NSPKU News&Views
The National Society for Phenylketonuria (UK) Ltd
Issue 112

Inside this issue...

Hellos and Goodbyes in Skipton

Vacancy for NSPKU Conference Organiser!

see inside for details!

In Touch

The Council of Management

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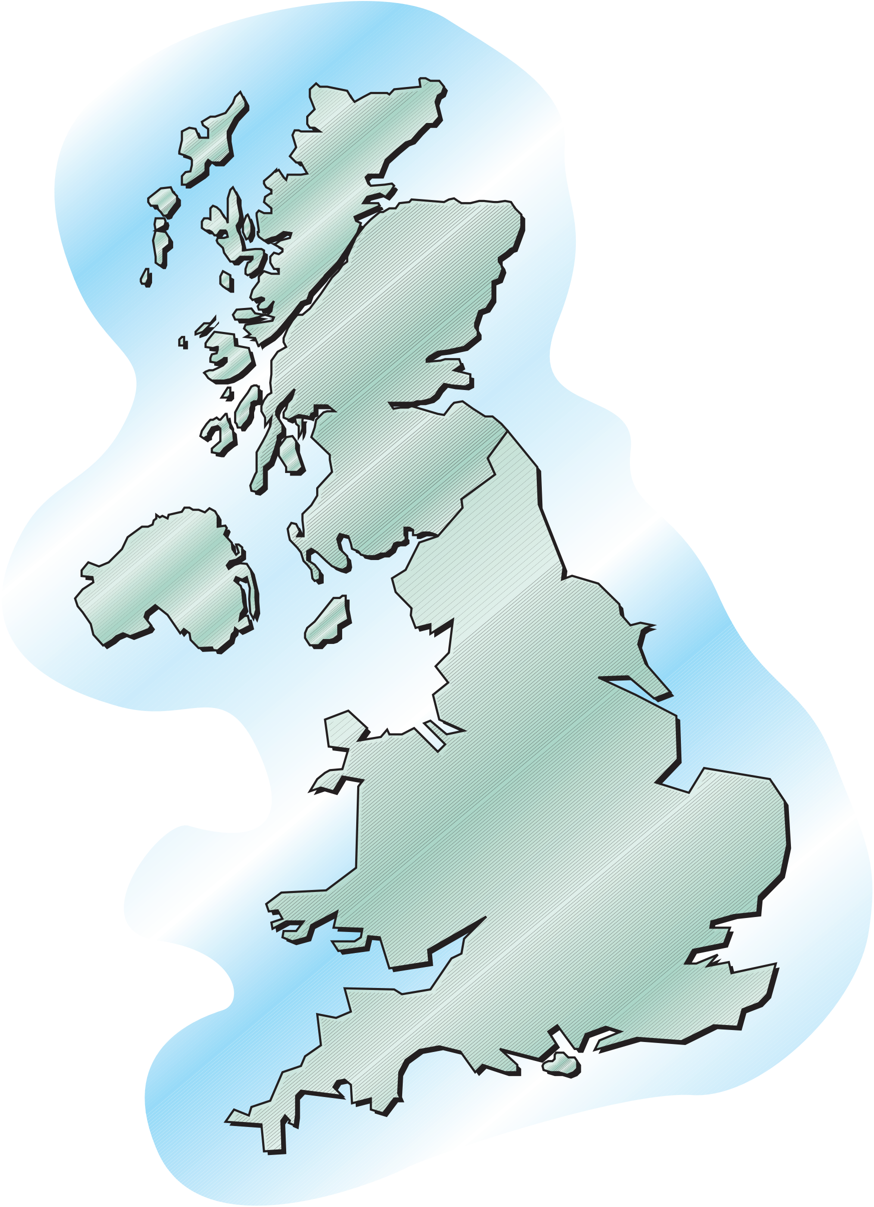

Contents

Editor's Report...

Well, we've got a packed issue for you this time! From Conference gossip to the contentious DLA issue, from the Newborn Screening programme to prescription problems, not to mention a selection of low protein recipes, I think we've covered most PKU related issues!

A paediatrician once told me, in the nicest possible way, that PKU was really rather a dull condition to treat. I'm not in the habit of disagreeing with any of the fabulous team who treat our son but, I, on the contrary, am regularly amazed at how interesting and varied as a subject PKU actually is. I suppose what makes it interesting are the people involved, their stories and the countless variations with which families and friends work around the PKU diet.

I find it wonderful too that so many people give up their time to help the NSPKU and Eleanor's article about the Council of Management explains some of the hard work that goes into the society. We all know that PKU is a treatable condition but that treatment takes a huge commitment on behalf of PKUs and their families. Without your donations, COM's hard work and your letters and articles, many PKU families would be left struggling with an unpalatable diet and feeling very isolated. So for once, let's all pat ourselves on the back and say well done, PKU hasn't beaten us yet!

Kiri Thomas.
Editor

Donations

__Donations to 31/3/05__ **(£30.00 and over)**

WAJ & Mrs EA Graham	100.00
RAF Marham X111Squadron	250.00
Vitaflo via Help with a Greeting	62.40
Mrs A.B. Russell	50.00
Mrs R. MacMahon	100.00
Lesley Thomas	150.00
Rebecca Deakin (Queensgate Primary School)	60.63
Yorkshire Building Society (Liverpool)	150.00
Mr & Mrs Hill	200.00
Sarah Kimpton	32.00
Mrs E Manning	31.50
Sandra Cox	195.00
Sandra McAlenan	56.00
Mr A Roberts	100.00
Miss FA Simpson	700.00
VD & C Ellis	30.00
J & Mrs DV Ridings	50.00
Mr & Mrs Goring	100.00
Anne Appleyard (via Kerry Pyecroft)	275.00
Gift Aided	
Cathy and Iain Darby	100.00
In memory of:	
Jenny Beckett	448.00

NSPKU
The National Society for Phenylketonuria (United Kingdom) Limited

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Treasurer's Report...

I can't believe Easter has already passed. There is one good thing from my point of view about the year progressing so quickly, it means that I have now survived the audit, conference and AGM. I am now entering into my "quiet" time of year (did I really say that… what I should have said is that my work needs to be done now instead of NOW!!)

You will find elsewhere in this issue the income and expenditure details from the financial statement and the thanks to our sponsors and donors.

Having dealt with the past (12 months of it anyway) we can now concentrate on the future. One of the committees aims this year is to evaluate our jobs and to try and make ourselves more efficient so we can concentrate on the development of the Society rather than the day to day grind of keeping it going. This of course will take time and, more importantly to a treasurer, money. I believe "speculating to accumulate" is the term. Having put our toes in the water with the acquisition of an administrator and the outsourcing of membership administration the success of these projects has prompted us to look at other areas of our work. It is thanks to our members and sponsors who have provided us with the financial stability that we are able contemplate these changes which hopefully will benefit us all.

Julia Bailey
Honorary Treasurer

Chairman's Report...

I would like to start this report by thanking Sara Bartlett for chairing the Society for the last 3 years and for her time on the Council of Management (COM) before that as vice chair and treasurer. She will be missed. I have just had a shock by looking back in my records to see when I was chair before. That was for the 7 years before Sara, so when I was asked by the COM to take on the role of Chair again, I could not say that I did not know what I was letting myself in for. We have also lost Pete Bramley from COM who will also be missed. Pete was the secretary and editor of this fine publication and was responsible for its make-over a few years ago and raising the overall quality.

But enough of the past, I am excited about the future of the Society, last November the COM locked ourselves away in a hotel for the weekend and took a long hard look at where we were and where we are going. We used a number of management tools to understand what needed to be done and put together an action plan to improve the way we do things. Since then we have developed these and are looking at the way we structure our meetings and tasks. In July we will have a follow-up session that will look closely at the way we run our conferences. I am also looking forward to working with a number of new members who have volunteered to join the COM and who will be co-opted on for a probationary first year. Already they are getting stuck in with enthusiasm and taking on responsibilities such as PR and the spring draw.

