The National Society for Phenylketonuria (UK) Ltd 102

News & Views

THE GREAT OUTDOORS!

South Wales Support Group Camping Weekend...

website: www.nspku.org

plus

Government News ● Dietitians Report ● Letters ● And much more ...

In Touch

The Council of Management

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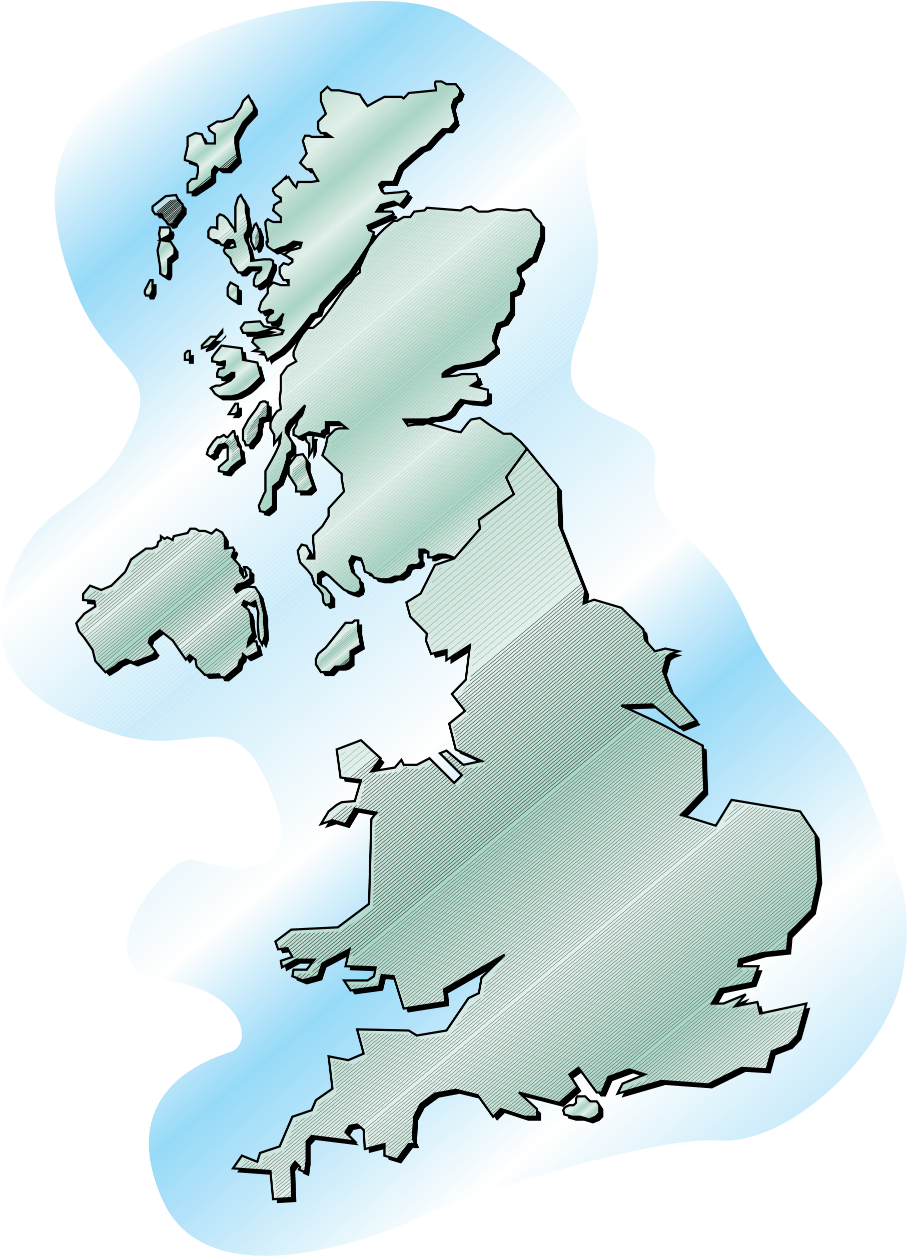
Internet: http://web.ukonline.co.uk/nspku



Contents







Editors Report

IN FOND memory of Paul Olivers (former News & Views Editor) late wife Margaret, this space is dedicated to her memory.

Margaret Ruth Oliver (Meehan)
27-07-53 – 29-12-01

Margaret and Paul Oliver joined the NSPKU in 1990 several months after the birth of their second daughter, Annelise. Annelise was diagnosed as PKU but an elder daughter, Joanne born on 14-11-87 was a perfectly normal baby.

After the initial shock of being confronted with PKU, Margaret came to terms with what being the Mother of a PKU child would entail and she rose to meet all the challenges this brings.

In the 1990's, Paul and his friends cycled across France and Germany to raise much- needed funds for NSPKU. Margaret was always extremely supportive of Paul's hair-brained schemes and backed him up to the hilt in everything he did. Indeed a spin off of the cycle rides were articles in "Bella" and "Reveille" outlining the problems of PKU sufferers and bringing PKU to a wider audience.

In 1993, Paul and Margaret helped set up the South Wales PKU Support Group. Unfortunately in 1995, Margaret was diagnosed with cancer.

She underwent 2 operations and 5 bouts of chemotherapy to try and combat this illness but after a terrifically, typically courageous fight she lost her battle on 29th December 2001.

Over 600 people attended Margaret's funeral (One of the largest seen in St Cadoc's R.C. Church, Llanrumney.)

Margaret was so ebullient, full of life, generous and with a fantastic sense of humour. Once you met Margaret, you wouldn't forget her. She had the knack of making you feel you had always known her. Such a great loss.

Pete Bramley
Editor

Treasurers Report

Donations

1st April 2002 – June 2002

(£30 and over)

Stewart and Ana Alexander	50.00
Mr. K.N. Young	550.00
Strathmore Golf Club	120.00
D105 Social & Charity Committee, Boots the Chemists	200.00
Mr. R.M. & Mrs M.L. Hill	300.00
Carlton & Arnold District Darts Association (via Andrew & Gina Guest)	231.00
Bristol Street Citroen (via the Guest family)	1,500.00
Anonymous	5,000.00
SHS International	100.00
Mrs Debbie Julian	45.00
Mr. J. Hair	200.00
The Selbie Family	100
Holburn West Playgroup	40
Pat Kimpton	270
Richard Chitticks	401.50
Christine McElvoy	205
Sheila Drewitt	250
Paul Jones	1,120.00

NSPKU
The National Society for Phenylketonuria (United Kingdom) Limited

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Reports…

Treasurers Report

IT'S A beautiful sunny day and I'm stuck in the office so I'm going to make this short and sweet!!

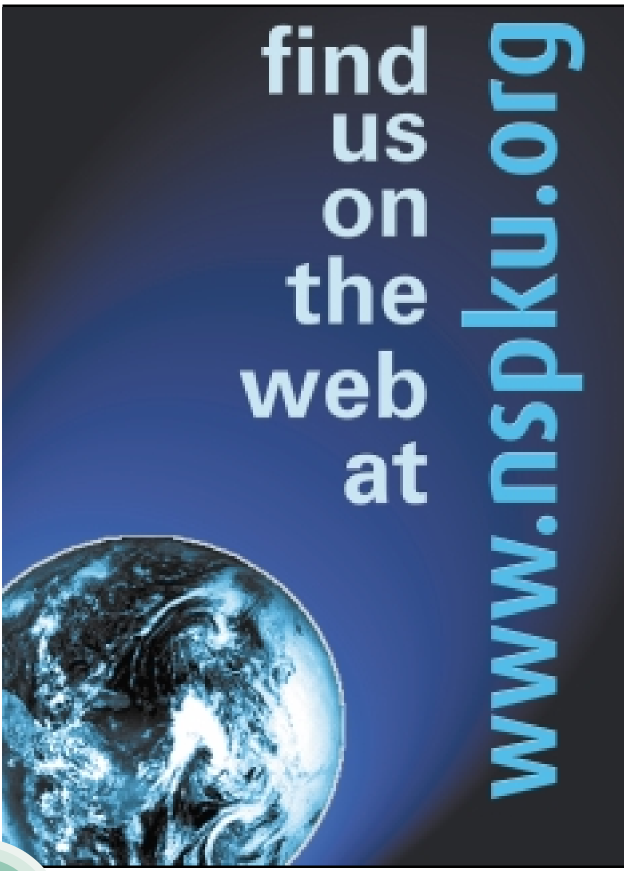
In the last issue I forgot to thank those who have sponsored us over the last 12 months so although belated but nonetheless heartfelt a very big thanks to the food companies; SHS, Gluten Free Foods, General Dietary and Vitaflo. Also to The Childwick Trust and our anonymous benefactor for their help towards Conference costs.

