



News & Views

Website: www.nspku.org

Issue 103



Merry Christmas
From the
NSPKU

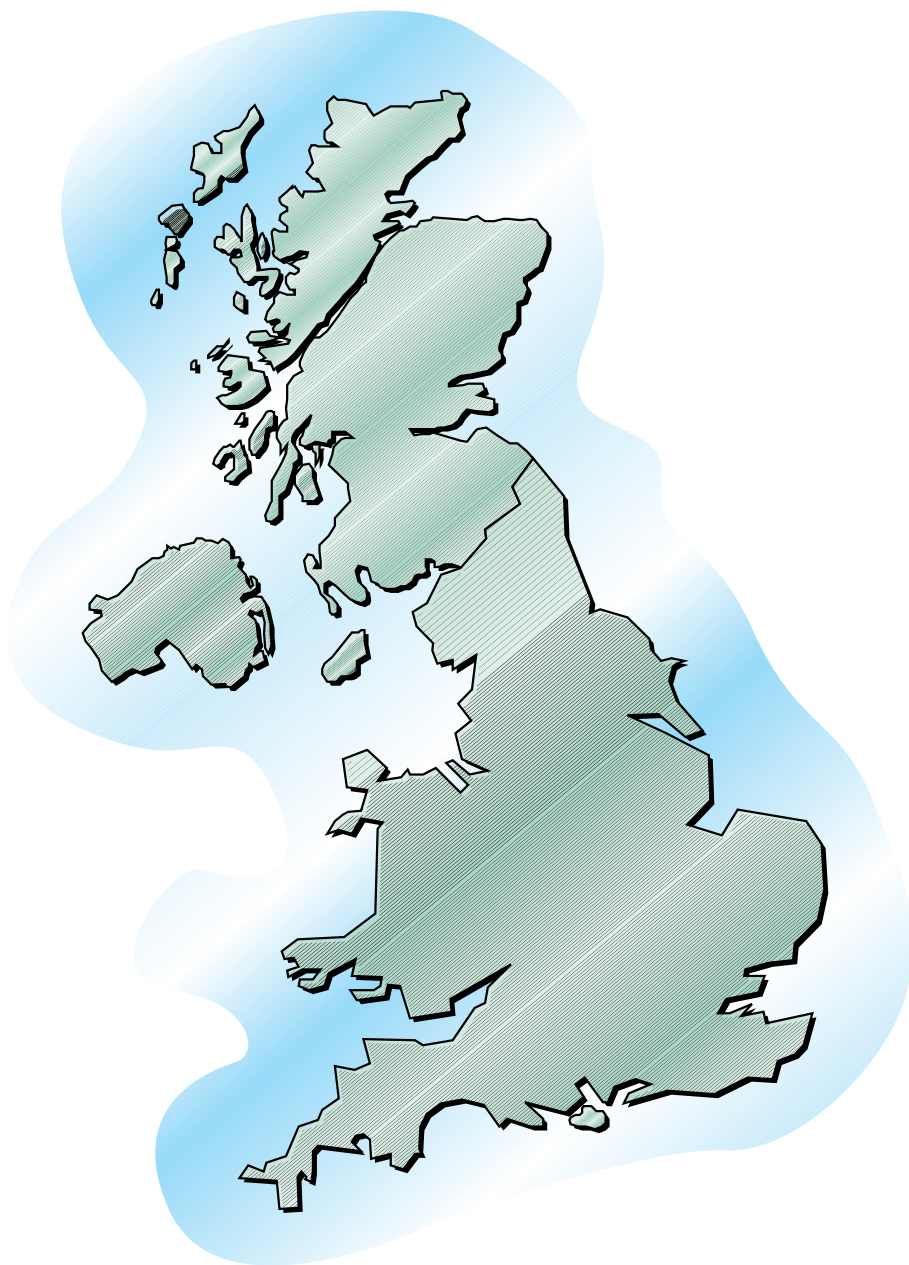
In Touch

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Editors Report

This News & Views Editor's Report takes on a slightly different flavour.

Now I know I'm treading on very very dangerous ground here, Culture, working arrangements and social roles will bear to the fore with the advent of a bloke volunteering a recipe for the PKU diet. This statement in itself will no doubt invoke a wrath of complaint from the guys who do the cooking or don't, or the partner who feels that the diet is thrust firmly into their lap by the respective partner. This, my good friends is a matter entirely for yourselves. I'm just passing over a recipe handed down from one generation (my own) to another (my own) for a great tasting italian-esque, pizza-hut-esque pizza that is both rich, light, great-tasting and copyrighted (not!). As my Home Economics teacher said, "

Bramley, you'll amount to nothing more than an Editor and Secretary for a small UK Charity". And he was right.



See page 5 for said recipe

Pete Bramley
Editor

Chairpersons Report

I'M SURE no-one will be surprised to hear that I find myself unable to give as much time to the Merchandise Officers job as I would like. I really need to concentrate on being effective as the Chair at the moment. So we are looking for someone to take over. The job involves receiving, making up and mailing out orders, taking goods to support group meetings and study days around the country (mileage allowance payable) and organising the stall at Annual Conferences. This is the best part of the job, getting out and meeting other members and having the opportunity to keep up to date about the care of PKU etc. I am particularly fond of going to cookery demonstrations with Rosanna and an empty

food box!

Recently this job has been done by a COM member but this is not essential. If someone comes forward to run merchandise and then wishes to report to a member of COM rather than attend our regular meetings then that would be fine. Alternatively if you are thinking of becoming more involved in the society and do wish to be a member of COM then this could be just the opening you are looking for.

On a final note, we will soon have some more kitchen scales for sale, probably the same model as last time. If you are desperate for some before the advert goes in the next edition then please give me a call.

Finally we are a little closer to getting our questions answered concerning the future of the PKU Register. Both the society and individuals within the society have been questioning the Department of Health and anyone else who would listen, about the lack of progress on this matter.

The society has been invited to join a Register Users Group to be run by the UK Newborn Screening Programme Centre headed by Dr Jane Collins. This group will oversee the future use of the PKU/CHT (Congenital Hypothyroid) registers. I am to attend the first meeting of this group in the near future and will report back to you.

We still have more questions than answers but we are one step nearer our goal.

In addition the Screening Programme Centre are looking for others to share their experiences to help develop the service offered during Neonatal Screening. If you would like to make a difference and to help establish new standards on a National scale for new-born screening, please contact Ruth Stewart on 0207 612 6606. Email: r.stewart@ioe.ac.uk for further details. A small allowance and travelling expenses will be available to those who take part. Remember, if it wasn't for new-born screening and the standards set, our story of PKU would be a very different one.

Sara Bartlett
Chairman

NSPKU
The National Society for Phenylketonuria (United Kingdom) Limited

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Treasurers Report

THANK-YOU to everyone who has organised or participated in any sort of fund raising over the summer months. We are now heading swiftly towards Christmas and I hope your festive efforts; Christmas fares, carol singing and the like will be as profitable and of course as enjoyable!!

