note thanks to all those who have raised money running marathons, mini marathons, fun runs etc. It's nice to know we are encouraging people to keep fit!

**Julia Bailey**

**Honorary Treasurer**

## Donations

### Donations to 30/06/03 (issue 106)

(£30.00 and over)

EC Harris (via Alun Oliver)	60.00
Mrs Lisa Doocey (via Philomena Farley)	95.80
Hertford Choral Society	435.00
Sutton Social Security OfficeSports and Social Club	345.37
Margaret Lappin	1306.20
Mrs S Osborne	207.00
Kerry Pycroft	220.00
TECHNIP Offshore Limited	500.00
Eversley Primary School (via J. Welch)	75.90
Anonymous	1,000.00

### **Gift Aided:**

J Noble-Nesbitt	60.00
JR Tuck	50.00
Hayley Mann	50.00

### **In memory of:**

Stella Harris	815.00
(including £490.00 gift aided)	
In memory of Ann Hutchinson	57.75

### **Research:**

Sue and Richard Davies	2008.53
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NEW

# they're a bit saucy!



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Protein level 1.2g/100g Phenylalanine 30mg/100g

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Simply mix with water in a saucepan bring to the boil

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Promin pasta in sauce is convenient and

easy to cook. It provides an instant meal solution for lunchtimes and tea times, you could even serve it for dinner with a side salad.

Promin pasta in sauce will soon become a necessary addition to your kitchen cupboard.

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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.

Promin Pasta and Promin Tri-Colour Pasta are now a well established brand and are available on prescription. Our pasta range also includes

Imitation Rice, Pasta meal (available by prescription) and Lasagna Sheets (available by mail order). More recently interaction with PKU patients, parents and Dietitians has resulted in the expansion of the Promin range.

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Firstplay Dietary Foods

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**Please consult your dietitian about how to count these meals in your diet as they contain phenylalanine.**

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# Letters

News & Views, 48 Hazeldell, Watton-at-Stone, Hertford SG14 3SN  
Email: [nspku.secretary@ukonline.co.uk](mailto:nspku.secretary@ukonline.co.uk)

*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 Bankers Draft for £214 raised for the NSPKU. This amount was raised by Barry and Philip McEvoy in conjunction with their friends, Mickey McGahow, Michael Smilt, Declan Collins, Paul Vallely, Conor McShane, Ronan Trainer and Cathal Hayes. The money was raised by running in the Belfast Marathon. Both Barry and Philip have PKU.

Kind Regards

**Christina McEvoy**

**Dear News & Views**

 I am sending a cheque for the NSPKU for the sum of £207, being the proceeds from "Mid Summer Notes", a concert of music and poetry held mid summers day, 21<sup>st</sup> June.

This is for my Grand-Daughter Hannah Bridges from Purley, whose Mum and Dad are Caroline and Ned.


Our concert was very succesful with perfect weather, and it seems that it is becoming an annual event now. We had lots of people attending and it was held in a friend's beautiful garden. Part of the garden is incorporated into the "Mid Summer Notes" programme cover (see photo).

With very best wishes

**Shirley Osborne**

**Dear News & Views**

Please find enclosed, cheques to the value of £220 for the NSPKU.

 My Daughter Hannah is now 7 years old and continues to benefit from all of your good work. She remains happy and healthy whilst coping with PKU on a daily basis.

I would especially like to thank my Dad (Hannah's Grandpa) – Don Appleyard for the kind donation. He recently celebrated his 60th birthday, requesting family and friends to donate money for the NSPKU in lieu of presents.


Also enclosed is a photograph of Hannah, brother Ben and their much loved Grandpa. Yours sincerely

Kerry Pycroft

**Ed** – Excellent idea for fund-raising. All of you "not young" (politically correct) people can do a bit of arm-chair fund-raising in the same way that Don has. However if this is the only method of gleaning new socks and underpants.....think on.



**Dear News and Views**

 I contacted you in April for sponsor sheets for the 10k run, well I completed it!!! It was extremely hard as I had a chest infection, but I completed it in 1 hour & 17mins which I was pleased with as it was my first ever run.

I have enclosed a photo of my daughter Carys Hopkins age 4 (PKU) with my medal as I was too exhausted to get mine taken! She is great and accepts that she is special and copes extremely well with her diet.



We have raised £1306.20 for the NSPKU with help from family and friends and especially my colleagues at Weatherproofing Advisors Ltd who were all very generous. (They probably expected me to bottle out

at the last minute).

I am sure you can put the money to good use.

Kind Regards

**Margaret Lappin.**

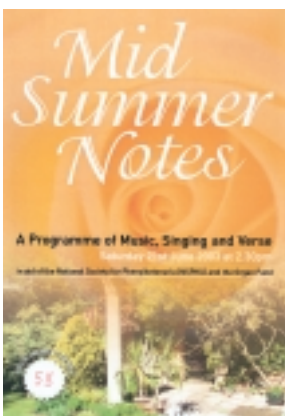
**P.S.** I've now decided to do the run next year, if I can keep up the fitness regime!!!

## Contacts

Hi there I am a 17 year old girl with P.K.U and would like to have contact with someone of the same age range or older that live near me. I live in Bingham which is in Nottinghamshire. I have never seen or heard from anyone one that lives near me with PKU. I would like to share my feelings and problems with you because hopefully you will understand what I am going on about. Thankyou. I hope I will get some replies soon.