I feel obliged to provide a family photograph but we don't take many of ourselves so please accept my apologies now as the photo is well over a year old and the kids have grown since then. The picture is of Lin and I with Claire (who has PKU) now 15 with Robert now 11 and Jamie now 8.

David Stening

THANK YOU

To ALL our supporters

On behalf of the committee and the membership I would like to express our thanks in the time honoured way to all those who have supported the NSPKU this year.

We have once again been very fortunate with our sponsors. A special mention must be made for the very generous support we received for the ESPKU conference in 2003:

Firstplay	£500
SHS	£4,500
Vitaflo	£1,000
Yes We Cook That.com	£300
Gluten Free Foods	£1,500
Fate Special Foods	£200
Milupa	£145
Hammermuehle	£157

Not forgetting those that provided services rather than cash!
Ainsworth and Parkinson Northern Ltd
Euroscope Television Facilities

SHS international continue to provide sponsorship for a number of projects:

£500	for the Baby exchange booklet
£2,500	for the dietary information booklets
£1000	Edale
£1000	Child with PKU
£1000	ESPKU conference 2004
£1500	AGM/Study day March 2004
£500	Pictoral Guide (continuing costs)

I would also like to express our sincere thanks to our regular donors, both those who contribute via Charities and Foundation or employer schemes and those who raise money on a regular basis. These form the back bone of the donations to the Society and are invaluable in helping us to continue in our work to support those who have PKU and their families. Though un-named they are certainly not forgotten!

THANK-YOU ALL.

DETAILED INCOME AND EXPENDITURE ACCOUNT

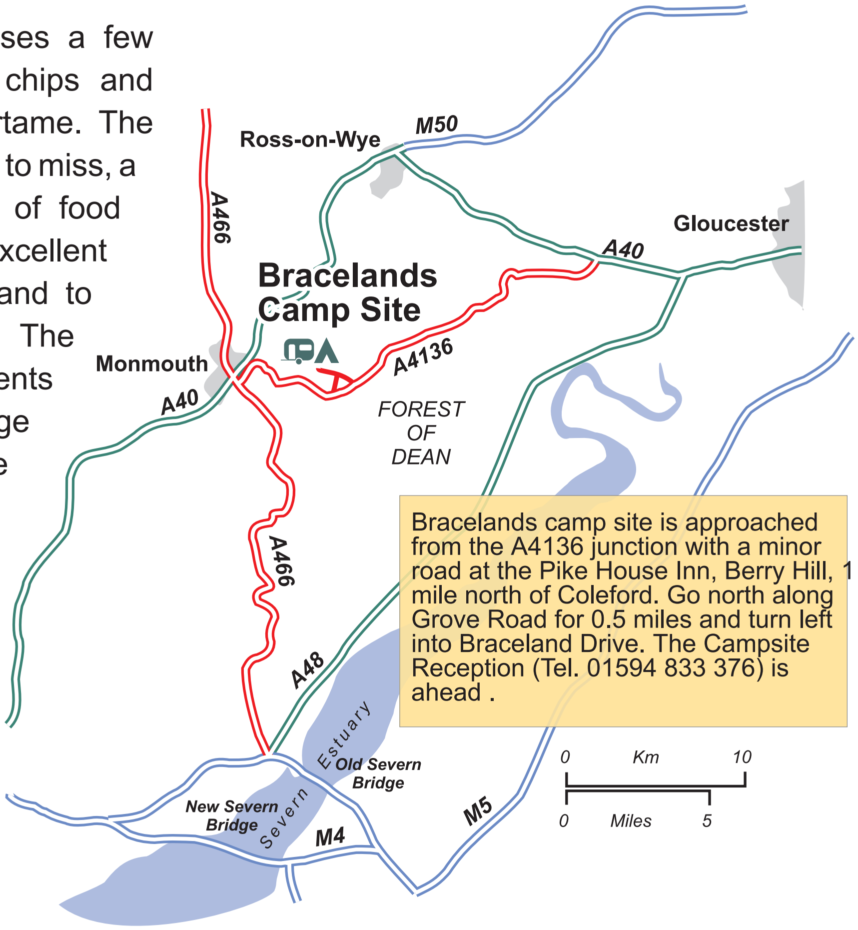
	2004		2003	
	£	£	£	£
INCOME				
Membership fees	12,359		9,777	
Donations and fundraising	26,970		32,666	
Conference Income	8,727		543	
Spring Draw	5,994		6,059	
Bank and other interest received	2,642		2,119	
Publications and videos	4,024		1,864	
Advertising	10,475		8,850	
AGM Meeting	1,362		-	
Sponsorship re publications	6,750		6,377	
Outward Bound course	1,071		1,050	
Other receipts	200		180	
TOTAL INCOME		80,574		69,485
EXPENDITURE				
Conference expenses	12,918		484	
Spring Draw	1,101		1,440	
Goods for fund-raising (net of stock)	1,663		(458)	
Newsletter and publications	7,902		22,012	
Telephone	2,057		1,693	
Postage	2,067		1,758	
Travelling expenses	3,341		8,288	
Insurance	1,711		1,571	
Stationery	800		600	
Equipment and software	1,881		916	
Depreciation	439		439	
E Weetch fees	13,005		13,732	
L Welch fees	4,080		2,948	
Sundries	275		327	
Committee meeting expenses	4,521		588	
MAP meeting expenses	1,567		121	
AGM Meeting	4,102		-	
Sponsorship	30		-	
Bank and finance charges	29		59	
Outward Bound course	1,642		2,479	
Audit	1,349		1,131	
Legal and professional	-		50	
Research costs	1,791		1,627	
Grants	297		595	
TOTAL EXPENDITURE		68,568		62,400
(DEFICIT)/SURPLUS OF INCOME		12,006		7,085

PKU Camping Weekend
24th June - 26th June 2005
Forest of Dean, Gloucestershire

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

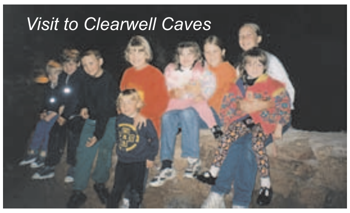
The first brave campers start to arrive early Friday evening, before too long they are sitting around gassing over mugs of hot tea or tins of cold beer. Saturday morning sees more arrivals including the “softies” who stay at local B&Bs.

Lunch at a local pub on Saturday raises a few eyebrows when families start weighing chips and checking the pop doesn’t contain aspartame. The Saturday evening entertainment is too good to miss, a mix of smoke, warm beer and all sorts of food cooking on the barbie. This event is an excellent opportunity to meet other PKU families and to experience coping with PKU ‘on tour’. The weekend is not exclusively for people with tents and caravans. Day visitors make up a large number of the party either just driving for the day or staying in a local B&B. The Forest of Dean is only a short drive from the M5 and M4 motorways, so make a date in your diary and come along for the weekend or just visit for the day. Remember the last weekend in June (25th to 27th June 2004).



Bracelands camp site is approached from the A4136 junction with a minor road at the Pike House Inn, Berry Hill, 1 mile north of Coleford. Go north along Grove Road for 0.5 miles and turn left into Braceland Drive. The Campsite Reception (Tel. 01594 833 376) is ahead .

Bracelands Campsite



Visit to Clearwell Caves

Please check at reception on arrival for exact location of PKU group.
Probable locations are the area of field J adjacent to field A for those requiring electric hookups and the area of field A adjacent to field J for others. Electric hook up pitches need to be booked in advance.