I apologise if this is beginning to sound like the Oscars but I would also like to thank on behalf of us all those who contribute via the "pay as you earn" scheme and the regular gift aided donors. I wish I could write a personal thank-you to you all but the processes involved make this difficult.

If anyone out there would like to join a payroll giving scheme you should contact your employer. For details about how to set up a regular gift aided donation please contact me, (contact details are on page 2)

Finally something for the (very near hopefully) future… we have been looking at our membership fee collection and are in the process of re-vamping it to benefit us all so watch this space for further news.

Julia Bailey
Treasurer



Chairpersons Report

Calling PKU's teenagers up

A WHILE ago we realised that we were not providing enough for you lot. We give lots of support and information for newly-diagnosed PKU's, continue providing it for your families but to be honest we don't really know what to do for you. You can be a difficult group to explain your needs! Things that we have tried to do at the conference have not always been well attended so it is obvious that we need to do something different. We have decided to organise a day conference which we hope as many of you as possible will come to. We will organise something for you to do whilst your parents are catered for elsewhere.

So the day conference on March 15th next year is for you too so please please come along. You may want to get together in organised groups to talk through specific things, perhaps have a demonstration of interesting drinks or cocktails (non-alcoholic I'm afraid) or you may just want to spend time together watching a video, listening to music and chatting informally. Let me know what you want us to provide, just put a note in the post. It doesn't have to be neat or written in your best handwriting or even say whom it's from, just give us some ideas. The hotel we are using is great – swimming pool, sauna etc and near to places that you might want to visit – shops, bowling alley, Space Museum, Stratford-upon-Avon…

Do you really want to sit at home and ponder the trials of PKU? Come and discuss how you can make the most of it. Go on, give yourself the chance to moan and groan without upsetting the olds and on a more positive note, exchange good ideas, tasty recipes or coping strategies. It might surprise you to find others who share your situation, your difficulties and your successes.

On a personal note, but on behalf of us all, I would like to say a BIG thankyou to Duncan-Noble-Nesbitt who has just left the COM and to say how sorry we are to be losing him after many years of hard and joyous work. Duncan we wish you and Sarah a very happy future together. A BIG thankyou also to Du Toit Verster who has recently left the COM. He was a valuable member of the team and will also be missed. We hope to see you at future events especially the ES.PKU Conference when it will be all hands to the deck to make our European Conference as successful as our annual ones.

Sara Bartlett
Chairman

Fundraising

PKU day in Yorkshire

FUND-RAISING has always been a difficult area for the NSPKU. Largely because of the nature of the Society's voluntary status. Council of Management members are largely engaged in the functional and informational nature of the Society.

However, there are notable giants who make substantial contributions to the Society's coffers. Some on an annual basis and some by virtue of a one off event – a marathon or even a covenant, anonymous or a high profile event worthy of public recognition. There are many in this magazine. All are deeply appreciated and all are recognised.

The day gave glorious weather and a great turnout of Yorkshire hospitality...

And thus enter John, Sharon, Danielle and Annabelle Skidmore. The former being the parents of the latter (PKU) and eager in their cause to bloat the coffers of the NSPKU and provide a congenial day of entertainment, food and refreshments.

John and Sharon have now made this into an annual event, which attracts not only neighbours and the locals of Normanton, West Yorks, but travellers as far as the Home Counties and Norfolk. This can be attributable only to the quality of PKU and non-PKU food but the quality of the stalls and entertainment laid on for the enjoyment of all attendees – 70 – 100 in all.

John Skidmore takes no prisoners when it comes to the sponsoring of his event and corporate money had obviously been hijacked for his pleasure and that of the Society. SHS had very kindly sponsored the kids entertainer who misguided young children into a career of Diablo, stick juggling and Unicycle injury. They loved it.

And what charitable day would be complete without the raffle and draw (big fluffy moose and questionable unused American manufactured deep fat frier as just a sample of the very best of UK derived raffle prizes!)

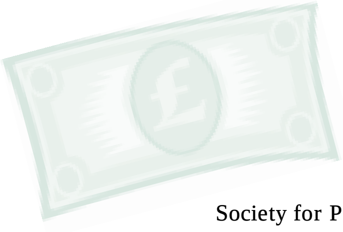
The day gave glorious weather and a great turnout of Yorkshire hospitality, which only added to the occasion. Many thanks to Graham and Mary who doled out the refreshments and food and all of those who contributed to the summer's day's activities which raised £1050 – a major donation.

On behalf of the Society – many many thanks to John and Sharon for their continuing efforts and generosity and to the organisers of the cake, perfumery and flower stalls whose valiant input only added to the days events.

Thanks too to Mrs S. L. Appy for her input, she raised a considerable amount with her poster and diary stall.

Fundraising cont.

Mandeville's Triathlon Star raises over £500 for charity

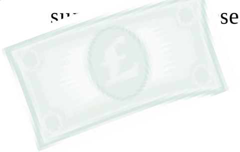


GENERAL MANAGER of Mandeville Retail, Peter Shrimpton has raised over £500 for the NSPKU, in a Triathlon which he took part in on Easter Monday. The NSPKU (The National Society for Phenylketonuria) is Mandeville Recruitment Group's chosen charity for 2002, the 2 year old son of Mandeville's MD, David Riley suffers with the condition. Phenylketonuria is an inherited disorder which prevents the normal use of protein food, and causes changes in the body chemistry which, if left uncontrolled, can lead to severe mental handicap. However, the condition can be controlled by a special diet, enabling many to lead a normal life.

The triathlon – which involved a 438 metre swim, a 20km bike ride and a 5km run – began at Hampton Court Palace. With a second hand bike supplied by TD Cycles in Taplow, Peter underwen months of intense training to raise his fitness levels for the rigorous event.

"The triathlon presented me with a real challenge to increase my fitness level. When I decided to go a step further and raise sponsorship for Mandeville's charity, I knew that it was something that I had to see right through to the end. It was really tough, particularly when I got to the last hurdle – the running. My legs almost went to jelly, but knowing that I'd raised more than 500 pounds for the NSPKU made it all the more worthwhile, and I'd definitely do it again'.

Sara Bartlett Chairperson of the NSPKU, comments, 'I feel honoured that Mandeville Recruitment Group has chosen the NSPKU as their charity for 2002 and we are especially thankful for Peter's efforts. This money will help our organisation to raise a[illegible]ss of phenylketonuria and to aid and su[illegible]search into the condition.'



Bristol Street Motors and the Guest family 'cough up!'

Andrew and Gina Guest and friends present a cheque for £3000 to Chairperson Sara Bartlett in recognition of a fantastic effort which included kind donations from local church, St Swithens, at Woodborough, The Arnold Mens Darts League and not forgetting the regulars at the Nags Head, Woodborough.

Well done to all and our sincere thanks.

DO YOU HAVE A COLLECTING TUB?

If you have, or you know the whereabouts of an NSPKU collecting tub could you please contact Julia Bailey on:
01252 728221 or at
nspku.treasurer@ukonline.co.uk

Income & Expenditure Account

For the year ended 31 October 2001

	2001 £	2001 £	2000 £	2000 £
Income:				
Membership fees	10,269		7,200	
Donations and covenants	36,246		23,269	
Contribution and sponsorship re Conference 2001	2,083		34,603	
Lottery 2001	6,773		6,812	
Bank and other interest received	3,956		3,936	
Publications and videos	1,703		3,697	
Advertising	4,200		3,025	
Fundraising	2,479		3,507	
Literature charges	2,399		1,748	
Sponsorship re international conferences	133		1,115	
Sponsorship re publications	900		2,304	
Sponsorship re Society administrator	–		3,000	
Sponsorship re assisted places	1,000		–	
General sponsorship	6,000		1,500	
Outward Bound course	734		1,474	
Donations re research	6,484		525	
Other receipts	–		348	
Total income		85,359		98,063
Deduct:				
Expenditure				
Conference 2001	9,291		35,351	
Lottery 2001	1,379		885	
Goods for fundraising	1,088		2,002	
Newsletter and publications	17,186		18,055	
Telephone	1,330		1,409	
Postage	1,656		2,372	
Travelling expenses	5,715		6,948	
Insurance	1,004		976	
Stationery	163		2,472	
Equipment and software	355		2,369	
E Weetch fees	12,036		11,140	
L Welch fees	3,356		556	
Sundries	479		346	
Committee meeting expenses	566		1,99	
MAP meeting expenses	208		973	
Dietitian’s meeting expenses	199		104	
International conferences	522		1,369	
Bank charges	39		37	
Carried forward	56,572	85,359	88,463	98,063
Outward Bound course	2,284		2,192	
Audit	881		969	
Research	699		4,837	
Grants	5,250		80	
Total expenditure		65,686		96,541
Surplus of income over expenditure		19,673		1,522

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.editor@ukonline.co.uk

Dear News & Views

Following a Canderel sampling held within my slimming world class, we became aware of your charity as the literature supplied to me advised my members of the effects of aspartame. We have a member in class who works as a nurse with PKU children and she told us a little about it and we decided to hold a charity raffle. The proceeds £116.50 are herewith enclosed.