We are well on the way now with our plans for the ESPKU conference to be held in the UK next October. This will of course be a somewhat larger expense than our normal yearly affair so any extra fundraising and ideas for sponsors would be very welcome.

Many of you may be aware of the "Gift Aid" scheme which many charities take part in that allows the tax to be reclaimed on a donation. This means at the current tax rate of 22% a donation of £50 gift aided to the Society would be worth £61.

The scheme does not cost the donor anything it simply means that we are able to claim the tax you have already paid back from the government. To participate in the scheme you must be a UK taxpayer, paying tax at least equal to the amount of the tax reclaimed on your donation(s). To allow us to do this all you have to do is complete a "gift aid declaration" form. If you would like a form please contact me (details on the "in touch" page at the front of this mag!). We also include the form intermittently in News and Views for you to pullout and use.

Julia Bailey
Treasurer

Donations

31/09/02

(£30.00 and over)

The Nags Head Woodborough (via the Guest family)	3,111.00
Mrs S Osborne	160.00
Claire Cooke	587.00
Mr A Billingsley	100.00
Joan Macritchie (via Tricia McKenzie)	593.15
Mrs A Knox	40.00
TSYS Europe	66.00
Polestar Watford	
GPMU M/C Room Chapel	100.00

Gift Aided

Mrs LHM Michael	30.00
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In Memory Of....

Thomas Meehan	346.00
Dick Raymond Scott	235.00



The Best PKU Pizza YOU'LL Ever taste

(I reckon)

Grab a pinney. Blokes pinneys must be masculine with naughty pictures on, whereas girly pinneys must be romantic and have fluffy clouds imprinted upon them. Now we are truly ready to begin.... Pour a glass of red wine and take one glug... now we are truly ready to begin... take another for good measure.... now we are truly etc etc...

Ingredients

Sauce

- ✧ 1 tin Sainsbury's chopped tomatoes with peppers and onions (available from all good Sainsbury's stores)
- ✧ 2tbsp double concentrate Tomato Puree (available from all good tomato plants)
- ✧ 1tsp Garlic Puree
- ✧ 2tbsp Extra Virgin Olive Oil (not available from any Virgin Record Store)
- ✧ 1tsp Mixed Italian Herbs (available from Italy or any UK supermarket)

Mix all of the above together in a bowl or a 200 gallon coopered wooden barrel. Either will do but not the barrel. Set to one side (not on its side, otherwise the mixture will fall to the floor) Be careful not to leave the sauce for any great length of time as it may claim asylum.

The Base

- ✧ 350mls of Water (hand hot)
- ✧ 100mls of Extra Virgin Olive Oil (plus extra oil for baking)
- ✧ 1tsp salt
- ✧ 2tsp Sugar
- ✧ 1 Box Juvela Low – Protein Mix
- ✧ 1 Sachet of Yeast (included in the above)
- ✧ 3 heaped teaspoonfuls of dried Oregano

Pre-heat oven to 220°C or Gas mark 7

Method

Because I'm non-PKU, I prefer to eat Pizza – Hut (registered trade mark apparently) pizzas which involve extremely limited preparation times on my behalf which I love. However. In the case of this recipe which has been wheeled out on many London and Home Counties charitable events, the comments have been staggering. Insulting even. The key is the extra virgin oil and the sugar for the base. Combined with the amount of extra virgin oil that lines the pizza tin and the extra virgin oil that poured on top of the pizza and the extra virgin oil that's in the sauce it seems likely that extra virgin oil has nothing whatsoever with the attraction of this recipe. And so....

- ✧ Put the low-protein flour in a large bowl ... NOW!!
- ✧ Add the yeast, salt, and sugar.
- ✧ Mix together with a wooden spoon or hand blender or Industrial Cement Mixer (remembering to extract previous traces of concrete in the latter) – ensure all ingredients are well blended.
- ✧ Add half the oil and half the water and mix well (if you are using a wooden spoon, it really takes ages and hurts)
- ✧ Keep adding the rest of the water and oil until you obtain a smooth mixture, which can be moulded easily (rather like Tony Blair) – form into a big round ball. Place the ball into a bowl, cover and place in a warm environment (airing cupboard etc) and leave 30 minutes until risen.
- ✧ Bring downstairs OR in case of living in a flat stay on the same level and proceed to the kitchen with your booty. Townhouse inhabitants should proceed accordingly. Others just go to the kitchen.
- ✧ NOW. You need some specialist equipment now: 3 – 7 inch round by 1 inch deep baking tins to get that “deep-pan” effect.
- ✧ Dust your hands and the surface with plenty of low-protein flour/mix to prevent the mixture sticking. Divide the mixture into 3 equal parts.
- ✧ Put one tbsp of extra olive oil into each baking tin and wipe around the tin being careful not to absorb the oil out.
- ✧ Plonk a third of the separated dough mix into the first tin – press down into the middle of the tin and outwards towards the sides ensuring that around the edge of the tin the dough is slightly higher than the middle. The middle of the base should be level to get the ingredients and sauce on.
- ✧ Pour 1 tbsp of extra virgin oil onto the top of the base in the tin. Mop around the whole of the surface.
- ✧ Grab your pizza sauce. Place enough in the middle to spread around your pizza base leaving the edges of the pizza clear from sauce. Like a proper pizza!
- ✧ Evenly sprinkle one heaped teaspoonful of Oregano around the topping.
- ✧ Repeat this for the other two pizzas.
- ✧ Place in the pre-heated oven for 15 mins or until golden on edges and remove. With all the olive oil hanging about there's no problem getting these babies out of the tin.

Alternatives

Sweetcorn – put this on before the oregano and divide evenly onto the pizza – I use 2 exchanges of sweetcorn (70g) divide the pizza into 4 and hey-presto! Half exchange per quarter.
Peppers – *Free Mushrooms* – free – you know the rest fill your boots!!
 Alternatively, don't do any of the above.

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.

Letters

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

Dear News & Views

Please find enclosed three cheques for the total amount of money raised by our charity sleep-over in the underground vaults in aid of PKU. We had a great evening and luckily nothing too spooky occurred and we all got out the next morning with our sanity as much intact as it had been when we entered the vaults the previous night!!

We managed to raise £587 and I have enclosed the sponsor sheets and also a gift aid certificate, which allows you to claim the tax back.

I have PKU myself as does my eldest brother and we hope that this money can be put to good use in helping to carry out research into the disorder and helping people who have not been as lucky as myself and my brother, Chris.

Best wishes
Claire Cooke

Ed – so much cash for so much shut-eye. Fantastic. Well done.



Dear News & Views

Please find enclosed a donation to the value of £170.

This money was collected by family, friends and work colleagues of my brother Matthew Bacon, who died suddenly aged 34.

My daughter, Rebecca (Matthew's niece) has PKU.