For more information contact :
Ifona or Alun Rogers on 029 20890065
email: rogersap@cardiff.ac.uk

National Society for Phenylketonuria

SUPPORT GROUP INFORMATION GUIDE

A support group information guide is now available that contains helpful hints and tips for support groups. The purpose of the information guide is to provide assistance to new and existing NSPKU Support Groups. It contains helpful tips on how to set up a support group with many suggestions on the role and activities that a group can play. The guidance is flexible to allow groups to evolve to meet the needs of those participating within an overall framework.

Support groups play a vital role in the “PKU family” with individuals and families coming together to support each other in many ways, as everyone gets on with their daily lives.

This guide provides a whole host of ideas however, it is important to remember that in some circumstances a support group can be an informal affair, involving the occasional get together. For example you may want to make contact with a child of a similar age to yours and your dietitian may be able to help here. You may meet up for a coffee and initial chat and develop ongoing contact. This may develop with one or two more people coming together informally to have an afternoon together. These friendships will probably develop and be of real benefit to the children and families. Christmas parties may be organised or a trip to the bowling alley or similar. The network may stay informal or may grow into a more structured support group. The most important thing to remember is to do what is right for you.

The NSPKU hopes this new guide will be helpful to existing and new families who want to establish a local support group. Further helpful information and contact details for support groups can be found on the inside front cover of News and Views or from NSPKU website www.nspku.org
Please take the ideas from this guide that will best work for you and the PKU families around you, whether it be a formal or informal group.

John Skidmore
NSPKU Support Group Co-ordinator

LONDON & HOME COUNTIES SUPPORT GROUP

CALENDAR OF EVENTS - 2005

7 May	Bowling at RAF Henlow, Bedfordshire - private hire and sole use for PKU , 1pm – 3pm, lunch provided
25 May	Golf Day at Stapleford Abbotts - sponsor a hole or play a round, fund raising event
27-30 May	Camping at Grafham Water, Cambs, open to all types of campers, caravans and travelodge guests welcome! Or come for a day. - arranged by Jo Savage of the East Anglia Support Group (Tel 01480 395024)
10 July	Annual Summer Picnic/BBQ with outside swimming pool - St Joseph's school, Hertford
September (tbc)	Soft Play – venue to be agreed
10 December	PKU Christmas Party, Harlow, Essex

If you are interested in coming along to any of the above events or wish to join our mailing list to receive further details of current and future events, please contact our Secretary, Mrs Sue Sims, 6 Cherry Trees, Lower Stondon, Henlow, Beds SG16 6DT, Tel 01462 813809, e-mail derricksims@breathe.com

If you would like to help us organise an event in your area, we are particularly looking for people to help who live in Middlesex and Kent, please also contact Sue Simms (contact details as above).

Letters

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

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

Dear News and Views,

Please find enclosed a cheque to the value of £275.00. It is with great pleasure that I am able to send this donation, kindly raised by my Mum, Anne Appleyard who recently celebrated her 60th birthday. She generously asked family and friends who attended her party to donate to the NSPKU in lieu of presents.

My daughter Hannah, now 8 years old continues to benefit from all the good work and research funded by the NSPKU and she remains happy and healthy whilst coping with PKU on a daily basis.

I would especially like to thank my Mum, Hannah's much loved Nan and enclose a photograph of them both.

Yours,
Kerry Pycroft.

Hannah Pycroft and Anne Appeyard celebrate Anne's 60th birthday

Dear News and Views,

We have sent you a photo of us doing the raffle which raised £60.63 for the NSPKU. Hope you like it!

Yours,
Millie Southern, Rebecca Deakin and Emma Hardy.

Millie Southern, Rebecca Deakin and Emma Hardy raffle for the NSPKU!

2005 SKIPTON CONFERENCE - REPORT

The weekend of 25th – 27th of February, saw The Hanover Hotel, Hinckley a bit quieter than normal, at least as far as guests with PKU were concerned. For the first time in a while the NSPKU conference moved from the Midlands, and headed north to the Market Town of Skipton, in Yorkshire. Originally, when we booked the hotel it was a part of the same group, Hanover Hotels, but in the last quarter of 2004 was taken over by a company called Rendezvous, the type of situation that could spell disaster!

The run up to the conference did not lend itself to any great indication that any prospect of disaster was pure pessimism. After the change of owner there was the prospect of an inevitable change of staff, but at the end of November this didn't look likely to be such a problem. Another aspect of the new ownership was alterations to the hotel, but in retrospect, while these were evident they caused no inconvenience, but on the contrary provided some nice benefits to the hotel.

Moving away from the hotel just now, normally we will regularly mention the hard work that Eleanor, our society dietician, does in the run up to the conference, and although we are all appreciative of that work, I not will go on about that. What I shall do is go on to talk about the "nightmare scenario" which eventually occurred. In the run up to the conference Eleanor has a lot of contact with the Head Chef at the hotel we are going to. The problem occurred when the head chef left with weeks to go to the conference. So the scene is now set, new ownership at the hotel, new head chef at the hotel (who had completed a crash course in PKU cooking), and weather more befitting Siberia than Skipton. The Towering Inferno, Airport '77, Volcano, Earthquake, surely these disaster movies don't have a look in…..

The Rendezvous Hotel, Skipton, is located on the outskirts of the market town of Skipton. It is not a modern building, and being situated right beside the canal that runs through Skipton, at one point must have a bonding house or such-like. From early on Friday afternoon families arrived having completed journeys that would make Ranulph Finnes cringe. Due to the inclement weather this was a trickle rather than a deluge. When the time the came for the civic reception, some nails were being bitten as we held the Lady Mayor in reception for as long as seemed as though we weren't holding her back in a panic. Things did start to fall in place. The Lady Mayor and her deputy welcomed us all to Skipton and officially declared the conference open. No turning back; now it was on to dinner.

On conclusion of the meal Eric Lange, as is traditional, announced the winners of the Spring Draw, drawn by the Lady Mayor. Many thanks go to Eric and his daughter, Rosanna, for the draw which raised over £5,000 for the NSPKU. We would also like to thank the Lady Mayor and her deputy for their participation.

Friday evening entertainment consisted of the traditional Conference Disco and after long arduous journey people were happy to get some rest in preparation for the coming events.

Something new that was added for this conference was a trip for the teenagers and young adults with PKU. A group of about 15 spent the day paintballing. Having listened to what was said at the last day conference we held, and in collaboration with them, it was something we were more than happy to arrange on their behalf. From what we hear a great time was had by all, so now all we have to do is find something to equal this for next conference. Kids were treated to two trips. On Saturday they were escorted to Eureka, a science museum, and on Sunday it was time for the now traditional Bowling. They were awarded certificates courtesy of the NSPKU on the Sunday afternoon. Many thanks to those who helped on the trips, without you these could not take place.


A thank you form our vice-chair , new chair Dave Stenning to our retiring chair Sara Bartlett

The talks, as always, provide the framework and foundation of the conference. In our experience, people come to conference for a myriad of reasons, but these reasons tend to fall into two categories, and both of these are based on the desire to learn. Firstly there is the direct learning, listening to the talks, and direct questioning. Secondly, and arguably more importantly (with no disrespect to the fabulous lectures given), indirect learning. This is the desire to mingle with other individuals, whether they are people who support or care for someone with PKU (either professionally or not), and also people with PKU. I personally believe that is for these reasons that our conferences are such a success and those who attend would, I hope, agree.

Speakers' abstracts can be seen in News & Views, and also on our website. As usual the quality of material was very high. Our thanks not only go out our speakers, but also to our suppliers who operated trade stands, in particular


A thank you from Chair to our retiring Secretary/ News & Views Editor

Continued on page... 10

Continued from page... 9

Firstplay Dietary Foods, SHS International, Vitaflo, and Yes, We Cook That.