Regards
Sharon Giles

Dear News & Views

Please find enclosed cheques to the value of £1,120. I raised this money for the PKU Society by running in a Marathon in 2001.

I've enclosed a picture of myself with Isabelle Gallagher who is the daughter of a good friend of mine. Isabelle has PKU and is coping excellently with her diet.

Kind regards
Paul Jones

Paul Jones and Isabelle Gallagher

Dear News & Views

Please find enclosed two cheques totalling £140. The first cheque for £40 was raised by Holburn West Playgroup. They held a juice morning and this year they chose to donate the profits to the NSPKU. The second cheque is a donation from the Selbie family as our beautiful daughter and sister Kate Mary Selbie who is 22 months old has PKU.

A huge thankyou to Gill Redmond of Holburn West Playgroup for choosing the NSPKU as their charity this year and also to the Society for their help ensuring our daughter lives a healthy normal life

Yours Truly
Lisa Selbie (Kate's Mum)

Dear News & Views

I am writing enclosing a cheque for £401.50, which I raised by running the London Marathon on 14th April this year. No mean feat when you get to the ripe old age of 45! I am married to Jane who is a teacher and have two great children, Emily and Joshua.
My daughter who is 12 (going on twenty – five) is classic PKU. Emily is, with the help of the NSPKU and Gt. Ormond Street Hospital, growing into a beautiful young lady who we are very proud of. She enjoys many things but most of all she enjoys her dancing. Both Josh and Emily go to the Poole Academy of Dance. Emily does Modern, Ballet and Tap. They were both in the Academy show this year, which was a great success.

I hope this cheque goes some way in saying thank you for the support the Society gives to the families who feel lost when their child is first diagnosed with PKU.

Yours truly
Richard Chitticks

Dear News & Views

Please find enclosed Draft for £205 raised for the NSPKU by all in the photograph. They raised this amount by running in the Belfast Marathon.
Barry and Phillip McEvoy both have PKU. The photograph below shows Barry McEvoy (inset left), Michael Smith, Phillip McEvoy, Eamonn Quinn, Paul McGrath and Declan Collins (Inset right)

Dear News & Views
Please find the enclosed cheques to the value of £250.

My Father had quite a hard life being disabled himself, but at 81 years when he passed away, he had always been a very proud Grandfather to Matthew who is PKU.

In 1973, dietary information was quite limited but we managed successfully. Matthew is a well adjusted, capable young man with excellent prospects at work and has enjoyed travelling as far afield as Australia, both in work and pleasure.

His sights are to further his travels with continued work with hopes also of a successful personal life ie marriage and a family.

We thank you for the continued help the Society gives and hope these donations help with the work you are all doing

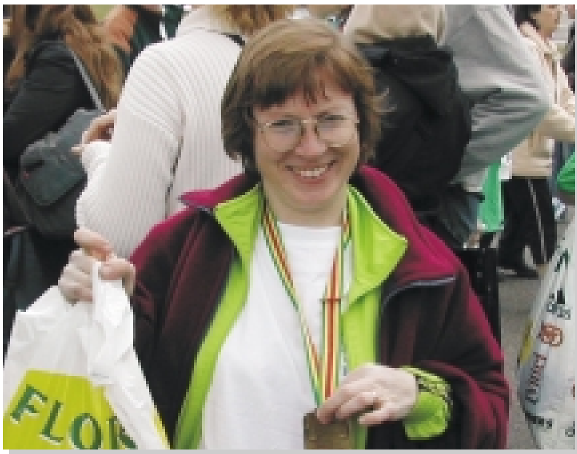
Yours faithfully
Sheila Drewitt

Dear News and Views
Please find enclosed a photograph of my daughter Evie receiving a cheque for the NSPKU, which hopefully will make the 102nd edition of News & Views. Evie's school (Abbot' Hill Junior school) has been fundraising this year for the NSPKU and although this photograph shows £225.00, the school eventually raised £425.00. Evie also helped raise another £377.83 by raffling her toddler bicycle and this was sent to our local London Home Counties Support Group

Regards
Sherryl McMichael

Dear News and Views
The London Marathon experience is certainly one to remember and cherish. The race day dawned and the weather was lovely. It was warm at the beginning (with even some sun) and it cooled off later (apparently – I thought it stayed hot!) The atmosphere was brilliant at the start – whereas a running club compatriot was next to Frank Bruno, I was next to a cardboard box from MFI! This chap was going to run with it over his head (I think it was for 'Dreams Come True'). The children were slightly impressed as I overtook a rhino. Ian has never let me forget that I was beaten by a camel in his first 10km (Ian wasn't). I ran most of the way with the Essex Police. Considering they were from Chelmsford where we were staying, it would have been nice if they had given me a lift into London. Paula Radcliffe did very well although as in The Great North Run she set off before me so I had no chance of beating her! Simon kept popping up at various places en route which gave me a great boost – especially as I didn't know where! I ran all the way although I found the last 6 miles hard. I did walk at the water stations because at that stage I didn't feel I could coordinate running and drinking. Getting going again was difficult but I told myself (amongst other things) that it wouldn't do for Simon to see me walking so I ran! The training for the marathon started on New Years Eve when I ran about 10miles (although I had run 4 half marathons including The Great North Run which prompted me to run the London!) I remember during one of my 16 mile runs I ran past a little boy and he asked his dad if I was training. I nearly answered and said I wasn't doing it for fun!! Although I do have to say most of the run was 'fun' (probably with all the training). The training for a marathon is a lot when you have other commitments. I did a half marathon last Sunday and it was lovely to be able to stop at 'only' 13.1 miles. If I did another marathon again (I'm not tempted) I would probably do one closer to home.
I would like to thank the NSPKU members I collared at Gateshead to give me money.

Pat Kimpton


Pat sports her winning medal


A panache and yet moody bin bag from the "Locale Orthority" collection

Contacts

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.editor@ukonline.co.uk

Dear News and Views
I'm a young woman in my early thirties and would love to chat with someone with PKU (female) about the diet, to share experiences and any ideas!

My address is -:
Gail McKendry
8 Allworthy Avenue
Belfast
BT14 6BU
Northern Ireland

Dear Editor
My name is Cristina Schofield and I am 10 years old. I am writing to see if there are any more PKU children out there that want to write or chat to me about my or your experiences with PKU. If so they can write to me at my home address which is 30 Meadway, Knebworth, Herts SG3 6DN or phone me on my home number which is 01438 815272 or my mobile which is 0792 9352874

HOLIDAY INFORMATION

The booklet ‘Travelling with PKU Hints & Tips’ has proved very popular and useful for members. We wish to build on this and aim to produce a list of useful questions/phrases translated into various languages. The languages we are looking at are:

French
Spanish
Swedish
Hungarian
Turkish
German
Portuguese
Norwegian
Polish
Italian
Dutch
Danish
Greek

The suggested information to be translated is: –

For medical reasons (a disorder called Phenylketonuria) I am not allowed to eat any products which contain a lot of protein, for example meat, fish, eggs, cheese and soya. Vegetables like potatoes and sweet corn, pulses and cereals are allowed in limited quantities and have to be measured exactly. Fruit, leaf vegetables, sugar, oil, butter and margarine are permitted freely. Any foods, drinks or medication sweetened with Aspartame (E951) are not allowed. To stay in good health, I have to follow this strict diet with medication.

A few questions/phrases to help you:

- *I have a medical condition called Phenylketonuria.*
- *Can you bring me a plate of vegetables only?*
- *Can I have a salad on its own?*
- *Does this dish contain meat/fish/egg/milk/cheese?*
- *Please could I have some potatoes/chips/French fries with vegetables/salad?*
- *Please may I have some fruit?*
- *Can you cook a portion of this pasta/rice /pizza base for my meal tonight?*
- *Can you heat this food for me?*
- *Can you warm my baby’s bottle?*
- *Can you toast this special bread for me?*
- *Can I have some butter?*
- *Can I have a bottle of water?*
- *Can I have a can or bottle of Coca Cola / Fanta / Sprite?*
- *Can I have some tomato sauce please?*
- *Can I eat my special medical food in your restaurant?*
- *I cannot take food or drinks containing ASPARTAME (E951).*
- *I cannot eat any meat, fish, cheese, eggs or milk products.*

A few general questions/phrases:

- *Have you got a fridge which I can use?*
- *Can I put this in your fridge?*
- *Where is the doctor’s surgery?*
- *Where is the hospital?*
- *Where is the British Embassy?*
- *Where is the post office?*
- *Thank you for your help.*
- *Protein*

For any urgent need, please contact the nearest medical centre as listed.