Love Kelly Singleton x x x e-Mail :  
[crazy\\_baby856@hotmail.com](mailto:crazy_baby856@hotmail.com)  
8 Queens Court  
Bingham  
Nottingham  
NG13 8FY  
Home No: 01949 877063  
Mobile no:07763961334

*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: [nspku.secretary@ukonline.co.uk](mailto:nspku.secretary@ukonline.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 kempston Drive  
Arnold, Nottingham,  
Notts, NG5 8EU  
Tel: 01159 202089



## Order Form *NSPKU Direct*

Product	Size	Colour	Price	Quantity	TOTAL
Adult Sweatshirts (Red, Black, Grey, Navy, Wine) S. M. L. XL. XXL		1ST CHOICE: 2ND CHOICE:	£12.00		
Adult Poloshirts (Red, White, Navy, Jade, Grey, Wine) S. M. L. XL. XXL		1ST CHOICE: 2ND CHOICE:	£9.00		
Children's Sweatshirts (Red, Black, Grey, Navy, Wine) 3-4, 5-6. 7-8, 9-11 years		1ST CHOICE: 2ND CHOICE:	£8.00		
Children's Poloshirts (Red, White, Navy, Jade, Black, Dk Green) 3-4, 5-6. 7-8, 9-11 years		1ST CHOICE: 2ND CHOICE:	£6.00		
Ballpoint Pens x 9			£1.50		
Sticky Bugs			60p		
Rubbers			80p		
Bibs			£2.25		
Baby Feeding Cups			£3.25		
Baby Toothbrushes			£2.50		
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NAME: \_\_\_\_\_

+ P&P £  
(see below)

ADDRESS: \_\_\_\_\_

**TOTAL REMITTANCE** £

POSTCODE: \_\_\_\_\_

TEL: \_\_\_\_\_

I would like to make a donation of £: \_\_\_\_\_

Please make Cheques and Postal  
Orders payable to 'NSPKU'

Send completed form to:

Mrs Sara Bartlett  
The Corner House,  
2 Stamford Road, Colsterworth,  
Lincolnshire NG33 5JD

**P+P COSTS:**

Order value up to £2.00	50p
Order value £2.01-£6.00	£1
Order value £6.01-£10.00	£2
Order value £10.01-£20.00	£3
Order value over £20.01	£4



# South Wales Support Group In Trouble Again !



If you could write a standard operating procedure (sop) for a PKU camping weekend then the South Wales support group's weekend would qualify with honours. On a gloriously hot weekend in June a plethora of PKU- interested parties pitched their temporary canvas houses and caravans in the delightful setting of Bracelands campsite in the equally delightful Wye valley.

Attendees from Surrey up to Birkenhead, Merseyside and from Wales across to east Anglia busied themselves in setting up camp.

Alun and Ifona Rogers had been meticulous in the logistical planning of the whole operation which goes some way to explaining why half of the happy campers ended up in the bottom field and the rest at the top!

Undaunted, the burly men

of the troupe lifted said tents aloft of their heads and carried them to the top field (much to the amusement and scorn of more seasoned outdoor officianados)

Often camping weekend success is measured by enjoyment rating but, not the South Wales soiree. Oh no this is gleefully measured by the amount of complaints from fellow campers and rollickings by the site Marshall. The final tally was 3 and 1, which is pretty tame and disappointingly down on last year. The traffic played up on the Friday which left the

travelling contingent weak and in need of beer and wine helped down with some food. One poor soul didn't quite make it in the daylight and spent the night in his comfy Citroen Xsara.

Thus to bed (or backseat if applicable) and waking up to a brilliant sunshine and a hearty fried breakfast before meeting together under the Gazebo to plan the day's events. This is a nonsensical activity as we all know where we are going to go and what will happen next (surer than eggs is eggs). Plan "A" - To the pub through the forest and back again after luncheoning at said hostelry (Plans "B,C & D" are exactly the same).

It is just before this happens that the namby pamby, airy fairy, wishy washy, lar de dar, weak kneed, day visitors arrive. Emerging from their 5-star velvet lined, mini bar toting, en suite hotel accommodation. Not for them the zest and thrill of a thin layer of canvas between them and the elements. Not for them wrestling with gale force maelstroms and wild unforgiving woodland animals. Not for them the raw feel of naked feet on damp meadow grass. Etc etc.

Then we went to the pub..... The long way. (Just who was in charge of the map?) Loaded up with supplements and PKU bread (thanks to Eileen Green of FATE foods) we rattled (supplement tablets in rucksack) down to the river Wye through the spectacular beauty of the forest of Dean.

The Forest of Dean is significant historically as it is an oak forest. Admiral Lord Nelson used it as his main source of wood to build his naval fleet. This was the first sustained re-forestation programme. That said, we arrived at the hostelry (all 35 of us) and demanded a big table at the already bustling country inn. The landlord was threatened with a big pair of scales and we nestled in. We drove the staff scatty with all of the strange demands that PKU attracts. A roaring trade in chips was had.

Once back at camp the siesta was interrupted (rudely) by a rule breaking game of rounders with girlies coming out on top through subterfuge and blatant cheating. The BBQ's were now being lit. Disaster was about to hit and with it some good fortune.

It would be rude to name names but one poor unfortunate conference organiser (name withheld) performed an equivalent of sawing a lady in half. But the lady was a picnic table and the saw was him. Completely demolishing a plastic picnic table just by sitting on it and collecting the table's contents in his lap, he had accidentally created a "disposable BBQ holder." The BBQ commenced, again with some fantastic PKU food courtesy of Eileen Green. Wood was also burned (site Marshall warning = 1 point) and children endeavoured to dance in the flames much to the annoyance of the adults. People wilted on all sides and drifted off when the wine had summoned them to bed.





Awaking again to a glorious sunrise, saw the closing of the weekend but endorsed the reason for “turning up”. The previous nights antics ensured that breakfast was dumbed down for non PKU’s because waking up wasn’t an option until midday even if you were on your feet. And so some travellers drifted off while the bravest of the contingent sauntered down to the river Wye to try their hand at Kayaking which is like canoeing but with stabilisers.

One of the nicest things tho’ is the fact that you know you can turn up to a weekend out without the fear of feeling “different” and where everybody is in the same boat – no food worries, no need to scour menus for the one thing on there that can be eaten. If you haven’t tried camping before, there have been many who have been converted by this sort of weekend. So next year, come and give it a go. You might enjoy it!



## ENER-G Low Protein Rice Bread

Have You Tried It ?

**FREE SAMPLES\***  
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**Prescribable**



**From General Dietary Ltd**

\*Subject to availability

# When the Diet becomes a Cruise

When we booked the holiday with Fred. Olsen Cruise Lines, we asked for a fridge and help in preparing and cooking for Annabelle's dietary needs.

On arrival on board ship, the fridge was already in the cabin and we received a letter inviting us to a meeting with the Head Chef. The Head Chef could not have been more helpful. He prepared and cooked pasta, kept the bread we had taken with us in the freezer, prepared vegetables and an extensive variety of fruit (melons, oranges, apples, kiwi fruit) daily – all perfectly presented.