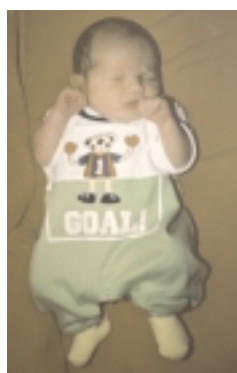
Yours faithfully
Mrs C Cogglesby

Ed – Our sincere condolences to you and your family on behalf of the NSPKU and its membership.



Dear News & Views

I'd be grateful if this picture of my baby could be put in News & Views.



So many people have asked to see a picture that I thought this would be the best way for everyone to see him.

I would also like to thank everyone for their good wishes.

Callum Tilsen Munro was born on Thursday 4th July at 13.22pm weighing 8lb 12oz. He is a good boy and growing fast. I defied all the advice I always give on blood sampling to my families – I

froze Callum in the bath prior to the midwife coming to do his Guthrie test! – she did arrive an hour early though (that's my excuse!)

Anyway, thanks again for all the messages of best wishes

Alison Munro
Gt Ormond St Hospital. Specialist Clinical Nurse.

Dear News & Views

Please find enclosed two cheques totalling £360 raised for the NSPKU by my friend Pam Manwaring, who organised a fundraising event in the aid of my son Alexander Cheale who has PKU and of whom Pam is very fond of.

Pam held an aromatherapy evening at her house selling 'Likisma' products and also had reflexologists, manicures and massage sessions for a full pamper evening. A great evening was enjoyed by all. Pam donated her commission and so did the other professionals, which was rather generous considering that none of them had ever heard of PKU or met with Alexander. The night was rounded off by a raffle of around 30 prizes, so most people won something. A big thank you to Pam and her friends for their generosity.



Alexander is 2 years old now and thoroughly enjoying life apart from recently deciding to stop drinking his Maxamaid following a holiday and presumably different routine. It has been hard to get him to swallow it again. I guess the 2 year old switch has turned on as he realises he can say "no" now.

If anyone has any tips on how to get a 2 year old to drink something they don't want to, I'd be very interested to hear from them. I have tried no treats, no food, no drink, bribery, plastic syringes (but he stored it up and spat it back at me!).

So far, me ignoring him and not looking or speaking to him sometimes works but I am finding it very hard what to do next. I would appreciate any help that could be given to me, from anyone who has been or is in a similar situation. It would be great to hear from you.

Best Wishes
Wendy Cheale

Ed – see "Contacts"

Dietitian "Rules"

- Treat protein substitute as a medicine
- Establish time routine
- Always supervise
- Be firm but give positive encouragement
- Do not allow excuses
- Be consistent



Dear News & Views

It is with sadness that I have to inform you of the sad loss of Thomas Meehan, less than 100 days after the loss of his daughter Margaret Oliver aged 48. This came as a deep shock to all the family in such a short space of time.

Tom was still in deep mourning for Margaret when he sadly passed away from an aneurism.

Mourners were asked to donate to the NSPKU instead of flowers and I enclose a cheque to that effect.

Sincerely
Paul Oliver
Past Editor - News & Views

Ed - Our deep condolences to you and your family



Dear Pete,

Here is a picture of myself with Joan Mac Ritchie and Morag Liddell after finishing the Glasgow 10k women's fun run. We all work at RHSC Yorkhill Glasgow. Joan is a staff nurse in the neonatal surgical unit with me and this is the 3rd year she has run this race and the 2nd time for NSPKU group, and this year with the help of one of the patient's grandfather Mr Hair who took a sponsor sheet to his work and raised £200 for Joan. We managed to collect £593.15.

Regards,
Patricia McKenzie.



Dear News & Views

My name is Melanie and I am Auntie to two children, Kerrie and Rhys Wibberley who attend Alder Hey Hospital near Liverpool as they both have PKU. I learn a lot from my niece and nephew about their disorder. Also about the different foods, the positives and negatives and about the dangers if their illness is not taken seriously.

I have learned about the blood tests and the blood levels and about themselves as children as they grow. They are very special to me as are their Mum and

Dad. I have written this poem as I continue to learn about PKU -

*Sometimes it's hard but true
I was born with PKU
They say "try some chocolate, try some meat"
"Come on Kez, have a treat"*

*They don't understand, they won't take the blame,
I try and tell them it will damage my brain
I'd like to give them a taste of my drink
I'd like to know just what they think*

*They wouldn't last on my food for a day
If I'd ask them, they'd say "No Way!"
That's why I'd like other kids to see
Having PKU is hard for me*

Composed by Mrs Melanie Wrench (Non-PKU)



Dear News & Views

We recently had a redundancy programme at my place of work and turfed out the "dead wood" so to speak. As their union representative it fell to me to dispense with these people's jobs. Luckily they were all volunteers which was a bit of a relief. To which end we had a big "leaving do" and much to my dismay and the discredit of the printing industry at large, the guests were unable to "drink" the proceeds left behind the bar. I am therefore forwarding you the remainder of these monies (£100) to be allocated to whichever means you see fit.

I thank you and the sober members of Polestar Watford's Machine Room Chapel

Pete Bramley
Father of Nicola (Bone-head) Bramley - PKU

PS: News and Views is looking fantastic these days - carry on the good work.

Contacts

Dear News and Views

I'm Cara McInnes. I'm looking for a pen pal in Scotland who also has PKU.

I'm 15 and my hobbies are horse riding and swimming as well as shopping! My favourite bands at the moment are Queens of the Stone Age and Avril Leigne. I would like to hear from anybody aged 15-16 (boy or girl) with similar interests.

My address is -:
Cara McInnes
6 Harburn lane
West Calder
West Lothian
EH55 8BP
Scotland

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

Take Cover!... Incoming!!!...

I AM writing on behalf of my colleagues at the Station Regiment Flight, RAF Cosford.

My daughter Elisha has PKU. Thanks to the professionalism and support of the team (Dr Dishpande, Di Asplin and Kim Robinson) here in the Shrewsbury area and the unrelenting efforts of her Mum Karen, Elisha is growing like a weed. However, the constant highs and lows of exchanges, taking bloods, and the feeding of a 19 month old demon child who resolutely refuses to take her gel in any form, have not gone unnoticed by my fellow instructors here at the section.

Their eagerness to become involved culminated in the unanimous vote for making the NSPKU the section Charity for a year.

Let me explain who we are and what we do and more to the point what we can do for the NSPKU.

RAF Cosford Station Regiment Flight is manned exclusively by Gunners of RAF Regiment. There are a total of 12 instructors responsible for the obligatory annual training and teaching of all station personnel in ground defence. The majority of our ranks are composed of the most renowned rogues and scoundrels the RAF Regiment has to offer. Our resourcefulness, skulduggery and jiggery-pokery are legendary. Between us we can get things done, if not unconventionally. We have a number of events and schemes planned,

such as sponsored events and open days here at the regiment section (details to follow) but, what we would like from the readers of News and Views are any ideas of how we can raise money for PKU. We are, after all, fit young soldiers in the prime of our lives and will do anything for money!!