If anyone can help by translating into another language or knows someone who can, please contact:

Lucy Welch, Administrator, NSPKU, PO Box 26642, London N14 4ZF.
Telephone: 0845 603 9136
Email: info@nspku.org

Government News

Higher standards to improve services for people with long term conditions

HEALTH MINISTER, Jacqui Smith announced today at the College of Occupational Therapists "Making Waves" Conference that the NSF for Long-term conditions will have a particular focus on the needs of people with neurological conditions and brain and spinal injury, and also address some of the common issues faced by people living with long term conditions.

Speaking at the Conference, Jacqui Smith, said: "This NSF will enable us to tackle unacceptable variations in the quality of care across the country for people with neurological conditions and brain and spinal injury.

"We know that people need help not only in the context of managing their medical condition but also in the light of their social, educational, employment and family lives. Their views and those of their family and carers are really important in helping to improve their independence and quality of life.

"These are challenging times ahead but occupational therapists have a key role in developing and implementing the NSF over the next 10 years. Your expertise in working with patients across health and social care boundaries will be invaluable to this work."

The NSF will build on NHS Plan principles: aiming to provide good quality, joined-up health and social services along the whole of the patient pathway, with users and carers at the centre of re-designed services.

The NSF will have a particular focus on services and support for people of working age. For example:

- *User-centred, interdisciplinary health and social care assessment and support including rapid referral for diagnosis;*
- *Specialist, community and vocational rehabilitation services; Community equipment services;*
- *Help with a range of common symptoms including pain and movement disorders;Information and support for carers and families;*
- *Support and services that help people with long term conditions fulfil their own responsibilities as partners, parents and carers; and,Developing the concept of the Expert Patient.*

The NSF project team has met with and received a number of submissions from key stakeholders including voluntary organisations, clinicians and health and social care professionals regarding their aspirations for this NSF. We are working closely with the Neurological Alliance and the Long-term Medical Conditions Alliance on the development of this NSF.

South Wales support group

SOME PEOPLE regard camping as socially acceptable second only to deep root tooth therapy by a disturbed dentist. (apologies to all dentists)

No more! The weekend of the end of July heralded the instigation of the South Wales Support Group's annual abuse of the term "Camping".

The turn-out was fantastic with 8 families involving 30 individuals destroying any chance of ever being invited to attend the same campsite ever again. Thus was the stuff of congeniality between the attending parties forged in a manner that was underlined by humour and sheer enjoyment. A fantastic weekend, a sunny weekend.

A weekend that really worked for PKU families and for the sharing of information.

This event has been rearing its head for some 4000 (Ancient Druid Genetically Driven) years and has its core organisers, Alun and Ifona Rogers who seem to accept that it is their duty to repeat this feast of mayhem on an annual basis.

Arrival for the victims occurred on the Friday. The venue being Bracelands campsite in the Forest of Dean near the Welsh Border and Gloucester.

Bracelands is a Forestry Commission campsite, which has standing in the Wye River Valley. A truly beautiful setting and a campsite that warrants great reason for a visit, not only for campers but any visitor who enjoys peaceful relaxation in green surroundings. The focal point in the Forest of Dean is Symonds Yat Rock just 1.5 miles from the campsite by forest trail or road. "Yat" is ancient English for gate and Symond was a local sheriff. It commands spectacular views of the Wye Valley and at the foot of said "Yat", nestles Symonds Yat East, a small hamlet endowed with fine hostelries and the opportunity to travel the Wye in either fine comfort (flower festooned ferry) or traverse the waterway in hand-propelled ferry for a nominal fee by way of a rope pulled mechanism.

Friday being arrivals day witnessed tired travellers and local arrivals greeting each other by virtue of the NSPKU (South Wales Support Group) gazebo generously labelled enough to absorb any unwary traveller, PKU or not!

This was basically a meet and greet day/evening with respective families familiarising themselves with each other and more importantly organising the next day's events. Extremely ad-hoc and totally up for negotiation.

Saturday was easy, Wake-up...........slowly..........feel guilty as head hits pillow again for the third time as kids begin to involuntarily forget the purpose of breakfast in favour of broadcasting early-bird alarm body slams on unsuspecting parents.

(For those who genuinely think that camping is roughing it these days – some of us had continuous heat, 60 watt lighting – with low voltage night lighting and gas 2 ring and grill – erm .....home taken from home!!) Granted the trip to the toilet block was a hundred yards or so but having got there they were very clean well lit and heated. Pioneers can now distance themselves from this sort of soiree!

The day's activities were already sorted from the night before. The trouble being that nobody could clearly recollect them due to all sorts of reasons – mainly complacency but more likely Lambrusco driven!

This did not stop an intrepid journey down river paths to the disused Wye Valley railway track leading to the suspended Biblins Bridge that spans the Wye River Valley. A couple of Mums (you know who you are) inspired the group by cheerfully refusing to cross the swaying bridge. They were coaxed by chocolate and titbits and the promise of this not appearing in News and Views. Ifona and Maria. That's them whom aren't to be mentioned.

After the bridge exercise, we were led expertly by PKU dad, Mick (RAF Instructor) who applied his compass to our plight and gained our worship as "The Man Who got us to the Pub – (Quickly)". Then we feasted on all sorts. PKU kids abounded and the sound of scales hitting the tables had heads turning. Big on chips and supplements.

Fantastic when PKU families are in the majority in an eating place – people turning round to have a look are few and they are quickly dismissed as the minority and out of order – lovely.

Once fed and watered, back to camp (up-hill) for more refreshment and relaxation before the manic feast of merriment, BBQ and general fire – starting that would last into the early hours, before being reprimanded for noise pollution by irritated Forestry Commissioners. Slap of wrist and straight to bed for those dastardly offenders!

Sunday brought a mini – mass departing of a couple of families. They missed out on the trip to Clearwell Caves. The caves are a mixture of natural caves and mine-workings that are still mined today. Pigments for paints (Ochre) and iron-ore are still extracted.

Whoosh back for a picnic lunch. Eileen Green from FATE foods turned up with a rake of PKU foods both on Saturday night and the Sunday lunch time so the PKU kids were inundated with food that they could shovel down their necks with impunity !! The noticeably odd thing was that all the kids were on different protein supplements.

The picnic lunch was a revelation when it came to

camping weekend

the taking of them. At least one child left with a different view to supplement taking and the desire to change her regime – a result of the weekend.

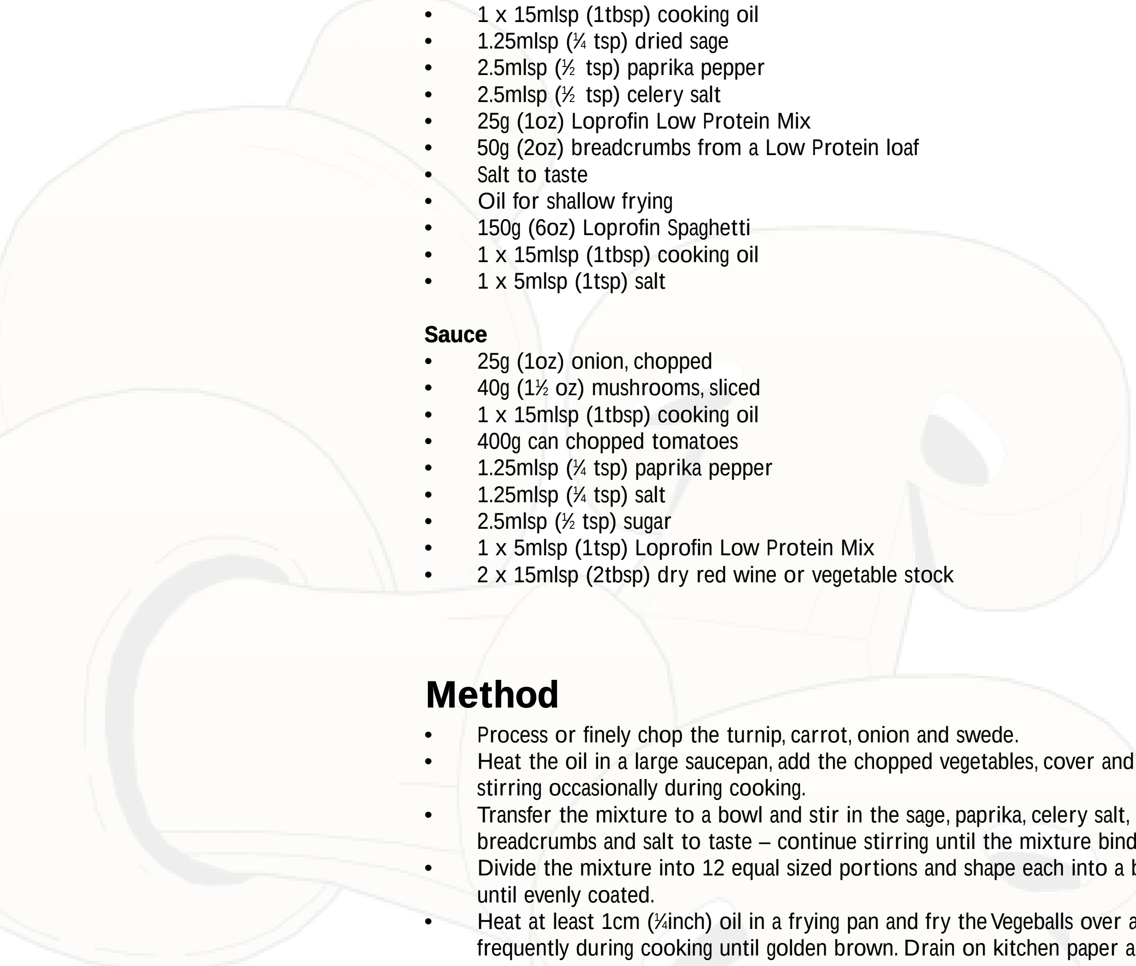
And then we all went our own way. But YOU MUST be there next year. If you do camping, you have anything to do with PKU and you have that weekend free, get there. It's a mix between a riot, conference, exercise and an outdoor relaxing weekend.

