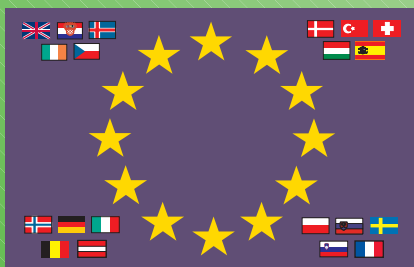


News & Views

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Issue 105

Hertford Choral Society come up trumps!



**EUROPEAN CONFERENCE 2003
BOOKING FORM INSIDE!**

In Touch

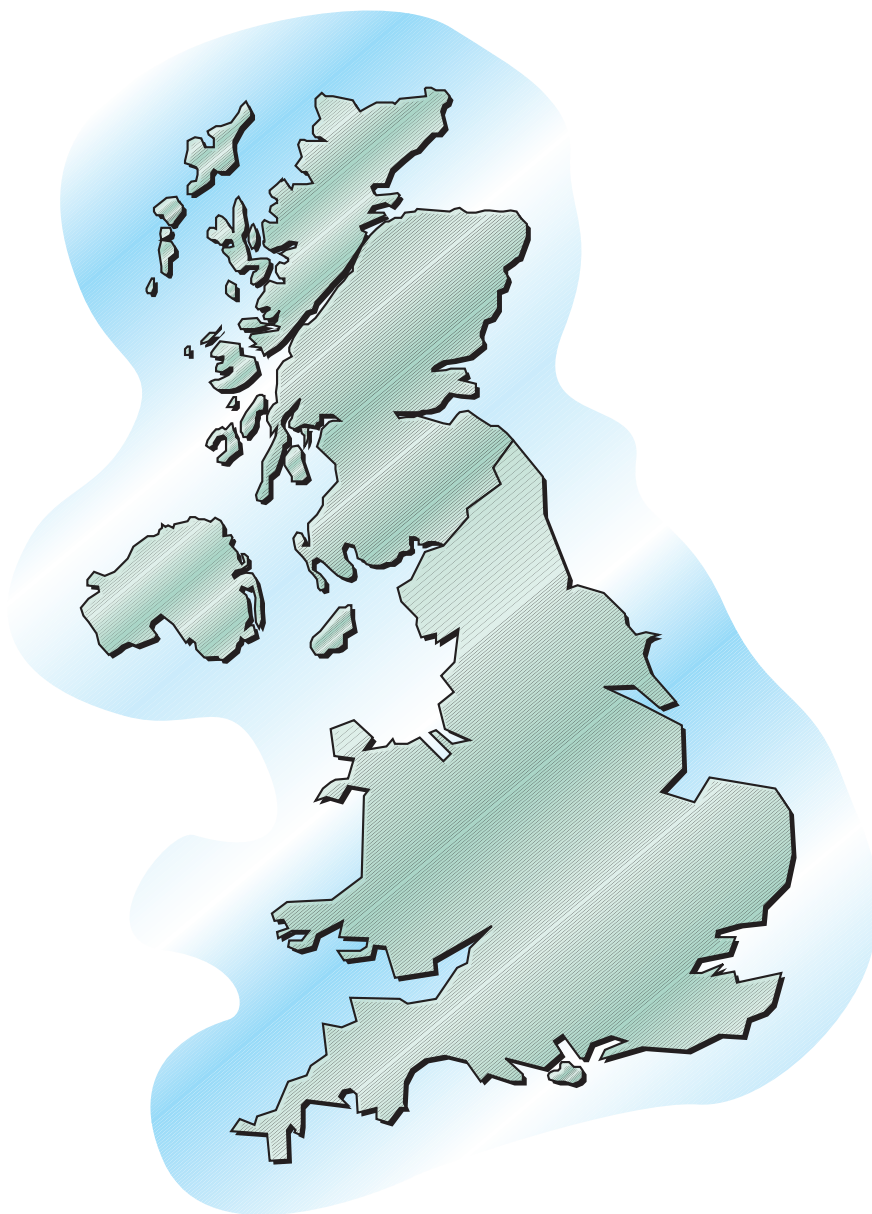
The Council of Management

Telephone Helpline: 0845 603 9136

Address: PO Box 26642, London N14 4ZF

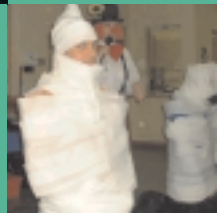
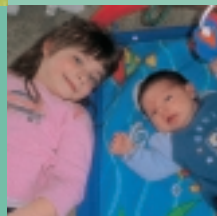
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Editors Report...

It is with unreserved embarrassment that I offer my apologies to Ellis Ward of PKU Foods Ltd. In my eagerness to flee the country towards sunnier climes, I omitted his company advertisement in the last issue (104) The first that I knew about it was when Mike Bailey (Conference Organiser) e-mailed me. Mike is working on sponsorship with PK Foods at the moment. The e-mail went like this-

Dear Chubs (pet name)

Bit of a Fopar on the ground dear chap (Mike speaks so far back he keeps his tongue in his trousers). Best make up with Ellis tout suite. Pip pip, must dash. If you require a presentation, can deliver.

Your most excellent host

Mike Bailey – Entrepreneur and all round entertainer (stubs) toot, toot and hurrah.pip pip. Beep beep etc. etc.

Mortified. What an e-mail from someone, who can only barely speak proper English about such a glaring omission. But I put on my philosophical hat and thought about like this.....

We, as a Society are embarking upon a new era. The research programme initiated by half a million pounds of funding from the Wellcome Trust and SHS International, will see the Society push much needed resources into the dietary treatment of previously untreated PKU patients. The Society has long needed to expand the PKU community and level of support that we offer into this area. We just haven't had the time to do it because of our voluntary status.

This is a major milestone for us. We are becoming a bigger community. We are able to identify with each other and more so now. This sense of community comes through the support we are able to offer to each other.

That's why an Editor can miss out an entire A4 advertisement and why Ellis Ward can smile about it. We are in the same boat, no point in putting a hole in it.

Pete Bramley

Editor

NSPKU
The National Society for Phenylketonuria (United Kingdom) Limited

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Treasurer's Report...

This issue contains details of the Society's income and expenditure for the year ending 31st October 2002. For the first time since 1995 our expenditure has exceeded our income. This is not as suggested by some due to my penchant for shopping! Our increased expenditure in certain areas mainly travel and the production of this fine publication coupled with a decrease in donations provides the cause. We are very fortunate that the combined efforts of our membership provide no small sum in donations each year. However with increasing costs it is time to think about increasing our income by other means. We are very lucky to receive sponsorship from various food manufacturers throughout the year (specific thanks are included in this issue), but sponsorship need not be provided by those companies directly connected to PKU alone. Perhaps the company you work for would be willing to provide sponsorship towards the activities of the Society. These might include administrator or dietitians costs for part (or even all!) of the year, the cost of stationery, telephone charges, travel expenses to and from meetings to name but a few. Any company providing sponsorship will be recognised on at least a yearly basis in News and Views and where applicable their logo's can be used, (I'm sure Lucy and Eleanor would not object to a tattoo!!)

If you have any ideas on this or any other income generating scheme please contact either myself or Eric Lange (fundraising and spring draw officer).

Julia Bailey (Honorary Treasurer)

Chair's Report...

I am very pleased to report that the AGM/Study Day held in March proved both successful and enjoyable. You will be able to read more about it further on in this issue. Our speakers were excellent, not just informative but thought-provoking, and Mike Bailey, along with Pete Bramley, had things working like clockwork. We are considering repeating this Study Day format in March 2004, following hot on the heels of the October ES.PKU conference at which I am looking forward to meeting as many of you as possible, as are our European families. Find the booking form and more details also in this issue. If you book early for this event Mike may be able to negotiate sole occupancy of the hotel, something that always helps make mixing more easy.

