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The Council of Management

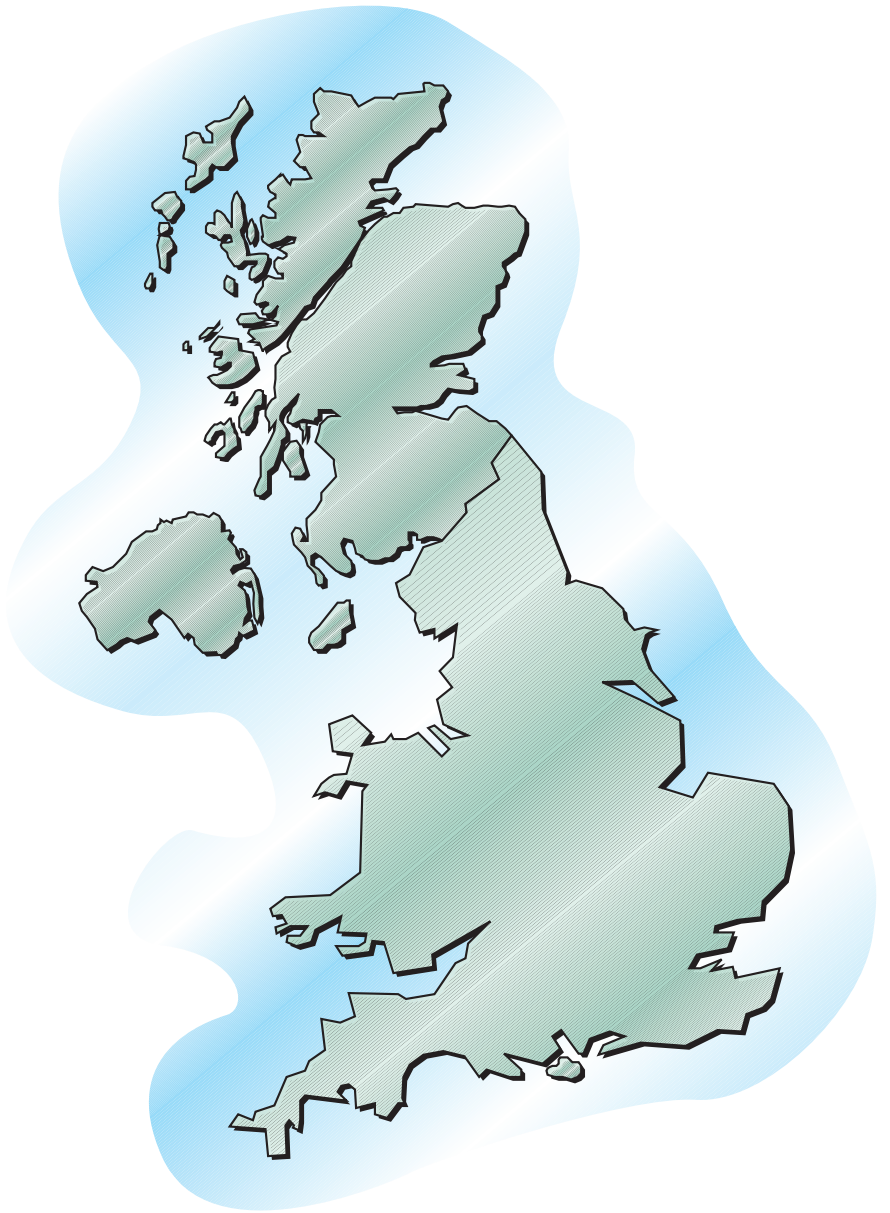
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Stand-in Editor's Report...

I have the happy news to convey that Kiri has had a baby boy. His name is Fintan and he weighed 8lbs 2ozs. Both mother and baby are well and I have spoken and heard them both. Fintan does not have PKU. His two little brothers are thrilled with him and I'm sure they will all provide Martin and Kiri with endless fun.

This issue contains reports for more fun and learning for all ages. Great Ormond Street Hospital held a day for adolescents on travelling and Barnsley features again on a cooking day they held in May. Birmingham held a darling of an Oscar's ceremony and Glasgow are cooking international PKU dishes. What a lot of activity and there's more to come. If you are able to go to a day 'just for you' it will be really worthwhile. A lot of work and commitment from your dietitian and the food manufacturers is worth supporting and really helpful friendships can be made both for children and adults with PKU and families and extended families.

There is information about the next conference at The Hilton in Northamptonshire too. It's a beautiful hotel, easy to find and we would love to see you there. The theme is going to be on the psychological side of managing the condition as well as all the other usual things we do such as cooking, what's new and chatting to others.

Eleanor Weetch



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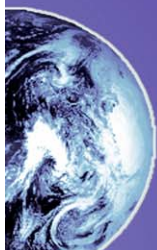
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Donations

Vicki King, Tarkwa, 65 Cromwell Road, Ribbleton, Preston, PR2 6YD

Donations over £30 to 30th June 2007

	£
Anne JJ Register	106.33
Belton Bingo Club	700.00
Pete Bramley	80.00
Mr & Mrs D & J Walker (via Vicky Ellis)	50.00
Matt Taylor - Bath 1/2 Marathon	233.00
Lynn Foy (in memory of John Foy)	305.00
Chris Cooksey (in memory of Karl Neidermeier)	1,692.50
Andover Golf Club	2,578.33
Dave Williams - London Marathon (final sum raised £761)	210.00
Georgia Jackson and Emma Martins	65.00
Mullarch Ltd	300.00
In memory of Trevor Rawson	125.00
Helen Monnelly - Fundraising Night	417.00
Easter Fayre organised by Catholic Mother's Union of St Peters Church, Westgate, parishioner donations and Thanet Police Theatre Group via Mr & Mrs Burne	540.00

THANKS TO OUR SPONSORS AND DONORS

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

- SHS who this year have provided a total of £16,000 which has been used for the Conference 2005 - specifically the children's and teens trips, PKU subsidies and assisted place and crèche costs and also for the ESPKU meeting in Spain, MAP meeting expenses and the cost of Amino Acid analysis.
- Vitaflo for £6,000 towards the cost of publications throughout the year

We have been especially fortunate in the support we have received from our members and their friends and families this year by way of donations and fundraising activities. We would like to express our thanks for the extra effort made by everyone who has supported the NSPKU throughout the year, especially to our own Eric Lange who ran the London Marathon, the Darby family who have raised £2.5k, the Skidmores and Neil Wilton who raised £1.5k each, Gorrins Triathlon team for their £5k and Geof Sydenham and colleagues for an amazing £10.5k. Not forgetting those who provide us with regular donations by direct debit or workplace schemes.