For those who wish to become part of The outdoor crew – the next embracement of nature is in the last weekend of June 2003 – just be there!

SHS recipe

Serves 2

Spaghetti with vegeball & chunky tomato sauce



Ingredients

- 75g (3oz) turnip
- 125g (5oz) carrot
- 50g (2oz) onion
- 65g (2½ oz) swede
- 1 x 15mlsp (1tbsp) cooking oil
- 1.25mlsp (¼ tsp) dried sage
- 2.5mlsp (½ tsp) paprika pepper
- 2.5mlsp (½ tsp) celery salt
- 25g (1oz) Loprofin Low Protein Mix
- 50g (2oz) breadcrumbs from a Low Protein loaf
- Salt to taste
- Oil for shallow frying
- 150g (6oz) Loprofin Spaghetti
- 1 x 15mlsp (1tbsp) cooking oil
- 1 x 5mlsp (1tsp) salt

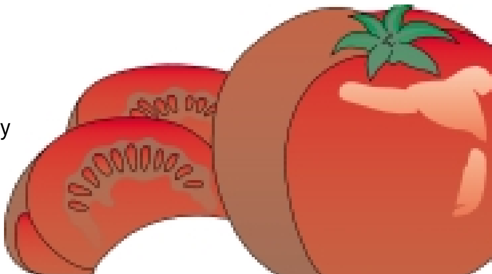
Sauce
- 25g (1oz) onion, chopped
- 40g (1½ oz) mushrooms, sliced
- 1 x 15mlsp (1tbsp) cooking oil
- 400g can chopped tomatoes
- 1.25mlsp (¼ tsp) paprika pepper
- 1.25mlsp (¼ tsp) salt
- 2.5mlsp (½ tsp) sugar
- 1 x 5mlsp (1tsp) Loprofin Low Protein Mix
- 2 x 15mlsp (2tbsp) dry red wine or vegetable stock

Method

- Process or finely chop the turnip, carrot, onion and swede.
- Heat the oil in a large saucepan, add the chopped vegetables, cover and fry over a moderate heat for 5 minutes, stirring occasionally during cooking.
- Transfer the mixture to a bowl and stir in the sage, paprika, celery salt, Loprofin Mix, 25g (1oz) Low Protein breadcrumbs and salt to taste – continue stirring until the mixture binds together.
- Divide the mixture into 12 equal sized portions and shape each into a ball, roll in the remaining breadcrumbs, until evenly coated.
- Heat at least 1cm (½inch) oil in a frying pan and fry the Vegeballs over a moderate heat for 2-3 minutes, turn frequently during cooking until golden brown. Drain on kitchen paper and keep hot.
- Three quarters fill a large saucepan with water, bring to the boil, add the pasta, 1 x 15mlsp (1tbsp) cooking oil and salt to the pan. Return to the boil easing the spaghetti into the pan, when completely immersed in the water stir the pasta. Reduce the heat slightly and cook for 8 minutes, stir occasionally to prevent pasta from sticking together. Keep hot.
- Meanwhile prepare the sauce: Heat the oil in a saucepan, add the onion, cover and fry for 2 minutes, over a moderate heat, add the mushrooms and fry for a further 2 minutes.
- Add the chopped tomatoes, salt, paprika and sugar to the pan, bring to the boil. Reduce the heat cover and simmer for 5 minutes, stir occasionally during cooking. Combine the Loprofin Mix and wine in a small bowl, stir into the sauce, reheat, stirring.
- To serve: divide the spaghetti between 2 warmed plates, pile 6 of the hot vegeballs in the centre of each plate of spaghetti and top with sauce. If desired sprinkle a few fresh chopped herbs over the sauce before serving.

Tip

when frying the vegeballs, keep them moving in the hot oil to prevent any loss of shape and over browning on the side touching the pan base.



SHS

Study day for adults

SHS are pleased to announce the next Study Day for Adults with PKU will be held on:

Saturday 9th November in London.

It will be organised in conjunction with Maggie Lilburn and Dr Philip Lee form the UCLH clinic, as in previous years.

If you attend the clinic you will be sent information on the meeting.
Others who wish to attend the meeting should contact SHS on 0151 228 1992, and ask to speak to Diane Fogg, Meetings Organiser, or Pat Portnoi.

There will be cookery demonstration,
discussion groups, and talks by health professionals and adults with PKU.

Dietitian's Report

Edale Outward Bound May 17th - 19th

report by Eleanor Weetch

I AM going to write just a short report about Edale this year. The weekend was a great success and followed a very similar well- tried pattern of events.

We made a few changes with the food putting on some hot puddings (because it wasn't too hot last year and we needed warming up) and having fresh bread made by Eileen Green. The children all ate well and the fresh air provided a great boost to everyone's appetite.

In place of the disco we played some games organised by Di Asplin who is a Brown Owl and a great source of ideas for keeping children occupied and amused. She's not for rent! One game I particularly remembered was "I went to Edale and forgot…..". Each child in turn had to repeat what the first and last person before them forgot. So it went like this " I went to Edale and I forgot my comb, my shoes, my hat, my scarf etc and the list had to be in the order in which it passed around the room. This is easy if you are number 3 or 4 in line but when you are number 26 …….it's hard! I was impressed!

The children were super and the helpers were a great support. I would like to thank in particular Di Asplin for being a Brown Owl and being so fantastic with children; Emma Crossley from SHS who really felt the cold but never complained; Evelyn Crawford from Vitaflo who kept us all amused; Anna, our doctor who has now got a baby and had him brought up for us all to see; Ann Daly dietitian from Birmingham who broke short her holiday in the Lakes to help and last but not least Lesley Robertson dietitian from Sheffield Children's Hospital who supports me each year and who is never short of something to say! I couldn't do it without them and I couldn't do it without the great children who come along. Same place next year all being well!

Research and Diet

Some of you may have read the article in the Sunday Express on June 2nd. The reproduction of this article has been included here *(see right)* for those who missed it.

However, I think that the newspaper heading is somewhat misleading. I believe, and hope, that most people with PKU would not describe themselves as "ill". PKU is a condition, which can be managed very successfully by diet. It's not easy, but with good treatment and control anyone with PKU can live a relatively normal life apart from eating a low phenylalanine diet.

I have also included information from Professor Muir at Hannah Research, about the work they are doing. (See bottom right).

I will report any further developments as they become available.

Safeway Pharmacies

John McKenzie told me that Safeway pharmacies have set up an account with Fate. Anyone will be able to go into a Safeway store and order Fate products, you just have to remember to pass on Eileen's telephone number: 01215 224433 (order line).

This arrangement is for those companies whose products have to be ordered directly with the company without the use of a wholesaler.

Labelling of Alcoholic Drinks for Aspartame

The Food Standards Agency has given the following advice about the labelling of alcoholic drinks.

- All drinks with an alcohol content above 1.2% do not have to carry an ingredient listing. However, if they contain a sweetener such as aspartame they must contain the words "with sweetener" accompanying the name of the drink. They must also display the phrase "contains a source of phenylalanine".

- If an alcoholic drink contains less than 1.2% alcohol there must be a list of all the ingredients (including aspartame) as well as the labelling "with sweetener" and "contains a source of phenylalanine".

  This is a change in the information given on the alcohol leaflet, which was printed in 2000.

This is good news. So any drink, both alcoholic and alcohol free, would display the 'contains a source of phenylalanine' warning if aspartame is present.