Send any ideas, no matter how bizarre to this address:

Micky Doyle,
Station Regiment Flight,
RAF Cosford,
Wolverhampton
WV7 3EX.

phone – 01902 377405
fax – 01902 377602

Ed – come on you lot get in touch with Mickey with your ideas. My idea is a sponsored “paint and redecorate the interior of my house from top to bottom” event! Over to you.

Your Editor Says...

Why not e-mail me your Letter?

nspku.secretary@ukonline.co.uk

or...

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

SHS recipe

SHS
INTERNATIONAL

Pear and Strawberry Sponge Pudding

Serves 4-6

Ingredients

- ★ 2 x 15mlsp (2tbsp) demerara sugar
- ★ 1 pear (approx 150g/6oz)
- ★ 50g (2oz) hard margarine, at room temp.
- ★ 50g (2oz) caster sugar
- ★ 1 Loprofin Low Protein Strawberry Flavoured Duo Bar, melted
- ★ 115g (4 1/2 oz) Loprofin Low Protein Mix
- ★ 1 x 5mlsp (1tsp) Loprofin Low Protein Egg Replacer
- ★ 1x 5mlsp (1tsp) baking powder
- ★ 75ml (3floz) Loprofin PKU Drink



17.5cm (7inch) sandwich tin,

Oven temperature: 190°C/375°F/Gas Mark 5

Method

- ★ Grease and base line the sandwich tin with non-stick baking paper. Sprinkle the demerara sugar evenly over the base.
- ★ Peel, core and thinly slice the pear, arrange over the demerara sugar, to cover the base of the cake tin.
- ★ Place the margarine, sugar and melted Duo Bar in a large bowl, beat well until very light in colour and texture.
- ★ Combine the Low Protein Mix, egg replacer and baking powder, alternately beat into the creamed mixture with the PKU Drink - until a smooth texture.
- ★ Spread the cake mixture over the pears, levelling the surface.
- ★ Bake in a preheated oven for approximately 20 minutes, until springy to the touch.
- ★ Lightly dust with icing sugar and if desired serve with custard made using Loprofin Snopro Drink.



Tip

Why not try using one of the other Flavoured Duo Bars and fruit of your choice, in place of the Pear and Strawberry flavoured Duo Bar.



The National Society for Phenylketonuria (United Kingdom) Limited

Saturday 15th March 2003

NSPKU ANNUAL GENERAL MEETING 2003

The Hanover International Hotel - Hinckley - Leicestershire

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

Phone: 01252 728221 for accommodation availability

Further details in the next News & Views

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Contributed by:
Mrs Ann Vincent Russell-Smith
RGN RNMH FETC RCNT
RNT STD (Lond)
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Church Crookham,
Fleet, Hants
GU52 6LN

Albania

One courageous lady's crusade to establish what we in the UK already take for granted ... this is her ongoing story...



Anne Vincent Russell - Smith

Question: "What has Neonatal Screening got to do with Albania?"

Answer: "Absolutely nothing at all!"

AND THAT answer is the reason I am contributing to this Newsletter.

Now-a-days, most people know quite a bit about Albania – where it is, something of its history, the fact it is a poverty-stricken land. But a few years ago, at the time I made my first trip to Albania to do voluntary nursing in a children's hospital, far less was known by the British public. Indeed, until I was accepted by the charity, 'Children in Distress' to do three months voluntary work in their hospital in the town of Sarande, southern Albania, I knew little. However, prior to my departure from England, in August 1988, I read about Albania, avidly. I learned about its turbulent history, its post-World War Communist Dictator, Enver Hoxha and the totally sealed borders, which isolated the country from the rest of the world for almost fifty years.

When those borders were opened after the fall of Communism, in 1991, the full extent of poverty and backwardness Albania had suffered was revealed. While a scientific revolution had raced round the globe since the Second World War, it had completely by-passed Albania. And when a Democratic Government was elected in 1992, the Albanian people responded by leaving their homeland in droves, never to return.

Amongst the stream of emigrants heading for Greece, Italy or America were many of the Country's best brains doctors, scientists, professors and teachers. Sadly today Albania continues to be an intellectual and academic desert. This means that many of the scientific advances we take for granted in England, simply do not exist in the Balkans generally and Albania specifically.

Albania is a stunningly beautiful country, of high mountains, sparkling rivers and lush lowlands. I fell in love with it and have returned many times since 1998. Not to the Hospital – it closed down in December 1998 – but to renew friendships and to work amongst the people of Sarande in a private capacity.

Earlier this year, while in conversation with an English-speaking Consultant Paediatrician in the town, talk turned to the care of children with learning difficulties, preventative medicine and health screening. Innocently, I asked where The Heel-Prick Tests were sent for analysis. My enquiry was met with a blank stare. I explained further, but to no avail. After further explanations, I realised this educated man knew something about phenylketonuria, but nothing of screening techniques, which are non-existent in Albania.



The Albanian Coastline

To cut a long story short, I eventually persuaded this paediatrician to join me in setting up a research project to screen all new-born babies in the Sarande area for phenylketonuria and hypothyroidism, for a period of six months. Since that day back in January, I have questioned the wisdom of suggesting the project. Yet, each time I've had doubts, another door of opportunity has swung open to propel my plans a bit further along the road towards implementation. So, when I return to Sarande, the paediatrician and I shall begin screening all New-born babies for phenylketonuria and hypothyroidism.

Preparation for implementation of the project has involved a great deal of hard work. Firstly, I ordered a supply of Guthrie Test cards, then I made contact with and visited The Neonatal Screening unit at Southmead Hospital, Bristol. The staff of the unit have been so supportive in many ways and when the project begins, the cards will be analysed by them. Results will be faxed to a local Bank in Sarande, which appears to be the only permanent fax number available in the town. The British Ambassador in the capital, Tirane, kindly put me in touch with The Policy and Planning Unit at the Albanian Ministry of Health, whose permission I needed to undertake the project. Once that permission was gained, I designed the record cards to be held by the medical staff in the Maternity Hospital. The card headings were translated into Albanian, then the design was printed and 500 cards prepared. A friend printed a supply of sticky, address labels so the Test Cards can be sent from Sarande to Bristol with the minimum of delay. A sympathetic Drug Rep. kindly arranged to supply 500 Lancets to obtain the blood samples, whilst an Italian Charitable Foundation has agreed to supply diets for babies with positive results, for the foreseeable future. Staff who will be involved in taking the blood samples have been trained outside Albania and are ready to start the project as soon as I get back to Sarande. I have only to get parent information leaflets translated, and we will be off!

At the end of the project, the statistics will be analysed and sent to The Policy and Planning Unit at the Ministry of Health in Tirane. It is my fervent hope that the Albanian Government will be persuaded to implement neonatal screening on a National scale and come into line with advances that other developed countries take for granted.