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



Where do I send my money?

Confused? Then read on.....

Vicki King
(contact details
are inside the front cover)
Donations
Invoice Payments
Miscellaneous payments

Lucy Welch
NSPKU, PO Box 26642,
London N14 4ZF
Publications payments
Subscription payments

Mike Bailey
(contact details
are inside the front cover)
Merchandise payments

Please make all cheques payable to: NSPKU – no cash

Income and Expenditure Report

	2006		2005	
INCOME	£	£	£	£
Membership fees	8,987		9,841	
Donations and fundraising	41,631		25,500	
Conference Income	677		2,489	
Spring Draw	5,842		4,352	
Bank and other interest received	3,308		3,651	
Publications and videos	5,719		3,818	
Advertising	14,400		13,817	
ESPKU 05 (04) Income	1,000		1,000	
Sponsorship	25,465		4,000	
Outward Bound course	770		3,165	
Other receipts	-		-	
TOTAL INCOME		107,799		71,633
EXPENDITURE				
Conference expenses	12,787		10,256	
Spring Draw	809		1,151	
Goods for fund-raising (net of stock)	5,703		3,412	
Newsletter and publications	24,684		27,968	
Telephone	1,286		1,302	
Postage	1,626		1,354	
Travelling expenses	1,894		2,936	
Insurance	1,739		1,916	
Stationery	835		860	
Equipment and software	488		1,433	
Depreciation	758		758	
E Weetch fees	14,632		14,859	
L Welch fees	4,252		4,686	
Sundries	155		106	
Committee meeting expenses	5,973		6,853	
MAP meeting expenses	897		1,444	
Advertising	175		-	
ESPKU expenses	2,167		4,071	
Sponsorship	2,112		100	
Bank and finance charges	53		99	
Outward Bound course	3,123		4,710	
Audit	1,410		1,410	
Membership Fees and Subscriptions	394		668	
Research costs	623		465	
Bookkeeping	971		-	
TOTAL EXPENDITURE		89,546		92,817
(DEFICIT)/SURPLUS OF INCOME		18,253		(21,184)



Letters

News & Views, 10 Silverdale Road, Chorlton M21 0SH
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,

I just wanted to comment on your editorial in the latest edition of *News and Views*. We went through the same thing with Jack about "being sick of being the only one with PKU" and it is very hard, I know. I just wanted to tell you how wonderful the outward bound weekend has been for building Jack's self-confidence and for making him feel less isolated. He's 11 now and has been lucky enough to go to Edale twice. You don't say how old Seamus is: perhaps he's too young to go yet? The first time Jack went, he was very worried that he would be the only one on so few exchanges, but he found a soul-mate in a similar situation, and this time he didn't mention that aspect at all.

I think you are right to try to introduce Seamus to other children on the same diet. When Jack was younger, the Christmas party at the Willink Genetics Unit (Manchester Children's Hospital) was a huge help in letting him know that he wasn't alone.

I strongly agree that PKU doesn't have to be anyone's defining characteristic, and we've worked hard as a family to minimise its impact and put the whole thing into perspective. Jack has always found great comfort in observing that his Grandpa also has to take some unpalatable powder solution twice a day (for cholesterol levels) so it was a bit of a boon in the early days that they drank their Maxamaid and Questran together in the evening, followed by a few grapes. As you say, we are all different, yet the same, and children have to learn that.

I am crossing my fingers for you and hope the mayhem in your household has subsided. Keep up the good work with *News and Views*, whatever you do!

With best wishes,
Barbara Broadbent



Dear News and Views,

My name is Paul Greenhalgh. I am ten years old and I'm in year five at school.

I'm writing to let other children know that being PKU should not stop you from having fun and going away with your friends. I have been away on three cub camps, and a school activity week without my family and I didn't have any trouble with my food. When I am going away, we get a copy of the menu so that we can decide what I can eat and what I need to take with me. For cub camp, I have taken my sausages and burgers and a small frying pan so that I can have a fried breakfast and a BBQ just like

everyone else. I always take my bread, puddings such as cakes, fruit flan, and free food in case I get hungry.

The first time I went away with the cubs, it was a bit scary as I had never done anything like it before. Some of my non PKU friends were also worried about going away, but they just had to eat whatever they were given. I could choose what I wanted to take!! I took my menu with me, which said what I was having for exchanges and how much to weigh. However, by the end of the weekend I was too tired to eat so I didn't quite follow it totally, but I did my best and enjoyed my self.

The next time I went with cubs, I still took my menu and I did a lot better because I didn't get so tired, and I had done it before. I also took some extra exchange foods so that if I didn't want what I had planned I could change my mind. This worked very well.

The longest I have been away is for a week when the school took us to an activity centre called Kingswood. We did quad biking, abseiling, orienteering, archery, wall climbing, laser quest etc. The Catering Manager and staff were brilliant because they have done lots of special diets before. They sent us the menu, we did our usual deciding what I could have and packed up a big cool box of food labelled e.g. Monday tea, defrost and fry, Tuesday lunch defrost and reheat. I took a box of free food such as biscuits and a box of exchange food. When it was time for my school to eat, I went to the front of our queue and got served straight away!

I think it helps if before you go away, you get used to weighing your own food and adding up your exchanges because then it will be really easy for you. If you work out your own exchanges, like I do, then you can choose what you want to have for your exchanges (I like to save them for chips!!!)

I hope you have a really good time if you go away.

Bye,
Paul



Dear News and Views,

I enjoy seeing so many friends and catch up with you all at the Conference having missed some recent events.

A niece of mine and her fiancé's mother had a joint birthday party from which they donate £260.00 to the NSPKU. Enclosed are two cheques to the NSPKU.