I am very pleased to report that two ladies volunteered to run the sale of our merchandise. Sarah, who will be taking over as of now, is a friend of a family who has a child with PKU. I want to thank her for going out of her way to support not only this family, but the bigger PKU family; not very common for someone to do this in our current 'me, me, me' society.

To contact the Merchandise Officer, see her details on page 2

Sara Bartlett
Chair

Donations

Donations to 31/03/03 (issue 105)

(£30.00 and over)

The Chartered Institution of Wastes Management (NE Centre)	263.50
The General Infirmary at Leeds (PKU Christmas Party)	70.00
Mrs E Manning	100.00
Wendy and Andrew Cheale	814.00
John Vernon and Daniel Coleman	355.00
Mrs J Blackmore	250.00
I.M.I (Yorkshire Copper Tube)	
Workplace Trust.	110.00
Bessell Leigh School	132.00
Gift Aided	
Cathy Darby	200.00
J Skidmore	30.00
D Appleyard	100.00
Anonymous	5000.00
In memory of:	
Capel Tennis Club in memory of Mr. Niedermeier	50.00
Robert "Bob" Williams	i.r.o. 2,917.00
Research:	
Mrs E Fiddiman	145.00
Price Waterhouse Coopers (via Mr Fiddiman)	135.00
Lodge Canongate & Leith, Leith & Canongate No. 5	500.00

Thanks To Our Sponsors and Donors

Throughout the year we are fortunate to receive sponsorship to cover some of the costs of the activities of the Society. On behalf of the membership I would like to express our thanks to those who have provided sponsorship this year in particular to:

SHS who this year have provided £2000 for ESPKU costs, £1,500 towards the cost of children's places at the 2002 conference in Gateshead, £500 towards the cost of the Outward Bound weekend in Edale and £4000 to cover the cost of the dietary information booklets, including the baby foods booklet and dietary information disks for dietitians.

UCB Pharma for sponsorship of £900 for conference 2001 abstracts

VitaFlo for £200 towards the abstracts for last year's conference

We also have a number of generous members who contribute on a yearly or monthly basis via direct debit payments to the Charities Aid Foundation and by Give As You Earn schemes at work. We pass on our thanks to all of you for your continuing commitment to the work of the Society.

(Please contact your treasurer if you would like details about donating on a regular basis)

Membership Changes – What Do You Think?

The changeover of membership collection to CAF is now well underway and in general seems to be going smoothly. I have received a few comments and questions and will be conducting a review of the procedures and the forms later in the year. It would help me greatly if you could let me know of any queries or problems you have had so that I can make any amendments before this year's renewal in November. My contact details are on page 2.

Julia Bailey
(Treasurer)

PKU Register

I am pleased to be able to report that there is some progress on the subject of what we have known as the PKU register. The 'old' register holds patient details on both PKU and congenital hypothyroidism and served as both a monitoring tool and a data set for research. This was started in the early 1960's and continued collecting data until the 1980's. Since then no new data has been collected. We have petitioned the Department of Health for some years for it to be reinstated but they decided in 1998 that the funding would go to a quality assurance programme for neonatal screening.

I recently attended a meeting of the UK Newborn Screening Programme Centre to discuss what to do with the existing data. The original paper forms collected are safe and have been catalogued and the database is being converted so that it can be accessed by those needing it for research purposes. The problem is that parental consent was not required when the data was collected so the meeting was left with two choices, anonymise the data, ie remove the names, dates of birth etc or get patient / parental consent. Anonymised data has some use but outcome is better determined if it can be referenced to the original entry. The meeting agreed to proceed with obtaining consent however care must be taken to do this in a sensitive and positive way. We will be consulted shortly about this. There is currently only a little funding for the immediate processing of the database and an application for a grant is being prepared to obtain consent.

In parallel to this, a 'new' register is being set up to record PKU, congenital hypothyroidism, cystic fibrosis and sickle cell disorders which has got full funding. Again I attended a meeting which outlined the requirements for the register. Consent will be required and data will be initially entered from the screening centres. There is a lot of work to do particularly ensuring that the data can be collected without requiring clinicians filling in a lot of forms. We are again going to be represented at future meetings and I am hopeful that a successful outcome will be found albeit with a disappointing gap in data collection.

David Stening
Vice chair



Letters

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



Robert "Bob" Williams

Dear Peter,

Please find enclosed a cheque for £132.00. Once again Bessels Leigh School (my place of work) has allowed me to organise a Christmas raffle for 9th year. All prizes were kindly donated by colleagues. Bessels Leigh School Oxford where I work is a very small boarding school for Boys with behavioural problems. We only have 30 boys on role. I would like to thank parents, staff and pupils for buying tickets and making the raffle a success. A special mention to Lorna Maskell, our retired Home Economics teacher who also very kindly donated to the cause. Our PKU daughter Amy will be 18 in May this year, and continues to flourish I would like to thank the COM for their continued hard work on all our behalves. I look forward to seeing my letter in print in the next edition of News and Views, which continues to be an invaluable publication.
Maureen Arnold

Ed- Thankyou to Bessels Leigh School for your kind donations. I think I'll reserve a regular slot in News and Views for you all !



Dear News & Views



Daniel Coleman running in the Great South Run

Please find enclosed 2 cheques totalling £355 raised for the NSPKU by our friend John Vernon and my son Daniel when they both ran the Great South Run in September 2002. Daniel is 9 years old and has PKU along with his younger sister Taylor, who is 4. This is the 2nd year that Daniel has run for the NSPKU and he is out to improve his time again next year. Our sincere thanks go to John for supporting the Charity and for all his efforts collecting from sponsors. I enclose a photograph of Daniel during the run
Yours sincerely

Karen Coleman



Dear News and Views



Cheyenne & Courtney Vaughn

Please find enclosed donation for £250 which is the proceeds of a raffle held at the Barking Indoor Bowls Club at Barking. The photo shows our Grand-daughter, Cheyenne Blackmore aged 2 years (PKU) with her big sister Courtney Vaughn aged 7 years, holding the cheque in front of the raffle prizes. All of the prizes were kindly donated.

Kind Regards
Mrs J E Blackmore



Dear News and Views,

We are pleased to advise that £1,948, US\$1,000 & £500 (a sum of approximately £2,917) has been raised for the NSPKU, albeit this is sadly as a consequence of the death in January of Robert "Bob" Williams, (Pictured left) father to Lorraine and Matthew, and partner to Valerie. Instead of floral tributes at his funeral, those wishing to pay their respects were encouraged to make donations to the NSPKU in order to further its causes in research, education, and welfare. In particular, research in the field of health and life science was a subject close to Bob's heart. This was because he was Chairman of UK-based Micromass, the leading enterprise in the world solely dedicated to Mass Spectrometry (MS) – a key enabling technique in analytical science which, amongst other things, allows functional proteins to be identified and characterised by exactly measuring their molecular masses. The high performance of the MS instruments and systems of Micromass is such that they are found all around the world wherever first class analytical life, earth and applied sciences are practised in universities, pharmaceutical companies and hospitals. Just before his death, Bob took a specific interest in the sale of Micromass scientific instruments to The Sick children's Department at University Hospital, Istanbul. These will supplement the existing Micromass neonatal screening equipment in Turkey to facilitate PKU-related research and analysis. Bob's personal interest in PKU issues was motivated by his grandfatherly attachment and concern for Georgina and Anastasia, the daughters of Lorraine. On hearing of his death, a professor at University Hospital has decided to name the laboratory where the instruments will be based after Bob. Bob would be pleased that his passing had a modest beneficial effect on the NSPKU, and we, his family, are very grateful to the many that made contributions from as far afield as Japan, USA, Canada, France, Holland (hence the different currencies!) and of course friends and family closer to home in Brighton.