There is little support for families with handicapped children and State care of people with disabilities, is abysmal. I feel strongly that if just one case of phenylketonuria or hypothyroidism can be prevented, then the project is worth-while. Ultimately, my aim is to change attitudes and to convince The Albanian Government that a national programme of screening will benefit the entire country, not just the babies of Sarande. Then, neonatal screening will have everything to do with Albania.



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**FATE LOW PROTEIN
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CAKE MIX**
only 13.2mg phe per 100g

EVERY PACK CONTAINS EASY TO FOLLOW RECIPES DEVELOPED BY EILEEN GREEN



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

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then ask your chemist to telephone our direct order line: 01215 22 44 33***

Helpline and General Enquiries Tel: 01215 22 44 34

FATE SPECIAL FOODS ~ SPECIAL FOODS FOR SPECIAL PEOPLE

Feenil-who-what-did-yo

A lighter-hearted view of living with PKU by a parent

ADMITTEDLY ON the day of diagnosis of our newly born daughter's condition we firmly believed we were witnessing 9 months of expectant planning, washed down the proverbial pan. The future had suddenly vaporised into a frightening and uncertain cloud. This was purely down to the ignorance of our then local GP (currently serving 10 years for fraud) who had rather dramatically put a call out on Radio 5 for information of our whereabouts. I think we were in Sainsbury's at the time but I could be mistaken. It might have been Tesco's.

So he caught up with us in the end (rather like the Fraud Squad did with him) and he imparted his trolley-full of woeful tidings as to how profoundly brain-damaged our daughter was to be and how his specialist field was paediatrics so he should know. Trust me I'm a fraudster. Our knowledgeable Consultant set our minds at rest as to the true prognosis and our journey into the unknown world of PKU began.

Talk about being slapped in the face with a sodden Guthrie Card! What with being new parents anyway and the added baggage of PKU we must have resembled the haggard stereotypical maniacs who thrive on flesh-eating stress. Pupils now indistinguishable from the bloodshot bits that surrounded them, wide and manic. Huge pulsating arteries pounding there way across furrowed brow. And hair, just don't go there because its gone, or most of it.

Those days seem like yesterday. The skills that you develop as the parent of a PKU child are profound and can be meted out to other unsuspecting and wary shoppers.

I now have the elasticity in my wrists to rotate any given jar/tin of foodstuffs through a full 360 degrees to ascertain the protein content. I have an 'A' level in not saying the full word "Phenylketonuria" twice when someone who doesn't know about the disorder asks, "how do you say that again?" "PKU" comes the second reply.

The new arrival of a non-PKU sibling only served to outline the tough nature of the dietary regime. Mind you, it was a bit like Christmas for me. In the green corner we have the measuring, the checking, the weighing and the administering of the both naughty and nasty supplements. And in the blue corner we have none of this. Now I could get my own back on the one they call PKU.

Brief flashes of stockpiled protein mountains being administered to the new arrival tripped their way across my sadly warped mind. Only for a second

though. It now transpires that said sibling is virtually a vegetarian. Where oh where did I go wrong?

I live for the time where scientists are capable of producing Doner Kebab in drip form, which can be easily administered undercover of darkness.

Now our daughter is coming up to double figures and I stand back and I'm thinking, "Just who gets the better deal here?" I have a diet that any discerning hog would turn its nose up at and my daughter has a highly tuned diet that

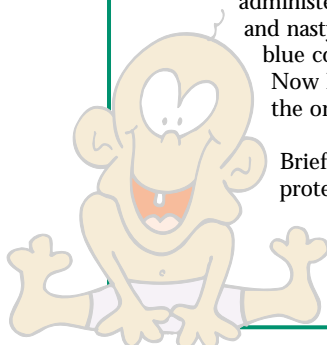
will push up her life expectancy up into the three-figure bracket and some. So it goes with any kid. You shovel all your resources into their tiny frames which is then rapidly absorbed leaving you a mere husk, a shell of a human being.

On holiday PKU seems to take on a spectre-like presence and our paranoid gene kicks in (this is my biggest and bestest gene). Hmmmmmm how are we going to cope with a tough diet abroad? And that's just me. Huge suitcases and tea chests full of low-protein foodstuffs can be justified but oh no, we've got to be much cleverer than that. Tins of preferred soups, packs of preferred foods and rapidly de-frosting home-made produce evict all of our clothes and snorkels. And you know why? Because any given country abroad doesn't actually produce tinned goods and its inhabitants have never even heard of a supermarket. It may be because we live on an island hmmmmmm.....

the skills that you develop as the parent of a PKU child are profound

Low protein cookery. What's that all about then? As regards me, it's like giving an 18 month-old his first chemistry set. You know one of those old ones with really, really dangerous chemicals in that now find their way to Iraq. I once had a poke at low-protein sausages and ended up with beef wellington. Low protein bread?? More like low-protein dead. Well I didn't know you had to use yeast.

It's always a dead give-away when I try my hand at low-protein cookery. Just as I start the proceedings all this loud scary music fires up and the skies go dark. Thunder and lightning kick off at an impressive pace and I have to pick my daughter up off the floor (It's the hysterical



ou-just-sayia?

of a PKU child

laughter that bugs me coupled with the rolling about the floor thing – in my book this represents a substantial trip-hazard) I'll persevere though.

And what of the blood sampling? That was a nightmare in the early years. Most of the time it was MY blood that ended up spattering the windows. No, in them days (patronising bit coming up) we had big stabby lancets that were more akin to amputation than blood sampling.

None of your namby pamby, wishy washy, airy fairy, lar de dar comfy, pain-free, pillow-esque, blood taking machines that actually asks your permission first. Like the one I use now.

Yet the demands of the diet seem to have abated somewhat with the onset of growing up

and the subsequent transference of responsibility for the diet into the hands of our daughter. Added to the support provided by the NSPKU, Medical Professionals and more of late, the specialist food manufacturers, who seem to be bringing more to the party, things look ever brighter. Gone are the days of having to boil up protein-free sweaty socks in rancid cabbage water. It's a good job I wasn't around in those pioneering days, I would have just applied to the High Court for an injunction against PKU.

And finally those who never had the fortune of the diet. Who never got the treatment or who were taken off the diet at an early age? There is no humour in their demeanour. But there is hope and there is the diet, which may alleviate the condition.

Anon

NEW

ENER-G® LOW-PROTEIN RICE BREAD



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Support Groups

Guy's & St Thomas' Hospital Trust

Guy's Hospital
St Thomas Street
London SE1 9RT
Tel 020-7955-5000
Metabolic Office
12th Floor, Guy's Tower
Jane Gick ext 5954
Tara Randall ext 3061
Jo Eardley
Fax 020-7955-4956

Dear News & Views

Just a short letter to show you the kind of fun our teenagers have here at GUYS. For the last three years we have held a teenagers day on a Saturday so that our teenagers can get together, learn a little bit more about their condition and ultimately have a bit of fun.