Please ensure that a letter of thanks for the £260.00 goes to Elma Moar & Hazel Eunson, Littaly, Firth,

Orkney for their assistance in fund raising and supporting the work of the Society.

Yours sincerely
Tom Copland



Dear News and Views,
I am a 34-year-old PKU who, 10 months ago, gave birth to a beautiful, healthy, baby daughter, Lucy. Thanks were totally due to the wonderful information and support given to me throughout and prior to pregnancy by dietitians at Dorchester & Bristol and to your informative newsletter.

My grandmother celebrated her 90th birthday last October and forfeited presents asking instead for donations to be made to the PKU. A grand total of £200 was raised, which I enclose herewith.

Thank you again for all your help and support.

With best wishes,
Tracey Readings



Dear News and Views,
My daughter Georgia who has PKU (aged 8 yrs) had a great idea to organise a garden fete to raise funds for NSPKU. She really enjoyed planning the event and many of her friends and family joined in organising a variety of stalls.

The fete took place on the 16th June and we had 60 people attend. We had great fun with numerous stalls, a bouncy castle and a BBQ.

We contacted a number of local businesses who kindly donated some prizes for our tombola which was a great success.

The local paper was very interested taking a picture of Georgia and including a feature about PKU.

Please find enclosed a cheque for £600.

We will look forward to Georgia's next fund-raising scheme!

Best wishes,
Judy Willits
(Georgia's Mum)



Dear News and Views,
STEPPING OUT FOR N.S.P.K.U in N.I.
When our second daughter Molly was born in 2006 with PKU, a condition unknown to us we both agreed that in the future we would like to do some fundraising for this Charity which was to become a big part of our lives.

Our brother in law and his wife, Samuel and Avril Miskelly run olde time dances and each year hold a dance for charity, they suggested their charity for 2007 be N.S.P.K.U. William and I were delighted as



we knew how popular the dances were. During the run up to the Dance we collected ballot prizes from many of the traders in the Crossgar area, ran a ballot for a Panasonic drill (kindly donated by McBride Tools) and a wet Sunday in May (quite a few to choose from this year) Avril and I loaded the car to capacity and headed to Dundrum for a car boot sale.

The evening of the dance approached, the Hall was decorated, the equipment set up and all the catering carefully laid out ready in the kitchen, we waited for the 'dancers' to arrive. Samuel and Avril were overwhelmed by the crowd that supported our evening, and their generosity showed no limits. Pauline had the task of counting the money and we were delighted to announce the amount raised to be £1600.00.

Over the following week other donations were made and when we finally added all the bits together we were able to write a cheque for £2024.00 to N.S.P.K.U.

We would like to thank Avril and Samuel for all their work in organising the Dance, (perhaps we'll persuade them to do it again in 2008) the traders in the Crossgar/Killyleagh area for their support, the ladies who provided the wonderful supper, Haladane & Fisher for the gas BBQ and especially to all the wonderful people who attended and helped us raise this fantastic amount of money. We would also like to thank our families, and especially the staff and dietitians at the RVH for their continued advice and support without which, we would have struggled to get this far.

With our thanks
Carol McCloy
Killyleagh, Co Down



Dear News and Views,
I am enclosing herewith a cheque for £87.40. This was raised at the most recent Rosebowl golf society meeting. One of our members, Roger Kerswill, lost his wife Angela just over 2 years ago and she had supported the charity as two of their grandchildren have PKU.

We had a small designated competition and the enclosed is the profit/balance we made.

Yours Sincerely
Peter Rose

Yes We Cook That @ Christmas too For PKU

Christmas Menu – All Zero Exchanges

Roast Peppers stuffed with Risotto (2)	£4.20
Vegetable Samosas (3)	£3.45
Cream of Roast Parsnip Soup	£1.45
Cream of Carrot & Coriander	£1.45

Yes We Cook That's Christmas Roast	£7.75
Can be sliced thinly or thickly, delicious with gravy, the perfect Christmas Roast for PKU. 2lb tin size	
Roast Breast of Turkeys with sage & onion stuffing balls	£4.95
Winter Hotpot with savoury dumplings	£4.95
Honey Roast Duckless Breast in Orange Sauce	£4.95
Chickless Supremes in a creamy mushroom sauce	£4.95

Christmas Pudding with brandy sauce, individual serving (2)	£2.50
Iced Christmas Cakes	£18.00
Glazed Mince pies (4)	£2.95
Baked Bramley stuffed with raisin and cinnamon crumble	£2.95

Festive Fancy cakes made to order

Snowman Cake	£25.00
Christmas Tree Cake	£25.00

Call 01290 332949 or 07773 342594 or E-mail sales@yeswecookthat.com

Freshly prepared PKU ready meals

Available near you*

Would you like...

To open the fridge to a freshly cooked PKU meal, labelled with the ingredients and exchanges waiting for you?

Yes We Cook That!

To open the freezer and find Spaghetti 'Meat'balls and Fishless Fingers and Chickless Nuggets, all with 0 exchanges?

Yes We Cook That!

To have a birthday cake and know that you can eat it all?

Yes We Cook That!

To have all this at Supermarket prices?

Yes... it is!

To know that we really understand PKU, really understand your diet and really know what exchanges are?

Yes... we do!

Working closely with PKU dietitians and PKU patients Leanora Munn and Pauline Young of Yes We Cook That.com now have a menu of 180 ready meals and snacks all suitable for PKU diets.

All meals are clearly labelled with the ingredients and any exchanges and are made using only prescriptive flours, egg replacers, milks and pastas.

Our menus are available through your dietician in some parts of the country or directly from Yes We Cook That.com

Our aim is to supply all PKU people with the opportunity to purchase ready made meals, breads, cakes and sweet and savoury snacks at supermarket prices.

*Available now in most of the UK and Ireland.

Phone Leanora or Pauline on 07773 342594

24 hour answering machine 01290 332 949

e-mail sales@yeswecookthat.com

Yes We Cook That.com, 39 Leggate, New Cumnock, Ayrshire, KA18 4NG

NSPKU 35th Annual Family Weekend & Conference 2008

The Hilton Hotel, Northampton, Northamptonshire
Friday 29th February to Sunday 2nd March 2008



Venue:

This years NSPKU Annual family conference weekend will be held at the Hilton Hotel, Northampton. This hotel provides us with an absolutely delightful venue to hold our annual event. The hotel provides us with luxury, comfort and superb leisure facilities.

