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**WIN £100 if you guess the finishing
time of our Marathon Runner!**

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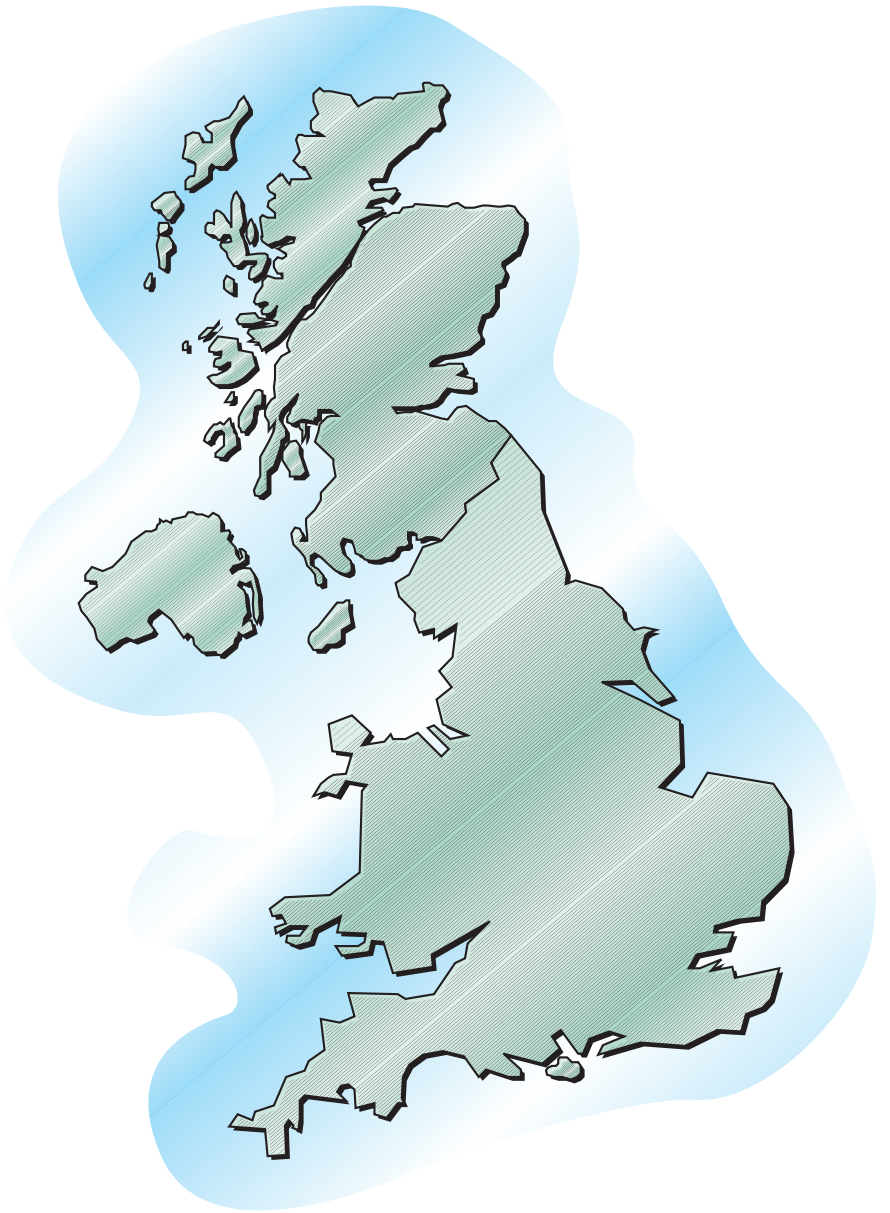
The Council of Management

Telephone Helpline: 0845 603 9136

Address: PO Box 26642, London N14 4ZF

E-Mail: info@nspku.org

Internet: www.nspku.org



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Editor's Report...

The New Year sees News and Views start off with a bang! Eric Lange has got us on our marks ready to run for the Society and a good thing too. As our treasurer Julia explained in our last issue, we're feeling the pinch here at the NSPKU but are far from powerless to do anything about it. Eric's marathon plans are admirable indeed but we're all capable of raising cash via a myriad of far more mundane methods! A cheque for a few pounds only requires a stamp and a shuffle to the postbox and for those with just a little more energy, Eric has listed some easy and fun ways to swell our coffers!

Our exercise theme continues with Sarah Kimpton's inspiring account of her running career. If we believed media accounts, most of us would think the modern British teenager undressed without an ASBO. Sarah proves there's more on some young people's minds than Class A drugs and a mooch round the local shopping precinct. Go Sarah, go!

Uncharacteristically in the extreme, even I, Mrs. K. Thomas have pledged to at least stroll for the NSPKU. I'm planning to engage in a 10k run in June. It happens to be taking place in Dublin, a location whose pubs and restaurants are not exactly a mystery to me. This, I hasten to add, is merely a happy coincidence but anyone in that locale that weekend, please feel free to join me for a what can only be described as pre-marathon hydrating exercise.

Now, enough rambling. I really should be undertaking some sort of training and so should you. Let's do it for the NSPKU and for ourselves too! There's nothing to lose and thousands to gain!

Kiri Thomas
Editor



The National Society for Phenylketonuria (United Kingdom) Limited

Please address all correspondence to the Editor, "News & Views", 4 Kenilworth Avenue, West Didsbury, M20 2LJ
Tel: 0161 4462396
Email: editor@nspku.org

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The National Society for Phenylketonuria (United Kingdom) Limited,
PO Box 26642,
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Helpline: 0845 603 9136
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Web Site: www.nspku.org

Registered address:
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Treasurer's Report...