Our aim is to encourage greater independence therefore food preparation or cooking is an ongoing theme. This year we chose to have a supermarket sweep whereby the youngsters had to provide themselves with a filling and nutritionally balanced lunch and were told how many exchanges they could use. We had three tables set out with free foods, exchange foods and prescription foods. They had two minutes working together in teams, three in all. In their dash, they were encouraged to read labels, work out the exchange values and make sure it was a lunch they truly would tuck into. Each team did exceptionally well and it was "a bit of a giggle".

We have also been very lucky to have access to our adolescent day care ward for these events and so in between meeting introductions and games, we were able to play music, table tennis and snooker which always seems to serve as a great ice-breaker.

Each year we ask for evaluation at the end of the day and ideas for the future. We have always had very positive evaluation and so far those that have attended on previous years have come back. Our biggest obstacle to overcome is encouraging the teenagers to actually attend. Most think it's a great idea but find it difficult to make that big step. Once they have made that first step each and everyone have said it was really worthwhile meeting other people of the same age with PKU and having a fun time in a very relaxed atmosphere. This year we decided to join together with teenagers from Great Ormond Street. Hopefully that link can be maintained in the future and we can alternate between the two hospitals.

We completed our afternoon this year with a trip to the London Dungeons, followed by a picnic lunch with football and rounders. Lunch was provided by SHS. Hilary, home economist sent a variety of snack foods. Most favoured were pitta breads and bread sticks. Starlight children's foundation again sponsored our day by providing monies for shop bought foods and refreshments. I'd like to thank both Hilary and SHS as well as the starlight children's foundation for another excellent day.

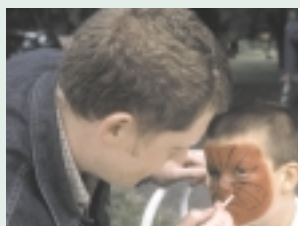
On the far left of the photo is myself. In the gallows is Nicky Mumford PKU Nurse Specialist at Great Ormond Street, Jo Eardley Metabolic Dietitian, Tara Randall Metabolic Dietitian and on the far right is Dr. Champion Paediatric Metabolic Consultant.

***Jane Gick
Paediatric Metabolic Nurse Specialist***





Summer Picnic



The annual picnic was held at King George's Playing Fields on Sunday 7th July 2002. Although the weather was

cold and windy, many families turned out and enjoyed themselves. They took part in races and enjoyed the bouncy castle and bouncy boxing ring (as did most of the parents!!) Also the face painting was popular especially Spiderman!

And in great British fashion just as all was packed away, and as the rhyme goes ...out came the sunshine and dried up the rain, and itsy bitsy, face-painted spidey man went home.



Notice of London & Home Counties Support Group Inaugral AGM

In the process of Charitable status and according to the articles of association of the support group the London and Home Counties Support Group will hold its inaugural annual general meeting on Sunday 26th January 2003 at 10.30am at King George's Hospital, Midwifery Centre, Goodmayes, Essex. All members are welcome to attend. Refreshments will be served.

Roller-Skating Event

Sunday 16th March 2003 from 12-2 pm at Roller City in Welwyn Garden City, Herts. Directions will be forwarded to you, Private hire to PKU L&HC, Resident DJ, FREE Skate Hire or you can bring your own. Food and drinks provided (PKU and non-PKU)

Please Contact –
Sandra Bramley,
48 Hazeldell,
Watton-at-Stone,
Herts, SG14 3SN
(Telephone 01920 427636)



Fate Special Foods recipes



FATE CHRISTMAS PUDDING

Hello,

I didn't really want to call this recipe Christmas Pudding, because it is too good to only be eaten once a year! It is easy to make, using Fate Low Protein Cake Mix, and unlike traditional puddings doesn't take hours to cook, It can be made and eaten straight away. They store well in the freezer and can be re-heated in the microwave. So why keep them just for Christmas? Eileen Green - Fate Special Foods

Ingredients

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

Pre-heat the oven Gas 5/190°C/375°F

Method

- * Place the finely chopped apple, currants, dried fruit, mixed spice and cinnamon into a mixing bowl. Grate the rind from 2 of the oranges and 1 of the lemons. Add this to the bowl. Squeeze the juice from the oranges, and measure 150mls of juice. Then squeeze the lemons and measure 50mls of juice. Add this to the bowl. Stir to blend well. Leave to rest for 5 mins.
- * Add the soft margarine and then add the packet of Fate cake mix. Stir well for about 1 minute until the mixture is all well blended together. Stir in a few drops of gravy browning to give a rich dark colour.
- * Leave for another 5 mins to rest.
- * Meanwhile, grease 6 individual pudding basins about 250mls capacity.
- * Stir the pudding again, and make a wish. Then place the mixture into the pudding basins. Set them into a deep roasting tin. Pour enough boiling water into the roasting tin to come about a third up the sides of the basins.
- * Bake in a pre-heated oven for about 35 mins for individual ones. When cooked, they should be risen and firm.
- * The puddings freeze well. Just defrost and reheat in the oven or microwave until hot.



MEMBERSHIP CHANGES

HAVE YOU received your membership renewal request lately? Are you worried, confused or just plain curious? Then read on and all will be revealed!

You may have noticed in my report in the last "News and Views" that I urged you to watch this space for news of changes to our membership renewal. Well this is that space and in it I hope to explain what the changes are and the reasons we have made them.

Over the years our membership, both family and literary has grown enormously. This has placed an ever-increasing workload on the membership secretary and the treasurer (not to mention other members of the committee) with the request and collection of the membership fees. Bearing in mind that all our Council of Management members are voluntary and that we all have careers and families to attend to this yearly task was becoming unmanageable. Added to which, as the Society has grown we have taken on more in terms of projects and involvement in all areas of PKU both professional and personal. This meant that time which could be used to much more value on these areas was being used on general admin tasks. After long discussions over a number of years the Council of Management finally came to the decision that the time had come to look at the possibility of "outsourcing" the membership renewal to allow committee members more time to work on other projects.

To this end we have spent the best part of the last year in discussion with the Charities Aid Foundation (CAF) firstly to assess the feasibility of this option and then ensuring that the whole of our membership renewal process was overhauled and dragged into the 21st Century. We felt that by making use of a professional agent we would not only relieve ourselves of a massive yearly task but also that our members would benefit in many ways. We have tried in the past to introduce alternative payment options but this has been far too complicated for us to manage on a large scale. We have also experienced endless problems with overseas payments often returned because we cannot accept the foreign payment. I think I can say we have surprised ourselves during the research of this outsourcing with the hidden benefits to the Society we have discovered. Such as the increased affordability for members with the payment spreading option and the capacity to follow up those forgetful members like myself who lose their forms or forget to post them! Not forgetting the cost-effective use of our time.