The hotel is located just 10 minutes drive from the town centre of Northampton, which has been a town of importance ever since the Norman Conquest of 1066. Northamptonshire is known as the county of "squires and spires", and the town is home to one of only four remaining round churches in the whole of England, this one surviving from Norman times. As well as this Northampton boasts a great example of Victorian architecture in its Guildhall, and the old town has a fine market square which is one of the largest and most impressive in England, which may be worthy of a visit if time permits.

Accommodation:

All rooms (from Hilton Rooms to deluxe and suites) all come with high speed internet access, Sony Playstation, Hairdryers, TV games, hospitality trays. Please bear in mind the rooms that are available will be allocated on a 'first come, first served basis' so early booking recommended! If interconnecting rooms are required, please state while booking. Also please let us know if you have any special requirements (other than the PKU diet).

Supervision of Children:

Whilst the children will be supervised in the crèche, the kids' club and outings, it is not possible for the Society or hotel staff to supervise or be in any way responsible for the children at other times or places. It is the responsibility of parents to supervise their children.

Facilities:

Keep fit in the Livingwell Health club, swim in the indoor pool, make use of the fitness suite, relax in the sauna or pamper yourself with a beauty treatment and a massage. Afterwards rejuvenate over a

specialty coffee at café Cino, or have a drink in the Court Bar, Northampton's contemporary bar which overlooks the courtyard. The Hotel is also not very far from Billing Aquadrome for the more adventurous among us

PKU Diet:

You will need to bring the protein supplements and vitamins and minerals. The diet will otherwise be catered for. A limited number of baby foods will be available. If however, your infant prefers certain foods we would ask you to bring these along with you.

Location:

Travel to the Hilton Northampton hotel, 10 minutes drive from Northampton town Centre and 20 minutes drive from Milton Keynes. The hotel is located just off junction 15 of the M1. The nearest Airports are East Midlands Airport and Luton Airport is located just 40 minutes away.

Assisted Places:

There is restricted funding available for those who require financial assistance with conference fees. Please enquire in the first instance to the conference organiser who will help you with your enquiry. All applications will be dealt with in the strictest confidence.

NSPKU 2008 Residential Conference Fees:

Non-PKU Adult (over 17 yrs)	£170.00
(Single Person Supplement £20.00)	
PKU Adult (over 17 yrs)	£85.00
(Single Person Supplement £10)	
Non PKU Child (6 – 16)*	£35.00
PKU Child (6 – 16)*	Free
All under 6's	Free

Day Visitor Fees:

Non PKU Adults (over 17 yrs)	£35.00
PKU Adults (over 17 Yrs)	£17.50
Children (0-16)	Free

Booking Conditions:

Additional nights, if you wish to stay an extra night before or after the conference, please contact the hotel & book direct. We have negotiated a special rate of £90 per room (Thursday) and £50 per room (Sunday), both rates include breakfast.

** Any child staying in their own room will be charged at half the relevant adult rate.*

Your NSPKU 2008 Conference Organiser is Sarah Lawson

45 Balmain Road, Kenton, Newcastle-Upon-Tyne, NE3 3QQ – Home Telephone: 0191 271 0464

Mobile: 07882 839223 – Email: conference@nskpu.org – Website: www.nskpu.org

The Day Hollywood Came



This was the day everybody had been waiting for; thousands thronged the streets of Birmingham to get a glimpse of the famous as they walked down the red carpet. As the champagne flowed the talk of the town was who was going to get the star prize at the PKU Oscar ceremony. This was the Oscars to beat all other Oscars, and the grand Birmingham's grand historical council house was hosting Marilyn Monroe, Arnold Schwarzenegger and Brad Pitt (alias guest speaker Dr Hendriksz). You may have guessed that this year we hosted a combined study day and Oscar event for all our children with PKU and their families

The day was themed around the Oscar's, with lots of glamour and glitz, with a fun session for the children and a teaching session for the parents. As each family arrived they posed for their photographs against a night of stars. Life sized 'cut outs' of Marilyn and Arnold were the gate keepers to the red carpet, and cartoon characters Dora the Explorer and SpongeBob Square Pants were on parade for the younger children. The adults had a series of short talks with discussions on PKU and future treatment possibilities (including the Biopterin trials and the use of phenylalanine ammonium lyase) these were

given by the Movie star dressed in shades and designer Armani suit. Other talks included the introduction of new style PKU clinics (the Birmingham Way) and a crystal ball look at the future for the adult services done by our very own Helen Mirren (Anita MacDonald) and Shirley Bassey (Di Asplin). The day finished with Eileen and Faye Green demonstrating 'Summer cooking' (with a difference) and a real-life delightful Bonnie and Clyde PKU story (Fiona and Joe O'Malley) and the overwhelming benefits of returning to diet.

Whilst the grown-ups just had to sit back and listen, the children worked hard backstage. They wrote Oscar stories, prepared a Newssheet, preened themselves for their debut and prepared a play 'Anitarella' – an adaptation of Cinderella, with two very not so ugly sisters (Annarella and Vanessarella)! They even held their own press conference (with the real press no less!) and no grown ups were allowed to listen to anything they were saying! A feast fit for royalty was then followed by the grand finale i.e. 'The Oscar Ceremony.' The High Sheriff of the West Midlands Peter Tomlinson (who was formerly an early presenter of 'Tizwas' for those of us old enough to remember) presented the Oscars with a little help from friends. The look on each child's face as they were declared a winner was truly delightful and their family and friends oozed with pride. There was much cheering and clapping as each child came forward to receive their well

To Birmingham

deserved award from the best dancer to the most improved protein substitute taker. There were many tear jerking moments as well as entertaining interludes. Every child was an Oscar winner and they now display their well earned Golden Oscar statues for all to see. One boy declared it was great having PKU 'because you have so much more fun' and a full page leading article about the Oscars and our very own 'PKU stars' appeared in the next day local news paper.

Thank you to all the people and our sponsors who helped with this day. You know who you all are and we are so grateful to each and every one of you for making this a fantabulous day.