I was surprised following my article "Sink or Swim" in issue 114 at the immediate response it generated. Thankfully it was a positive response rather than (as I had half expected) "what are you doing with our money"!

I have had a few emails sent to me of money generating ideas which will be looked at in due course, and offers of help, which are always well received. But don't rest on your laurels...keep those emails coming.

I believe the discussion in a Senior Officers meeting which prompted the article has also spurred into action our Secretary. Usually to be found clubbing the night away in some sleazy joint I believe he is now seeing the other side of the early hours of the morning as he trains for the London Marathon,

running to raise funds for the NSPKU. I only hope he lives to tell the tale! (Not really Eric, I'm sure you'll survive and raise wads of cash as well). Let him be an example to you all, (in other words if he can do it so can you!).

Whilst Eric has been enjoying his new fitness regime, I have had my nose to the grindstone preparing for the annual audit the outcome of which will be presented at the AGM, so if you want an in depth view of the Society's finances and what we do with our money, come along to the conference and take a pew at the AGM. Failing that the statement will be included in the next issue of News and Views.

Julia Bailey
Treasurer

Donations to.

If you are sending us some money please note that payments should no longer go to the Treasurer:

If you are sending a donation or a subscription payment please send it to:
NSPKU
PO Box 2664
London N14 4ZF

If you are sending money for anything else please send it to:
NSPKU
c/o Vicki King
Tarkwa
65 Cromwell Road
Ribbleton, Preston, PR2 6YD
Please send only cheques or postal orders
NOT CASH

Donations

<i>Donations to 3/12/05 (£30.00 and over)</i>	£
West Lodge School	1,500
Lee Butler	1,325.60
Gorvins Solicitors	1,400
John & Sharon Skidmore	1,101.35
John & Sharon Skidmore	225.10
Janie Johnstone	368
David Casale	582.50
Richard, Nik & Andy (Charity Triple Challenge)	2,375.72
Jon & Louise Porter	1,345
Mr K.J. Phelps	39.50
Eleanor Weetch	67.50
Mrs M. Nash	36
Mrs Aileen Wheeler	430
Mr & Mrs Eggleston	125
HMS Chatham's Officers Mess	1,114
Mrs Rita Veazey	100
Julie Roberts	400
Mr John Darby	130

In memoriam:

In memory of May Parkin	50
In memory of Thomas Bowling	52
In memory of Phoebe Barnwell	285

Support Groups

We have had a letter from Stephen Oliver and Ifona and Alun Rogers. They wish to announce the closure of the **South Wales PKU Support Group**. They feel new blood and ideas are required and were unsuccessful in finding anyone else to take over the mantle.

A Bicycle Made for Three!

Another inspirational and fun fundraising story comes via Richard Newton, Andy Egerton and Nik Olliver who cycled on a triplet (a bike for three) from John O' Groats to Land End. They raised £2,375.72 for the NSPKU and some more money for two other charities too. Good work fellas!



SHS **recipes**

Curried Onion Dip

Ingredients:

- 1 x 15mlsp (1tbsp) olive oil
- 50g (2oz) onion, very finely chopped
- 1 x 5mlsp (1tsp) medium curry powder
- 4 x 15mlsp (4tbsp) mayonnaise *

* Check NSPKU Handbook for a suitable brand of mayonnaise

Method

- ① Heat the oil in a small frying pan, add the onion and curry powder, cook over a moderate heat for 2-3 minutes, until the onion is tender and lightly browned, stir occasionally.
- ② Transfer the curried onion to a small bowl and allow to cool.
- ③ Stir together the mayonnaise and onion, chill until required.

Letters

News & Views, 4 Kenilworth Avenue, West Didsbury M20 2LJ
Email: editor@nspku.org

The treatment of phenylketonuria varies for each individual patient. No patient should alter their own treatment as a result of reading how another patient manages their diet without first consulting their doctor or dietitian.



Dear N&V,

Please find enclosed a cheque for £400. The money was raised from sponsorship following my second successful attempt at the Great North Run. I completed the course of 2 hours and 33 minutes alongside my daughter Morgan.

I ran to celebrate the success of my eldest daughter Ruth who has PKU. Ruth is now 23. She has a degree in Food and Nutrition and has recently returned from travelling to New Zealand and Fiji.

She is currently working to fund further travel next year to Asia.

The photograph shows myself and my daughter Morgan proudly sporting our medals at the end of the half marathon.

Yours,
Julie Roberts



Editor's Note: The letter below was sent to our Society Dietitian Eleanor Weetch and is a fundraising inspiration to us all. Happy Anniversary Mr. and Mrs. Evans!



Dear Mrs. Weetch,

Thank you for your letter of the 11th October. It was good of you to respond to my queries so comprehensively and I found the information both helpful and instructive.

My wife and I celebrate our Golden Wedding Anniversary on 27th December (Editor's Note: this letter was sent just before Christmas 2005) There is really nothing that we need or want so we have asked our guests to make a contribution to the NSPKU instead, giving the London PO Box address. We have no idea how they will respond but we hope that whatever sum of money is realised will be helpful to the society in its work.

Yours,
Mr. H.D.G. Evans.



Dear News and Views,

I attach photographs from our visit on board HMS Chatham on Monday 31st October 2005 when the Warrant Officers and Chief Petty Officers Mess handed over a cheque for £1,114 to the Darby Family (Cathy, Iain, Emily (6yrs) & Charlotte (4yrs - PKU)) to pass onto NSPKU.