Now for that Gwyneth Paltrow moment. You probably noticed that the impending disaster never occurred. The reason for this is the hard work done by everyone behind the scenes, and before I start I apologise now for anyone I miss out. Firstly, and most importantly, it is due to the tireless work of Eleanor that this was a success. You have only read of some of the adversity she has coped with in the run up to the conference. Secondly, the staff at the hotel were wonderful, they were willing to bend over backwards for us. By lunchtime on Saturday the staff in the Dining Room were all wearing NSPKU T-shirts. Thanks also go to our retiring conference organiser Mike Bailey, who has possibly missed his vocation in life as clock maker, as he made this conference run like clock work. Finally, thanks must also go to everyone that attended the conference, because it would not have been the success it was without you.

SEE YOU ALL NEXT YEAR!!!

John McKenzie

"Excellent my young apprentice"....
Well his name is Luke!!!"

CONFERENCE 2006:

STOP PRESS! ***STOP PRESS!*** ***STOP PRESS!***

FIRST ANNOUNCEMENT OF 33RD NSPKU ANNUAL FAMILY CONFERENCE WEEKEND - 2006:

Guess what - the hotel venue and dates for our annual family conference weekend have now been confirmed.

Hotel Venue:	Hinckley Island Hotel, Hinckley, Leicestershire.
Dates:	(Friday) 3rd to (Sunday) 5th March 2006.
Web Address:	www.paramount-hotels.co.uk (for full details of the hotel venue only)
Conference Details:	Full conference details/booking form/costs and programme of events will appear in either News & Views edition 113 or 114 released later on this year. Watch This Space!.

MAKE SURE YOU BLOCK OUT THESE DATES IN YOUR DIARY NOW. WE LOOK FORWARD TO SEEING YOU ALL AGAIN THERE!!!.

Best Wishes

Your NSPKU Council Of Management

NEW

NOW AVAILABLE ON PRESCRIPTION

Start your day with a Hot Breakfast

THREE GREAT TASTING HOT BREAKFASTS FOR YOU TO ENJOY

Promin Low Protein Breakfast Is a brand new fast food product available in three tasty flavours.

1. Original flavour. Protein level 0.21g/100g Phenylalanine 5.03mg/100g
2. Chocolate flavour. Protein level 0.37g/100g Phenylalanine 6.53mg/100g
3. Apple & Cinnamon flavour. Protein level 0.25g/100g Phenylalanine 2.18mg/100g.

Simply mix with hot water. Promin Hot Breakfast is convenient and easy to make. Its an instant hot breakfast, you could even enjoy a bowl for your supper.

Promin Hot Breakfast is a great 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 available by prescription also includes Imitation Rice, Pasta meal and Lasagna Sheets they are also available by mail order. More recently interaction with PKU patients, parents and Dietitians has resulted in the expansion of the Promin range. New products have been designed to reflect the needs of a maturing PKU population leading busy hectic lifestyles.

Call us for more information or with your dietary suggestions.

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

Always consult your dietitian before trying something new.

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

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

DLA - A Good idea?

This issue, we're taking another look at the Disability Living Allowance (DLA). This is a state benefit paid to anyone with special needs. It is not means-tested but must be applied for and is not automatically granted to anyone. The process of application is quite arduous and often needs to be supported with letters from Paediatricians and G.P.s. Many PKU families have been refused the allowance only to be granted it when they appealed.

This can be quite a contentious topic and there are lots of differing opinions. The NSPKU takes a neutral stance on the DLA. Why?

Dave Stenning, Chair of the NSPKU, explains that to some parents, getting DLA equates with labelling your child disabled. They feel that this label could be used at some time in the future as an excuse to discriminate against their child and this idea is very worrying to them. Pat Kimpton, whose daughter Sarah has PKU, looked into applying for an older version of the DLA some years ago. She and her husband felt most uncomfortable with the form which asked questions they believed irrelevant to the way PKU affected their family life. One of the questions they were asked for example, was if they had to "attend to their child in the night". They decided against applying and do not regret this decision. Pat thinks obtaining the DLA "sends the wrong message" as she and her husband have always been very positive about their daughter's condition and do not consider her disabled.

Of course, there are those who disagree with this position and one of those is Alun Oliver. Alun's seven year old daughter has PKU and Alun feels strongly that if the government allocates money for those with a particular need, then those eligible should apply. He is also bewildered by the idea that by applying for the DLA he is labelling his child disabled: "Only parents can create such labels through their own views or widely discussing their "private" family issues". Pete Bramley, our ex-editor here at News and Views, is in agreement: "it is the care component of the diet (the amount of care that your child requires over and above that of a "normal" child) that sets the amount of care way above in excess that is normally required. DLA was, and is, set up to award those people, parents and carers an additional allowance for that extra care." He agrees with Alun that the government has set money aside precisely for families coping with conditions such as PKU and adds: "In basic terms, when I take out a car insurance policy and I have an accident, I've paid the premium. I expect to receive compensation. With NI contributions I expect support from the Government when I have an issue with a claim for extra support for a child with a condition that requires a greater degree of care (care component and PKU)."

So we can see that there are some very differing and heartfelt opinions on the DLA. Because the NSPKU represents all families dealing with PKU, it was felt that a neutral stance should be taken. In other words, the NSPKU doesn't promote applications for DLA but neither does it advise against submitting a claim. Actually, the NSPKU publishes an example application on the internet which can very useful. The address is:
http://www.nspku.org/Documents/DLA%20GUIDE.pdf
If you have anymore thoughts about the DLA or any questions, please do not hesitate to contact us here at News and Views. Remember, the NSPKU is here to reflect your views and ideas. To do that, we have to know what they are!

Kiri Thomas

Prescription Problems?

One of the main complaints I receive from the parents and adults who come to our clinic in Glasgow is about problems regarding their prescriptions.

It would seem that if you can get what you want, when you need it and in the quantity you require, then some of the concerns surrounding managing the diet for PKU would be helped enormously. In addition, it seems that the attitude of the professionals involved can result in reluctance on the part of the family to try out different foods.

There are several reasons why these problems could arise. They include:

- Ignorance about the diet by the G.P, G.P's receptionist, your pharmacist or the person who serves in the pharmacy
- Poor stock levels at the pharmacist's wholesaler
- A variety of sources of low protein products, often not stocked by the wholesaler
- The computerised list of foods requested in the past by you at the G.P's surgery not being kept up to date.

These problems only seem to accentuate the stress caused in managing the diet. On one hand you have your dietitian and doctor at the clinic encouraging you to increase the variety and quantity of the low protein products and on the other hand you cannot receive the products when you want them.

There are several ways you can try and improve on this problem. The main way is by communication:

What can help?

- Find out what is actually on your prescription. It may need updating. It may be you have asked for new items to be added and they haven't or it may be that items have not been taken off when you do not require them any longer, or the quantities on the list are not correct. Tidy the list up!
- When you go through the list, try and work out the amounts you require for a month and update the list for these amounts.
- When you take the list back to your G.P, ask to speak to the practice manager and go through the prescriptions with them. Often this will save time when you next put in a request. The practice manager will have access to the computerised prescriptions and is able to update the list for you.
- If you need to make an appointment with your G.P, ask about the procedure the practice has about repeat prescriptions and the addition of new products.
- You should talk about the need to have fairly large quantities of different products to last for about a month at a time and a variety of types. Not many people go to the supermarket and stick to one type of pasta, why should you!
- Discuss if the practice has any limitations with amounts you can order, and discuss what the reasons they have for this.
- You should also show the G.P. the list of low protein foods, or Pictorial Guide, this will show them the variety of products available to you.
- Ask your dietitian to write to the surgery about the need for a variety of foods and the quantities you will require to back up your request.
- Download the leaflet for pharmacists from the NSPKU website. This will give them more information about the diet and also contact numbers if there are problems.
- Always check your prescription when you get it, preferably before you leave the chemist's shop. If errors have been made, it is easier to rectify at the time, rather than having to make a special journey. Check use by dates as well, as occasionally the chemist is supplied with short shelf life products. Occasionally gluten free products are sent by mistake, the pharmacist or shop assistant may not be aware of the difference.