Val, Lorraine, Peter, Matthew, Bia, Deborah, Chris, Brigitte, Georgina, Christian, & Anastasia



Ed – On behalf of the NSPKU may we offer our sincere condolences to the family and friends of Bob. It is clear he made a big difference with his life and beyond.

*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*

NEW

they're a bit saucy!



TWO GREAT TASTING SAUCY FLAVOURS FOR YOU TO ENJOY

Promin Low Protein Pasta in Sauce is a brand new fast food product available in two tasty flavours.

1. Pasta Elbows in a Cheese and Broccoli sauce.

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

2. Pasta Shells in a Tomato, Pepper & Herb sauce.

Protein level 0.96g/100g Phenylalanine 20mg/100g

Simply mix with water in a saucepan bring to the boil

and then simmer for
10 minutes.

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.

Available direct from Firstplay, see the contact details below.

Full analysis available on request.



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.

New products have been designed to reflect the needs of a maturing PKU

population leading busy hectic lifestyles. Call us for more information or with your dietary suggestions.

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



Pasta in
Sauce

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

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

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

NOW AVAILABLE ON PRESCRIPTION
TOGETHER WITH
LASAGNE SHEETS &
COUS COUS



Letters

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

Dear News & Views

Please find enclosed cheque for £280 for the NSPKU. I hope this will help with ongoing research.


My Grand-daughter Laura has PKU. She is a healthy 10-year-old who is doing well at school. She loves sport including swimming, netball and running to name but a few. We are very proud of her development thanks to her very special diet.



Laura with her cousins, Mark and Steve)

We, as a family, decided that we would like to help in some small way with a sponsored walk along the West Highland Way (95 miles) between the 24th-30th August 2002. My son and his wife and their 2 children Mark (12 yrs), Steven (10 yrs) and my husband completed the walk in the allotted time. Laura should have been with them (she had done all the training walks

leading up to the event) but unfortunately, a few days before, she came down with a heavy cold and high temperature so could not go. She was very disappointed.

My son works for Price Waterhouse Coopers who have an excellent scheme called Project Seedcorn, whereby they help colleagues who submit a fundraising project for charity. They have submitted a cheque for £135 along with our cheque for £145  which makes a grand total of £280.

We are grateful for the work carried out by the NSPKU. Please accept our small contribution to your funds.

Yours faithfully

Mrs E Fiddaman

Dear News and Views

Please find enclosed cheques to the value of £815.00 in memory of my Grandmother, Stella Harris, who sadly passed away on Tuesday 18 March, aged 87.

I am writing on behalf of my family as I am a 30 year old PKU and my Grandmother was one of the first fundraisers when the Society was in its infancy. She regularly organised Coffee mornings in the Gloucestershire village where she and my Grandfather lived. On moving to Bristol to live with my family, on the death of my Grandfather in 1985, she continued to fundraise, with my mother and father. Her fundraising efforts were tireless to the end of her life and her wish was that any donations made at her funeral be specifically used by the Society for further research into PKU.



My Grandmother played a very important part in my life and will be sadly missed by myself, and my family, and by the many people she touched with her kindness, thoughtfulness and generosity. I would like to take this opportunity to thank all of those friends, and family, who donated so generously in memory of my Grandmother and trust that monies raised will be used according to her wishes.

Kind regards

Amanda Dart



Ed – Our sincere condolences. A very kind gesture from someone who worked for so long on behalf of the Society.

Contacts

Forward your "smoothie" recipes (see "Letters") to – The Randall Family, 50 King Richard Drive, Bearwood, Bournemouth, Dorset, BH11 9UF
e-mail – lynnechipmunk@AOL.COM

*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*

Dear News & Views,

We recently held a couple of fund raising events for the NSPKU which turned out to be great fun. I decided to turn my 40th birthday party into a fund raising event. We hired a hall, disco. And ensured there was plenty of beer and wine for the evening. We contacted local businesses/shops/garden centres who kindly donated gifts or vouchers which were used as raffle prizes and friends and family gave donations instead of presents. We also left a few donation boxes by the bar and the more they drank the more they filled up the boxes! The party raised £699. A great time was had by all, especially me!

My friend Pam held another health and beauty products and pamper evening to which her customers gave generously, raising £145 for the NSPKU.

I enclose a picture of Holly (6, non PKU) and Alexander (2, PKU) in their party outfits!

Alexander is now drinking his maxamaid again after months of difficulties last year, aided by a sticker chart! As long as I find different stickers each month to keep his interest, he seems to drink his supplement. I now realise this is probably one of many supplement drinking problems that we will encounter on this PKU journey, but at least there is light at the end of the tunnel and you do get through it. Until the next defiant age, I presume!

With very best wishes

Wendy and Andrew Cheale

Ed – Fantastic idea for fund-raising. Next time I'm 40, I'm going to try it.



Dear News and Views

Please find enclosed a cheque for the sum of £345.37 raised by my colleagues and I at work.

My daughter, Madison is 5 yrs old and has PKU. She just started school and is loving every minute of it! She is full of energy and enjoys all the new things that school can bring to a 5 year old. Madison knows exactly what she can and can't eat and has had to tell her classmates all about her diet.

We raised the money for NSPKU, which was our nominated charity, by doing things such as a paintball event, cake sales, jeans for genes day, Christmas donations instead of giving each other cards and various other things.

A lot of people in my office have met Madison over the last 5 years, and can see that she is happy cheeky little thing, and they know all about her diet and can see that she is just like any other 5 year old.

Sincerely

Jo Hough

Dear News & Views

Some time ago I contacted Lucy Welch (NSPKU administrator) regarding raising money for the NSPKU by taking part in the Plymouth half-marathon in May 2002. I now enclose a completed sponsorship form and cheques totalling £200 (which includes £35 gift-aided) raised by my husband, Iain, as a result in completing this event in a time of 1hr 24mins and 13 seconds. Unfortunately I broke my ankle 3 weeks before the event and couldn't take part.

Our relationship with the NSPKU started when our second daughter, Charlotte, was diagnosed with PKU in July 2001 at 2 weeks old. We have really appreciated the support provided by the NSPKU since we joined and thankfully, Charlotte is an extremely healthy and forward 18-month-old toddler.

I apologise for the delay in sending this to you but I've been trying to catch up with my in-tray all year!

Kind Regards

Cathy Darby



Dear News & Views

We would just like everybody to know about our new arrival, Kyle. Kyle was born on 6th January 2003. He is fine and does not have PKU unlike his 4 year old sister, Jade.

I have a tip for you all if you have children who don't like fruit too much (like Jade!). We have just bought a smoothie machine. Even with the Lo-profin milk, fruit and some sorbet the drinks are delicious. Jade loves them and isn't even aware of the fruit. If you have any good smoothie recipes, please let us know.
Regards

Lynne, Rob, Jade and Kyle Randall

Ed – see "contacts" on pg 8



Dear News and Views

We would personally like to thank Lisa Lee of Clayton-le-Woods who came to our rescue after we organised the NSPKU AGM and Study day. We were left tired and hungry. Lisa's fine home-made meat and potato pies certainly got us on our toes again, Lisa having cooked them herself and transported them to Leicestershire at over 70 miles an hour!. And we still have the bits in our teeth to prove it.