The Birmingham Dietetic IMD Team

Newsflash! PKU Registers

Over the last year we have been contacting all people who were registered on the old PKU register to get their permission to hold their details and to contact them in the future.

That project is now coming to an end.

We are now beginning to wind up this project partly because funding for modernising this register is coming to an end.

What next?

We will be reporting the outcome to a steering group later this year and discussing the relevance of the findings for our follow up now of infants identified through screening.

It's not too late for you to register if you have not been contacted and think you should have been: -

If You or a family member have PKU or hyperphenylalaninaemia and would like to receive an information pack about the registers, including a consent form so that information about you/your child can be held on the register

Please call Alison Munro on (free phone) 0800 432 0184 or email the PKURegister@gosh.nhs.uk ideally before 30th September 2007 to request a pack however all **signed consents must** be returned by Friday 26th October.

Please leave your / your family member's full name, date of birth, address including postcode and a contact telephone number.

Thank you.

Alison Munro
Research Nurse
UK Newborn Screening Programme Centre

Food Technology - Top mar

My name is Hannah Dawson and I attend Lancaster Girls' Grammar School in Lancashire, where I have recently completed my GCSEs in a variety of subjects, including Food Technology.

The Food Technology GCSE comprised of a 2 hour exam worth 40% of the overall mark, and the other 60% was obtained through coursework that the class worked on over a period of roughly 9 months.

At the start of the coursework, the whole class was given the same design brief, which was:

"Design and make a special diet product for a chosen group of consumers that could be sold in a major food retail outlet".

After doing some initial research into various special diets, including vegetarianism, a gluten-free diet etc, I decided to base my coursework on creating a product suitable for a person diagnosed with PKU, creating a low-protein product.

I decided to base my coursework on this diet as, I admit, I had not heard of it before, and I doubted many people would have, so it was something different, that I knew would challenge me during the course of the project.

The first thing we had to do was carry out thorough research on our chosen diet, and find out the dietary needs of people on the diet, and consider what the consumers would like to see in a product, and look at existing products already available in retail outlets (such as supermarkets like Sainsbury's).

In order to carry out my research on the diet, I used the NSPKU website, amongst other online resources, and contacted Eleanor Weetch, the NSPKU dietician. Mrs Weetch was extremely helpful and provided me with dietary booklets, leaflets and other invaluable information, without which I would have found the coursework more difficult.

In order to consider what the consumers wanted in a product, I wrote a short consumer questionnaire, which was distributed by Mrs Weetch and Ms. White at Pendlebury Hospital, at their PKU clinics. I would like to say a huge thank you to all the people who took the time to fill out the questionnaire and return it to me, and for all the helpful comments and suggestions.

As well as this, we had to study existing products suitable for our chosen diet available in retail outlets. However I found that there were no ready meals available in supermarkets for PKU patients. So I instead carried out research into existing low protein ingredients available for purchase, which I was able to purchase from my local chemist. I also wrote to 'SHS International', 'PK Foods' and 'General Dietary Ltd', and asked if it would be possible to have some information concerning

available products, and sample packaging.

All of this research allowed me to get a good idea of what was already available for people on a low protein diet, and what I could incorporate into my product to make it more appealing.

Following this research I came up with 15 initial ideas for products, which varied between sweet and savoury, from Fajitas to Summer Puddings. I then concept screened these ideas, i.e. I evaluated all 15 ideas against a specification that I felt would give me a product that was both suitable for a low protein diet whilst still being appealing.

From this I had a list of 8 design ideas which included: vegetable kebabs with cous cous salad, jam sponge pudding, mixed vegetable fajitas with tomato salsa, pumpkin and apple curry, aubergine and vegetable bake, individual summer pudding, apple pie and vegetable lasagne.

From this list I had to choose 1 product to take forward and develop. So I made each of the 8 products, and then carried out sensory analysis to ascertain which products were the most appealing and would work well if mass produced, to be frozen and reheated etc.



Mixed Vegetable Fajitas with Tomato Salsa



Individual Summer Puddings

After manufacturing and trying all 8 design ideas, I eventually decided that the Aubergine & Vegetable Bake would be the best option to take forward and develop.

ks for Hanah



Pumpkin and Apple Curry

The developing stage of the coursework required the separate elements of the product to be individually tested to improve. For example, the original topping of the Bake was a crumb mixture using breadcrumbs and dried onion, sage and parsley. However I then considered four options: the original breadcrumb mixture, a creamy breadcrumb topping, with cream (40ml cream as exchange), a potato topping, using 80g potato as exchange (boiled, mashed and piped), or a Scone Topping (Cobbler), which is mini scones arranged around the edge of dish.



After making and testing all four options, I decided to use the scone cobbler option, as it looked good, was different and showed manufacturing skill (something I always had to consider as I was constantly being assessed by my Food Technology teacher).

The next stage was then to develop other aspects of my product, such as scone topping flavours, vegetable mixes, pasta types, sauces, accompanying salad dressings and storage and reheating options. After developing all of these aspects, I was able to make and evaluate my final product, and see if the developments improved my product.



Before developments



Final Products

Having completed the practical element of my coursework, I then had to do the final evaluation, and complete nutritional and cost modelling, which allowed me to assess the nutritional aspect, and also attempt to work out how much my product might cost. The overall cost came to approximately £4.91 per portion, which is admittedly high but the computer program factored in hypothetical marketing and advertising etc. Also the price of low protein ingredients is quite high. However despite this I was very happy with my final product, as I felt it was colourful and generally appealing to consumers who required a low protein product, which this product definitely is. It uses a low protein flour substitute, low protein milk substitute and low protein pasta, and used a wide range of vegetables etc.

I was very happy with my coursework, and was extremely pleased to find out I had received full marks for it recently. I would again like to thank Eleanor Weetch, without whose help I could not have done this coursework, and also a huge thank you to the people who took the time to fill out and return my questionnaires for me. It meant a lot that you had helped me, and I hope you all think that my product at least looks good, even if it never does make it to the shops. Thank you all very much.

Hannah Dawson.

London and Home Counties Picnic

We were lucky. We had organised the London and Home Counties Picnic before June. June was extremely moist with splashings of more moistness to accompany the moistness i.e. wet.