If your problems continue, it may be worth discussing with your pharmacist if you can put in a copy of the request to them at the same time as the request goes into the G.P. The pharmacist can then check what you are ordering against the prescription when it is issued and rectify any errors. They can also get a head start on the order.

The low protein foods and protein substitutes are expensive, so if you do get errors in the prescriptions, they should be rectified as soon as possible in order that a good relationship with the pharmacist and G.P. is maintained.

Newborn Blood Spot Screening

As you can already see this article is a bit on the long side but I hope you find it worthwhile reading as it contains information on treatment for future PKU's that may also have implications for the treatment you, or someone in your family are currently receiving. Reading it may provide an opportunity for you to review your own situation and get some idea of how to change it if you find your needs are not currently being met. Alternatively, and I hope this will be the case, you may recognise and appreciate the high quality of care that your own doctors, dietitians and nurses are providing.

UK Newborn Screening Programme Centre
Over the last two years members of the COM and parents with PKU children including Wendy Cheale, Caroline Bridges and Sue Davies, whom we would like to thank for their participation, have been involved in the work of the UK Newborn Screening Programme Centre (UKNSPC and hereafter referred to as the Centre). The Centre was established in 2002 with the overall objective of assuring high quality neonatal screening services. Funded by the Department of Health and partly with money previously allocated to the National PKU Register, the Centre is a collaboration between Great Ormond Street Hospital, the Institute of Child Health and the Institute of Education.

For many reasons the NSPKU has been keen to be involved in this project, not least because we know the experience of parents, who have gone through neonatal testing and the first few days and weeks after receiving a positive diagnosis for their baby, can be best placed to help identify the needs of other families at these times, and also possible improvements in the service offered to future parents. We have also been working towards the re-establishment of the PKU Register. When it became clear that government funding would not be given to this in the future we saw that a better option was to work with the Centre on the setting up of a Newborn Register on which would be recorded details of other conditions as well as phenylketonuria.

For over 30 years, since 1969, successful screening has been carried out nationally for PKU, and since 1981 for Congenital Hypothyroidism as well. In addition, other conditions have been screened for in different parts of Britain and for some time it has been recognised that neonatal testing should be expanded nationally. At the same time the Department of Health acknowledges that the public require assurances that the screening programme is performing successfully and to this end that it needs to be evaluated as well as expanded.

Policies and standards for newborn bloodspot screening
The Centre has worked to develop clear policies to guide those working in neonatal screening and has set out a framework for its performance management. Their remit has not been to instruct clinicians, biochemists or other healthcare professionals but rather to develop standards that should be followed nationally and then to monitor them. Two levels of standards have been identified, Core Standards which demonstrate how to get the basics right and Developmental Standards which build on the basics and identify best practice.

So, a little about the consultation that was undertaken before these standards were developed. All of us taking part in the various meetings were supported and welcomed enthusiastically by the Centre's team. More importantly perhaps, we were encouraged to contribute to the discussions and believed that our opinions were valued. A complete review of the 'screening journey' took place and draft policies and standards were piloted and sent out for consultation – some of you will have been asked directly by me for your comments, some by the Centre and some have become involved as a result of a request posted on our web-site. I would like to thank everyone who took the time to put their experiences and comments forward.

Following this extensive consultation process the Core Standard Recommendations were set out in a new document, the details of which follow.

- 95% of first samples to be taken 5-8 days after birth (DOB is day 0) but ideally will be taken on day 5
- 100% of samples to be received by laboratory within 4 working days of sample being taken screening test result or record of parents refusal to have test done to be recorded for 100% of babies at 8 days
- 95% of blood spot cards to include babies' NHS numbers to aid identification and tracking
- 100% of untested babies to be identified by 19 days
- 100% of positive results for PKU and CHT to have clinical referral initiated within 4 working days of laboratory receiving sample for testing

The Developmental Standards enhance and enlarge these basic recommendations. In addition guidance has been laid out for obtaining consent and taking samples, and a code of practice has been written for the retention and storage of residual blood spot samples.

Initial Clinical Referral Standards for phenylketonuria
This section of the guidelines are of great importance to us. They look at giving parents the opportunity of access to care at specialist centres even if they wish their child to be cared for primarily at a local hospital. They also set out recommendations for initial treatment.

- When two samples are found to be over 240 umol/L laboratory staff will refer the baby to a Specialist Team. This team should consist of a Consultant Paediatrician with relevant experience, currently managing at least 20 cases, a dietitian with specialist training in PKU, and a nurse.
- The specialist team should then contact the GP to co-ordinate local support and also inform the midwife.
- The specialist team should then contact the family and inform them of the positive screening result. If this is by telephone then a face to face meeting should take place within 24 hours, perhaps at the family home.
- The specialist team will ensure that the local team have up-to-date information on the management of PKU if they are to be involved in providing joint care along with the specialist team.

The NSPKU recognises that the majority of children with PKU in the UK receive a very high quality of care from their health care professionals. We do however receive requests for help from some who do not, and we are aware that problems can sometimes be experienced by those receiving care at some of the hospitals centres who do not treat many PKU's. The recommendation of shared care could provide the opportunity for those who find it difficult to travel a long distance to still have contact with a specialist centre. Telemedicine, a form of video conferencing is something that may be available in the NHS in the near future to help some with this specific problem.

Remember, shared care is a recommendation only, but the fact that it has been made by a respected body, following wide consultation may help you to seek this type of treatment if you or members of your family might benefit.

Future work
Work by the Centre will now be progressed to include looking at the information to be kept on a new newborn screening register, work that the NSPKU obviously remains keen to be involved with.

The need for improved information supplied to parents before testing and following a positive screening result has been highlighted. Information supplied at the moment can be inaccurate, out of date and alarmist. Initially a leaflet is to be produced that will be distributed nationally to all women in the 3rd trimester of pregnancy with details of the conditions being tested for, the test itself and the importance to every newborn baby in being tested. Contact details of the NSPKU will not be included at this stage. However, details will appear in information that is to be supplied following receipt of a positive Guthrie result. We will prepare for the increase in the number of enquiries that we anticipate will be generated by this and look forward with enthusiasm to the opportunity we will have of being able to help more parents at this critical time. It also means that we will be afforded the opportunity of reaching more potential members and anticipate offering free short-term membership for all those parents who make contact with the society at this time.

To improve the knowledge and support provided by doctors, midwives, maternity care assistants, neonatal nurses and health visitors, a Health Professionals' Handbook will be produced and be easily accessible to all those involved in the screening process. The format of this information has not yet been decided upon and could be written material, a CD Rom or be available via the internet. It will provide up-to-date information on the screening process and standards of treatment for all conditions tested, to enable professionals to be prepared and informed when they care for children and support parents. Hopefully no longer will be uttered such immortal words as 'Don't worry about this test, I have never seen a positive result in…….years of practice' or 'PKU is a condition that he/she will grow out of' etc. etc. On a very positive note, each one of our professionals should in the future be enabled to relay relevant, pertinent and helpful information at the time when we most desperately need their wisdom and reassurance.