Pete Bramley and Mike Bailey



Jade and Kyle Randall



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

Vegetable Kebabs With Tomato Dip

Kebabs Ingredients

- 1 bamboo skewer, halved
- 25g (1oz) red or yellow pepper - 4 pieces
- 25g (1oz) courgette – 4 pieces
- 25g (1oz) red onion – 4 small wedges
- 15g (1/2oz) mushrooms – 2
- 1 x 15mlsp (1tbsp) cooking oil

Tomato Dip Ingredients

- 2 tomatoes (approx. 175g/7oz)
- 2 x 5mlsp (2tsp) tomato puree
- 4 x 15mlsp (4tbsp) mayonnaise *
- 300g (12oz) cherry tomatoes
- 1.25mlsp (1/4tsp) sugar
- 1 x 15mlsp (1tbsp) tomato/hamburger relish *
- Salt and pepper to taste

Method

- 1 Soak the pieces of skewer in water for 10 minutes – to prevent the wood burning during cooking. Drain.
- 2 Preheat the grill.
- 3 Thread the vegetables onto the skewers, with a mushroom in the centre and brush with the oil.
- 4 Grill the kebabs for 10 minutes, under a moderately hot grill, turning occasionally during cooking.
- 5 Remove the skewers and serve on/in **Loprofin** Partbaked Rolls or Homemade Pitta Bread, drizzle a little Tomato Dip over the Kebabs before serving.
- 6 Sufficient for 1 roll or pitta bread.

Tomato Dip Method

- 7 Skin the tomatoes and discard the seeds and any liquid.
- 8 Place the flesh in a blender with the remaining ingredients, whizz until smooth.

Tip

* Check NSPKU Handbook/Nutritional Information on product, for suitable brand

Mediterranean Salad

Ingredients

- 75g (3oz) **Loprofin** Low Protein Pasta Spirals
- 1 x 15mlsp (1tbsp) cooking oil
- 1 x 5mlsp (1tsp) salt
- 25g (1oz) capers
- 100g (4oz) celery
- 125g (5oz) baby plum tomatoes
- 1 small red onion
- 2 x 15mlsp (2tbsp) chopped fresh basil

Dressing:

- 4 x 15mlsp (4tbsp) olive oil
- 2 x 5mlsp (2tsp) balsamic vinegar

Method

- 1 Three quarters fill a large saucepan with water, bring to the boil. Add the pasta, oil and salt to the pan. Return to the boil, stirring. Reduce the heat slightly and cook for 8 minutes, stir occasionally to prevent pasta from sticking together.
- 2 Meanwhile prepare the vegetables: halve the capers, slice the celery and quarter the tomatoes. Thinly slice the onion.
- 3 Place the dressing ingredients in a small screw topped jar and shake for a few seconds, until thoroughly combined.
- 4 When the pasta is cooked, drain and rinse well with cold water, drain thoroughly and transfer to a large bowl
- 5 Add the vegetables, chopped basil and dressing to the pasta. Toss together lightly until well combined and coated with dressing.
- 6 Serves 2 as a main course or 4-5 as an accompaniment.

Tip

For a change replace the capers with 40g (1 1/2 oz) sliced black olives

Detailed Income & Expenditure Account

For the year ended 31 October 2002

	2002	2002	2001	2001
Income:				
Membership fees	9,659		10,269	
Donations and covenants	31,865		36,246	
Contribution and sponsorship re Conference 2002	7,050		2,083	
Lottery 2002 (Spring Draw)	5,633		6,773	
Bank and other interest received	2,882		3,956	
Publications and videos	2,757		1,703	
Advertising	3,150		4,200	
Fundraising	1,911		2,479	
Literature charges	–		2,399	
Sponsorship re international conferences	3,133		133	
Sponsorship re publications	3,000		900	
Sponsorship re Society administrator	–		–	
Sponsorship re assisted places	–		1,000	
General sponsorship	1,500		6,000	
Outward Bound course	1,064		734	
Donations re research	50		6,484	
Other receipts	126		–	
Total income		73,780		85,359
Expenditure:				
Expenditure				
Conference 2002	8,876		9,291	
Lottery 2002 (Spring Draw)	2,113		1,379	
Goods for fundraising (net of stock)	842		(2,936)	
Newsletter and publications	24,472		17,186	
Telephone	1,726		1,330	
Postage	1,906		1,656	
Travelling expenses	8,905		5,715	
Insurance	1,329		1,004	
Stationery	290		163	
Equipment and software	1,891		355	
E Weetch fees	11,897		12,036	
L Welch fees	3,056		3,356	
Sundries	434		479	
Committee meeting expenses	1,016		566	
MAP meeting expenses	85		208	
Dietitian's meeting expenses	80		199	
International conferences	1,522		522	
Bank charges	418		39	
Carried forward				
Outward Bound course	2,330		2,284	
Audit	940		881	
Research	–		699	
Grants	3,570		5,250	
Total expenditure		77,698		61,662
Surplus of income over expenditure		(-3,918)		23,697



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Reflections of the AGM & Study Day March 15th

When Mike Bailey, the AGM organiser, rang me with less than 3 weeks to go to say only 7 people had booked, all committee members, I have to say I was rather disappointed and alarmed. We all thought you were waiting for the big ESPKU conference in October and understandably could have anticipated that an AGM might not be very interesting. So the NSPKU committee got the publicity machine in motion and as a result over 80 attended.



The Hanover International Hotel is huge, with an impressive entrance and streets of shops selling all the kinds of things you like but don't need! It is used by groups as diverse as first division football teams, Evangelical congregations and us! Registration, the first meeting point for most, was in the Rotunda. This is a large round room rather like the centre of a wheel with everywhere else leading off from it like spokes. All the food manufacturers were there providing lovely little gifts for the children, lots of nice food to try, recipes to take away and helpful advice was on offer. We are very grateful to all the companies who came and thank them for their support.

The day started at 10am with a warm welcome from Sara Bartlett, the NSPKU chair. There were three speakers. Dr Philip Lee from the National Hospital for Neurology and Neurosurgery, London was first. He spoke about the work, research and outcome of maternal PKU using information from the old PKU register. This vital information could have been lost but for a donation from the Society to finance the retrieval and analysis of records. This information will help the medical professions to determine the best treatment. It was rewarding to hear how the donation was used and Dr Lee's presentation was, as always, clear and informative. His work is being written up for a medical paper and I hope to be able to report in more detail about the presentation when this has been done.

The next two talks were from Kati Colcombe who is on diet and Kerry Winters who is not. Both are adults with PKU who have made their decisions with the help of their medical advisors. Careful consideration of their individual symptoms, general health and circumstances brought about their decisions. They spoke frankly about their lives and how PKU affected them both. This could not have been more different. PKU, like many conditions, has degrees of severity. Most people with PKU in the UK (80%) have the severe classical form but others are more mildly affected. Recent work using Magnetic Resonance Spectroscopy (MRS) suggests that some may have a protective mechanism of the brain, which stops the high levels of circulating blood phenylalanine entering the brain. There is much more to learn about PKU and as time goes by treatment could well be more closely tailored to the individual, particularly as they grow into adulthood. Certainly these talks provoked a lot of discussion but the advice of the experts is that everyone should stay on strict diet until adulthood or until education is completed. With present knowledge diet for life is advised as the safest option but everyone should maintain contact with their clinic to keep appraising their own treatment whether on diet or off. Diet for preconception and pregnancy is essential for the best outcome. There is no choice about this.



After the talks the AGM followed pretty rapidly to prevent people sloping off! Actually, the NSPKU AGM is always interesting. Sara gave a report of all the Society has been doing and Julia Bailey, treasurer, reported on the financial state of the Society. Dave Stening presented the Medical Advisory Panel Report and a report on the PKU Register that is written separately.

Adult Support Group

As part of the AGM meeting we learnt about a new support group for adults which has been set up by Angela Murphy and Jonathan Beaumont from London. They have put a great amount of effort into getting a group established and Angela gave a report about why they had decided to do this and the progress made. Angela and Jonathan's contact details are in the front of the magazine so do contact them about future events. The meetings are all very informal and they will try to organise the events and socialising you want.

