

Inside this issue...

Editor's Report

Donations

Barnsley Fun Day

Pat Portnoi retires

Home and away
with PKU

PKU Pronto!

Fate Special Recipes

Dietitian's Report



Cooking for fun in Barnsley

2007 Conference booking form
and details inside!

In Touch

The Council of Management

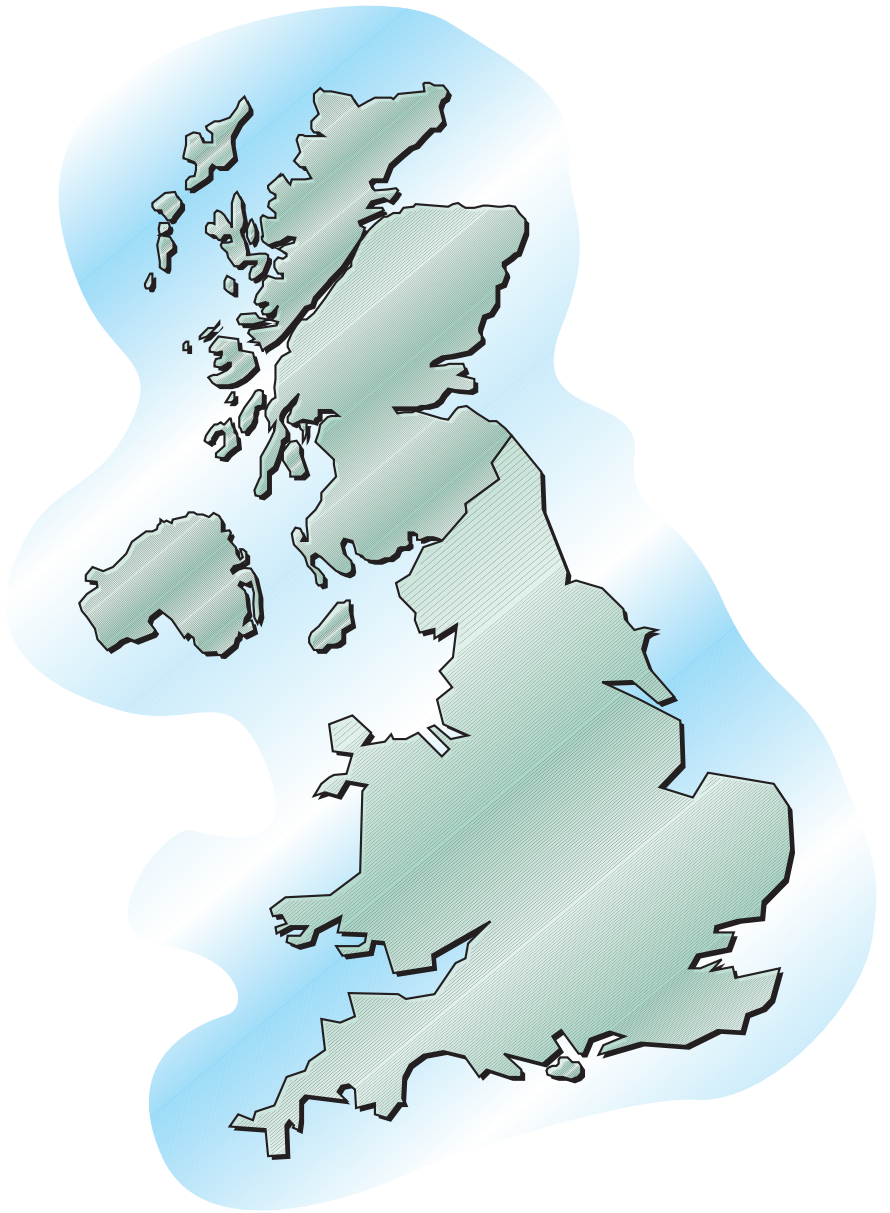
Telephone Helpline: 0208 364 3010

Recorded Information Line: 0207 099 7431

Address: PO Box 26642, London N14 4ZF

E-Mail: info@nspku.org

Internet: www.nspku.org



Contents

- | | | | |
|---|--|----|--------------------------------------|
| 1 | Editor's Report | 11 | Home and away with PKU |
| 2 | Treasurer's Report | 13 | PKU Pronto! |
| 3 | Donations | 14 | Fate Special Recipes |
| | Letters | 15 | Dietitian's Report |
| 5 | What is happening to the PKU register? | 17 | SHS Recipes |
| 8 | Barnsley Fun Day | 18 | NSPKU 34th Annual Conference Details |
| 9 | Pat Portnoi retires | | |

Editor's Report...

Well, I made it! 10 kilometres is nothing to hard core runners like our Eric Lange but believe me, it's something I never thought I'd be able to do! In the process, I raised £100 for our society and while that's not a lot, if we all raised half or even a quarter of that every year, the NSPKU would be looking a lot healthier! Come on, if a chubby old housewife like Kiri Thomas can shuffle around Dublin, imagine what you more glamorous and energetic types could achieve. Let's be having you!

I hope you tried Barbara Broadbent's recipes in the last issue. She's come up with another great one this time – have a look on our Letters page. No surprises either to learn that our very own Eleanor Weetch has given us some more great meal ideas in her report too; check out what she suggests you do with sweet potatoes!

Something else occurred to me whilst compiling this issue. Most of us cope pretty well with PKU but I can't imagine that any of us would actually choose for our children, family, friends or even ourselves to have the condition. We need to keep up the pressure for research to solve the problem in a much simpler way. Perhaps from the PKU community ourselves we could pull a few from our ranks to get in there and work as dietitians, scientists and doctors in metabolic medicine. How empowering and exciting it would be to have someone with PKU help solve the problem of PKU once and for all! With that in mind, have a read of Pat Portnoi's thoughts on a career in PKU as she retires from SHS. She certainly inspires me.