*Chef sorts out the menu with his young customers*

The Head Chef was very positive to help in any way he could – “If you need anything (other than Annabelle's special food) that is not on board, I will arrange to get it from where we disembark at the next port – Nothing is a problem to us!”

We listed each day what Annabelle needed and gave it to the head chef. The waiters knew what was prepared for Annabelle and they ensured she was served at the same time as the other children. The quality of and attention to detail in managing Annabelle's diet was first class.

Before we went on holiday we were concerned about how Annabelle's diet would be catered for and we took with us a small suitcase of supplements and free food. However, our worries quickly disappeared, we had someone else preparing and cooking food and this made it very special for us.

The children were all catered for; the food, service, facilities and entertainment on board was outstanding. We had a wonderful cruise and cannot over emphasize the help and support we received in dealing with a PKU diet.

One problem we did experience and hadn't foreseen was weighing out exchanges whilst cruising at sea. The scales worked but did fluctuate, however, we overcame this by weighing a number of exchanges out in advance when in port. On a couple of occasions we had to make very best guesses based on our previous experience because the scales fluctuated.

We hope our experience is of interest to others.  
Yours sincerely

John and Sharon Skidmore



## We Need YOU!!!

### Sub- Editor Required

Working Hours - 12 Hours per annual quarter - Voluntary position

Person Specification - Creative, Computer Literate, Timely, Graphic experience desired but not essential.

Producing the main line of communication (News & Views) for the Society's membership is an extremely rewarding experience. All too often members comment on just how much they look forward to the publication dropping through their letterbox. It is their way of dispensing with the isolation of the disorder. Can you help? Do you think that you would profit from the satisfaction of knowing that your input was a major part of the infrastructure of the NSPKU

We need a sub-editor to help share this responsibility as the publication goes from strength to strength and its quality increases.

The main duties are to gather and collate articles for each edition, type them up for the design studio and forward for publication. To liaise with suppliers, manufacturers and distributors for advertising needs and requirements. Ensure deadlines are met in conjunction with the Editor. Proof read primary articles and amend pagination to fit the magazine in conjunction with the Editor. Liaise with COM members for their input into the magazine (help will always be at hand through the Editor!)

Have a good sense of humour because deadlines can be a right pain!!

If you want to join up and make a profound input at a very limited time expense please contact -

Pete Bramley (Editor) on Home - 01920 427 636  
Work - 01923 652 602  
E-mail nspku.secretary@ukonline.co.uk

I look forward to working with you - Pete Bramley - Editor

# Yes We Cook That.com

Specialist Dietary Foods

Freshly prepared ready meals  
for PKU sufferers Now available in England\*

## 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 some flavoured sliced bread made from prescriptive low protein flour?

**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 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 dietician 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.

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7 Capel Avenue, Newton Mearns, Glasgow, G77 6EL



**NEW**

# *Fasta Pasta*



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 (1/2 an exchange per pot).

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

**SHS**

## Speedy Calzone Pizza

### Ingredients

- 150g (6oz) **Loprofin** Low Protein Mix
- 1 x 5mlsp (1tsp) **Loprofin** Egg Replacer
- 1 ½ x 5mlsp (1 ½ tsp) baking powder
- Pinch salt
- 40g (1 ½ oz) economy butter
- Cold water to mix
- ½ x 390g can ratatouille
- 1.25mlsp (½ tsp) dried mixed herbs
- Olive oil
- Oven temperature: 200 C/400 F/Gas Mark 6

### Method

- ❶ Combine the **Loprofin** Low Protein Mix, **Loprofin** Egg Replacer, baking powder and salt in a large bowl, cut the butter into small pieces and rub into the mix until the texture resembles breadcrumbs.
- ❷ Stir sufficient water into the dry ingredients, to give a soft manageable dough.
- ❸ Lightly knead the dough on a surface dusted with **Loprofin** Low Protein Mix, about 30 seconds, until smooth. Roll out, to a circle approximately 22.5cm (9inch) in diameter.
- ❹ Transfer the dough to a lightly greased baking tray and spread the ratatouille mix over half of the dough, to within 1cm (½ inch) from the edges.
- ❺ Moisten the edges, fold the plain piece of dough over the vegetables and press to seal.
- ❻ Brush a little olive oil over the surface of the dough and bake in a preheated oven for 15 minutes, until pale golden brown in colour.
- ❼ Serve hot with a crisp salad.
- ❽ **Serves 2.**

### Tip

If desired the remaining ratatouille may be heated and poured over the Calzone, before serving.

## Minted Pineapple Crush

### Ingredients

- 432g can pineapple slices in syrup
- 200ml carton Low Protein **Sno-Pro** Drink
- 4 large mint leaves
- Sprigs of mint to garnish

### Method

- ❶ Break the pineapple slices into pieces and place with the syrup from the can in a liquidiser (or food processor).
- ❷ Add the **Sno-Pro** Drink and mint leaves to the liquidiser and blend for 1 ½ minutes, until smooth.
- ❸ Thoroughly chill the drink before serving garnished with small sprigs of mint.
- ❹ Makes approximately 625ml (1 ½ pint)

### Tip

Please note this recipe provides half an exchange.

Please consult your dietitian for advice on how to count this drink in your diet.

# Maternal PKU

## Maternal Phenylketonuria: Report from the United Kingdom Registry 1978 - 1997

Dr Philip Lee

*The Charles Dent Metabolic Unit, The National Hospital for Neurology & Neurosurgery,  
Queen Square, London WC1N 3BG*

### *Introduction*

Newborn screening for phenylketonuria (PKU) has been one of the great success stories of preventative medicine in the last century. Without early dietary treatment PKU results in severe learning disability and behavioural problems associated with medical problems such as eczema and epilepsy. However with dietary restriction of phenylalanine, parents can expect their child with PKU to have essentially normal development and social integration. It has meant increasing numbers of people with PKU are reaching adulthood, able to work and form relationships. However, over the past 40 years it has become apparent that the children born to mothers with PKU are at risk of damage from the effects of phenylalanine. High phenylalanine levels in the mother are associated with a distinct syndrome: unusual facial features, microcephaly (small head), developmental delay and learning difficulties, and congenital heart disease. A Medical Research Council Working Party in 1993 recommended that women with PKU should start a phenylalanine-restricted diet before conceiving to protect against these effects. In this article, I report the experiences of maternal PKU within the United Kingdom from the UK Phenylketonuria Registry.