Whilst all this was going on the children were kept really busy and wonderfully entertained by two play specialists, Jenny Dyer and Charlotte Bramley from Great Ormond Street. These two were magnificent and the children emerged with so many fabulous things they had made we all wished we could be children again!

Lunch was a welcome break and gave everyone a chance to talk to one another, always an important part of any meeting. In the afternoon Birmingham Children's Hospital video was shown on blood collection. As with all procedures the right way looked easy, quick and featured untroubled people. I know that it is not always so unstressful but the video helps with really practical advice from professionals and from the equally important parents too. Look out for more information about availability of the video and accompanying booklet in future editions.

The afternoon was used to run small discussion groups. There was a choice of diagnosis and the early years run by Lesley Robertson, Chief Dietitian from Sheffield Children's Hospital; adult support group with Angela and work and travel with John McKenzie. As the groups were only small discussion flowed easily and exchanging of experiences is helpful for all ages.

Tea and refreshments were served in the Rotunda and all departed at 4pm. It was the first time the Society had held a one day AGM and study day. The committee learnt a lot about organisation in the hotel which will be helpful for October when we return. As the full family conference weekend is October we will not be running another weekend in March 2004. I think we all need to gather energy so we may run the AGM study day again in 2004 and return to the normal family weekend in March 2005. It's a long time ahead but think about being with us, it's a valuable day out, you can make new friends and the effort of getting up early on a Saturday morning will be worthwhile!

Eleanor Weetch
(Society Dietitian)

Preliminary Programme Of Events

Theme: Past, Present & Future

(DAY 1) – THURSDAY 30th OCTOBER:

- 1200 hrs - E.S.PKU 17th 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 31st OCTOBER:

- 0700 – 0915 hrs - Full Breakfast will be served in the hotel
- 0930 hrs - E.S.PKU 17th 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 17th 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 17th Annual Conference 2003 will be greeted by the
Lord Mayor & Mayoress of Hinckley, Leicestershire)
- 1830 hrs - E.S.PKU 17th Annual Conference 2003 Welcome Dinner
- 2000 – 2400 hrs - Evening Entertainment: DJ & “Halloween” Discotheque – (Optional Fancy Dress)

(DAY 3) – SATURDAY 1st 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 Ninad Blau (Speaking about BH4)
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”:
Dr Nick Shaw (Consultant Endocrinologist on Calcium & PKU)
Christinnah Sarkissian (Speaking about PAL- Phenylalanine Ammonia Lyase)
Carol Ferguson (Speaking about learning skills)
- 1545 hrs - Afternoon coffee/tea break & biscuits (PKU Food Manufacturers Exhibition Open)
- 1800 – 1930 hrs - Children's PKU Party: (Including surprise children's entertainer)
- 1930 hrs - E.S.PKU 17th Annual Conference 2003 Final Dinner
- 2100 – 2400 hrs - Evening Entertainment: Live UK PKU Band: The “Grand Boys”

(DAY 4) – SUNDAY 2nd 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 - PKU Workshops:
- 1230 hrs - Luncheon will be served in the hotel

END OF E.S.PKU 17th ANNUAL CONFERENCE 2003

“HAVE A VERY SAFE ONWARDS JOURNEY HOME”

My Life With PKU

Katie shares her experiences of growing up on the PKU diet...

My name is Katie Stevens. I am 25 years old and have been on a low phenylalanine diet for my whole life. I was born in Australia and grew up in Sydney. Some of you may have met me at the NSPKU conference last year.

I was treated at the Royal Alexandra Hospital for children where I was diagnosed in the late 70's. At that time information about PKU and its treatment in Australia was quite new and continually changing. I remember mum telling me that when I was diagnosed that her and dad went to library to read up about PKU and what they found was often about untreated PKU's and was quite upsetting for them.

I was one of the first PKU patients that my Doctor at the children's hospital had treated so he was learning at the same time we were. As I was growing up I was always promised that I could stop the diet in 'a few more years' but as the years went on and as more research about the benefits of diet came to hand I ended up staying on the diet. I have never been off my diet although I am not as strict as counting units/ exchanges as I have been previously.

Although having a special diet has its disadvantages it also has its advantages. It has meant that I have eaten quite healthily due to the way the diet is. Having the diet has also made it much quicker for me to decide what to eat when at a restaurant. When for example whomever I am eating with has to go through the whole menu to decide what to eat I can skip straight to the vegetarian section, then skip all the ones that have cheese, nuts, tofu etc and then it is much quicker to decide.

Having PKU has also helped me to decide what to do for a career. I spent a lot of time with dietitians at clinic. I used to like seeing the dietitian as in Australia, it was the Doctor who was 'the mean one' who limited how many units (of protein) I could

have. The dietitian was the one who would find new things to eat and ways of sticking to the diet and taking my supplement. When the time came to decide what I wanted to do I thought maybe being a dietitian was something I would like to do.

I like the way diet can have such a big influence on so many conditions, not just PKU. I thought being a dietitian was interesting and I also thought I might be good at it as I would be able to empathise with people on special diets.

Having PKU has not stopped me from travelling although sometimes it makes it a bit difficult. But it has also helped me to do more with my diet.

I first came to the UK as an exchange student when I finished high school and have also managed a trip to Thai-land with university.

I have now been back in the UK since August 2001 and have been living and working in Birmingham since then and also trying to fit in as much travel as I can.

Although travelling on a special diet can be hard coming to the UK has been very good for my diet because of the support and easy access to low protein foods. There are so many new products over here that I had never even heard of at home. Also being able to get PKU foods on prescription is fantastic and makes it much easier to stay on the diet. At home we have to buy all our low protein foods from the manufacturers and importers which can be expensive. And also because of the smaller population there is less demand so we don't have the choice of products that there is over here.

The NSPKU here is also great as the conference and all the support they give is very helpful in controlling your blood levels.

Since I have been over here I have been able to expand my dietetic experience and now I am working at the Childrens hospital which is something I have always wanted to do. And I am learning so much.

While I am here I would like to find out as much as I can about the other side of PKU (More of its treatment from the side of the dietitian rather than the patient!)

Working at the Childrens' Hospital has also helped my blood levels as you are much less likely to cheat when you are working with your dietitian every day and you may get a surprise blood test at any time!

Although I am working quite a bit here I have managed a bit of travelling. I have been to Morocco, Ireland, Amsterdam around the UK and most



recently to Brussels. I have more travel planned. Hopefully a trip to Spain and Portugal in May, Zurich in July and then from September till the end of the year I will hopefully be able to do a big trip around Europe starting in Russia and travelling around as many countries as possible heading back to Australia in time for Christmas. I can't wait as I know it will be very interesting but also a challenge to try to stick to my PKU diet in so many different countries and languages.

My ambitions when I return to Australia are hopefully to continue to work in paediatric nutrition and hopefully inborn errors of metabolism, I am also interested and working in sports nutrition. I am also planning to do more travelling to see the areas of my home and the rest of the world that I have not yet had time to explore. I will certainly miss the ease of management for my diet that I have had in the UK.

I hope you have enjoyed reading a bit about my experiences with PKU. Although having PKU can make some things harder I do not mind as I think it has helped me to become the person I am now. It has made me healthier and although when I was young having to be 'different' was hard it is now just a part of my life and I can't imagine my life any other way.

Katie Stevens



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Life Beyond The PKU Diet

Kerry Winters recalls her early memories of growing up on the PKU diet...