One last thing – the conference! Please check out the programme of events in this issue and get booking! For those of you who've yet to attend an NSPKU Conference, it is a fabulous opportunity to get recipe ideas, learn about research advancements and chat to other PKU families who totally understand the challenges we're all facing. The hotel at Skipton is perfect for families and for those without children, they pull a great pint in Yorkshire! Please come and meet us, we have enormous fun and really help each other out.

Best of luck with exam results, the start of new school terms and the run up to Christmas and please, please keep sending in your ideas and stories. We love each and every one.

Kiri Thomas
Editor

NSPKU

The National Society for Phenylketonuria (United Kingdom) Limited

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

While every care is taken in the preparation of "News & Views", the society cannot be held responsible for any information given or views expressed.

All articles in "News & Views" are copyright of the Society, and must not be used without the Council of Management's authority.

The National Society for Phenylketonuria (United Kingdom) Limited,
PO Box 26642,
London N14 4ZF
Company No. 1256124.
Charity No 273670.

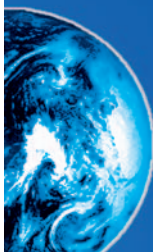
Helpline: 0845 603 9136
Email: info@nspku.org
Web Site: www.nspku.org

Registered address:
'Merrywood' Green Road
Wivelsfield Green
West Sussex
RH17 7QD

Layout by **The Keystroke Mill**
www.keystrokemill.com
Printed by **Action Press**
Tel: 01444 236204

find
us
on
the
web
at:

www.nspku.org



Treasurer's Report...

Firstly apologies for the Society's income and expenditure not making it to the last issue, my report probably made even less sense than usual but at least I had an excuse this time! Not sure what happened but hopefully you will find it in this issue.

I am pleased to report that our last budget report shows that our financial situation (all being well) should be better than thought at the beginning of the year thanks to a now predicted increase in donations this year. I knew you could do it! (and of course keep it up!)