The money was raised by the mess at several events on Chatham's recent deployment, including 'Reindeer Racing' on the ships flight deck on Christmas Eve off the Gulf of Arabia. Other fund raising events included a village fete, quiz nights and various donations made by mess members.

I sent the real cheque separately in the post!.

Regards
Cathy Darby



Onboard HMS Chatham



Dear News and Views,

Please find enclosed a cheque for £1,298.60 and one for £27.00. This was raised by us and by Lee Reynolds who ran the London Marathon in April 2005. Callum, (4 yrs PKU) and Lauren, (8yrs non-PKU) are in the picture alongside Lee at the finish of the marathon. We all thoroughly enjoyed the day along with Lee's parents.

We would like to say a big thank you to Lee for running the marathon for the charity and also to his and our families, friends and work colleagues for their support and generosity.

Yours,
Mr. and Mrs. K.W. Butler.





Letters

News & Views, 4 Kenilworth Avenue, West Didsbury M20 2LJ
Email: editor@nspku.org



Dear News and Views,
Please find enclosed four CAF cheques which are the combined result of sponsorship money collected by the Casale family and friends for David Casale's Three Peaks Challenge.

We divided up the money for two charities: £582.50 for CLAPA (Cleft Lip and Palate Association) and the same amount to the NSPKU.

We hope that this will help you in some small way to continue supporting those families affected by PKU and to show thanks for your work.

Yours,
Sally Casale.



Dear News and Views,
Please find enclosed a cheque for the sum of £1,400 representing the amount that Gorvins solicitors raised for your charity in the 2004 Salford Triathlon.

I also enclose the Gift Aided Sponsor forms which cover most of the donations. The Triathlon raised money for both St. Ann's Hospice and for the NSPKU and your cheque represents half of the funds that we have managed to collect.

Regarding the Triathlon itself, both of our teams successfully completed it after a very early start on Sunday 25th July, in the lashing, icy rain typical of a

Salford summer. The swimmers both exceeded expectations with Lisa Chambers (mum to Holly Chambers of Stockport, 9yrs PKU) racing around the 750m circuit in around 18 minutes and John Kitching managing 23 minutes after only having learnt to swim in January! The cyclists were then handed the timing chip baton. Marc King, recovering from pneumonia, sped around the circuit closely followed by Colin Perrin, both returning competitive 20k times before handing over, exhausted to the runners Dave Pickering and Tracy Rodgers. Dave ran the 6.6k in a personal best time of 32 minutes before Tracy, recently delivered of a new baby, brought home the second Gorvins team.

Yours,
John Kitching,
Associate Solicitor, Gorvins.



From left to right: Marc King, Lisa Chambers, Tracy Rogers, Dave Pickering, John Kitching and Colin Perrin

All PKFoods are now available on prescription



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TEL: 020 8953 4444 FAX: 020 8953 8285

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

THE BRITISH 10K LONDON RUN

At last! For all you budding runners and young Olympians out there; we have secured 12 places for the British 10K London Run. This is the UK's 3rd most prestigious fund raising event.

Hyde Park, The Ritz, The National Gallery, St Pauls Cathedral, Tower Bridge, The London Eye, The Houses of Parliament.....take them all in as you pound the streets of London!

Feel the history of our great metropolis while jogging around it with thousands of others and, raise funds for the NSPKU at the same time.

This year's run is on Sunday July 2nd at 9.35 am.

The Organisers' conditions of entry are as follows-

You must be 15 years or older on the day of the run. You must be able to complete the run within a timeframe of 2 hours.

The NSPKU conditions of entry are quite simple:

Please try to raise as much money as you possibly can for the Society!

Kill two birds with one stone. Take in the best sights of London while you run and raise money for the NSPKU.

So, if you wish to run and represent the NSPKU, please email me on secretary@nspku.org and tell me why you want to run and how much you think you can raise for the NSPKU. This will not

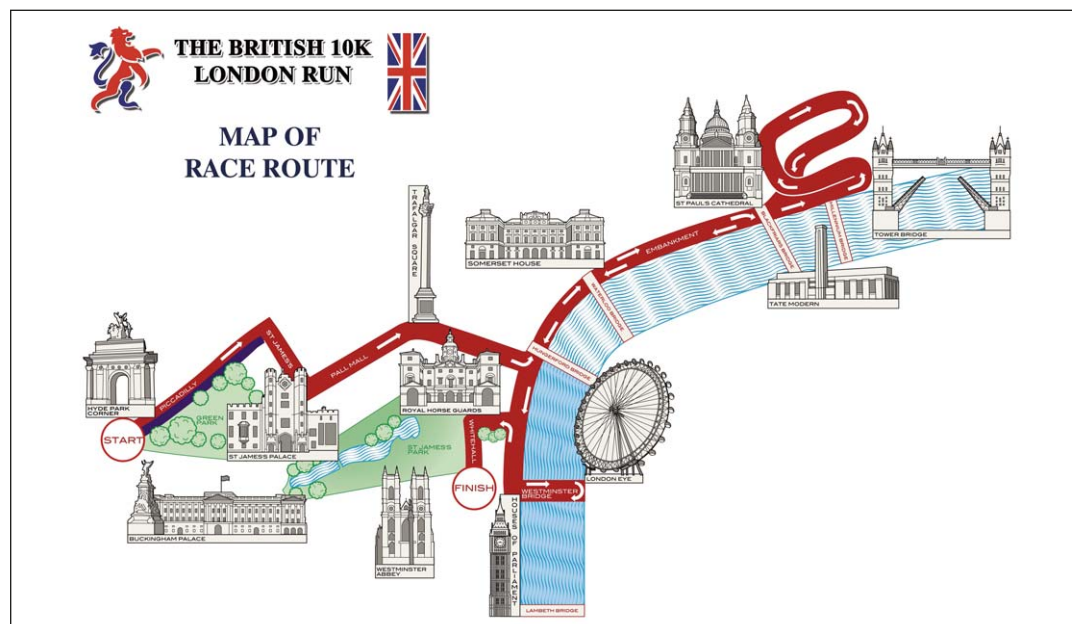


necessarily be on a strictly first come first served basis.