This is my story, one of which is based upon my vivid early childhood memories of being on the PKU diet and my experiences and life since coming off the diet some 23 years ago at the age of 10. That gives my age away, I am now 33, married and live in my home town of Corby, Northamptonshire. I am an I.T. trainer at RS Components Ltd in the town, an international engineering component distributor where I have worked for the past 16 years. My hobbies include keep fit, socialising and travelling to name but a few.

I was lucky enough to have been detected as having PKU at birth, whereas my elder brother Martin (born 1964) was not detected until he was 9 months old. Somewhere in some dusty film library there sits a nursing training video in which I starred when only 9 days old - I may have some royalties to collect!

The diet is very strict as many people will know, but despite this, I have some fond memories with regards to the things I could eat, particularly the treats that I thoroughly enjoyed. When we used to visit one of my favourite Aunts in Lancashire, she would prepare a traditional English breakfast for all. There was however one main omission, everyone's bacon rind would be missing, as she would cut it all off and grill it for me - I was allowed the rind but not the bacon! I was allowed crisps, and one other strange habit was dipping crisps in water before eating, I have to admit to still doing this sometimes to the horror of my husband Jack! I was allowed a small amount of milk as a treat, I loved milk and this was great! Much better than the prescribed PKU milk supplied in brown medicine type bottles - yuk!

There are other things that I recall about the diet that were awful, particularly aminogram (a white bland paste like substance) - a protein supplement I had to eat. I suffered the special protein free bread

too, supplied in memorable distinctive round red tins.

Following advice from my specialist at the time (Professor Wolfe), I was gradually weaned off the diet from the age of 8, being completely off by the age of 10. This was a memorable occasion, to celebrate I was allowed an ice cream and a whole glass of milk, I was in heaven! The diet has to some extent affected my food preferences now, I do not eat much meat (chicken is my favourite), nor cheese or fish. I do enjoy milk, bread and anything pickled!

I have always been keen on self development, and I have studied hard to attain school CSE's, and College Diplomas and recently an NVQ level 3 in training and development, I have recently qualified as an NVQ assessor. This has mirrored my career progression from Call Centre advisor through various roles in Human Resources into my recent promotion as an IT trainer.

Clearly I have been off the diet for some considerable time and this does not seem to impact me. I am fit and healthy and keen to understand any potential benefits by returning to the diet. I have regular annual check ups in London, with Doctor Lee and Maggie Lilburn - they seem quite happy with my progress and see no reason why I should go back on the diet. Clearly PKU affects people very differently, and some may feel much better by returning to the diet. I am keen to better understand ongoing research into PKU and participate in this research where I can. I have presented at both NSPKU meetings and PKU study days, and I am very interested in other peoples' experiences too.

Kerry Winters

Cover Story

Hertford Choral Society Sings For Our Supper!

Every Christmas the Hertford Choral Society holds its festive delivery of a fine repertoire of songs and carols to a packed audience of music lovers. At the event, generous donors contribute to two elected charities nominated by the members of the choir. This year the NSPKU were honoured by being one of those charities that were nominated. The NSPKU would like to pass on their sincere thanks for the fine sum of £435.50 raised by the kind individuals of the audience and choristers. This will help us in our work in the field of research and support. To receive the cheque, Editor's daughter Nicola Bramley aged 9 (pictured left) supported by close friend Hannah Cooke aged 9 (pictured right) attended one of the Society's rehearsals and were presented the cheque by Director Derek Harrison (centre).



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“The Bigger Picture”

My revolutionary experience of the proper PKU diet...

Ask yourself these 3 questions:

Are you ‘on diet’ at the moment?
Are there times when you don’t weigh
your exchange foods exactly?
Do you find it hard to get consistently low
blood levels?
Have you ever experienced excessive tiredness or
mood swings?

If you answered yes to any of these (or even if you
didn’t) – what I have to tell you may finally
persuade you that sticking to a strict PKU diet may
actually make you feel better than you’ve ever felt
before! (and it’s not so hard, either!!)

I was inspired to speak to you today after I read the
transcript of Kerry Winter’s talk at last year’s Adult
PKU Day. She spoke of her experiences being off
diet – and they were so contradictory to my own,
that I felt compelled to tell you ‘the other side’.

Many of you may recognise yourselves in my
experiences. I have been on the PKU diet since I was
diagnosed at birth in 1971. In my childhood, I was
always reassured that I would come off the diet
when I was older – but 8 became 12; and then 12
became 16.....By the time I reached adulthood, of
course, it was no longer an obvious choice. Staying
on the diet was the recommended way to go.

So I tried. My adult experience of the diet has
ranged from a very liberal 40 exchanges (from the
ages of 18 – 22), to a more controlled 12 – 15
exchanges during my mid-late twenties.

I was experienced enough (I thought) to
know what sort of proportions of exchange
food I could have. Potatoes, rice – I
estimated the quantities (because I couldn’t
be that far out, could I?!)

I was brought up in a culture of loving and
appreciating food. My Mum is an
enthusiastic cook who likes trying recipes
from Italy to India and from Asia to the
Orient. So of course I like eating out. And
who’s to notice if the ‘vegetarian’ option
isn’t exactly what the dietician would have
recommended?!

So I enjoyed my food, and struggled on with
the diet. My blood levels ranged from 800 to
2000+ - but I wasn’t too worried. After all,
you have to live your life as well, don’t you?

By the age of about 23 or 24, I was noticing
more and more how tired I felt all the time.
I suspected it was something to do with
having to work full-time and earn a living

(?!), but I was still frustrated by the fact that anything
less than 10 or 11 hours sleep a night didn’t seem
enough.

I even went to talk to my GP about it. She was
sympathetic, but thought it was just work. I also
expected times to be quite hard - after all, I never
expected training to be a teacher to be a doddle! So
I put it to the back of my mind and struggled on.

I also noticed that if I went away on holiday and
abandoned the diet for a while – after just one week
I felt quite out of sorts. I got increasingly
argumentative (i.e. more than usual!) and felt
stressed and over-emotional. I seemed to cry a lot
and felt generally horrible. It was so off-putting that
I started to take my Aminogran (amino acid
supplement) on holiday with me and resisted the
eggs and cheese and general dietary free-for-all.

But still the tiredness pursued me. And it was sheer
exhaustion. If I went to bed any later than 10pm I
could not get up for work at 7am. If I stayed up a bit
later at weekends to see friends, I was compelled to
sleep for at least 12 hours before being able to face
the day (and then spent it exhausted anyway). It was
depressing, infuriating, and getting me down – but I
grew to accept it.

Any suggestion when I went for my check-ups that
perhaps I should aim for lower blood levels seemed
to be asking for the impossible. I knew I had severe
PKU and the prospect of really giving up so many
nice, ordinary foods seemed unfair and extremely
difficult.

This is what has always been a psychological barrier
for me. I thought staying on the diet meant giving
up certain foods forever – and I just couldn’t bear to
do it. These are the items that I could not bear to
live without:

Bread (wholemeal, granary, foccacia – you name it, I
love it!)
Cheese (especially melted on pizza, pasta or toast!)

So not that many things – but crucial ones.

Before I tell you how this all changed – let me ask
you to reflect on the questions I asked at the
beginning again. These would have been my answers
18 months ago:

- Yes I’m on a diet – but I try not to think
about it too much and I don’t let it stop
me doing anything.
- I never really weigh my exchange foods –
I know what the amount looks like. And
if I started weighing them, then I’d have
to count the naughty ‘extras’ I slip in



every now and then to make me feel better (such as chocolate, bread, vegetarian dishes at restaurants, etc...)

- Yes, my blood levels are inconsistent and can go quite high – but that's because my PKU is quite severe – not because I'm not doing the diet correctly.
- Yes, I'm very tired and high blood levels give me mood swings and make me feel awful – but there's nothing I can do is there?

STOP FOOLING YOURSELF !!!