I have finally got around to tackling the first of my major projects...a review of the Society's insurance. What a fun summer I've had! But I now know all about liability (product, employers and public), indemnity (professional and executive), fidelity (and I don't mean marital) and all risks and it really is as boring as it sounds. My next task will be the exciting topic of bank accounts.....who wants to be the next treasurer!!!

Julia Bailey
Treasurer

Detailed income and expenditure account

| | 2005 | | 2004 | |
|---------------------------------------|--------|-----------------|--------|---------------|
| | £ | £ | £ | £ |
| INCOME | | | | |
| Membership fees | 9,841 | | 12,359 | |
| Donations and fundraising | 25,500 | | 26,970 | |
| Conference Income | 2,489 | | 8,727 | |
| Spring Draw | 4,352 | | 5,994 | |
| Bank and other interest received | 3,651 | | 2,642 | |
| Publications and videos | 3,818 | | 4,024 | |
| Advertising | 13,817 | | 10,475 | |
| ESPKU 04 Income | 1,000 | | – | |
| AGM Meeting | – | | 1,362 | |
| Sponsorship re publications | 4,000 | | 6,750 | |
| Outward Bound course | 3,165 | | 1,071 | |
| Other receipts | – | | 200 | |
| TOTAL INCOME | | 71,633 | | 80,574 |
| EXPENDITURE | | | | |
| Conference expenses | 10,256 | | 12,918 | |
| Spring Draw | 1,151 | | 1,101 | |
| Goods for fund-raising (net of stock) | 3,412 | | 1,663 | |
| Newsletter and publications | 27,968 | | 7,901 | |
| Telephone | 1,302 | | 2,057 | |
| Postage | 1,354 | | 2,067 | |
| Travelling expenses | 2,936 | | 3,341 | |
| Insurance | 1,916 | | 1,711 | |
| Stationery | 860 | | 800 | |
| Equipment and software | 1,433 | | 1,881 | |
| Depreciation | 758 | | 439 | |
| E Weetch fees | 14,859 | | 13,005 | |
| L Welch fees | 4,686 | | 4,080 | |
| Sundries | 106 | | 275 | |
| Committee meeting expenses | 6,853 | | 4,521 | |
| MAP meeting expenses | 1,444 | | 1,567 | |
| AGM Meeting | – | | 4,102 | |
| ESPKU expenses | 4,071 | | – | |
| Sponsorship | 100 | | 30 | |
| Bank and finance charges | 99 | | 29 | |
| Outward Bound course | 4,710 | | 1,642 | |
| Audit | 1,410 | | 1,349 | |
| Membership Fees and Subscriptions | 668 | | – | |
| Research costs | 465 | | 1,791 | |
| Grants | – | | 297 | |
| TOTAL EXPENDITURE | | 92,817 | | 68,567 |
| (DEFICIT)/SURPLUS OF INCOME | | (21,184) | | 12,007 |

Donations

Donations £30 and over to 30th June 2006 £

| | |
|--|--------|
| Gail and Stephen Seavor | 335.00 |
| Charity Triple Challenge (via A Egerton) | 145.50 |
| Judy Willits | 94.50 |
| R. Masters | 70.00 |
| Mrs Ellen Masters | 150.00 |
| Peter Rose | 77.70 |
| Wood Mackenzie (via Eleanor Weetch) | 75.00 |
| Mirfield Parish Church | |
| Whist Drive Group | 46.00 |
| Geoff Chapman | 45.00 |
| Andy and Geraldine McNaney | 265.00 |
| Laura Porter | 516.20 |
| Dr B.A. Broadbent | 50.00 |
| Mrs Shirley Osborne | 225.00 |

In memoriam:

| | |
|--------------------------------|--------|
| In memory of Mrs Dorothea Bray | 103.00 |
|--------------------------------|--------|

Donations to.

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

If you are sending a donation or a subscription payment please send it to: NSPKU, PO Box 26642, London N14 4ZF

If you are sending money for anything else please send it to: NSPKU, c/o Vicki King
Tarkwa, 65 Cromwell Road,
Ribbleton, Preston, PR2 6YD

Please send only cheques or postal orders NOT CASH

Letters

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

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

Dear N&V,

The Mid Summer Notes Concert was held on 10 June in baking heat in the beautiful garden of Kate and Ian Findlay. The music was beautiful and the verse and poetry very entertaining.