For further information about this event, go to www.thebritish10klondon.co.uk -an excellent website.

Remember that the topics of this year's Conference are health and keeping the weight off! So get running now!

Eric Lange
NSPKU Secretary



The London Marathon and the Untreated Trial

It turns out that a 10k run is only the beginning of Eric's plans. Here he explains his next ambition.....

April 23rd is normally associated with St George's Day and Shakespeare's Birthday. However, this year it is the date of the London Flora Marathon. Your esteemed Secretary (40 something) has worked his way into getting a place via the BT Corporate Team. To get this place I had to write a short précis as to why I should be given the place; how much I plan to raise; finally how I'm going to raise that money.

Naturally I'm running for the NSPKU!

I have promised to raise £6,000 to help raise funds to complete the "Untreated Trial". This worthwhile project needs another £22,000 to complete it and has no funding for 2007 at the time of going to press.

Can you help me reach this target?

Yes it's agony, as I think of all those miles to get myself into shape to run the 26.22 miles non stop! Stop laughing- with your help, it can and will be done.

To raise this amount, I calculate that I need the equivalent of 228.833 people to sponsor me to the tune of £1 a mile. As I write this piece, recovering from a "short" run of 5 miles, I have several hundred pounds pledged already. I would be grateful for any contribution that you, the membership can make.

Great ideas for raising money!

- Did you know you can run your own lottery down your local pub or club? Charge £1 a go (numbers 1 to 49). Pick one or two winning numbers and split the money with £25 in prizes and £24 to the NSPKU. If you can do this for 4 weeks that's £96! If there are 10 people in the Society who can do this, that's £960!
- Can you organise a coffee morning, a quiz night, a tombola?
- Are you a member of the Lions or Rotary? Can you organise NSPKU Charity night?

- Are you on your child's PTA or Board of Governors? Can you organise an event where the NSPKU will be the beneficiary eg a non uniform day?
- Can you organise a dress down day at work (£1 a go) where the employer will match what you raise?

Let me know as every penny helps!!!

You might like to sponsor me direct. If so, please contact me via my details on the inside cover or see the links on the NSPKU website. Alternatively, please contact me if you can help and need further details on: secretary@nspku.org

Competition time (see enclosed flyer)

Guess my time to complete the London Marathon in hours, minutes and seconds. The nearest person will win a prize to the value of £100.

3 guesses for £1 or 20 guesses for £5.

Closing date for the competition is 23rd April.

I have pledged to finish in 5hrs 30 min- quite forgetting that it will take 25 minutes to cross the start line! The guesses should range between 4 hrs 30 mins and 6hrs 30 mins.

Think about this. If 50% of the membership asks 5 people for 4 guesses how much do you think we could raise as a Society?

Let's say 300 members x 5 people x £1 = £1500
Power to the members!

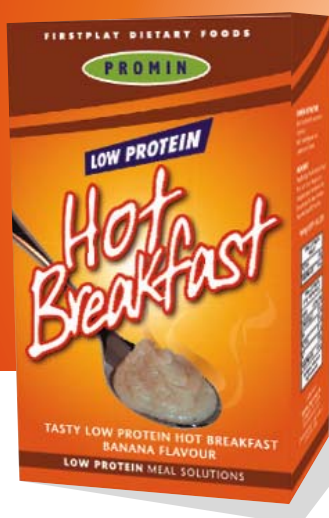
All cheques should be made payable to the NSPKU and sent to:

Eric Lange
27, Western Road
Sutton
Surrey
SM1 2TE

Thank you in advance, and good luck with the fundraising.

Eric Lange

Now you can choose Breakfast, Lunch and Dinner



GREAT TASTING MEAL SOLUTIONS WHATEVER THE TIME!

With more and more meal solutions being added to the Promin range you can be sure there's a great tasting fast food option available to satisfy your taste whatever time of day it is.

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

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NEW to the range is our great tasting burger mix, you can easily shape it into burgers, sausages, meatballs or even dinosaurs for the kids! - they taste great with chips or mixed with some of our pasta.

See our website for more details and a full analysis on all our products.



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 available by prescription also includes Imitation Rice, Pasta meal and Lasagna

Sheets they are also 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 or visit the website for more information or with your

dietary suggestions.

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



Always consult your dietitian before trying something new.

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

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

Sarah Kimpton: running and PKU

Just in case you haven't got the message, Sarah Kimpton outlines to us below the advantages of exercise for everybody in general and for PKUs in particular!

The general population has a larger and larger percentage of obesity occurring each year. This is also true for the PKU sufferers as they have the same risk, also the risk of diabetes. If a PKU sufferer were to get diabetes it would be much more difficult for them, considering the diet they will have to live on. The reason the number of obese and diabetic people is increasing is due to over-eating of the 'bad' foods (high in saturated fat) and under-eating of the 'good' foods (low in saturated fats). On top of this, lack of exercise is a problem.

Exercise has been proven to help you sleep better, it is good for your weight control, it can improve your resistance to infections and lower your risk of obesity as well as cancer, heart disease and diabetes.