The loyal picnic goers had swarmed all over Willows farm to meet and greet other like-minded parents and kids.

This is an annual homage where all can discuss and share experiences of the trials and tribulations of the diet. We also share the successes of the diet with families who are new to PKU. It was great to see some new families with new babies who turned up.

Willows Farm is situated in Hertfordshire and is a great venue for a meet and greet. Not only are there rabbits and the world's biggest guinea pig village but it is also home to great big cows and tractors that can run you over if you aren't careful!

We had our own marquee to shelter us from the elements. The kids ran amok, and legged around the farm in a random fashion, only visiting the tent

when they had become hungry or looking for more food to feed the animals.

The weather was kind. This meant we could filter through the Jams and Pickles Shop into the animal area. Here, there were sheep, owls, horses, cows and a big bouncy castle (Bouncious Castleanness) with a Zip Wire just to put a countrified feel to the experience.

The kids loved it and made the most of their stay. It's great to see those who support the efforts of the London and Home Counties Support Group.

If you live in the Home Counties, why not make the effort and join us next year for the next Summer Picnic or more imminently, get yourself and kids on the mailing list and get sent details of the upcoming events which will include a Christmas Party – all events are free and your child has a great time and you get to meet other PKU parents!

Please contact – Sue Sims/Caroline Greasby (Joint Secretary) on pkusupport@tiscali.co.uk

All PKFoods are now available on prescription



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Cooking 4 Fun Day 2007

Barnsley

Another fun packed day was had by all who attended Barnsley dietitians' low protein cookery day, which was back due to popular demand.

The day began at 8am, nice and early for a Saturday morning, to set up for our second year running low protein day for children and adults from Barnsley and Sheffield on low protein diets. The day was held in a village Resource Centre in Barnsley. We used the centre's kitchen classroom for the cookery workshop and two classrooms for the two workshops, which did not require the preparation of hot food. The day was very kindly sponsored by FATE, SHS International and Vitaflo.

Again we had 3 workshops but this year they all involved the preparation of food and recipes. Eileen Green of FATE cooked a fabulous spread and with the assistance of her daughters Kate and Faye, and taught the groups how to cook low protein sausages, a casserole and a variety of breads and desserts. Eileen demonstrated how to prepare the different vegetables and incorporate them into the different recipes, which were delicious. Everyone got stuck into the cooking and thoroughly enjoyed the session.

Emma Darlston, sales representative of SHS International, ran a workshop on recipe ideas suitable for packed lunches or meal accompaniments. Recipes included pizza rolls, garlic fingers, quick and easy rice and pasta salad, ratatouille rolls and a yummy crunchy fruit layer. Individuals were given the choice of what recipes they wanted to make. Emma then talked them through each recipe step-by-step.

Louise Dorgan and Kate Parker, sales representatives from Vitaflo ran workshops on making and decorating Easter eggs made with Vitabite and using fresh strawberries, mango, kiwi, blueberries and raspberries, which soon disappeared, to dip into a Vitabite chocolate fountain.

A raffle raised money for the NSPKU. The fantastic prizes were; a Chocolate Fountain with lots of Vitabite and a bottle of wine, for the adults, kindly donated by Vitaflo; and a very useful hand held food blender presented by SHS International.

The day ended with lunch, using the food that each group member had made as well as extra goodies that Eileen had cooked up.

The feedback from the participants on what they enjoyed included; making different things; the cooking session; all of it; getting new ideas for recipes; decorating Easter eggs; making new meal ideas and meeting people. Suggestions for next time included: more cooking; a longer day; more of everything; no changes; make fudge. Everybody said they enjoyed all the workshops and would definitely come again.

A big thank you goes to our sponsors which without their help the day would not have been possible. I also thank the dietitians Eleanor Weetch from NSPKU and the Northern General Hospital, Sharan Lowry from Sheffield Children's hospital and our own Jeannine Mitchell for all their help and support on the day and of course to the staff of Barnsley Resource Centre.

NSPKU MERCHANDISE

NSPKU will be selling two NEW designs of Christmas cards this year.

Each packet contains 10 cards with envelopes and will retail for £3.00 per packet.

This message inside reads:

*With Best Wishes for Christmas
and the New Year*

*For more information please contact Mike Bailey, see
inside front cover for contact details*



SHS **Homeward**

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Adolescent Day



On June 2nd we held our first Adolescent Day. We had 11 of our young people aged 10 to 14 years. The theme of our day was travel.

Many of them had travelled abroad and attended school trips with no problems. Five of them spoke about their experiences of holidays without their parents and how worried they were. But they all managed very well and now are very sensible and realistic about what to expect.

Nick Blundell 14yrs had recently visited China on a school trip and had made a superb film which we showed to the



group. It was fascinating and caused quite a discussion as he had eaten scorpions and a birds head!! He spoke about managing his PKU diet and how he had



to improvise using a teapot to mix up his supplement.

Eleanor Weetch the Society dietitian was kind enough to come down to tell us all about Edale, the outward bound weekend and recruited three of the young people and a dietitian!

We then went on to have a PKU quiz which I thought I might have made too difficult but the results were fantastic! They all knew so much about their PKU. The top two winners were Sam Cooper and Tamsin Hurton who both won prizes. Sam was delighted with his chocolate fountain!

We then went on to have a 'funky lunch'. SHS had kindly made several lovely foods and sent them down for us. Our dietitians had spent time in the kitchen making burgers and pizzas and setting up the chocolate fountain. Vitaflo had made us chocolate covered fruit and chocolate fudge and provided us with lots of goodies for the gang to take home too.

We finished off with our dietitians doing an interactive session around travel.

And finally everyone had an information package to take home and lots of goodies sent by SHS, Vitaflo and Braintree Tesco.

The day went down really well and everyone enjoyed themselves. So much so they all want to come to the same group clinic!!

Nicky Mumford
PKU Nurse specialist, Great Ormond Street





AVAILABLE ON PRESCRIPTION:

Fate Low Protein All - Purpose Mix

Fate Low Protein Cake Mix

Fate Low Protein Chocolate Flavour Cake Mix



“As a mom with two daughters who both have PKU, I fully understand the low protein way of life. I have developed these mixes and many recipes to help everyone make great low protein food.”