In conclusion the NSPKU recognises the importance of the work being undertaken by the Centre in identifying standards of care that should be given to families during the testing process, and the potential for providing efficient effective treatment immediately after the detection a positive result. We look forward to continuing to work with them for the benefit of current and future members. On a final note it is worth highlighting that conclusions to date have been reached by looking at current good practice. We recognise that on the whole we are fortunate to have such dedicated, knowledgeable and caring teams of professionals looking after us, with our best interests at heart and those of our offspring.

Sara Bartlett
Tel: 01476 590194
All comments welcome!

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>
> Eileen Green

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The Council of Management - What Is It?

I have been asked to write an article about the Council of Management which on first reading might seem a bit of a dry subject , actually it isn't, but I will still keep the information brief!

First of all we all refer to ourselves as members of COM, much less of a mouthful than Council of Management. Every member of this group is a volunteer, who works without payment, except myself (the dietitian) and Lucy Welch, our administrator. All the volunteers and Lucy too, have a child with PKU or have PKU themselves. They are all committed to improving the lives of anyone with PKU. I am not the exception to this, it's just that I don't have PKU nor do I have a child with the condition but I have worked for the Society for 16 years so it's nearly the same! The PKU community is like one big family to me.

There are around 14 of us. I say 'around' because if someone shows a special interest and mid conference asks about helping or getting involved in some way we ask them to be a co-opted member. They then come to meetings to find out how we work and this then enables them to decide if they would like to get involved more deeply. Often they do and we have found it helps new members to decide on their commitment.

This brings me to that word 'commitment' because all the members give a considerable amount of their time to helping run the Society. Each year there are 5 meetings held in Hinckley on a Sunday and 2 at the conference as well as a weekend meeting to develop our plans for the future and assess what we are doing in the present. The COM runs the Society. We organise; the conference, help at study days, produce written information with the help of our medical advisors, run the web site, provide support in many ways to anyone involved with PKU in whatever capacity, raise money, extract money, invest the money wisely and publicise our work whenever possible. I'm sure I've forgotten lots that we do but I can assure you we are not idle! I must give a special mention to our medical advisors who give precious time to helping us. These are all experts in the treatment of PKU so we know that the advice we give is sound. We meet with them twice a year but our contact is much more than that as they are always there to advise all through the year.

All of those on the COM have a job to do. There's the treasurer, the conference organiser, the publications officer and so on. Everyone has to report on their activity at each meeting. You may wonder with all this work what do the committee members get back? The answer is 'a lot'. Being involved brings its rewards in the form of friendship, knowledge and a real sense of helping to put something back and make a difference. All of this is immeasurable and actually quite difficult to convey to you on paper.

I hope that this has given you some understanding of what COM is and that even you may consider joining us at some time or offering to help when we need it. You would be made very welcome I can assure you of that!

Eleanor Weetch
Society Dietician

COM hard at work!

Fate Special Foods recipes

FATE SPANISH OMELETTE

Hello
As the original Fate Omelette recipe has proved to be very popular, I thought it would be good idea to do a variation. Spanish omelette is traditionally made using just onions and potatoes for the filling, but here, I've made it using a variety of vegetables and sweet potatoes to save on exchanges. This adds to the flavour, and colour of the finished dish. ~ Any combination of vegetables can be used as long as they are allowed in your diet, just keep to the approximate quantities used here. The omelette is freely allowed. It is delicious served hot. Any left over can be eaten cold. It is surprisingly good served in a sandwich with HP sauce!

Ingredients

For the vegetable filling:
1 tbsp oil
knob butter
80g sweet potatoes cut into 1 cms pieces
75g onion, finely chopped
75g red or green peppers, roughly chopped
75g mushrooms, roughly chopped
75g French beans, fresh or frozen, cut or snapped into 3 cms pieces
1 medium sized tomato, roughly chopped
1 tbsp chopped fresh herbs such as parsley or chives, or 1tsp dried herbs
generous salt and pepper to season

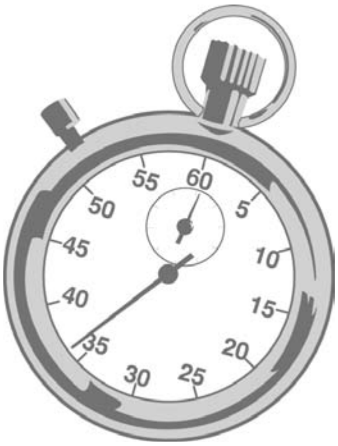
For the Omelette:
75g Fate All-Purpose mix
1 tsp baking powder
salt and pepper to season
a little yellow colouring (optional)
30 mls oil
100 ms water
A little extra oil for cooking.

Method

First, prepare the filling: Heat a frying pan over a medium heat, and add the oil. When it is hot, add the butter, then straight away add the chopped sweet potatoes and onions. Stir and cook for a couple of minutes. Add the peppers, mushrooms, and French beans, and cook gently for about 5 mins until the vegetables are just cooked but not soft. Season generously with salt and pepper. Stir in the chopped tomato and the herbs and leave to cook for a further minute only. Place the mixture onto a plate to cool.
Prepare the Omelette mixture:
In a separate bowl, place the Fate All-Purpose Mix, baking powder, salt and pepper. Mix well.
Measure the oil and water and add just a few drops of colouring to give it a light yellow colour.
Pour the water and oil onto the dry ingredients and using an electric hand mixer, mix on high speed for about 1½ minutes. It should then be a smooth and light mixture which looks like a light and creamy mayonnaise.
Using a spoon, gently stir in the vegetable filling. (It doesn't have to be completely cold)
Heat your frying pan until quite hot, then add a little oil. Add the omelette mixture to the pan and quickly spread it over the base of the pan. If you are using a pan that is more than 8 ins (20cms) in diameter, do not spread it to the very edge, as this will make the omelette too thin. Just use a spoon to make the edges neat. Leave to cook over a gentle heat for about 2 -3 mins until the underside is browned and the top of the omelette looks dry.
Turn the omelette over using a wide spatula, or, you might find it easier to tip the omelette right over onto a large plate so that the cooked side is on the top. Then, gently slide the omelette (uncooked side down) into the pan. Leave to cook for another minute or so. Serve hot or cold.

Best wishes, Eileen Green ~ Fate Special Foods

PKU Pronto!



This issue, I thought we'd look at a quick and nutritious snack popular with young kids and older people alike. This one is adaptable depending on appetites and tastes and is another meal idea that can be tweaked to suit PKUs and non-PKUs. In our house, we call it **"Little Dippers"**! I'll describe how we do it first of all and then suggest some variations.

1. Take a selection of free vegetables e.g. peppers, carrots, cucumbers. Slice them into sticks.
2. Take some low-protein toast cut into soldiers, or some cooked low-protein pasta or perhaps some low-protein crackers.
3. Put a couple of tablespoonfuls of ketchup or free mayonnaise into a small ramekin or teacup.
4. Place the ramekin or teacup in the middle of a plate. Arrange the sliced vegetables and toast, pasta or crackers in a circle around ramekin. Now dip away!

Variations

- If you want to get some exchanges in, you could weigh out some Cheezly cheese, and cut that into batons for dipping too. Check the NSPKU booklets carefully as each of the Cheezly range differs in its weight per exchange. See also our Dietitian's Advice on page 21 regarding Cheezly Cheese.
- Other dips you could use are a free salsa or branston pickle both of which could be combined with a free mayonnaise to make a creamier dip. In fact the NSPKU booklet lists numerous free dressings, sauces and mayonnaises which could be used as dips.
- As for "dippers", again check the list of free vegetables – mushrooms and cherry tomatoes are another hit with our boys.
- **Pudding Idea.** As a treat and as a way to encourage more fruit eating, you could also try this dessert variation. Use apple, orange and mango segments as the dippers and use a "free" sauce such as English Provender Raspberry Coulis or Askey's Maple Syrup. You could also try grapes, pears and many other free fruits here. Check the booklet for other free dips and dippers.
- **NON-PKU** idea. Our non-PKU son uses "normal" bread or toast for dipping and I often give him hoummous for his dip instead of ketchup or mayonnaise. He also dips pieces of cold meat in there too. Needless to say, "normal" bread, hoummous and meat are NOT ALLOWED on the PKU diet!