### Methods

The Phenylketonuria Register supported by the Medical Research Council has collected information on virtually all known girls with PKU born in the United Kingdom since 1964. A few were reported because of problems with their children which led to the diagnosis. The original aims of the study were to alert doctors caring for these women about the risks of maternal PKU; to provide an overall picture of the situation in the UK regarding maternal PKU; and to collect data to compare the outcome of pregnancies in women receiving dietary intervention at different stages of their pregnancies. The main outcome measures were birth weight, birth head circumference, intelligent quotient (IQ) at 4 years and 8 years, and the presence or absence of heart problems in the children.

### Results

155 women with PKU had 228 pregnancies resulting in live births between 1978 and 1997. Seven pregnancies resulted in twins, and these have been excluded from the analyses. Complete information was available for relatively few pregnancies.

For comparisons, the pregnancies were divided up into three diet groups: those in which phenylalanine-restricted diet was never started ( $n = 18, 8\%$ ), diet was started at some stage during the pregnancy ( $n = 91, 42\%$ ) and diet was started before conception ( $n = 110, 50\%$ ). Birth weight and birth head circumference were greater in those diet before conception than in the other two groups. Heart problems in the children were present in 12/72 (17%) whose mothers started diet during pregnancy and in only 2/84 (2%) of those born after diet started before conception. For those children whose mothers were never on diet, heart disease was present in 1/15 (7%).

An IQ of 100 is average for a 'normal' population. Looking at IQ at 4 years, the average for those never treated was 72.3, for those started during the pregnancy 96.8 and for those on diet before conception 108.9. Average IQ at 8 years for those never treated was 39.5, for those started during the pregnancy 86.5 and for those on diet before conception 103.4.

Five clinics cared for the pregnancies of between 12 and 55 live births. 87 centres looked after less than 8 pregnancies during this time. Birthweight was lower (2,906 g v 3,076g) and head circumference was smaller (32.8cm v 33.4cm) in those centres with least practical experience of managing these pregnancies, although there was considerable spread of outcome results.

### Summary

Despite a recent consensus statement from the National Institutes of Health in the United States, many questions remain about the management of PKU into adult life. The only situation where it is quite clear that dietary intervention is of benefit, is to protect the unborn child of women with PKU. The information collected from this group of women with PKU from the United Kingdom support the need for the early introduction of a phenylalanine-restricted diet for these pregnancies and for management of these pregnancies in centres with experience. Birth weight and head circumference were greater, the occurrence of congenital heart disease was lower, and IQ was higher at 4 and 8 years of age in those children whose mothers went on diet before they were born.



It is important to bear in mind that the information in the PKU Registry is not perfect. Over 90 centres provided variable information about their patients and pregnancies, as resources to support their collection were limited. The quality of information makes it impossible to look at precise blood phenylalanine levels or differences in diet therapy during the pregnancies. Much of the information for each pregnancy was incomplete. Nevertheless, the Registry has provided very important information.

There remain lots of questions about maternal PKU to be answered. These include the effects of introducing the diet after conception, what concentrations of blood phenylalanine should be aimed at, whether or not different quality diets effect outcome, the effect of both the baby's and the mother's genetic make-up and the effects of the home environment in which the child is brought up. Hopefully in the years to come, some of the answers will be found. In the meantime, the message has to be that women with PKU need to plan their pregnancies and start diet before conception with the support of an experienced dietitian.

**Acknowledgements.** I would like to thank all the centres that contributed their data to this registry, which was supported by grants from the Medical Research Council and the Department of Health. Dr Isabel Smith ran the Registry throughout its life. The UK Newborn Screening Programme Centre latterly provided direction. I would like to thank the National Society for Phenylketonuria for providing support for the analysis of these data, which was performed by Deborah Ridout.



The National Society for Phenylketonuria (United Kingdom) Limited

Thursday 30th October-Sunday 2nd November

**ESPKU ANNUAL CONFERENCE 2003**

Immediate booking advised

**The Hanover International Hotel - Hinckley - Leicestershire**

Contact: Mike Bailey, 37 Old Park Close, Farnham, Surrey, GU9 0BQ

Phone: 01252 728221 for accommodation availability

See enclosed booking form for prices and information

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**CONFERENCE**

**2003**

# Dib Dib Duffy!

Stephanie Duffy, on the challenge set by her Scout troop...

Hi! My name is Stephanie Duffy. I am 14 years old and I live with my big brother, Andrew (non-PKU) my mum and dad in Kilsyth near Glasgow. I am a member of the Cumbernauld and Kilsyth Kayak Club and the 1st Kilsyth scout troop.

Until recently, cooking for my diet has been a problem for my mum. But now I have been set a challenge by my scout leader Marion Rankin to prepare my own food for a troop camp. As part of this challenge I have to set my own menu, quartermaster my foods and supplements and fit in preparation of food in to the camp programme. In February 2003 we were camping at Fordell Firs campsite. We arrived late on Friday night at the site, pitched our tents and had little time for supper so I had to be ready. I cooked a potato and onion burger on a hike gas stove while the other members of the troop had hot dogs. My burger was supplied along with some of the other food by Leonora from Yes we cook that. Saturday morning's programme was climbing then archery. So for breakfast I had porridge and a cereal bar for my first load of exchanges of the day. I use PKU express and I find sachet form fast, easy and GREAT for camp.

Life at camp can be very hectic with a lot of activities. So as part of my project I had a look at how to prepare fast filling foods quickly. I am lucky that PKU food companies have been considering the same thing and I was able to try a PKU pot noodle (curry flavoured), that I picked up at a maternal PKU information evening the week before. My compliments to SHS. The afternoon saw me and the rest of the troop practising putting up patrol tents, doing map and compass work and making camp gadgets. We then had free time to go exploring the tunnels before dinner. I was lucky Barbara, my dietician from Yorkhill, had introduced us to Leonora and her company, who are experimenting with pre-cooked PKU meals. Leonora and I discussed my requirements for camp food by

e-mails and although she has never supplied any boil in a bag food before she very kindly agreed to buy equipment necessary and try for me. As there were twenty-seven other scouts camping and the camp cookers were being used I was back to my trusty hike gas stove to boil water for my very first PKU boil in a bag meal. I had chosen a sausage and mushroom casserole (vegetable sausages). Once the water was boiled it took ten minutes to cook a hot, delicious meal and I was able to time it to sit down with my friends. Saturday night continued with a camp fire with all the troops at the campsite and back to our own campsite for a quick quiz and supper. After supper we prepared to go and then sleep IN THE TUNNELS THAT NIGHT UNDER THE CAMPSITE!!!