Eileen Green



**Ask your Doctor to prescribe Fate mixes,
then ask your chemist to telephone our direct order line : 01215 22 44 33**

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Fate Special Foods recipes



Hello

This recipe has become one of our favourites, Onion Bhaji are served as an accompaniment to an Indian style meal or as a snack. They are so useful because they can be served hot or cold. Traditionally they are shaped into rough balls and deep fried, but if you want to shallow fry them, it is best to flatten them slightly before you cook them to ensure the middle cooks through easily. If you like them really hot and spicy, just add more chopped green chillies. They freeze well, so it's good to make double the recipe, and store them in the freezer. Just defrost as needed, and eat cold, or reheat in the oven or microwave.

FATE ONION BHAJI

50g onion, thinly sliced
1-2 tbsp fresh coriander, roughly chopped
2 tsp fresh chillies, finely chopped
3 tsp curry powder such as Madras or Rogan Josh
150g Fate Low Protein All-Purpose Mix, and extra to shape
1 tsp salt
Black pepper to season
120 mls water
Oil for cooking

Place the sliced onion, coriander, chillies and curry powder into a mixing bowl. Add the Fate All-Purpose Mix, and the salt and pepper. Stir well.

Pour in the water and mix well until blended together.

Using a little Fate All-Purpose Mix on your hands, take about a tablespoon of the mixture and form it into a rough ball. It does not have to be very smooth. Then if you are going to shallow fry them, just flatten slightly. Place a few bhajis into hot deep oil, preferably with a wire basket, or shallow fry in a frying pan. Cook for a few minutes until golden brown and cooked through.

Drain well. Serve hot, or leave to cool then store in the fridge to eat cold, or reheat. They can also be frozen.



NOTE ABOUT PANASONIC BREAD MAKERS:

For a long time now, I have been recommending the Panasonic Automatic Bread machines to make Fate Low Protein bread. The two models that I use are the SD252 and SD253.

At the end of July 2007, Panasonic introduced two new models, the SD254 and the SD255. They are direct replacements for the older machines.

I have now tested both of these new machines, and they work exactly the same way, and produce fantastic loaves. The best programme to use is the Basic Bake Rapid, XL size with Medium or Dark crust. (The only change is an extra 5 mins baking time if you choose Dark crust)

Panasonic told me that they are gradually phasing out the older machines, and there may be some bargains around as some retailers discount the old machines before stocks of the new one takes over.

Give me a call on 0121 522 4434 if you need any further details, or send your name and address to me for an up to date leaflet about making Fate Bread in a machine.



SD254



SD255

Dietitian's Report

Blockbuster Video Hire

I was told that Blockbuster sell some Jelly Beans which are protein free. I went into my local shop and found them. They are made by the The Jelly Bean Factory and come in 200g tubs and little boxes. The flavours sound really different – there's Marshmallow, Banana Split, Popcorn, Candy Floss, Raspberry Jam and Bubblegum to name a few! When I've finished photographing them I think I might just have to try them to see if the flavours are true to their names.



Weight Watchers Jelly Crystals

Barbara Cochrane, dietitian in Glasgow, told me about the Weight Watchers Jelly Crystals. These come in small sachets and each sachet makes 2 servings of 14 calories per serving. They are protein free so very useful if you are watching the calories.

Haribo Halal Sweets



Julia, our treasurer asked me about the Halal Haribo sweets. She thought they were protein free but asked me if I could find out. Well the good news is that they are protein free. A synthetic type of gelatine is used. There are 8 different sweets in the range and they come in 100g bags. Stockists are Asda, Sainsbury's and Morrisons as well as Bestway Cash and Carry and selected Hancocks Cash and Carry. The bags are clearly marked 'Halal'.

Gummy Bears
Wummis (worms)
Gummy Zoo
Tropical Fruit
Sour Tongues
Sour Delicious
Cola Breeze
Mega Sour

Pizza Hut

Janice Willis told me about a very good experience she has had at her local Pizza Hut in Stevenage. She went in with her son and asked to speak to the manager. She took in her own pizza base and they let Sean choose the toppings he would like on his pizza and they did his own low protein one for him. You may also try ringing before you go in just to check that they will do this for you but I thought I would tell you about this accommodating outlook that this chain restaurant had. Well done Pizza Hut!

Amino Acid Analysis

I am starting to make another list of foods you would like to have analysed for phenylalanine content. Drop me a line or email or ring me or ask your dietitian to contact me and I will get all your suggestions together and we'll choose the top 10 again. It's made such a difference to the diet and it's important to keep new things coming into the diet to keep up the variety.

Apple Snapz



These apple crisps come in a variety pack of different flavours. There's original apple flavour and then also apple crisp with a hint of banana, blackcurrant, orange and strawberry. They can be counted as free from exchanges. Good for the lunch box, travel or a free snack.

Amino Acid Analysis of Cassava and Tapioca Crackers

When we had these types of crackers analysed for the phenylalanine content we analysed only those containing cassava, tapioca and free ingredients. It was on the results of these analyses that the recommendation was made that cassava and tapioca crisps could be allowed as a free food in the PKU diet.

If there are other ingredients such as whey powder, milk protein, yeast extract and other protein containing foods then you must work out the amount for an exchange using the protein declaration on the pack. In most cases you will still get a generous amount for an exchange but it can't be classed as a free food.

Patak's Bombay Potato Flavour Crackers



With the fiery taste of red chilli and warm spices These crackers are made from tapioca and cassava but they do contain some whey powder (from milk) and some milk proteins so they can't be classed as a free food. However, the protein content is quite low and contain 1.2 g protein per 100g.

So 85g = 1 protein exchange.

This is a whole bag and the information on the bag has a ½ bag as a serving so you could have half a bag for ½ an exchange which is a good amount.

Baby Food Exchanges

The baby food exchange list is up-dated every 6 months. I am in the process of doing this now but I want to remind everyone to the fact that it is still important to check the nutrition labelling of foods as manufacturers change their recipes. Cow and Gate have recently changed the recipes of some their baby foods but are still calling them by the same name. In one instance a cereal had milk powder added to it which increased the protein from 2.6g to 14.1g. You can use the Ready Reckoner card to work out the amount for an exchange and if you are at all in doubt ask your dietitian.