The changes:

- ★ **Payment Options:** will be a real benefit allowing CAF to collect cheque, direct debit and credit card including those overseas as well as spreading the cost throughout the year. Soon anyone will be able to pay online... (Watch for another space!)
- ★ **Membership Fees:** have unfortunately increased this year. Possibly your immediate reaction is that this was to pay for the outsourcing. However let me explain the reasons for this increase. We have not increased our fees for the last few years but of course our suppliers have not been so kind!! We have a new look News and Views, which I am sure you will agree, is fab! The exchange booklets contain more and more products with each edition being bigger and better. We are producing more leaflets and booklets that ever before with more in the pipeline, and we are planning to bring our merchandise up to date too. Our annual conference attendance is swelling and we are working hard to add interest to the huge cross section our membership covers. Of course all these improvements are not without cost and if the Society is to continue its good work we need to remain viable. We have also lost the Section 64 Grant of £5000 that the Department of Health used to provide... a considerable dent in the Society's purse.

The new fees will be as follows:

Family Membership (UK)	£17	for quarterly payments £18 (4 x £4.50)
Family Membership (Overseas)	£23	
Literary Membership (UK)	£25	
Literary Membership (Overseas)	£33	

All memberships will be payable by credit card, however this will incur an additional fee of £1.

- ★ **Change of renewal date:** Although this change was not strictly necessary it was pointed out that December was not a good month with the pressures of Christmas. Added to that our conference deposit being due in January it seemed we were expecting a lot from our members at that time of year. We have therefore decided to make November 1st our renewal date as this ties in with our accounting year and also it is not vastly different from our old system saving the need for a change over year of part payments.
- ★ **Return Address:** By returning the renewal form and payment direct to CAF it will relieve us of a huge workload.

We hope that the changeover to this new system will run smoothly and that you will appreciate the need for this change. Don't forget we are always eager to receive your comments.

All PKFoods are now available on prescription



*Chocolate
Chip
Cookies*



Crispbread



*Cinnamon
Cookies*

Pasta Spirals



Cherry Jelly Mix



*Orange
Cookies*



Orange Jelly Mix



Egg Replacer



White Sliced Bread



Flour Mix



aminex Cookies

aminex Biscuits



aminex Rusks

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ELSTREE BOREHAMWOOD HERTS WD6 3SS
TEL: 020 8953 4444 FAX: 020 8953 8285

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

Dietitian's Report

PRESENTATION OF HONORARY MEMBERSHIP TO DR CAMPBELL DAVIDSON

AT THE SHS International Inborn Errors of Metabolism meeting in London in March the society presented Dr Campbell Davidson with Honorary Membership of the Society. Dr Davidson, consultant paediatrician, has been closely involved in the care of PKU patients at Alder Hey Hospital in Liverpool since the mid seventies. He has been a very active member of the Society's medical advisory panel several times. There is so much work that he has done for which the Society is grateful but it must be acknowledged that he was the medical advisor who pulled together all the information for the management of PKU document to present it in its present very professional but easy to read form.

Dr Davidson continues to maintain his personal contact with his patients by always being at the PKU clinic in spite of all his commitments. Patients always come first. He has also supported the development of dietetics in PKU recognising the importance of their expertise.

Finally, on a personal note I have need to be extremely grateful to Dr Davidson as he sat on the interview panel which appointed me nearly 15 years' ago!

I would also like to thank SHS International Ltd for obtaining the photograph of the presentation from the video made of the day.

Dr Davidson wrote the following letter to the chairman of the Society soon after the presentation.



*Dear David,
I am writing to thank you most sincerely for the honour which the Society has recently bestowed on me of Honorary Membership of the Society. I greatly cherish this honour.*

I wish the Society every success in the future.

With kind regards,

*Yours sincerely,
Dr D C Davidson
Consultant Paediatrician*

MISLABELLING OF ALCOPOP DRINKS

The Food Standards Agency has contacted me to inform people with PKU about the mislabelling of some alcopop drinks. The drinks contain aspartame but there is no indication on the bottles that it is present. By law any drink both non-alcoholic and alcoholic must display the warning sign 'Contains a source of phenylalanine'.



The drinks which contain aspartame but are not labelled are:

Sound Vodka Orange Drink
Vodka Storm Blueberry
Maverick Code Red Tequila and Watermelon
Maverick Code Green Tequila and Lime
Rum Tribe Lemon and Lime
Echo Vodka Lemon and Lime.



All these drinks have been removed from sale but readers may have some on their shelves at home so please be warned.

The drinks were tested by consumer experts at Durham County Council and they are working with the Food Standards Agency and other enforcement authorities to ensure that the manufacturers and suppliers of the failed alcopops rectify the problems and supply products which meet the legal requirements.

INGREDIENT DIFFERENCES OF BRAND PRODUCTS MADE ABROAD

A parent of a PKU girl asked me recently to investigate a drink made by Coca-Cola called Fanta Orange. This was the normal Fanta and not the 'light' version. The drink was bought in France and contained no warning message about aspartame. Fanta Orange in the UK contains aspartame. The parent was understandably concerned that the drink may not be correctly labelled.

However, after contacting Coca-Cola in France they assured me that Fanta Orange made in France does not contain aspartame. All members of the EU must comply with the labelling regulations for aspartame so please always check products even though the product was suitable the last time you used it and be aware that recipes may be slightly different in different countries.

WHAT NEXT SWEET COMPANY

The **What Next Sweet Company** make some jelly tree decorations which are allowed freely in the diet. They are available in Woolworths under the What Next name but different sweets for the tree can be found in other shops either under the shop's name e.g. Sainsburys. or the What Next Name

All of the following contain 0.2 grams protein per 100grams:

- ★ The jelly tree decorations are available in Woolworths under the What Next name.
- ★ Candy Cane with Jelly Tree Decoration sold under Sainsbury's name and also in Disney Stores
- ★ BHS – A tree bauble of 2 jellies back to back of bears and penquins under What Next name.
- ★ Somerfield Jelly lollipop under the What Next Candy Company name
- ★ Safeway Jelly Lollipops of different characters under What Next Name

CHOCOLATE DECORATIONS

The mother of a little boy with PKU has been very inventive and resourceful in producing an advent calendar and Easter Egg for her son. She wrote to me explaining what she had done and I thought that it might be helpful to pass the ideas on.

“ I bought an ordinary chocolate advent calendar i.e. Bob the Builder, carefully undid the bottom, slid the mould out with the chocolate in, tipped these out, washed the mould out, dried it and then melted Vita-bite and filled the mould again. I put it in the fridge until it was set and then put it back into the calendar, making sure I put the mould in the right way up! For Easter I borrowed an egg mould from my nephew (it was about 6 inches high). You can buy the chocolate egg moulds from some art and craft shops along with a special paint brush for chocolate making. I melted Vita-Bite bars then painted it onto the inside of the egg mould until the thickness becomes 2mm to 3mm. Leave it to set before each layer of chocolate (you can speed this up by putting in the fridge). It is time consuming but worth it. When I had finished I put the two halves together and I put a small packet of Jelly Tots in the middle of the egg.”

You could also use Duobar in the different flavours for the advent calendar and Easter Egg. Lakeland Plastics also do a lovely Pudsey Bear Mould which makes 4 Pudsey Bears two and a half inches high. You get two moulds which make 8

bears altogether and they cost £3.95. A donation of £1 goes to the Pudsey Bear Appeal.