SUNDAY EXPRESS

02/06/2002, By Kevin Lowry

Scientists give ill Carys, 3, a new appetite for life

A LITTLE girl whose diet is constantly modified because she suffers from a rare illness has been given a new lease of life after a revolutionary scientific breakthrough.Carys Hopkins, three, has to avoid certain proteins because she suffers from the rare illness Phenylketonuria (PKU), which prevents her eating normal foods.

The brave youngster is only allowed five grammes of protein a day which have to be measured out precisely by her mother. The rare genetic disorder affects only one in 10,000 babies across the UK and is only treatable by a strict low-protein diet and daily doses of medication. Sufferers are unable to eat normal high-protein foods such as meat, fish, poultry, cheese, bread and milk.

But now the lives of sufferers could be transformed after researchers at the Hannah Research Institute, Ayrshire, developed a new process to enable people to enjoy a more normal diet. They have invented a new compound which will act as a safe protein and could be used to manufacture safe and tasty foods for PKU sufferers.

The company has been given a £125,000 Proof of Concept Award by Scottish Enterprise to help develop the new technology. Carys' mother Margaret, 30, from Blantyre, Lanarkshire, is delighted with the breakthrough. She said: "Carys was diagnosed very early after birth so we had put her onto special milk.

"She has to follow a very strict diet because she could be left brain damaged if she eats a lot of protein-rich foods. It is difficult, but she is very brave. "When we take her to McDonalds she sits there with her friends just eating chips and salad. She just doesn't complain. "She knows that she cannot have certain food and just gets on with life. "Occasionally she will ask 'why me mummy?' but generally she just takes it in her stride. "She will not eat anything that she doesn't know until she has checked it with me or her father first, which is reassuring to know. "This new compound will be of great benefit to a lot of sufferers as it will allow them to have a much wider diet. Any safe substitute for protein will allow Carys to eat a more substantial diet."

The breakthrough was helped by the funding from an agency called the Charis Initiative - a £1million project to help Scotland's food industry develop new products.

A Glimmer of Hope of Sufferers of PKU

People suffering from PKU have a deficiency in an enzyme that breaks down the amino acid phenylalanine. As a result they must avoid consuming protein that contains the offending amino acid or suffer distressing consequences. This poses a problem because protein is an essential element of the human diet. In addition, many common foods use protein to stabilise an emulsion (eg ice cream, cream liqueur or low fat spreads) or to provide structure (eg in cheese). Therefore, the PKU sufferer is denied many elements of normal diet.

Although very few proteins do not include phenylalanine in the primary structure, some peptide fractions are free from phenylalanine. Glycomacropeptide, a peptide derived from kappa-casein (a milk protein) is one example. However, although the peptide is well known and completely characterised, isolation of the peptide from casein hydrolysates has not been carried out on a large scale because of the substrate cost and because of the difficulty in isolating substrate in a concentrated form. Processes developed at The Hanna Research Institute have revolutionised the problems associated with preparing an enriched substrate - substrate can now be produced at a fraction of the cost of previous methodologies. As a result, a path is open to produce batches of material on a 1kg scale. Practical tests will be carried out to establish the efficacy of the discoveries and the success of the end products for nutrition of PKU sufferers. It is anticipated that the evaluation process will be completed within a year.

Parallel work aims to establish method of producing attractive emulsions using non-protein emulsifiers. The key is manufacturing a fat rich product with a creamy rather than greasy mouth feel.

The application of these new discoveries offers the hope of a more palatable diet to sufferers of PKU without exacerbating their condition.

Professor D Donald Muir Bsc PhD FIFST Cbiol FIBiol

Mis-labelling of Drinks

The Food Standards Agency has informed me that 3 alcopops drinks have been mislabelled. The following drinks do contain aspartame but give no indication of this on the label.

The drinks are:

Rum Tribe:
lemon and lime blend with rum – 275ml bottle

Echo Vodka:
lemon and lime blend with vodka – 275ml bottle

Maverick Code Red:
tequila, orange and grenadine – 275ml bottle

The drinks are made by The Drinks Company Ltd and they are taking steps to withdraw the products from the market. These drinks are only available through a limited number of outlets (certain bars and off-licenses).

Packed Meals Booklet

We need to up-date this publication and I would like to know what you put into packed meals. There are lots of new dressings and snacks around so what do you find is always eaten? Ideas for printing in the new booklet would be helpful so please share your packed meal with me!

Ultrapharm Ltd

Aglutella Rice: Ultrapharm have informed me that the manufacturers of Aglutella Rice have ceased production of this product. At the moment the only low protein rice available is First Play Dietary Foods Promin Low Protein Imitation Rice. I am also including information from Professor Muir at Hannah Research, about the work they are doing. I will report any further developments as they become available.

Top 10 Recipes

Which are yours? We would like to produce a collection of favourite recipes but need your help with this. You do not have to write recipes out which are in existing books, just tell me which ones they are, but I will need the recipe for your own home designed dishes.. Let's see what we can put together.

Can the food companies help with this too? Which are the recipes most used by your consumers? What type of recipe is most popular?

Burdall's Gravy Salt

Unfortunately, this product has been discontinued. The company which manufactured it was taken over by another company and production was stopped a year ago.

PKU FORUM

All adult PKU's are welcome to join this new venture at the national Hospital. We are creating a new ideas forum for adult PKU's to access. The service will be run by PKU's for PKU's and have the added bonus of back-up from the hospital.

This will be a chance to get together and share ideas.

If you would like the chance to meet other adult PKU's in an informal environment or plan regular days to get together to create an adult PKU network, then put your names forward to Johnathan Beaumont on: 0781-3438045 or e-mail:

angela.murphy@UCL.ac.uk

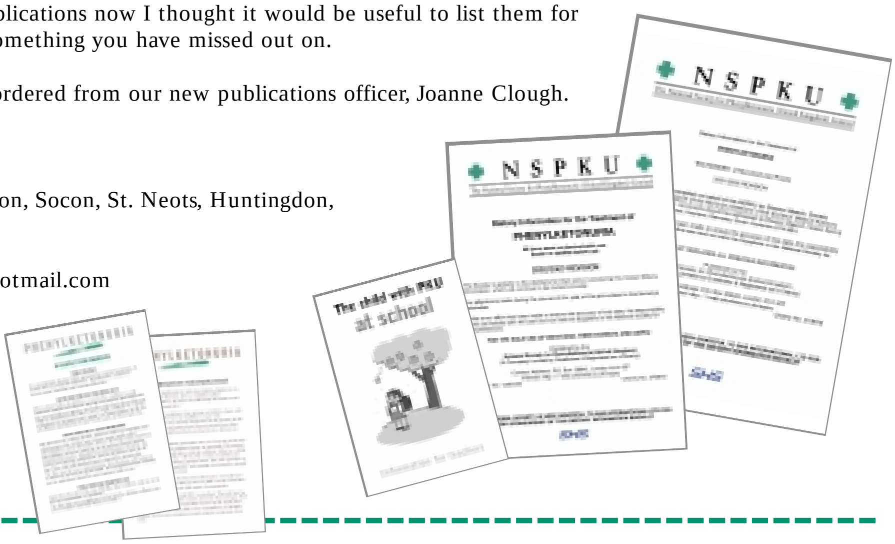
Publications

We have so many publications now I thought it would be useful to list them for you in case there is something you have missed out on.

Any of these can be ordered from our new publications officer, Joanne Clough.

Joanne Clough
(Publications Officer)
15 Raleigh Close, Eaton, Socon, St. Neots, Huntingdon,
Cambs PE19 8NN

joanneclough2001@hotmail.com



Publication	**Price**	**Quantity**
News and Views quarterly magazine	£1.00	
Booklet The Child with PKU	£1.50	
Management of PKU (professional roles to support PKU)	£5.00	
Packed meals Booklet	£1.50	
Green Dietary Information Booklet	£1.50	
Manufactured Food Exchanges	£1.50	
Baby Foods Exchanges	£1.50	
Dietary Treatment of the Previously Untreated PK	£1.50	
'Mummy, why can't I eat your food?'	out of stock	
Travel Hints and Tips	£1.50	
PKU Poster	25p	
Parents	25p	
Teenagers	25p	
Maternal	25p	
Teachers	25p	
GPs	25p	
Employers	25p	
Alcohol and PKU	25p	
Dental Care (for parents)	25p	
Dental care (children's booklet)	25p	
Total Cost		