Sunday morning above ground, for breakfast I had hot porridge and a cereal bar before the mornings activities began. After site flag break our main activity was to collect and prepare enough wood to cook lunch over an open fire before departing for home. The troop elected to do backwoods cooking (tin foil) I decided to test Leonoras boil in a bag on a open wood fire. So after boiling the water I placed the boil in a bag of pasta and tomato in and was able to eat the meal with my camp buddy, Aislenn, before taking down our tents and getting ready for home. Looking back I have to thank Marion, my scout leader for setting me this challenge, Barbara for introducing Leonora, Leonora and SHS for all the wonderful food, and my dad, assistant scout leader, Mike Duffy, for helping me with this project and reminding me to always to be prepared. My next challenge is to use PKU foods on a three day two night unsupported hike. Wish me luck!!!!

(a child with PKU) Stephanie Duffy







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**BREAD AND PASTRY THAT BROWNS NATURALLY IN THE OVEN**  
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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**

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*Your Editor Says...*

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or...

*If you have an entry, send it on a floppy disk and  
you will be my most greatest of friends - forever!*

## NOTICE

The Birmingham Children's Hospital  
Steelhouse Lane  
Birmingham  
B4 6NH

Saturday 5<sup>th</sup> July day conference has been postponed until Saturday November 8th 2003  
– Further details will be in the next News & Views.

For further information contact – Di Asplin on 0121 333 9963

May we take this opportunity to apologise for any inconvenience

# Provisional Programme of Events:

## Theme: Past, Present & Future

### (DAY 1) – THURSDAY 30<sup>TH</sup> OCTOBER:

- 1200 hrs - E.S.PKU 17<sup>TH</sup> Annual Conference Registration Desk Officially Opens in the hotel  
 1900 hrs - Scientific Advisory Committee (SAC) Meeting  
 1930 hrs - Buffet Dinner will be available in the hotel  
 (at an extra nominal cost depending on final numbers)

(PLEASE NOTE OVERNIGHT ACCOMMODATION WILL BE AN EXTRA CHARGE)

### (DAY 2) – FRIDAY 31<sup>ST</sup> OCTOBER:

- 0700 – 0915 hrs - Full Breakfast will be served in the hotel  
 0930 hrs - E.S.PKU 17<sup>TH</sup> Annual Conference 2003 Welcome Address  
 0945 hrs - The “PAST” :  
 Dr Ragna Foelling Elgio (Speaking about her fathers work – Dr Asbjorn Foelling)  
 Dr Campbell Davidson ( Speaking about 30 years of treating PKU patients)  
 1115 hrs - Morning coffee/tea break & biscuits (PKU Food Manufacturers Exhibition Open)  
 1145 hrs - SHS International: Cookery Demonstration  
 1245 hrs - Luncheon will be served in the hotel  
 1400 hrs - E.S.PKU 17<sup>th</sup> General Meeting  
 1515 hrs - Afternoon coffee/tea break & biscuits (PKU Food Manufacturers Exhibition Open)  
 1530 hrs - Scientific Advisory Committee (SAC) Meeting – (Reports on latest PKU Developments)  
 1730 hrs - Civic Drinks Reception:  
 (E.S.PKU 17<sup>TH</sup> Annual Conference 2003 will be greeted by the Lord Mayor & Mayoress of Hinckley, Leicestershire)  
 1830 hrs - E.S.PKU 17<sup>TH</sup> Annual Conference 2003 Welcome Dinner  
 2000 – 2400 hrs - Evening Entertainment: DJ & “Halloween” Discotheque – (Optional Fancy Dress)

### (DAY 3) – SATURDAY 1<sup>ST</sup> NOVEMBER:

- 0700– 0830 hrs - Full Breakfast will be served in the hotel  
 0830 hrs - Professional Nursery Playgroup: (Infants & Children under 8 years)  
 Optional Children’s Trip: (Children over 8 years will be taken out this morning with adult carers)  
 0900 hrs - Opening Introduction E.S.PKU Executive Committee (General introduction & Functionality)  
 0915 hrs - The “PRESENT”:  
 Dr Nick Shaw (Consultant Endocrinologist on Calcium & PKU)  
 Dr Linda Tyfield (Speaking about Genetic Update)  
 1100 hrs - Morning coffee/tea break & biscuits (PKU Food Manufacturers Exhibition Open)  
 1130 hrs - PK Foods: Cookery Demonstration  
 1230 hrs - Luncheon will be served in the hotel  
 1400 hrs - The “FUTURE”:  
 Carol Ferguson (Speaking about learning skills)  
 Dr Nenad Blau (Speaking about BH4)  
 Christinnah Sarkissian (Speaking about PAL- Phenylalanine Ammonia Lyase)  
 1545 hrs - Afternoon coffee/tea break & biscuits (PKU Food Manufacturers Exhibition Open)  
 1615 hrs - Free Time  
 1700 – 1830 hrs - Children’s PKU Party: (Including surprise children’s entertainer)  
 1930 hrs - E.S.PKU 17<sup>TH</sup> Annual Conference 2003 Final Dinner  
 2100 – 2400 hrs - Evening Entertainment: Live UK PKU Band: The “Grand Boys”

### (DAY 4) – SUNDAY 2<sup>ND</sup> NOVEMBER

- 0700– 0830 hrs - Full Breakfast will be served in the hotel  
 0830 hrs - Professional Nursery Playgroup: (Infants & Children under 8 years)  
 Optional Children’s Trip: (Children over 8 years will be taken out this morning with adult carers)  
 0900 hrs - PKU Workshops:  
 (To be finalised but will take the format of approximately 4 different topic matters)  
 1100 hrs - Morning coffee/tea break & biscuits (PKU Food Manufacturers Exhibition Open)  
 1130 hrs - Fate Foods: Cookery Demonstration  
 1230 hrs - Luncheon will be served in the hotel