It all changed for me when I decided to go on the pre-conception diet in August 2001. What I learned about the way I was doing (or, more precisely, not doing) my diet taught me some hard truths about myself and the way I had been fooling myself for all these years that I was really 'on diet'.

This is my advice to you:

- Weigh your exchange foods – at every meal time!
- Don't turn a psychological 'blind eye' to the 'extras' you eat and don't count.
- In weighing exchanges properly, you can discover how you can eat what you want. **Nothing is banned, AS LONG AS YOU COUNT IT!**

But the most powerful thing that happened to me, when I started to do the diet accurately and my levels plummeted to below 250 (recommended for pre-conception) was that I felt I had so much energy I was bouncing with joy.

And I do not joke!

- I can get by on 7-8 hours of sleep or less
- Even when I have very late nights, once I'm up the next day I get a surge of energy and I'm full of beans
- I've been accused by work colleagues of being on drugs!
- I generally have so much energy that I feel like a new person
- I still eat out at restaurants several times a month (chefs are always obliging and no-one notices my digital scales)
- I eat cheese more or less every day (and milk, chocolate and even ordinary bread on a regular basis)
- I have lovely tasting low protein bread as I make it myself
- I've discovered some extremely tasty low protein recipes (such as celeriac and

sweet potato soup – courtesy of SHS)

- I've become a dab hand at adapting recipes and can rattle up an innovative dinner party menu in 5 minutes!
- **But most of all I love life and have finally been able to accept who I am and that by following the diet so strictly, I have actually freed myself – not bound myself in chains.**

SO STOP FOOLING YOURSELF THAT YOU ARE DOING THE DIET PROPERLY.

Be honest about who you are and start challenging the 'demon within'.

Next time you make a meal, weigh your exchange foods accurately.

Keep a food diary to see how often you really indulge in those 'twice a year' treats.

Finally, ask your doctor or dietician for help in doing the diet properly – it really could revolutionise your life.

*Written by Kati Colcombe, age 31, now 5 months pregnant
October 2002 (updated April 2003)*

Dietitian's note

The way that Kati now manages her diet needs to be put into perspective.

Kati is now managing her PKU diet in her own way as an adult. Dietitians would not recommend cheese for younger patients because it is very high in protein. A portion of 30 grams of cheese would provide 6 exchanges. A slice of ordinary bread would provide 2 or 3 exchanges. This is why we would not advocate these foods for anyone with moderate or severe PKU. There are very good low protein equivalents to these foods which in the case of bread can be taken without counting. There are also some low protein cheeses and other spreads which can be used and allow more realistic helpings. Once a child develops a liking for the normal foods it is very difficult to persuade them to eat the low protein substitutes. It is more difficult for the older patients who may have relaxed their diets and started to eat more protein, including ordinary bread. We would not advocate this for the younger child as through experience it has been found to make diet control more difficult.

Support Groups

SKATE PARTY

If nature had intended for us to fall over she would have put wheels on the bottom of our feet.



Unperturbed by this lack of foresight, London and Home Counties Support Group ushered 50 poor souls into the Welwyn Garden City skating rink in Hertfordshire, put wheels on the bottom of their feet and then propelled them at great velocity around the hall. Joyous mayhem ensued. Most of the time the wheels were in the air and in some cases with very low mileage being achieved. Others used their whole bodies as weapons to effectively "wipe-out" other unwary skaters in an uncannily similar scenario to ten-pin bowling on wheels, with humans for pins.

In a lull in the carnage, attendees hoovered up masses of "Free" food and low exchange fodder washed down with aspartame-free squash. This only served to "fuel the fire", with greater speeds being attained and an increased casualty rate. By far the most effective attendees at moving around the rink on their hands and knees without the aid of a safety



net or even skates was Chris Adams or "horizontal Adams" as he is now known. The prize for "juggling a paper plate full of party food during a wipe-out", goes to Mike Bailey. Extremely agile man.

If you fancy it, there will be more catastrophe next year. You are welcome to come if you are in the area.

London & Home Counties Fathers Day Picnic!



Sunday June 15th 2003

We've booked the weather and the venue all we need is for you to turn up! Everybody is welcome so even if you aren't part of L&HC support group, if you are in the area please do come. The event starts at 11 a.m. And finishes when people drift home. WHY NOT GIVE THE DAD IN YOUR LIFE A DAY OUT TO REMEMBER! Here's some of the attractions to lure you to this bristling soiree!

Bouncy Castle Childrens' Entertainer Sack Races Five-a-side footie
Egg and Spoon races Fully licensed outdoor bar Face-painting

Venue - The Police Sports and Social Club, Chigwell, Essex - Further travel details will be forwarded to you when you confirm that you will be attending.

Time - 11 a.m. Start.

Food - There will be a cake stall but you should provide yourselves with a picnic lunch

Contact :- Kersten Cruickshank on 01708 866470 or at 3 Severn Road, Aveley, South Ockenden, Essex, RM15 4NR

Reading and District Support Group

CHRISTMAS PARTY MAYHEM !



Our Christmas Party Mayhem!

If anyone would like to be involved in the group or has any ideas or information regarding events we can be involved with, then please contact us. Due to a very successful 2 years of fund raising, we have a healthy bank balance and currently only host a Christmas Party. This is a very successful and well-attended function, but is really only suitable for the little ones. We would like to do other things during the year, but lack support and ideas.

We would love to hear from any interested party.

Many thanks

Nicola Cragg
13 Blomfield Dale
Binfield, Bracknell
Berkshire, RG42 1FY
Telephone – 01344 482654

East Anglia Support Group **CAMPING WEEKEND**

WEEKEND OF JUNE - 6, 7, 8th 2003

The venue located at Grafham Water in Cambridgeshire is a small well appointed site 2 minutes off the A1. There will be games for the kids and the obligatory cycle ride around the reservoir - weather permitting. Everybody is welcome but you will have to be quick to reserve your place. Wine will flow and fires burned! *IN TWO MINDS?, PHONE ME AND SEE IF I CAN CONVINCE YOU INTO A WEEKEND OF FUN.*

Please contact in the first instance - Jo Clough -

Phone: 01480 395024 - E mail: publications@nspku.org

FRESH PKU BREAD EVERYDAY. HELP IS AVAILABLE PROVIDING ANY OTHER
PKU FOOD ON REQUEST. FRIDGE & FREEZER USAGE IS POSSIBLE.