I have PKU and I am a runner. Managing my diet around my training has never been a problem. On a race day I sometimes have to take my supplement really early in the morning and also late at night – only if I have chosen to take it with me for the day, but other than this it has caused no problems. I have to make sure I am eating foods containing sufficient energy as well as low protein!

I got into running through primary school. There was a 'try out' evening at the local running track. I went along with a friend from school, I enjoyed myself and so I started training regularly. The group I started off in was 'beginners' in which I got to take part in all parts of athletics.

After I had been running at the club for a while and I started to participate in races I got moved up to the 'intermediate' group. One winter I took part in a cross-country race, and a running coach from my athletics club watched me run. At the end they told me they were impressed with my race and ASKED me to join their group! This was more of an 'expert' group than the others I had previously been in. Everything was much more serious – but I still found it just as fun to do.

At the moment I train at my local athletics club two evenings a week and most weekends I race. Recently in a schools cross-country race I managed to get through to English Schools championships which is a race consisting of students from all the secondary schools in England. Also in the Summer I ran a county 3000m race for my school and finished first, which is the best position I have achieved in a schools race.

The type of sport I do is competitive but doing sport non-competitively is just as good for your well-being! Taking part in sport can make you feel healthier and this encourages you to eat more fruit and veg which is perfect – good food for you and low in protein. I think the fact that I take part in sport helps me with my diet because it makes me feel like eating more healthily, including low protein foods as well as my Low Protein Bread, Pasta and Biscuits – mostly because they are filling.

Exercise is popular to take part in because it helps you feel good by increasing your energy levels. It improves the efficiency of your heart and it can help treat or prevent many disabling or fatal diseases such as: heart disease, cancer, stroke, hypertension, chronic obstructive pulmonary disease (COPD), diabetes, osteoporosis, obesity, arthritis, depression and dyslipidaemia.



Just because you have PKU, it doesn't mean that you should avoid taking part in sport and physical exercise. In fact, it will probably make your PKU diet easier!

Sarah Kimpton

PKU in the sun – the ESPKU Conference 2005



You may recall that a couple of issues ago, there was a competition to “win a trip to Sardinia in October and write a report for News & Views!” I’m unsure of the response rate, but there were two winners, Katy Tuck and myself! This is our account of the weekend.

Having met up at Gatwick and checked in, we headed for customs and the land of duty-free; “where to go first?” The bar of course! Pint in hand, we talked about the latest product to come from SHS and how snacking for PKU’s can be disastrous for the day’s exchanges!

Shopped out, we all met up at the gate to board the fruity coloured “we-only-sell-snack-products” airline and shortly flew over Brighton, then Paris, the Alps, (all clearly visible) and descended over the Mediterranean into sunny Olbia.

The 4-star hotel was about 20 minutes from the airport and the setting was idyllic, with dramatic views of the harbour across the mountainous landscape. The rooms were spacious with a handy mini-bar and enough room for much needed drinks of Cooler!

We later gathered in the bar (again!) and reflected on how PKU features and fits into our lives. It’s quite amazing how we all (effectively) have the same diet with the same choices and yet we use them differently! Manufacturers began to arrive and we met some of them just before dinner, which was quite an elegant affair. There wasn’t a lot on offer for PKUs (the conference officially started on

Friday), so we found a selection of pasta and made the most of the wide variety of fresh fruits and vegetables.

The end of dinner was marked with a trip back to the bar to meet others who had been arriving throughout the evening, and of course to sample the local wines! However, it wasn’t long before the day’s events had caught up with us all and so it was off to bed!

Friday morning was the General Meeting of the ESPKU and as the conference was just warming up we spent time taking in the sights of the hotel and also took on the rather appealing task of testing the outdoor swimming pool and soaking up the Mediterranean sun before lunch.

The schedule for the afternoon was the Scientific Session and covered the areas of “Having a Newborn Child with PKU” and “Nutrition and Dietary Treatment”. We heard from mothers of young PKUs and learnt that developing a ‘positive attitude’ from the beginning helps the child to cope from an early age. Nicky Oliver from Bournemouth also described how she tried to ‘create curiosity’ in her PKU daughter Catherine, which I believe is great advice.

An interesting point mentioned during this session was the information that new parents are given; it can all seem a bit much for a newcomer and even to me. There are some aspects that I still find confusing! The afternoon ended with a look at the benefits of staying on the diet for life and it was extremely reassuring to hear health professionals speak so highly of our diet.

Friday night’s dinner was excellent as there was much more on offer for the PKU’s. Pasta was a hit and we would find all the varieties cooked for us over the coming days as well as some interesting and very sweet desserts. Meal times also offered the opportunity to compare supplements; with Katy choosing to take 60 Aminogran tablets a day, while Iain opted for 4





drinks of Cooler. We were entertained with some questionable singing that night in the bar which certainly inspired some more exciting ideas for Hinckley this year; watch this space for embarrassing antics from committee members!

Saturday morning's lectures were about the BH4 trial currently in progress across Europe. As this was new to me I found the research very interesting and urge any teenager or young adult with PKU to find out more by visiting <http://www.bh4.org> and <http://www.pku-bh4.com>. After the much-needed break from the half Italian/half English lecture a small group of us headed out in search of the cookery demonstration. It was presented by a friendly and very efficient Italian cook and we watched as he demonstrated a couple of dishes, both very easily prepared (even students could do these!). However, the sponge described as 'plum cake' seemed to be lacking the key ingredient of plums, perhaps something was lost in translation with that recipe!



The afternoon offered a choice of two things; the ESPKU Scientific Advisory Committee or the "Costa Smeralda Bus Tour". I would just like to say at this point that neither of us is on the committee and it was a very sunny afternoon!