END OF E.S.PKU 17<sup>TH</sup> ANNUAL CONFERENCE 2003

“HAVE A VERY SAFE ONWARDS JOURNEY HOME”

# NSPKU Spring Draw 2003 Prize Winners

<u>Prize No.</u>	<u>Prize</u>	<u>Ticket No.</u>	<u>Name</u>
1	£500	24237	S Bramley, Watton-at-Stone, Herts
2	X-BOX + 2 Games	2588	H Sandford, Oxted, Surrey
3	Personal CD Player	20565	S Bingley, Alfreton, Derbys
4	£50 M & S Vouchers	23390	T Howarth, Ashford, Middlesex
5	£50 BHS Vouchers	44092	B Mills, Dudley, West Midlands
6	£30 Boots Vouchers	16483	D Payne, Barnard Castle, Durham
7	£25 BHS Vouchers	47226	V Theobald, Witney, Oxon
8	£25 Argos Vouchers	1973	J Costley, Edgmond, Salop
9	£25 Woolworths V/rs	404	P Collins, Chesterfield, Derbys
10	£25 Boots Vouchers	16131	S Petterson, Ellesmere Port, Cheshire
11	£25 Book Tokens	24204	M Sutcliffe, Watford, Herts
12	£20 BHS Vouchers	33995	Mrs Shepherd, Bucksburn, Aberdeen
13	£20 Argos Vouchers	244	M Foster, Newark, Notts
14	£20 Virgin Vouchers	35778	G Close, Leyburn, N Yorks

First of all, an apology to non Family & Overseas Members for sending you all Raffle tickets in error. However, thank you to those who bought tickets.

We are very grateful to The Alcan Charitable Trust for their generous donation towards the prizes for 2003 Spring Draw.

Thank you to all who bought and / or sold Raffle Tickets on behalf of the Society, especially those who asked for more tickets.

The Prize for selling the most number of Raffle Tickets went to Lisa Turner who sold £175 worth of tickets. Next years target?

The total raised was just over £5,000. We can raise a lot more through this event, but that depends on YOU

Eric Lange  
4<sup>th</sup> April 2003

## News Flash - Cookworks Bread Machines

A couple of years ago, I tested many different bread making machines using Fate All-Purpose Mix. There were a quite a few machines that made really good bread, but the one that I found best of all was the Cookworks machine (model BO906) available from Argos stores across the country. This is the one that I have been demonstrating and recommending to families. Not only did it make great low protein bread, it was the cheapest machine that I tested.

Now, Argos have a new catalogue, and the Cookworks machine has been upgraded and changed slightly. The new model is XBM 128, and the catalogue price is £34.95. I bought one of these new machines last weekend, and when I got to the till, the price had been reduced to an amazing £24.50!

Using the recipe for machine bread which is included in each pack of Fate All-Purpose Mix, (taking out 200g of the made up mixture) I gave it a thorough testing, using it over and over again on different programmes.

I am **extremely** pleased with the results. I made lots of loaves, and each one was fantastic. The bread pan is slightly larger than the old model, but still a good shape, in fact, when the loaf is sliced, it looks the same size and shape as ordinary sliced bread.

You now get a choice of dark, medium or light crust colour, and the programmes have changed slightly. I recommend that you try the BASIC programme which takes 3 hours, or the QUICK programme which takes 2 hours 20 mins.

I also had great results using the RAPID programme, which takes 1 hour 50 mins, the loaf was a bit smaller, because it gives less proving time, but the bread was still fantastic.

Also, every loaf I made was really good colour. Set on dark, the bread really does come out with a dark brown crust, even the top of the loaf was a golden brown.

So, all in all, I would say the new Cookworks XBM 128 bread machine is my new recommendation ~ and at £24.50 who would be without one?

### NOTE

I've just seen a huge pile of bread machines in our local Asda supermarket priced at £29.99. They are called Pacific PBM-3. Guess what? They are exactly the same as the Cookworks machine sold in Argos. So, there's two places you can get a great bread maker. I wonder if Argos reduced their catalogue price because Asda had such a good offer on?

Eileen Green ~ April 03



# Fate Special Foods recipes



## FATE SAUSAGE ROLLS

### **Hello,**

*This is something that I have been asked for many times. It's a low protein version of that great party and picnic favourite ~ the sausage roll, and this is it! For the filling, I use a mixture of vegetables, flavoured with tomato purée and a touch of herbs. You can change the type of vegetables and herbs used, as long as they are allowed in your diet. The important thing is to make sure that the filling mixture is quite dry and firm when it is cooked. This will ensure that you have nice crisp pastry on the sausage rolls when they are baked.*

*The sausage rolls can be frozen. They can also be prepared and frozen before baking*

### **Ingredients**

#### For the filling:

150g sweet potatoes, peeled and grated.

150g onion, peeled and finely chopped

150g mushrooms, finely chopped

20g butter

2 tbsp tomato purée

½ tsp dried thyme

½ tsp dried sage or oregano

Salt and pepper to season

#### For the pastry:

250g Fate Low Protein All-Purpose Mix

½ tsp salt

125g butter or block margarine

50mls water

A little extra All-Purpose mix to roll out.

### **Method**

First make the vegetable filling: Put a large frying pan over a gentle heat, and when the pan is hot, add the butter. Add the grated sweet potato, chopped onion and mushrooms. Stir well. Cook for 5-10 mins until the vegetables are softened and browned. The heat must be kept quite high so that the moisture from the vegetables evaporates, and keeps the mixture nice and dry.

Stir in the tomato purée, thyme, sage or oregano. Then season with salt and pepper to taste. Leave to cook for another couple of mins, then leave to cool.

#### Then make the pastry:

Place the Fate All-Purpose mix into a mixing bowl, and stir in the salt. Rub in the margarine or butter until the mixture resembles fine breadcrumbs, then continue mixing until it resembles coarse breadcrumbs.

Add the water and mix quickly with a metal spoon until smooth. Do not worry if you think the mixture is very soft, just leave to rest for a couple of minutes.

Lightly dust the work surface with extra Fate All-Purpose Mix, and knead the pastry for about a minute until it is smooth.