NSPKU MERCHANDISE

HOT OFF THE PRESS! *HOT OFF THE PRESS!*

Help! Help!!. Help!!!. Calling all adults, teenagers, children, food manufacturers and medical professionals (and anyone else I might have forgotten. Ooooppps - sorry). I really want your help please............

I have just taken on the role of NSPKU Merchandise Officer and my brief is to look hard at the type of merchandise that the NSPKU put out for you, our membership. Over the years, we have tried to tempt and tantalise you with a range of different items of merchandise (some with success and some not). I would like to try and change that over the coming months.

Before I really get going on this whole evaluation process, I would value your own views as part of the exercise. What I need to know from you is what types of merchandise you feel that the NSPKU should offer and why. I would like our merchandise to have a much wider appeal to all age groups and would love to be in a position to offer you a good range of merchandise that we can sell!. Not only will it benefit each and everyone of us, but more importantly, raise money for the NSPKU. Should we be branding our merchandise with the NSPKU logo or not?. Are there certain merchandise items that we must have?. Is colour important?. These are just a few pointers to get you started. Remember, whatever your own thoughts might be let's talk about them.....

I cannot do this all on my own (oh you poor mite I hear you all say.....).
No seriously though, please drop me an email or write to me with your ideas at the following address:

Mike Bailey - NSPKU Merchandise Officer
Grove Fold House, Claughton-on-Brock
Garstang, PRESTON, Lancashire
PR3 0PU

Home Tel No: (01995) 641119
Email: conference@nspku.org

Dietitian's Report

SPLENDA

This new artificial sweetener, made by Tate and Lyle, is made from sugar and is phenylalanine free. It is available as tablets for drinks and also mixed with sugar for a reduced calorie granulated sweetener. It contains one third less calories than sugar. The granulated version is called Light Cane and can be found with ordinary sugar in the supermarket.

Light cane can be used in cooking and baking as well as on cereals and fruit and in drinks.

DIET COKE

The next bit of good news is that Coca-Cola is planning to use Splenda in a new version of Diet Coke. It will be called Diet Coke Sweetened with Splenda and this will be launched in June.

Tate and Lyle have seen profits rise significantly since it bought Splenda from McNeil Nutritionals. It would seem that the potential for this sweetener is huge and this can only be good news for those with PKU.

CHEEZLY

Those of you who came to our fabulous conference at Skipton this year will have picked up a free sample of one of the dairy free cheeses known as Cheezly and made by the Redwood Company. There are 10 different versions of the cheese including some melting ones which really do melt. I tried it on my toast! The cheese has to be counted as an exchange but this is a really useful product. It can be used in sandwiches, melted on veggie burgers (there are 2 versions which are slices), melted into a sauce, grated on to vegetables, low protein pizzas, baked jacket potatoes and so on. The exchange values are as follows:

Red Cheddar Style Cheeezly	25g
White Cheddar Style	25g
Cheddar Style with Cranberries	30g
Nacho Style	30g
Garlic and Herb Style	25g
Melting Edam Style	20g
Melting Gouda Style	20g
Melting Mozzarella Style	20g
Melting Mozzarella Style slices	20g
Melting Cheddar Style slices	20g

The Cheezly is available from health food shops but the company also do a mail order service and have introduced a special rate of 20% off for the NSPKU. Anyone wanting an order form can get one from me. Just leave your details on my answer phone and I will send one to you. PLEASE speak slowly and clearly. Sometimes it is really difficult to make out messages if you speak very quickly, this may be my age but when I ask one of my daughters to listen they too can find it hard!

ANOTHER GREAT FIND!

I am very grateful to Dr Barbara Broadbent who rang me to tell me about some vegetable stock cubes which she had found.
Marigold Organic Swiss Vegetable Bouillon Cubes
These stock cubes can be classed as free. The protein content is 0.2g per cube and a cube makes up to 500mls. This is a really useful product for making soups and gravies for extra flavour. It can be found in Sainsbury's. Look out for it in stock cube section or the organic section of the supermarket.

My great researcher Barbara Cochrane told me about Asda Wobbly Jelly. This comes in several flavours and is a ready made individual jelly which is protein free. Useful for the picnic box or travelling.

ASDA

Lakeland
This company which is well known for its cooking utensils and storage also sells some rather special foods. Sara, our past chairman, told me about some crème sweets which they sell. The sweets are called Charbonnel et Walker Crèmes Parisiennes and they come in lemon, vanilla, strawberry and tangerine flavours. They do not contain phenylalanine. Sara gets them at Christmas time for her daughter. They are quite expensive but delicious.

Rice Dream
There is a new version of Rice Dream available which has added soya. The packaging looks the same as the freely allowed version but it says 'with added soya' in tiny writing in the corner of the carton. Be careful to avoid this one as it is higher in protein than the normal version.

Amoy Straight to Wok Noodles
Some of you have telephoned me about the Amoy noodles. There are three types of noodles; fine, medium and rice.

It is the Rice noodles which are the most useful as the other two have a higher protein content. The Rice noodles contain 1.6g protein per 100gms so 65gms is one exchange. I can't find them here in Sheffield but the company tell me they are available in selected Sainsbury's, Somerfield, Waitrose and Kwiksave Stores.

HOLIDAYS AND THE PKU DIET

It is always a big help if the place you visit or stay can help with low protein foods. Karen McKittrick from SHS International kindly sent me some information about Disney World USA which she obtained from a professional at a regional metabolic centre. Apparently Disney World USA stock low protein foods. If you call the restaurant in advance they will prepare specific low protein foods. If you don't call in advance all the restaurants will have at least some pasta and flour. Now I'm sure there are masses of eating outlets at Disney World but it might be useful to know about this service in advance and through your travel company find out where to go and what to do. I would like to research this one for you but sadly……………….!!!

ANNUAL CONFERENCE SKIPTON 2005

This conference was a great success and the food this year was wonderful. Many people asked me about the recipes so I thought I would say again that they came from SHS The Low Protein Collection (available free of charge), the new red recipe folder from the West Midlands Support Group called simply Low Protein Recipes and PK Foods Recipe booklet.

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

Low Protein Recipe Folder costs £10. Cheques should be made payable to BCH Charity Fund 333 050 and send directly to:

Dietetic Department
Birmingham Children's Hospital,
Steelhouse Lane,
Birmingham
B4 6NH

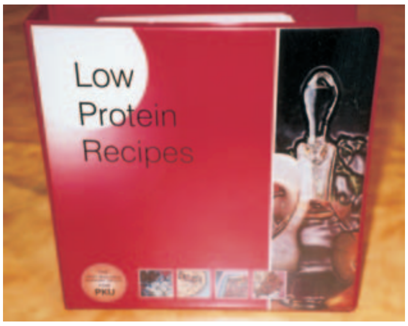
Gluten Free Foods
PK Foods Range
Unit 270
Centennial Avenue,
Elstree,
Borehamwood
Herts
WD6 3SS

Don't forget to let them know your address!

One of the really nice things about coming to the conference is that often children who have been very fussy about what they will and will not eat change completely! When they see other children with PKU eating different foods they have a go themselves. This can help children along the road to a more varied diet which is a huge help to the cook of the family and even whole families can be converted in this way. We have often tried new foods in our house and because of this have discovered a passion for a new vegetable or fruit. Our current favourites all round are sweet potatoes roasted in a little olive oil until a little bit charred and fresh mango.