The tour was excellent, our guide was funny and the scenery was breath taking. By stopping to paddle in the Mediterranean Sea and drink Italian coffee, Katy's culture cravings were satisfied, while the stops and viewpoints were dramatically picturesque and can be seen in my picture gallery online at <http://www.pkuteens.co.uk>.

On arrival back at the hotel the folk show for the evening was being set up so we had time to search for the "Olympic" swimming pool. Whilst watching a beautiful sunset over the pool I heard the word 'tennis' quite randomly dropped into conversation. Now the thought of five adults on one tennis court with eight balls and a lot of energy is a dangerous (if not disturbing) one! However, it was immense fun and when we were thoroughly shattered after an ace game of "who-can-lose-the-most-balls", we retired for a very quick change before the folk show started. Again, pictures of this are available.

The evening was entitled "A Taste of Sardinia", and what a taste of it we got! Dinner was well presented and vin gratuis was on the menu! Everyone had a great time and the children thoroughly enjoyed the food. The evening ended in the bar, our now regular haunt, chatting to a variety of Europeans from Italian and French-Swiss to Scottish! It was fantastic to meet and connect with so many people touched either personally or professionally by the diet and it helped me to see it as a positive influence in my life.

Sunday morning was a low-key affair (why is there never enough time at a conference to talk to everybody?!). We had the best offerings in terms of lectures and it was unfortunate for us that we had to leave at 10:30 in order to catch our flight home.

The talks were aimed at teenagers and young adults, focusing on "What if Compliance with Diet is Poor?" and exploring personal experiences with the diet which we both would have found interesting and relevant but unfortunately we had to miss it.

The conference was a wonderful experience for which we'd like to thank the society. I'd like to end by pointing out that I'd never been to Italy before but through my diet, and the people and events it connects me with, I have been able to not only travel to another country but also make some new friends and learn more about my amazing condition. It really is "Probably the best diet in the world!"

Iain Williamson & Katy Tuck.

Kevin Creek

Our next story is a bittersweet one. Kevin Creek died at the dreadfully young age of 38. Kevin's early death was not in any way related to his PKU – he suffered a brain haemorrhage - but really Kevin's life was a great success story for PKU and indeed for adoption. The Creeks opened their hearts and home and showed that with a flexible attitude and a great deal of love, a tiny baby with difficulties could grow into a beloved son to be proud of.

Kevin's Mum and I spoke on the phone and she described his short but very happy life as follows.

The Creeks adopted Kevin at 7 weeks old and his PKU was diagnosed at 3 months. In the 60s, low-protein foods were in their infancy. Choice was incredibly limited and what was on offer was almost inedible. Kevin was prescribed a supplement so thick that it wouldn't go through the teat! Mrs. Creek had to feed it to her tiny baby with a spoon. Later, the only biscuits the Creeks could get for Kevin were low-protein rusks and in those days, they were so hard that birds in the garden broke their beaks on the discarded crumbs! Mrs. Creek had no formal access to a dietitian and was incredibly grateful to Dorothy Frances, a Great Ormond Street dietitian, who sent her hand written letters with valuable advice.

As they struggled with the diet, Kevin grew into a chubby toddler and a happy child. He didn't find it easy to take his supplement and eat the allowed food but, Kevin's family helped him to adhere firmly to the diet. He developed well, had friends and a wonderful relationship with his Mum, Dad and sister Linda.



Todler Kevin with his Dad Ray

After a few years, the Creeks met up with a small number of PKU families at Longleat Safari Park. This was the first time any of them had met anyone else dealing with PKU and Mrs. Creek said they didn't stop talking for the entire weekend! From this one weekend grew an annual camping trip to Savernake which Kevin and his family attended regularly and very much enjoyed.



Kevin and his sister camping at the PKU weekend in Savernake



Kevin at a recent PKU camping weekend in Savernake

Kevin and his Dad ran a small family business and indeed Kevin lived at home until his death. Kevin was a talented mechanic and lovingly restored a vintage 1960 Ford Anglia as we see in one of the photographs. His love for nature is reflected in the final resting place of his ashes – a Life for Life forest near Yeovil.



Kevin and his Ford Anglia

I truly feel that Kevin's life, and his parents' attitude to their adopted son are an example to us all. By sticking together, the Creeks conquered PKU. It is beautiful to think that a baby who needed a family and a couple who needed a son should have found each other and fitted so perfectly together. Truly a love story, don't you think?



Kevin and Mum

PKU Pronto!

I've got a great recipe for you here inspired by Asda and brought to us via the inimitable Eleanor Weetch! Eleanor spotted a veggie loaf on a leaflet in the supermarket and had a clever hunch that with a bit of tweaking, it might work beautifully for those with PKU. She was not wrong. I only had to adapt this a little bit and have come up with something which would work beautifully along side a Sunday roast with potatoes for exchanges and perhaps some free gravy and other vegetables. Served cold in slices, it would also be delicious for school lunches with free chutney or even tomato ketchup!

Veggie Loaf

I will admit that it doesn't quite qualify as a "pronto" recipe but one loaf can be frozen in slices which can then be zapped in the microwave and served up to make a very quick supper. Some of the ingredients may seem a little strange but believe me, they should be available in your

local supermarket. However, in case of trouble, I have also suggested some alternatives and sources.