PKU Camping Weekend

27th June -29th June 2003

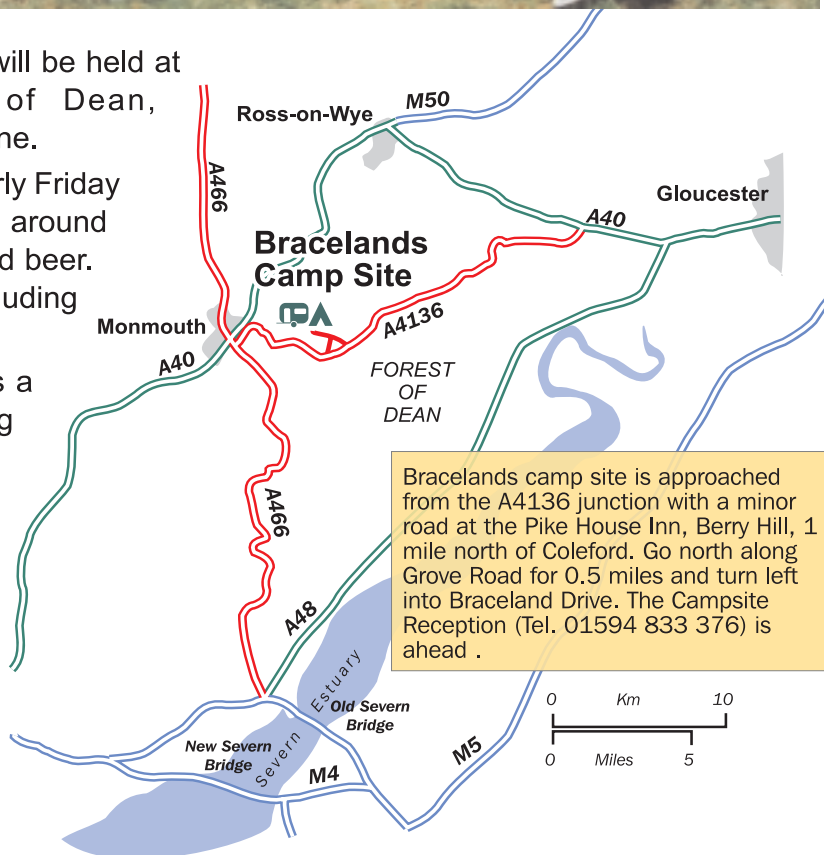
Forest of Dean, Gloucestershire



The annual NSPKU camping weekend will be held at the Bracelands campsite, Forest of Dean, Gloucestershire over the last weekend in June.

The first brave campers start to arrive early Friday evening, before too long they are sitting around gassing over mugs of hot tea or tins of cold beer. Saturday morning sees more arrivals including the "softies" who stay at local B&Bs.

Lunch at a local pub on Saturday raises a few eyebrows when families start weighing chips and checking the pop doesn't contain aspartame. The Saturday evening entertainment is too good to miss, a mix of smoke, warm beer and all sorts of food cooking on the barbie. This event is an excellent opportunity to meet other PKU families and to experience coping with



PKU 'on tour'. The weekend is not exclusively for people with tents and caravans. Day visitors make up a large number of the party either just driving for the day or staying in a local B&B. The Forest of Dean is only a short drive from the M5 and M4 motorways, so make a date in your diary and come along for the weekend or just visit for the day. Remember the last weekend in June (27th to 29th June 2003).

**For more information contact :
Ifona or Alun Rogers on 029 20890065**

Dietitian's Report

DOLMIO SAUCES

I have recently received information about Dolmio Sauces.

Bolognese Lasagne Sauce, Protein 0.5g per 100gms. Can be added to the list on page 17 of the Dietary Information Booklet.

The following weights of sauce provide one exchange.

STIR IN SAUCE WEIGHTS

Stir-in Sauces

Sun-dried Tomato	65g
Sweet Pepper	65g
Tomato and Roasted Garlic	70g
Tomato and Roasted Vegetables	75g

Dolmio Finest

Mushroom	50g
Basil	50g
Garlic	55g

Dolmio – Jar Sauces

Original	60g
Extra Garlic	60g
Extra Mushroom	55g
Extra Spicy	60g
Extra Vegetables	65g

Pasta Bakes

Creamy Mash	90g
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DISCONTINUATION OF MARKS AND SPENCERS DRESSINGS

The following dressings have been discontinued:

Creamy Italian Dressing
Classic Italian Dressing
Roasted Red Pepper Dressing

NESQUIK POWDER CHOCOLATE FLAVOUR

The nutrition information I received from Nestle about their Chocolate Nesquik was wrong. It is listed in the Dietary Information Booklet as a free item. Chocolate Nesquik contains 2.5g of protein per 100g. Therefore 40g of dry powder is one exchange. This is a lot of Nesquik for one exchange, so your own dietitian will advise you about how you should count it in your own or your child's diet.

USEFUL NEW PRODUCT!

Our publications officer, Jo, recently told me about some lovely, sophisticated looking new jellies with fruit available from Waitrose. For us all living in the north this is disappointing but for those in the south they might be useful for picnics, packed meals, children's parties.

Tokyo Café Sparkling Fruit Jelly with fresh fruits. There are 3 flavours of jelly all with different fruits e.g Sparkling Apple Flavoured Jelly with Fresh Green Apple and Blackberries.

The protein content is 0.1g per 100g. The tall container of jelly and fruit weighs 175g. These jellies are therefore free.

AMINO ACID ANALYSIS RESULTS

Sometime ago we requested the analysis of some more foods and drinks for their phenylalanine content. These results are now through and the following are so low in phenylalanine they can be used freely in the diet.

Coconut Milk
Rice Dream (a rice milk)
Sharwoods Prawn Crackers
Tapioca Starch
Cassava Flour

The following should be counted as an exchange:
Unpopped popcorn 10g provides one exchange

PRE-PAYMENT CERTIFICATES- LOOK AFTER THE PENNIES...

Anyone who is on a low phenylalanine diet can save money by obtaining a pre-payment certificate. This certificate lasts for one year and entitles you to all your prescriptions for the year. The certificates can be bought to cover 3 months or a year.

Clare Hawkins, told me that you can save a bit more money if you re-new your certificate before April 1st even if your present one runs out after April 1st. This will not help you this year as the deadline is passed but make a note on your diary or calendar for next year.

So if your certificate was due to expire on April 20th you could still buy the annual certificate to cover April 21st onwards at the old price if you buy before April 1st.

The cost of the pre-payment certificate for 2003 – 2004 is £90.40 for the year and £32.90 for 3 months.

(The cost of the certificate before April 1st was £89 and £32.40. It's not a lot of difference but every little helps)

If you have any queries about the pre-payment certificate you can call the prescription Advisor Office on 0845-8500030

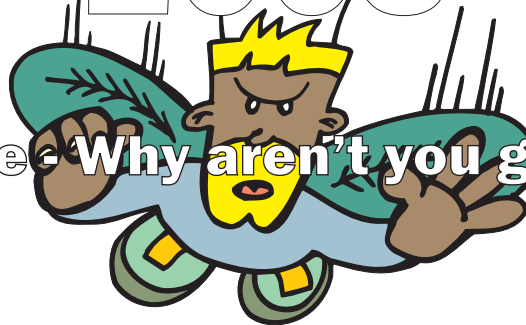
Or write to them at:
PPC Issue office,
PO Box 854,
Newcastle upon Tyne,
NE99 2DE

Thank you Clare!

OUTWARD BOUND WEEKEND

2003

Edale - Why aren't you going?



Age 9-12 years with PKU (boys and Girls)

When: July 25th-27th.

Cost: £50

Places available: 2 only

Contact Eleanor Weetch

Tel: 01226 742494

email: nspku.dietitian@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		
Wallets			£3.75		
'Bryan Pearce' Greeting Cards (sold individually) NEW			60p		
Mug 'Probably the Best Diet in the World!' NEW			£3.50		
Christmas Cards - 'Teddy Postbox' 10pk			£3.00 pk		
Christmas Cards - 'Golden Tree' 10pk			£3.00 pk		

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

Variety for Life from SHS



Biscuits
Breakfast Cereals
Breads
Egg Replacers
Milk Replacers
Mixes
Pasta

SHS continues to combine innovation with the latest research to design state of the art formulae for the nutritional management of PKU.

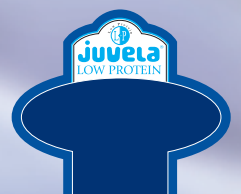
The SHS Loprofin and Juvela Low Protein product range offers a choice of tasty, convenient phenylalanine free protein foods and snacks designed for ease of use to people on a PKU diet.

- **Comprehensive product range**
- **Continued excellence in customer service**
- **40 years of experience in diet and PKU**

Contact the SHS Advice Line on 0151 228 1992
or visit our website at www.shsweb.co.uk

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INTERNATIONAL

SPECIALIST CLINICAL NUTRITION



SHS International, 100 Wavertree Boulevard, Liverpool L7 9PT.