Preheat the oven Gas 6 200°C 400°F

#### Then put the sausage rolls together:

Dust the work surface lightly with All-Purpose Mix. Take about half of the pastry, and roll it out into a strip about 8 or 9 cms wide, and about ½ cm thick. Place spoonfuls of the vegetable mixture in a line down the middle of the strip of pastry. Moisten the edges with water. Then gently fold the edges of the pastry together to enclose the vegetable mixture. Press down lightly to seal the edges. Cut into the desired size. Repeat with the remaining pastry and vegetable mixture.

Place on a baking tray, and bake in a preheated oven for 10 - 15 mins till cooked and golden brown. Serve hot or cold.

# Support Groups

## LONDON & HOME COUNTIES FATHERS DAY PICNIC – THERE ARE NO EXCUSES!



The kids were oblivious to it all, being entertained with a bouncy castle and children's magician. Experiences were shared and some important contacts made for future reference

(Ned Bridges stumbled into the lair of Pete Bramley – hence the new look design of the News and Views Cover – well done Ned)

If you are in the area, why not come along next year? It's fun and it's free and you might make some friends. We promise to nail Dave Emerson's head to the floor so he can't make you do the sack race. Promise (not!)

Behaviour and Dave Emerson. Two different words only linked by the word – dodgy. The day experienced baking temperatures and the headcount numbered near 60. The venue was fantastic – The Police Club in Chigwell, Essex served as a pseudo sporting venue for PKU Mums, Dads and kids alike. In vain, attendees tried unsuccessfully to relax and take in the precious rays. Dave Emerson (MC) was having none of it. He tore into the very heart of an atypical English picnic and placed distressed people into Post Office sacks (Sorry Officer, they weren't there when I left home) and made them hop from start to finish line in a most undignified manner. The prize? – just bitter humiliation, that's all (where does this bloke get off?)





# Reading and District Support Group

READING AND DISTRICT SUPPORT GROUP - LONDON MARATHON APRIL 2003.



Richard Daview and son William  
(age 3)

On 13th April 2003, my husband, Richard, successfully completed the London Marathon in a time of 3 hours 54 minutes. It was his first ever marathon and despite it being an extremely hot day he was really pleased to finish in less than 4 hours. (He finished 7716th out of 23952 in the Mens race.) We managed to raise an amazing sum of £2008.53 for the NSPKU and we would like this money to go towards research.

William has classic PKU and is presently on 5 exchanges per day. He is such a happy, lively, cheeky little boy and is doing really well with his diet..at the moment !!!! Hopefully this will continue. Our daughter, Alice, age 4 and non-PKU, understands his diet, and is very protective of him.

Thank-you to News and Views for all your wonderful and informative articles.it has kept me going, and given me some great ideas over the last few years.

I am also helping Nicola Cragg in running the Reading & District Support Group. We would love to hear from anyone interested helping the group.

Please contact

Sue Davies or  
Nicola Cragg  
"Braeside"  
13 Blomfield Dale  
9 Chantry Road  
Binfield,Bracknell  
Maidenhead  
Berkshire, RG42 1FY  
Berkshire, SL6 1TR  
Telephone - 01344 482654  
Telephone - 01628 628402

The cheque is in the post as we speak.

Regards,  
Sue Davies



# Dietitian's Report

## NEW ARTIFICIAL SWEETENER SUITABLE FOR USE IN THE PKU DIET

Many of you will remember Simon Kimpton who was the secretary of the Society for many years. He sent me an email message recently asking about a new artificial sweetener he had seen in the supermarket and thought it was OK in the PKU diet but just wanted to make sure before his daughter used it.

The sweetener is called SLENDA and it is perfectly all right to use in the PKU diet and especially useful for those who are trying to lose a bit of weight. It is available in major supermarkets and chemists.

### SLENDA

Splenda is a new sugar alternative and it is made with sucralose: a sweetener made from sugar which tastes like sugar but doesn't have all the calories of sugar.

Splenda comes in granular form like sugar and in tablet form.

A teaspoon of granular Splenda contains 2 calories per teaspoon.

A sweetening tablet contains 0.2calories.

Splenda Low Calorie Sweetener can be used like sugar for example Splenda granular can be used in hot and cold drinks, for sprinkling on cereals and fruit and it can also be used for cooking and baking.

### Regulatory Approval

Splenda was approved for use in the UK in March 2002 and in Ireland in January 2003.

It has been approved in 50 countries. These include USA (1998, Australia 1993 and Canada in 1991.

EU-wide approval is expected in 2004.

This is all good news for those with PKU. When I spoke to the company about the use of Splenda in a wider range of foods and drinks I was told that this was to be expected in due course. Of course we are hopeful that Splenda will become the sweetener of choice by food and drink manufacturers. This will make life easier for us all!

## TRIAL OF LOW PHENYLALANINE DIET FOR PREVIOUSLY UNTREATED PKU PEOPLE

I am delighted to tell you that two professional research staff have now been recruited to run the trial.

### Research Dietitian

Lesley Robertson, who was formerly the Chief Dietitian at Sheffield Children's Hospital, has been appointed as the research dietitian. Lesley has an enormous amount of experience in the treatment of PKU and has been a great supporter of the NSPKU. Many of you will know Lesley either through her involvement as a medical advisory member of the NSPKU, representative for the Society in ESPKU matters, helper at Edale or as a colleague. We are delighted she has taken on this new and exciting challenge. I know that countries all over the world are very interested in this work and look forward eagerly to the results at the end of the 3-year trial.

### Research Psychologist

We are equally delighted that Allayne Amos has been appointed as the research psychologist. Allayne comes to the trial with a huge amount of experience in many aspects of psychology. Allayne obtained her doctorate in psychology at Bristol University, was a lecturer and researcher in Child Psychology at Birmingham University for 8 years and has worked in industry, privately and voluntarily. She comes to the trial with the experience of all these many types of work and has told us that she is very keen to be involved in some research which really makes a difference to people's lives.

We are very fortunate to have found two excellent researchers and I hope that the work that they do will be of great value to those families living with the tragedy of untreated PKU.

From time to time I will keep you informed of the progress I am allowed to divulge. At the end of the work these two will undoubtedly be in great demand as speakers for PKU study days and conferences when they will be able to tell us the full story.

# Dietitian's Report

## BOOKS BEYOND WORDS

The Royal College of Psychiatrists and St George's Hospital Medical School have published 26 titles in the series Books beyond Words. These books tell stories in pictures about important or difficult events that have happened to people in their lives. The pictures speak for themselves.