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Postcode

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Fate Special Foods recipes

RASPBERRY MUFFINS

Hello,

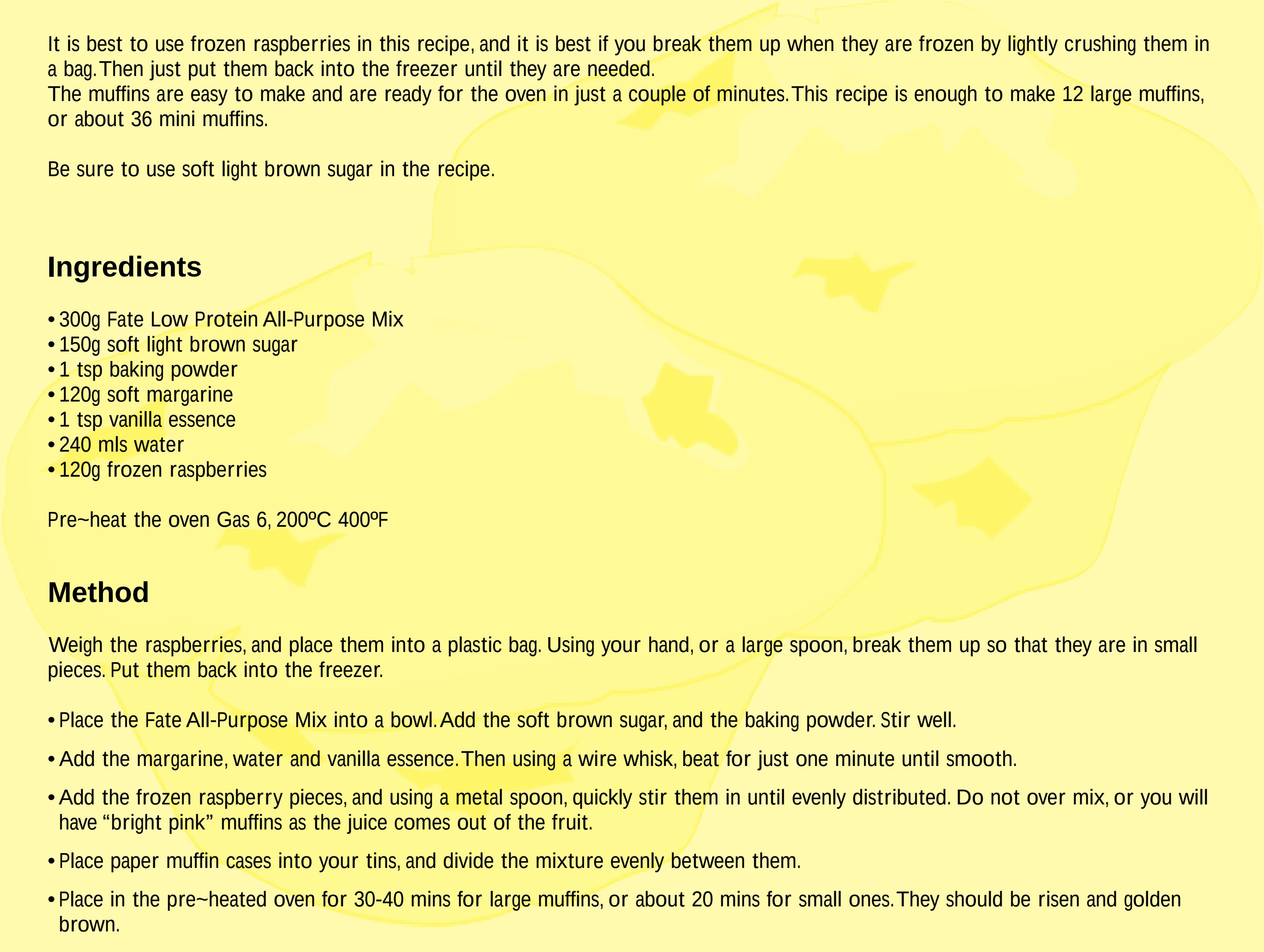
As you know, I thoroughly test all my recipes before I send them out to anyone, and this raspberry muffin recipe was no exception.
When I had finalised the ingredients and method, I tested it again and made a dozen large muffins. When they were cooked, I tried one and it was so lovely, all hot and fluffy, before I knew it, I had eaten three! I just could not resist them.

A short while later, I demonstrated these muffins at Birmingham Children's Hospital PKU conference. I told everyone how pleased I was with the recipe and how good the muffins turn out, then ashamedly I allowed myself to say that I had eaten three of these giant muffins straight from the oven!
A couple of days later, someone left an anonymous message on my answer machine saying - I beat ya Eileen! - you only managed three? I've just eaten four!

I hope you find them as delicious as we did.

It is best to use frozen raspberries in this recipe, and it is best if you break them up when they are frozen by lightly crushing them in a bag. Then just put them back into the freezer until they are needed.
The muffins are easy to make and are ready for the oven in just a couple of minutes. This recipe is enough to make 12 large muffins, or about 36 mini muffins.

Be sure to use soft light brown sugar in the recipe.



Ingredients

- 300g Fate Low Protein All-Purpose Mix
- 150g soft light brown sugar
- 1 tsp baking powder
- 120g soft margarine
- 1 tsp vanilla essence
- 240 mls water
- 120g frozen raspberries

Pre~heat the oven Gas 6, 200ºC 400ºF

Method

Weigh the raspberries, and place them into a plastic bag. Using your hand, or a large spoon, break them up so that they are in small pieces. Put them back into the freezer.

- Place the Fate All-Purpose Mix into a bowl. Add the soft brown sugar, and the baking powder. Stir well.
- Add the margarine, water and vanilla essence. Then using a wire whisk, beat for just one minute until smooth.
- Add the frozen raspberry pieces, and using a metal spoon, quickly stir them in until evenly distributed. Do not over mix, or you will have "bright pink" muffins as the juice comes out of the fruit.
- Place paper muffin cases into your tins, and divide the mixture evenly between them.
- Place in the pre~heated oven for 30-40 mins for large muffins, or about 20 mins for small ones. They should be risen and golden brown.
- Place on a wire rack to cool.
- Store for a couple of days in an airtight container, or place in the freezer.

Eileen Green - Fate Special Foods

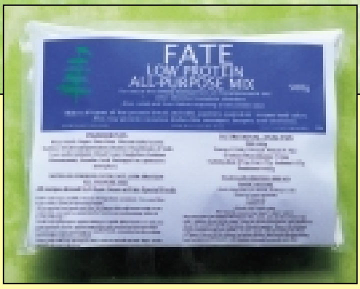
FATE
Special Foods
™

NOW AVAILABLE ON PRESCRIPTION
THE NEW WAY

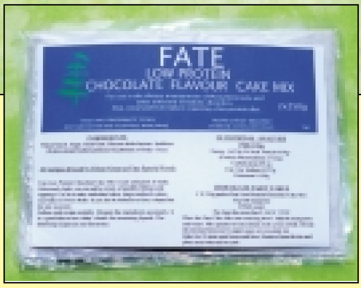
QUICK AND EASY MIXES
BREAD AND PASTRY THAT BROWNS NATURALLY IN THE OVEN
LIGHT SPONGE CAKES ~ INCLUDING CHOCOLATE CAKE ~
MIXED IN ONE MINUTE
OMELETTES AND SAUSAGES THAT LOOK LIKE THE REAL THING
EASY TO ROLL PASTRY

THE VERSATILE PRODUCTS YOU'VE BEEN WAITING FOR:

FATE LOW PROTEIN
CAKE MIX
only 1.6mg phe per 100g



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



FATE LOW PROTEIN
CHOCOLATE FLAVOUR
CAKE MIX
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**

Just ask your Doctor to prescribe these new products
then ask your chemist to telephone our direct order line: 01215 22 44 33

Helpline and General Enquiries Tel: 01215 22 44 34

FATE SPECIAL FOODS ~ SPECIAL FOODS FOR SPECIAL PEOPLE

Support Groups

PKU Toddler Group - Great Ormond Street Hospital

ON SATURDAY 27th April, 22 families attended a toddler Group in medical outpatients at GOSH. The families all had one thing in common, their children having PKU or tyrosinaemia. Tyrosinaemia like PKU is an inherited disorder, which prevents the normal metabolism (breakdown) of food containing protein and is a much rarer condition. However the outlook for these children like those with PKU is very positive.

The treatment for tyrosinaemia is like PKU and involves severely limiting the amount of protein in the child's diet. The balance between the excess and adequacy is measured just like PKU by regular blood tests and the diet may be altered according to the results.

The toddler group was aimed at the families who have children attending the PKU and metabolic clinic at GOSH under 5 years of age. The group gave the families an opportunity to mix and share experiences. Special low protein foods (which were available on prescription) were available to taste and for samples to be taken home. A special packed lunch and picnic food display also gave the families an idea of the sweets available from the supermarket shelf which are relatively low in protein The dietitians had also made some very low protein products which both adults and children alike enjoyed.

The families were keen to meet an older child with PKU. One of our adolescent patients Michael (15) came along with his Mum and answered a number of questions from the families about how he coped with his PKU throughout his childhood. His Mum, Mary, was also able to share her experiences of bringing up Michael and his brother Jack (7). A couple of families also joined the London & Home Counties Support group as a result of the day.