Did any of you watch Jamie's School Dinners? I would like to think that all of us could score top marks in the vegetable and fruit recognition game!

Eleanor Weetch



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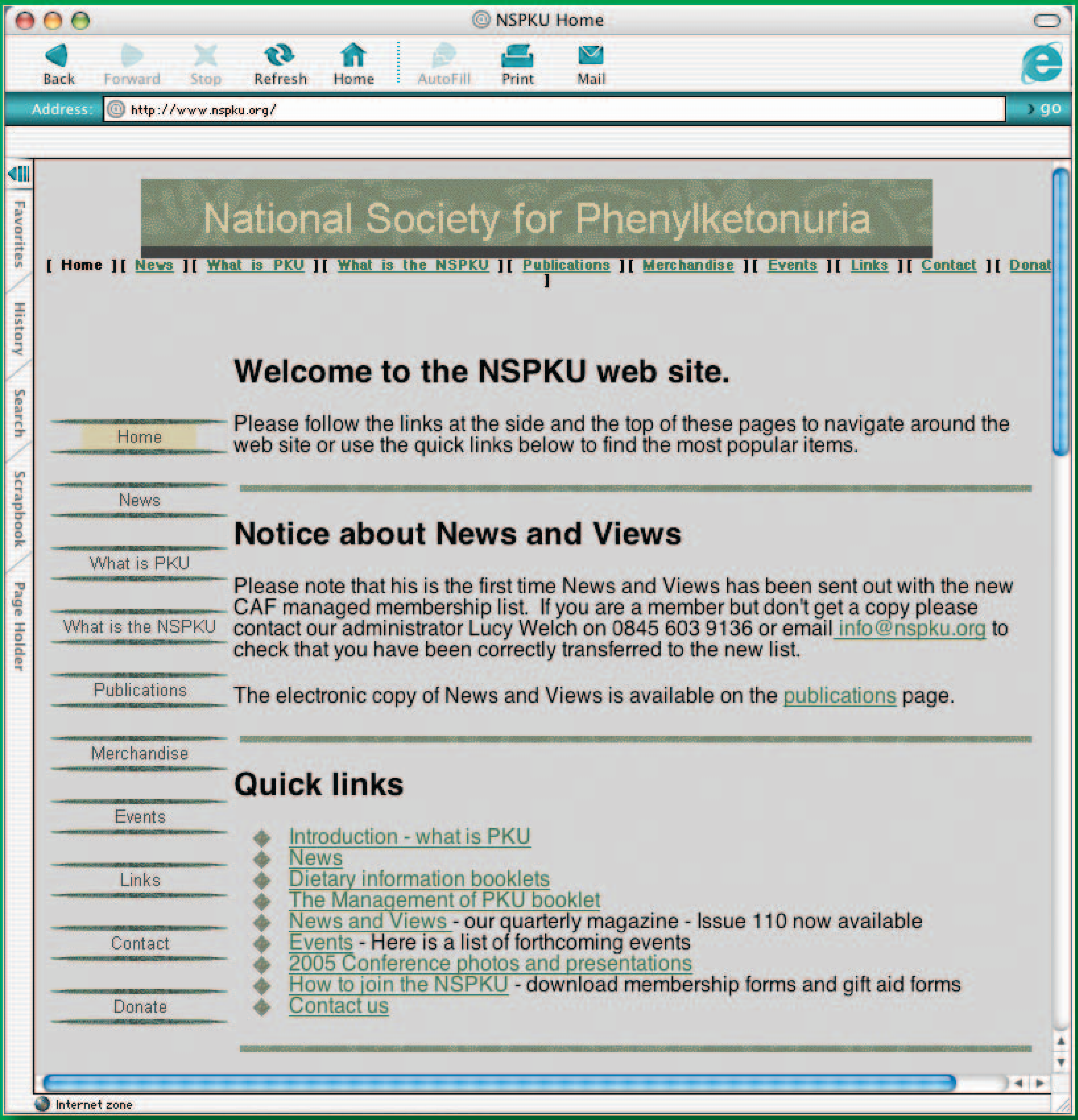

Welcome to the NSPKU web site.

Please follow the links at the side and the top of these pages to navigate around the web site or use the quick links below to find the most popular items.

Notice about News and Views

Please note that his is the first time News and Views has been sent out with the new CAF managed membership list. If you are a member but don't get a copy please contact our administrator Lucy Welch on 0845 603 9136 or email info@nspku.org to check that you have been correctly transferred to the new list.

The electronic copy of News and Views is available on the publications page.

Quick links

- Introduction - what is PKU
- News
- Dietary information booklets
- The Management of PKU booklet
- News and Views - our quarterly magazine - Issue 110 now available
- Events - Here is a list of forthcoming events
- 2005 Conference photos and presentations
- How to join the NSPKU - download membership forms and gift aid forms
- Contact us

www.nspku.org

Tuscan Stlye Pasta Stew

This dish is a great way to use up cooked pasta; alternatively the pasta can be freshly cooked, for 8 minutes, before combining with the remaining ingredients at stage 3.

Ingredients

- 50g (2oz) carrot, thinly sliced
- 65g (2 ½ oz) onion, chopped
- 100g (4oz) celery, thinly sliced
- 125g (5oz) fennel, thinly sliced
- 2 medium cloves garlic, crushed
- 500ml (18floz) home-made vegetable stock
- 400g can chopped tomatoes
- 75g (3oz) **Loprofin** Low Protein Penne Pasta
- 2 x 5mlsp (2tsp) dried parsley
- 1 x 5mlsp (1tsp) dried oregano
- 1.25mlsp (½ tsp) salt
- 2.5mlsp (½ tsp) paprika pepper

Method

❶ Place the prepared vegetables, garlic, stock and tomatoes in a medium sized saucepan. Bring to the boil, reduce the heat, cover and simmer for 10 minutes.

❷ Stir the **Loprofin** Penne Pasta, herbs and seasonings, into the pan, bring to the boil. Reduce the heat cover and simmer for a further 10 minutes, stirring occasionally during cooking.

❸ Serve at once with Low Protein Bread Rolls.

Serves 2

Tip: If you have the time to chop fresh parsley, use 4 x 5mlsp (4tsp) in place of the 2 x 5mlsp (2tsp) dried, as this will improve the flavour of the dish.

Krispie Pasta

Ingredients

- 150g (6oz) **Loprofin** Pasta Twists
- Oil for deep-frying
- Salt to season

Method

❶ Three-quarters fill a large saucepan with salted water, bring to the boil.

❷ Add the **Loprofin** Pasta Twists; return to the boil, stirring. Cook for 8 minutes.

❸ Drain the pasta and rinse well with cold water. Thoroughly drain and, if possible leave for a few minutes to dry.

❹ Heat the oil in a deep pan, gradually add a **small handful** of pasta to the oil and fry for a few minutes (the pasta should sizzle then rise to the surface, if it takes longer than a few seconds, the oil is not hot enough).

❺ Cook the pasta for about 4 minutes or until it stops sizzling, when it is “quiet” the pasta is cooked. Remove from the oil with a slotted spoon and place on kitchen paper to absorb any excess oil.

❻ Whilst still hot sprinkle with salt to taste, then leave to cool.

❼ Repeat cooking process with remaining pasta.

❽ When cold, store the pasta in an airtight bag.

NB: Ensure the pasta is drained thoroughly before frying, as excess water will react badly with the hot oil causing it to ‘spit’.

Spicy Krispie Pasta

Follow the basic method for Krispie Pasta, but add 1 x 5mlsp (1tsp) Rogan Josh curry powder and 2.5mlsp (tsp) turmeric powder to every ½ litre (1pt) water used to cook the pasta.

NEW

Fasta Pasta

Flavours Now Available
Curry and Tomato & Basil

at lasta...

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