Books Beyond Words can be used by anyone with learning or communication difficulties and those with literacy problems. People with learning disabilities trial the pictures before publication to ensure they can be readily understood. Using Books Beyond Words can help family members to overcome communication difficulties and anxieties and supporting text and guidelines are given at the back of each book for relatives, supporters and professionals.

The authors are all experts in their fields and people with learning disabilities trial the pictures before publication to ensure they can be readily understood.

Titles include 'Getting on with Cancer', 'Going into Hospital', 'Looking after my breasts', 'Going to the Doctor'. The price is £10 each.

For further details and order forms please contact:

Book Sales,  
(Books Beyond Words),  
Royal College of Psychiatrists,  
17, Belgrave Square,  
London,  
SW1X 8PG

Tel: 020-7235-2351 ext. 146 for enquiries and credit card orders 9.30am to 2pm.

Online ordering  
[www.rcpsych.ac.uk/publications/bbw](http://www.rcpsych.ac.uk/publications/bbw)

## NEW AND USEFUL MANUFACTURED FOODS AVAILABLE IN SUPERMARKETS

*I am very grateful to all of you, families, dietitians and food manufacturers, who have contacted me about useful new foods in the supermarket. This information is really helpful for all those managing the PKU diet so please let me know of anything you find out there. It all makes the diet more varied and a little bit easier.*

### SAINSBURY'S

#### Free-From Range

There are 2 products in this range which Barbara Cochrane, dietitian in Glasgow, told me about.

A dairy free cream

Free From Dairy Free Just Pour  
Protein content per 100ml is 0.9g.

This means that 110mls will give one exchange.

This is a lot of cream and a normal helping would be much less than this. Please consult your dietitian about how to count it in your own diet.

Just Pour can be found in the free from aisle and is a UHT product which does not require refrigeration until it is opened. This is another useful feature of the cream!

A cheese type spread

Dairy Free Soft Spread

Described as a delicious alternative to soft cheese.

Protein content 2.5g per 100g. This means that 40g of the spread provides one exchange.

This product can be found in the soft cheese section.

Mushroom Pate

Lin Stening, our vice-chairman's wife, told me about this mushroom pate which her daughter really likes!

Mushroom Pate can be found in the refrigerated section.

Protein content is 3g per 100g. This means that 35g of the pate would provide one exchange.

She also found some biscuits in the free from range aimed at the gluten free market but with a low protein content.

The biscuits are savoury ones looking very much like the digestives you find in cheese biscuit selection packs.

The protein content of each biscuit is 0.2g so 5 biscuits would make one exchange. They are made from buckwheat flakes and brown rice flour.

# Dietitian's Report

## **WINNER**

*This Swedish company makes a full fat soft cheese which is dairy free.*

The protein content is 2.5g per 100g.  
40g of the 'cheese' would provide one exchange.  
You can find Winner products in some supermarkets and in health food stores.

My thanks go to Katherin Senior for this information.

## **FIRST GLACE**

*A non-dairy ice cream which, the manufacturers say, is as rich and creamy as ice cream.*

First Glace is available in 4 flavours: Classic Vanilla, Strawberry Sensation, Chocolate Supreme and Vanilla Chocolate Fudge Swirl.  
The protein content is 0.7g per 100g so 145 g provides one exchange.

The glace is also enriched with calcium.  
The glace is available in health food shops only.

## **Del Monte World Fruits**

*Jo Clough who is our publication's officer, sent me the cardboard outer box wrappers from some sorbets on sticks which are so low in protein they can be allowed freely in the diet.*

The protein content is 0.1g per 100ml and each lolly weighs 90ml.  
The two flavours are Mango and Passion Fruit and Kiwi and Papaya.

## **THORNTONS**

*I am very grateful to Sharon May, the nutritionist at Thornton's, who is always thinking about us and gets in touch if she thinks a new product would be suitable in the diet. She sent me an email recently about 2 new Roald Dahl sweets which can be classed as free products.*

Snozcubmers - Lime Flavoured Jellies  
Froboscottle - Strawberry Flavoured Sweets

## **LAKELAND LIMITED**

*I know that many of you are aware of this company for its wide range of cooking utensils and equipment. In a recent catalogue sent to me I noticed something which I thought looked really nice for the PKU diet. It is called a frozen fruit treat maker. There are 3 shapes for freezing bananas, soft fruits and oranges. All you do is skewer the fruit and put it into the plastic container and then freeze. It's as simple as that! The frozen fruit then comes out and it ready to eat on a hot day (should we get any more of those). It looks a novel way of getting fruits into children (and adults) with little effort.*

The 3 different shapes cost £3.95 each.

Lakeland Limited,  
Alexandra Buildings  
Windermere,  
Cumbria  
LA23 1BQ

Tel 015394-88100  
[www.lakelandlimited.co.uk](http://www.lakelandlimited.co.uk)

Eleanor Weetch  
Society Dietitian

## **FOCUS GROUP ON NEWBORN SCREENING FOR PHENYLKETONURIA (PKU)**

Do you remember when your newborn baby had a heel-prick test? Did the results show that your baby had PKU? If so, can you help us by participating in a focus group to discuss parents' information needs about newborn heel-prick testing? One of the focus groups will be for parents of children with PKU.

A new UK-wide Centre, based at Great Ormond Street Hospital, was established in April 2002 to carry out a five-year programme of work to set national standards for newborn bloodspot screening. Working with health professionals and parents this Centre will set standards for all aspects of the newborn heel-prick tests, including: the information parents receive; and the choices parents are offered; how and when the blood sample is taken; the nature of the tests which are carried out; and, how and when the results are reported.

We are organising focus groups and interviews with parents discuss issues around information and communication about newborn bloodspot screening. We are planning to hold a group on 19th September in London. Alternatively, you may prefer to participate in an interview at a time convenient to you. If you take part, we hope to reimburse expenses and will pay a small allowance to thank you for your time. If you are interested in participating, know someone who might be interested, or want to know more about the focus groups, please contact **Katrina Hargreaves** by email at [k.hargreaves@ioe.ac.uk](mailto:k.hargreaves@ioe.ac.uk), or telephone 020 7612 6573.



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