Method

1. Preheat oven to 180°C.
2. Grease and line a loaf tin.
3. Fry onion and celery in the melted butter over medium heat for 5 mins.
4. Add mushrooms and cook for 10 mins. Tip into a bowl.
6. Add remaining ingredients and mix well.
7. Place in prepared tin and bake for 50 mins. At this stage, if golden brown on top and firm in centre remove, otherwise cook for another 10 mins. I'm always anxious about timings so for this sort of thing, so, I take a skewer, stab the centre of the loaf, then carefully feel the tip of the skewer to see if it's piping hot – or not. That way, I can tell for sure if the loaf is cooked right through.
8. Allow to cool a little on a rack before turning out otherwise the loaf may fall apart a little. Having said that, a little bit of crumbling never did anyone any harm and I guarantee, you'll love this in pristine loaf form or fragmented bits!

Ingredients

- 1 medium onion, finely chopped
- 2 sticks celery, chopped
- 25g butter
- 500g mushrooms, chopped (a mixture of different types would be nice here but use whatever you can get)
- *240g vacuum-packed chestnuts, chopped (try a greengrocer if the supermarket doesn't have them)
- 2tbsp fresh parsley, chopped
- Juice ½ lemon
- 125g dried cranberries (you could use sultanas or other free dried berries here if you can't get cranberries)
- 2 tpsps dried egg replacer suitable for PKUs mixed with 4 tpsps water

*up to 100g Chestnuts is free.

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Dietitian's Report

NEW FOODS TO TRY!

Blue Dragon Rice Flour Pancakes

These pancakes are allowed freely in the PKU diet. The traditional way to prepare them is to slip them into very hot water, let them soften for a few seconds and then remove, drain and fill with stir fried vegetables, spring onion and a free sauce such as Blue Dragon Sweet Chilli Dipping Sauce or Sharwoods Hoi Sin and Plum. These are really good and fun to make.

Well, I have been told about how to make Indian style Popadums with them! You will remember Sara Bartlett who was our Chairman just before Dave Stening. Sara rang me the other day to tell me that you can cook them in the microwave. You simply brush the uncooked pancake with oil, put it on a paper towel and microwave on high for 30 seconds. Turn over, brush with oil again and microwave for 30 seconds again. This works well and avoids the risks of deep frying. However, I did get a slightly better result when I shallow fried the pancakes. You need to get the oil in a small frying pan very hot. Slip in the pancake and it will puff up beautifully. Turn over after a few seconds and do the other side. Drain on a paper towel. Perfect poppadums. And they are free!! A lovely addition to your vegetable curry and low protein rice with mango chutney.



WRIGLEY'S BUBBLE GUM

I did not include all the flavours of bubble gum in last diet information book (purple edition) which are suitable and do not need to be counted in the diet. The following is the complete list of all the gums:

Hubba Bubba
Atomic Apple
Seriously Strawberry
Coca Cola
Mix and Match Sour Strawberry and Vanilla Ice Cream
Mix and Match Sour Raspberry and Watermelon

OAT SUPREME

First Foods

This company do a range of products which are quite low in protein and therefore useful to us.

Oat Supreme Milk – 285mls = 1 Exchange
Oat Supreme Cream – 190mls = ½ Exchange
First Glace Ice Cream – Chocolate – 85gms = 1 Exchange
First Glace Ice Cream – other flavours – 140gms = 1 Exchange
Oat Supreme Ice Cream Bar Chocolate – 1 bar = 1 Exchange
Oat Supreme Lite Ice Cream – 150gms = 1 Exchange



The products can be found in most independent health food shops (ie not Holland and Barrett). The 'milk' is in Asda, Morrisons, Somerfield, Sainsbury's and Tesco and the 'cream' is in Asda and Tesco.

To check availability in your local store you can ring the customer care lines.

Tesco 0800-505555

Asda 0500-100055

VALPIFORM BISCUITS

Low Protein Shortbread Biscuits
Low Protein Cookies with Chocolate Nuggets
Low Protein Savoury Bites Herb Flavour
Low Protein Savoury Bites Tomato Flavour

These biscuits, distributed by Gluten Free Foods Ltd, have been temporarily discontinued. However, they will be back again by the time you read this under the Ultrapharm Foods label. That's good!!

WARNING NOTICES ON LOW PROTEIN FOODS

You will have seen the following notices on all of your low protein foods e.g. biscuits, pasta, energy bars etc.

This product is for special medical purposes and must be used under medical supervision. This product is not suitable as a sole source of nutrition.

For use in the dietary management of Phenylketonuria and similar amino acid abnormalities, renal and hepatic failure, liver cirrhosis and gluten sensitive enteropathies.

One of the low protein food companies told me that they do receive enquiries about this notice because people think that anyone who eats the food but does not have PKU may be harmed. This is not the case. The food is low in protein but is entirely safe. Of course it would be harmful and wasteful for anyone who does not have PKU to eat the food (without protein substitute) regularly for meals, but we are talking about the times when maybe a non-PKU child or adult eats it to try it or by mistake.

The PKU low protein food is prescribed at tax payers' expense for those with the condition. It is essential for them but it is not harmful to others. However, we are very privileged in this country with the variety and quality of our low protein products but they are for those with PKU !!

MY FAVOURITE TOPIC! AUTOMATIC BREAD MACHINES!

If, like me, you have always thought a bread making machine was just another piece of kitchen equipment which will be used once and then put away to gather dust then please think again. I was very sceptical about a bread maker until persistent requests from my daughters paid off for them (and all of us). I bought one and it has been used every day since it came into the house two years ago. The smell of fresh bread in the morning is wonderful.