The Lakeland Catalogue is full of excellent cooking utensils and bakeware. Hilary Marshall used their Christmas biscuit cutters at the Adult PKU Study Day in London.

Lakeland address:
Lakeland Ltd.,
Alexandra Buildings
Windermere,
Cumbria
LA23 1BQ

Telephone 015394-88100

Internet: www.lakelandlimited.co.uk

BLUE DRAGON

Blue Dragon Rice Spring Rolls 35grams for one exchange.

TAYTO BOB THE BUILDER SNACKS

Available from Tescos
Bob the Builder Cheese: one 16gram bag is one exchange,
Bob the Builder Prawn: 20grams for one exchange,
Bob the Builder Pickled Onion: 20grams for one exchange.

MARS MAGIC STARS

There has been a recipe change for Magic Stars. The protein content is 6.9 grams per 100g which means that there is an increase in the amount for one exchange.

The labelling of these sweets has been incorrect but I am assured that 6.9grams is the correct figure.

Magic Stars now 15grams for one exchange

AMINO ACID ANALYSIS

We are currently undergoing more analysis of foods for phenylalanine content. As soon as this is completed there will be notification in the magazine. We are always pleased to hear your suggestions for analysis and the choice of new foods to analyse is taken on usefulness and popularity.

Eleanor Weetch
Society Dietitian

Outward Bounds

*By: Barbara Cochrane,
Senior Dietitian,
Royal Hospital for Sick
Children, Yorkhill,
Glasgow.*

Derwent Hill, Keswick September 2002

I CANNOT remember this being part of the job description, I thought as I plunged down a rock into cold water.

We were back again. Two years ago a group of young people with PKU from Scotland joined up with groups from the North of England at a beautiful Outward Bound centre in the Lake District and having forgotten the lack of sleep and being constantly on the go - we were back.

This time our group had grown to 40 young people aged between 9 and 16 years of age. Derwent Hill is an Outward Bound and conference centre situated within beautiful grounds overlooking Derwent water. We had originally chosen the Lake District as it was near enough for everyone, but the professionalism of the instructors and the welcome we had been given, made us return to the same place. We were fortunate to have 7 adult helpers: Carolyn and Clare from Scotland and George, Carol and Elspeth from Newcastle and Joanne from Leeds and myself.

The majority of the children and young adults came from Scotland and many had never met anyone with PKU before. They were fairly quiet on the way down in the bus - although we could start to see the gangs forming!

Andy Jones, who was in charge of our group for the weekend, greeted us on arrival and directed us to



the water activities very enjoyable. We were gorge walking and canoeing on the first day, and it was fascinating to see the young people do things they would not normally have dreamed of doing, such as plunging down rocks into water over their heads. We had all the usual complaints of "this wet suit makes me walk funny", "I've damaged a nail" and "just look at my hair".

After lunch we were canoeing, which was fun until Joanne and I realized we were the only ones rowing and everyone else was admiring the scenery. The day was rounded off by a trip to the centre's shop, team games and a disco.

Sunday brought another sunny warm day and the rope course and wall climbing. The highlight of the rope course was jumping off the totem pole and leaping off a 40-foot tree on the double death swing. Watching the excitement and hearing the screams brought a lump to the throat.

It is amazing how quickly everyone got to know one

another, how well they all got on and also how quickly the leaders forgot the lack of sleep, pacing the corridors trying to keep everyone in bed and trying to keep everyone seated at mealtimes. The young people approached each new challenge with

watching the excitement brought a lump to my throat...

the dining-room as the round of supplement making and exchange weighing was to begin the evening meal. It was made a bit more complicated as one of the boys had developed diabetes a month before and trying to remember protein and carbohydrate exchanges was a challenge. This was a time consuming part of the day and we seemed to underestimate how long it always takes. Especially when the children are all so excited and want to explore and find out where they are sleeping.

After the meal, we were directed to our rooms and then went out to explore the grounds in the dark with torches.

Finally it was time to try to get everyone to bed! By now everyone had got to know one another and it became like a big sleepover, with noise to match. I hear all the mums groaning at this point, yes it was that bad!

The next morning all the leaders, there were 7 of us, were up early to organize the supplement making and getting everyone up. That was not as bad as expected, but getting everyone in the right place all together was difficult. There seemed to be no end of excuses why they couldn't stay seated for more than 10 minutes.

The weather was perfect all weekend, which made

enthusiasm; they helped one another and enjoyed every minute.

When asked what they thought about the weekend, the comment of "everyone being the same as me" summed it up for me. Needless to say, we are booking for next year!

Many thanks to the NSPKU, Vitaflo, SHS International, Yorkhill NHS Trust and the many individuals for helping out with the funding of the trip.



they're a bit saucy!

NEW



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.

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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
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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.



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

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

Pasta in
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NOW AVAILABLE ON PRESCRIPTION
TOGETHER WITH
LASAGNE SHEETS &
COUS COUS

PKU RECIPE CALENDAR

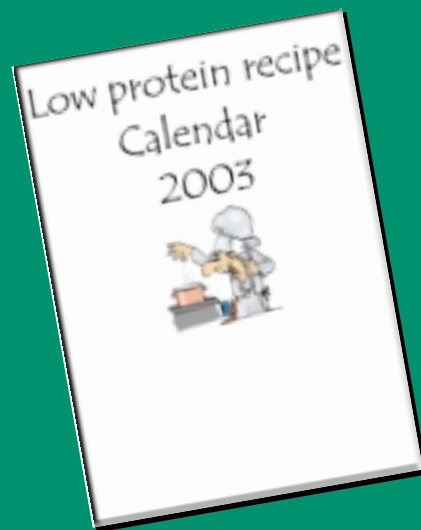
A low protein recipe calendar has been produced at a cost of £3.99 + 50p p+p.

It features a recipe for a each month with spaces for writing on and also a bit for special dates on each month.

The calendar has one page A4 / month and is mainly in colour.

It can be ordered from:

Barbara Cochrane
Senior Dietitian
Dietetic Department
Royal Hospital for Sick Children
Yorkhill
Glasgow
G3 8SJ
0141-201-0163



Low Protein Recipe Calender

Please send me copies of the calendar at the cost of £3.99 + 50p for postage and packaging. I enclose a cheque/ postal order for £

please make cheques payable to: 'Metabolic Activites Fund – 902'

please send to :-

Your Name.....

Your Address.....

Postcode: Contact Telephone Number

Please send this form to: Cochrane, Senior Dietitian, Dietetic Dept, Royal Hospital for Sick Children, Yorkhill, Glasgow, G3 8SJ – Contact phone number: 01414 201 0163

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.

Mrs. Sara Bartlett
(Merchandise)
The Corner House
2 Stamford Road
Colsterworth
Lincolnshire NG33 5JD
Tel: 01476 860 379



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

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