A short teaching session was held for the parents to explain about the genetic aspects of these metabolic disorders and how families can have pre-natal testing if they wish to, prior to planning future pregnancies. Dr Andrew Morris, a consultant in metabolic medicine, answered questions related to a variety of different aspects of the children's care.

Whilst the adults were busy learning about new foods and products the children had a great time playing outside on bikes and climbing frames, watching videos, dressing up and creating magical artwork colouring their own special low-protein packed lunch boxes. And of course tasting lots of great goodies form the dietary displays. They were delighted with the lunch-boxes and drink containers they were able to take home full of goodies suitable for their low protein diets.

The PKU team hopes to continue to hold other events like this as the families all report they find them most beneficial.

Alison Munro –
PKU Clinical Nurse Specialist – GOSH




NEW

they're a bit saucy!

TWO GREAT TASTING SAUCY FLAVOURS FOR YOU TO ENJOY

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

1. Pasta Elbows in a Cheese and Broccoli sauce.
Protein level 1.2g/100g Phenylalanine 30mg/100g
2. Pasta Shells in a Tomato, Pepper & Herb sauce.
Protein level 0.96g/100g Phenylalanine 20mg/100g

Simply mix with water in a saucepan bring to the boil and then simmer for 10 minutes. Promin pasta in sauce is convenient and easy to cook. It provides an instant meal solution for lunchtimes and tea times, you could even serve it for dinner with a side salad.

Pasta in Sauce

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.

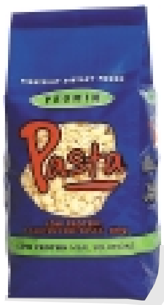
PROMIN

Firstplay Dietary Foods was formed in 1993 to produce Promin Low Protein products from a small factory in Stockport, where we only produce low protein products.

Promin Pasta and Promin Tri-Colour Pasta are now a well established brand and are available on prescription. Our pasta range also includes Imitation Rice, Pasta meal (available by prescription) and Lasagna Sheets (available by mail order). More recently interaction with PKU patients, parents and Dietitians has resulted in the expansion of the Promin range.

New products have been designed to reflect the needs of a maturing PKU population leading busy hectic lifestyles. Call us for more information or with your dietary suggestions.

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



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

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

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

NOW AVAILABLE ON PRESCRIPTION
TOGETHER WITH
LASAGNE SHEETS &
COUS COUS

A Perspective on PKU from Across the Atlantic

THAT DAY began much like any other in the Autumn of 1977. My wife Carol and I were beginning to get into the routine of being “new parents.” Owen was born in Cardiff, on the 30th September that year, whilst I was beginning my last year as a student of theology at University College Cardiff and St. Michael’s Theological College, Llandaff. My early morning routine was chapel, followed by breakfast, and then a lecture. When I got back mid morning the midwife was making a visit and explaining to my wife that she was going to take a test to screen for a rare disease. “Nothing to worry about,” she said, “I’ve done thousands of these and I’ve never had a positive!” I wonder if those words sound familiar to some of you. We never met that nurse again and wonder if she ever found out the result of Owen’s test! We knew something was “up” when two people from the Health department showed up in the early afternoon. They did their best to settle our anxieties explaining, that in some cases, a second test was necessary.

Our anxieties were well founded – by late afternoon Owen had been admitted to the University of Wales Hospital – The Heath Hospital, Cardiff. Over the following days he was diagnosed with classical PKU and placed on his diet. In the years that followed we learned to do what was needed to maintain his phe levels at an acceptable rate. We joined the NSPKU and, up to 1984, attended a number of conferences, read the newsletter and continued to receive treatment at the Heath hospital.

I accepted a position at an Anglican Church in Elkhart, Indiana. (In the U.S. the Anglican Church is called the Episcopal Church) When the possibility of the move to the U.S. became a reality one of the things that had to be considered was Owen, and his medical needs. No national health service meant that we would have to pay for his treatment and food supplements. By chance, during what turned out to be our last visit to the Heath Hospital, we had the opportunity to speak personally with a doctor who was visiting the Heath Hospital from the Riley Children’s Hospital, in Indianapolis, Indiana. He immediately made contact with an individual who was to become Owen’s doctor when the move was made. The chance meeting, leading to the contact with Owen’s “doctor to be,” certainly made the move much easier. Within a few weeks we met with that doctor, at Riley Children’s Hospital, and Owen continued under their care until we moved in the Summer of 2000 to the state of Virginia. I was appointed as the rector of “The Historic Episcopal Church of Little Fork,” in Culpeper County, about 50 miles from Washington D.C. Here, Owen is under the care of the University of Virginia Hospital in Charlottesville, just 50 miles south of our home.Of course, Owen is now 24 years of age, so what’s he been doing? Well, like many PKU patients he has struggled off and on with his diet over the years, occasionally switching from one supplement to another, and even back again. For the past several years he’s been using the Phlexy-10 products, mainly the drink mix, of which he takes six packets a day mixed in with a readily available fruit punch drink. Until very recently most of his medications have been covered under my employer provided medical insurance policy. However, when we moved to Virginia, his Phlexy-10 was not available under my policy so we’ve had to purchase the needed amounts from the supplier in the U.S. Currently Owen, who works with computers, pays $99.00 per box of 30 packets – i.e. five days supply. Scientific Hospital Supplies, the manufacturer of Phlexy-10, have been more than helpful, offering assistance whenever they were able. In fact this very article comes as a result of their concern for Owen’s treatment. Owen graduated with an Associates Degree in General Studies in December of 2001. Soon after he completed his classes he left for Kitale, Kenya, on mission work for the Wycliffe Bible Society. Using his computer skills he had been recruited to set up a “Computer Translation Station,” for the Bible translation team that had been expelled from the Sudan. The team wanted to continue their work in a more stable environment but needed someone to program the network of twenty computers that they used. Owen had a great time there and managed his diet using the Phlexy-10 drink mix supplemented with the bars and capsules. He took the required amount with him, for his time in Kenya, and planned to purchase Phlexy-10 in the U.K. to last him during a three week stay with family on the way back. In his attempt, (through my sister, who lives in Brecon) to purchase the Phlexy-10 we again came into contact with the NSPKU. That contact led to this article and a correspondence, via email with the dietician for the society.

I have read your “News and Views 100th Edition,” – It’s a wonderful publication and beats anything I’ve seen in the U.S. hands down. I also “walked down memory lane” when I viewed previous copies of the News and Views, provided me on disk. Yes, our name was there – especially the years when we won free attendance at the National Conference because we had sold the most raffle tickets!. (Do you still sell tickets?) The society has come a long way and needs to be congratulated for its fine work. Surprisingly, perhaps for some, I believe that Britain is well ahead of what is being done in the U.S. in the ongoing research and treatment of PKU – perhaps it’s a money thing!

For those new to PKU I would encourage you not to permit the disease to take control. PKU patients can do anything the rest of us can (except the protein thing!) – they can move to different parts of the world, and travel to other parts that some of us can only dream about. I guess Owen should have written this article himself but when he sits in front of the computer he is, in a matter of moments, off exploring something or other on the world wide web. My warmest regards to all the members, and officers, of the NSPKU. I’ll be waiting for the 200th edition of “News & Views.”

NSPKU will be hosting the

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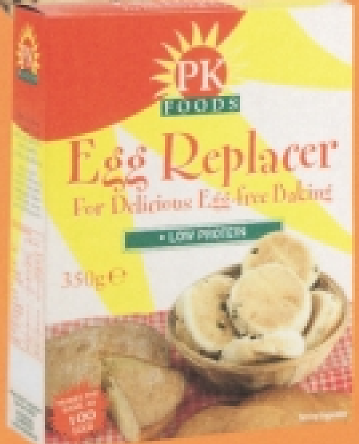

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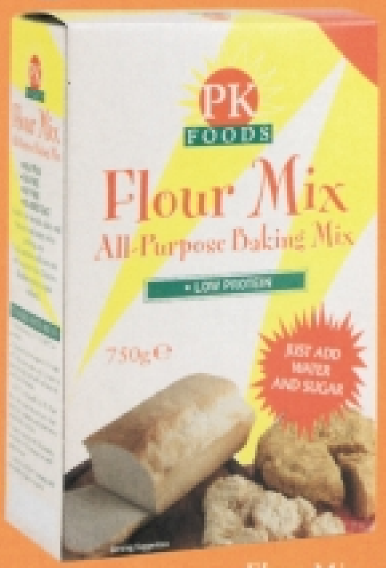

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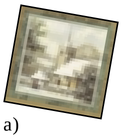
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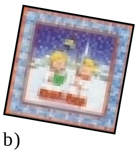
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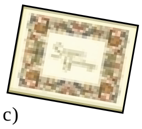
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