Eileen Green has researched automatic bread machines again. There are now so many on the market this has to be done very now and again to keep up to date. Eileen says if you intend to make mostly low protein bread and only the occasional

ordinary loaf then the Panasonic SD252 is the best. If you want to make a lot of different types of ordinary bread as well as low protein bread then choose the Panasonic SD253.

These two machines are more expensive than many other machines but they are very sturdy and well made and will give years of good service. The Good Housekeeping Institute has endorsed them.

Eileen's company FATE Special Foods and SHS international Ltd both produce booklets on bread making using a bread maker and they both contain some lovely recipes. To obtain a copy of Eileen's full report on machines and recipes and/or SHS Bread Making made Simple send a A5 (15cmsx21cms) stamped addressed envelope to the relevant company.

FATE Special Foods
Unit E2,
Brook Street business Centre,
Brook Street,
Tipton,
West Midlands,
DY4 9DD

Customer Services,
SHS International Ltd.,
Wavertree Technological Park,
Liverpool.
L7 9PT



WHERE TO STAY AND WHERE TO EAT?

Hotels Recommended by Readers

Peter Stockton told me about The Sandbanks Hotel in Poole, Dorset. He said it was expensive but very good! I rang them to find out how expensive and here is the bottom line!

The following is per person for dinner, bed and breakfast.

Adult £81.00
 Baby under 2 years £6.00
 Age 2-3 years £10-£31.50
 Age 3-8 years £22.00-£55.00
 Age 8-14 years £35-79.20

You can view the hotel at the following web site

www.sandbankshotel.co.uk

email enquiries@sandbankhotel.co.uk

Tel 01202-707377

Please let me know of places you have been which have looked after you exceptionally well and I can let others know about these little gems.

EDALE 2006

EDALE OUTWARD BOUND WEEKEND

We shall be running the Edale outward bound weekend again from July 14th to 16th 2006.

If you are aged between 9 years and 13 years and have PKU you might like to think about coming along. It's great fun, you learn a lot and make new friends. For further information please contact me by 'phone, email or post. Details on the inside cover. Have a look at Sarah's article about her sporting activities. It does make you feel good!

Helping Each Other

At our last meeting we were talking about the tricky issues which arise and how everyone copes with them. Of course we all do things differently, some ways can be more successful than others! Are you faced with a problem you don't know how best to handle? There will probably be someone else who has been in the same position and they have found a way to get round the difficulty. We thought it might be useful to put a question and answer section in the magazine. I'll start it off with one I'm asked quite frequently.

"I find it really hard to buy suitable drinks for the PKU diet. Summer is coming and I wonder if you could give me some suggestions?"

I would like to hear from you on this subject. What is popular in your house? What have you found that's good?

Please let me know by 'phone, letter or email. My contact details are just inside the front cover of the magazine.

Eleanor Weetch
 Society Dietitian



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Eileen Green

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KATE'S FAVOURITE FATE BURGER

Hello,

Last time you would have seen my recipe for Fate Burger Buns. So, this time I thought I'd give you our latest Burger recipe to try. They are Kate's favourite at the moment. They were developed after a trip to one of the Nando restaurants. These restaurants have an open plan kitchen and Kate saw how the vegetable burgers were prepared. She really fancied trying one, but we knew they would be too high in protein, so we decided to go home and try to make a low protein version. This is the result.

You can buy a variety of different Nando's sauces and marinades which are suitable for use in a low protein diet. In this recipe, we use either *Nando's marinade and stir fry with sundried tomato and basil*, which has a good flavour with a little spiciness, or *Nando's marinade and stir fry with hot peri-peri*, which is much hotter.

You can of course serve the burgers without the marinade or use another suitable marinade or sauce if you prefer.

FOR THE BURGERS:

250g Sweet Potatoes, peeled.
175g mushrooms
175g onion
1 tbsp oil
30g butter
Salt and pepper to season
Pinch dried thyme
Pinch dried sage
1tbsp tomato puree
Few drops of suitable gravy browning
100g Fate All-Purpose mix and a little extra for shaping



Grate the sweet potato and mushrooms. Finely chop the onion.

Heat a large frying pan and add the oil and butter. When the butter has melted, add the sweet potato, mushrooms and onion. Stir well. Keep the heat quite high so that any moisture from the vegetables evaporates.

Cook for 5-10 mins until the mixture is softened and beginning to brown.

Stir in the sage and thyme and season with salt and pepper. Add the tomato purée and a few drops of gravy browning, just enough to give a rich brown colour, but not too dark. Stir well.

Take the pan off the heat, and stir in the Fate All-Purpose Mix. It might be best to use a large metal spoon. Make sure that the mixture is well blended.

Leave to cool slightly. As soon as it is cool enough to handle, take a spoonful of the mixture, (about 50-60g) and using a little Fate All-Purpose Mix to prevent it from sticking, shape into a burger shape. It is easier if you shape it into a smooth ball first, and then flatten it. Place onto a plate and leave to cool completely.

At this stage they can be frozen. When needed, just defrost and reheat in a pan, under the grill or on the barbeque.

Serve with Fate Burger buns.

TO MAKE KATE'S NANDO STYLE BURGERS:

Heat a frying pan and add just a small amount of oil. When the oil is hot, cook the burger on both sides until nicely browned.

When they are hot and cooked through, brush the top with a little Nando's marinade~ see note above then turn the burger over, and then brush with marinade again. Add as little or as much as you like, but remember the flavour is really good, but it can be quite hot.

Then ~ Take a warmed Fate Low Protein burger bun, and cut it through the middle. Spread with a generous amount of suitable mayonnaise, and place the burger in the bun. Top with a slice of tomato, some shredded lettuce, and a few rings of onion. Serve straight away.



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