E Numbers

I was recently checking out some E numbers on a packet to see what they were. I thought it might be of help for you to know what a few relevant ones are when you are looking at food labels.

The following can be included in the PKU diet:

E955 is Sucralose
E950 is Acesulfame K
E954 is Saccharine

To be avoided:
E951 is Aspartame
E962 is Acesulfame K and Aspartame

Any food or drink which contains aspartame should always carry the label 'Contains a source of Phenylalanine'. You can double check that it's OK by looking for the E numbers E951 and E962.

Eleanor Weetch
Dietitian

Recipes of the month



Making the difference in metabolic care



PILAU RICE

Preparation time: 5 minutes

Cooking Time: 9 minutes

Makes 1 portion

Ingredients:

75g (2oz) Loprofin Rice

5ml (1tsp) Olive oil

1 Clove of garlic

1 Small red onion, peeled and finely chopped

5ml (1tsp) Garam masala

Method:

1. Rinse the rice under cold water in a sieve, place in boiling salted water and cook for 9 minutes.
2. Meanwhile, in a small frying pan heat the oil then add the diced onion and garlic and fry for 3 minutes, add the garam masala and fry for a further 2 minutes.
3. Rinse the rice with boiling water.
4. Mix the onions and the spices into the cooked rice.

This meal is exchange free.

* Refer to NSPKU information booklet for an appropriate choice of sauce.

VEGETABLE JALFREZI

Preparation time: 10 minutes

Cooking Time: 20 minutes

Makes 4 portions

Ingredients:

300g (10oz) Cauliflower, broken into small florets

175g (6oz) Carrots, topped, tailed and cubed

85g (3oz) French beans, topped, tailed and cut into 3

1 Jar of Jalfrezi cooking sauce *

Method:

1. In a large saucepan boil the vegetables in salted water for 10 minutes.
2. Drain and divide into 4 portions.
3. Add the jalfrezi sauce, bring to the boil and simmer for 10 minutes
4. Serve with one portion of plain boiled Loprofin rice or make pilau rice.

Four tasty NEW products added

NEW
NOW AVAILABLE ON PRESCRIPTION



The Promin range just keeps growing which is good news when you are on a restricted diet, and because we are a family run company we can react to our customers needs that's why we keep adding new products to our range. Two new desserts' chocolate and banana and strawberry and vanilla also a chocolate spread - the Kids will love this one and pasta spirals in a morroccan sauce. With more meal solutions being added to the Promin range you can be sure there's a great tasting option available to satisfy your taste whatever time of day it is.

Choose: Hot Breakfast - Original, Apple and Cinnamon, Chocolate, and tasty Banana flavours. For lunch or an



evening meal: Pasta Shells in Tomato, Pepper and Herb sauce, or Pasta elbows in Cheese and Broccoli sauce. A popular addition is our great tasting Burger Mix, you can easily shape it into burgers, sausages, meatballs or even dinosaurs for the kids! - they taste great with chips or mixed with some of our pasta. Visit our website for more details and a full analysis on all our products.



www.promin-pku.com

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. The range also includes Imitation Rice, Pasta meal and Lasagna Sheets. By talking with PKU patients, parents and Dietitians new products have been developed to reflect your needs. Please call or visit the website for more information and keep sending your recipe suggestions. Firstplay Dietary Foods produce low protein foods especially for your diet.

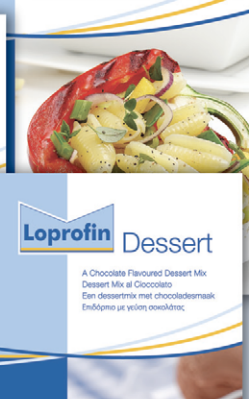
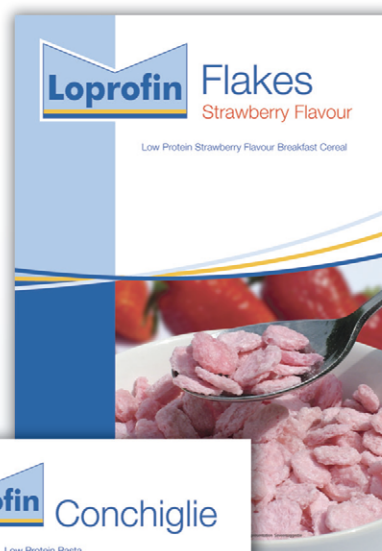
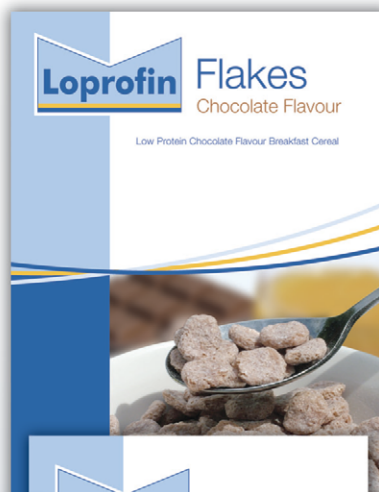
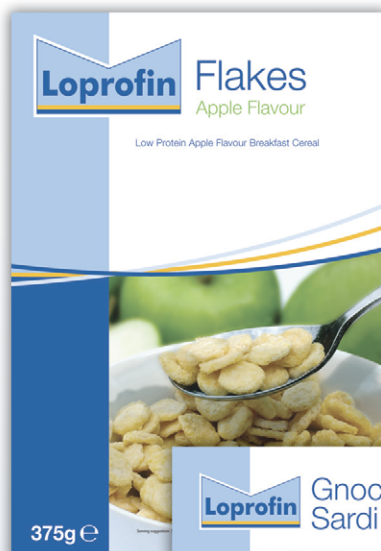


Always consult your dietitian before trying something new.

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For further information and regular product updates please visit:

www.lowproteinliving.co.uk

Register to Win!

Register your details using promotional code **NSPKU** by 30th November 2007 to enter our free prize draw for **£50 worth of John Lewis vouchers**.*

*Members already registered will not be included in the draw.