Champagne Flutes again entertained us and this year we were delighted to have more young people playing for us. They were: Isobel Williams playing saxophone, Mark (Isobel's brother), Rebecca Prince playing piano and Michael Stone playing piano jazz. It was truly wonderful and the audience was spellbound.

Afternoon tea was served in the interval and later the raffle was drawn. The first prize was a trip in an Austin 12 motor which Wendy Barlow won and was treated to a short spin around Charlecote and back!

Thank you, thank you to Kate and Ian and everyone who performed, helped with the catering, baked cakes, loaned gazebos and who supported NSPKU and Save the Children by coming to the concert in such an enthusiastic way. A super sum of £450 was raised.

Shirley Osborne



Hannah Bridges, PKU



Wendy wins first prize in the raffle - a ride in a Austin 12 motorcar!



Letters

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



The ensemble Champagne Flutes provided the music



Enjoying the singing and the garden

Barbara Broadbent has come up with yet another great recipe for us. Thanks again Barbara!

Dear N&V,
Recently, I made a soup from a recipe on one of Sainsbury's recipe cards. We all liked it. It's easy to make, exchange free, and the quantity given makes a great quantity of soup, so there is plenty to freeze. Here it is:

Secret Soup

Grate 2 courgettes, 2 carrots and a sweet potato. Add these to a large saucepan with a little olive oil, a chopped red onion and a chopped red pepper and

We've also got yet another London Marathon success story; Laura Porter ran the course in 5 hours and 17 minutes and raised £516.20 for the NSPKU. *Thank you so much Laura, your efforts are sincerely appreciated!*



cook gently until soft. Add a pinch of dried oregano, a bunch of chopped fresh basil, 2 cartons of Sainsbury's Premium Chopped Tomatoes and a litre of vegetable stock and simmer for about an hour. Whiz with a hand blender or in a food processor.

With best wishes,
Barbara Broadbent

Changes to telephone contact

Please be aware that we are changing our telephone helpline number. The old 0845 number is being phased out and replaced with 0208 364 3010. This will reduce the cost of the calls to both the Society and to many of those who call it.

The number was set up a number of years ago when local calls were cheaper than national calls however these days many users have call packages with inclusive calls but 0845 numbers are often excluded or more expensive. The Society has had to pay a standing charge every month plus the cost of the calls transferred. Please update your records.

The 0845 number will continue to be answered for at least a year until it's use declines.

We are pleased to announce a new service, a recorded information line. This will provide basic information regarding events and contact details. It will reflect much of the information available on the web site and will benefit those without internet access. The number is 0207 099 7431, feel free to give it a try.

What is happening to the PKU Register?

Background

The UK Phenylketonuria (PKU) register was set up in 1964 with MRC funding in order to monitor the long-term health and development outcomes of children who had an early diagnosis of PKU through newborn screening. The register is internationally unique and has answered many important questions about the longer term health of those with PKU, including, for example, whether children with PKU have more behavioural problems and whether the children born to women with PKU who are not on treatment are healthy and develop normally. The register has also been used to make sure that the national screening programme is working well, by giving information on the timing and quality of treatment for children diagnosed through newborn screening.

Data collection for the register was continuous until the mid 1990's when funding became uncertain and finally stopped in 1998. Unfortunately this meant that since 1994 the register has not included all children with PKU in the United Kingdom.

In 2002 the UK Newborn Screening Programme Centre (UKNSPC) was set up to develop standards and monitor the quality of newborn blood spot screening in the UK. Custodianship of the PKU register was transferred to the UKNSPC, which has also been given the task of modernising the register.

We began this work by storing all the register paper files, which are now held at the Records Office at UCL, where only authorised individuals working at the UKNSPC can access them. The computer files have been converted to a modern format where they can be easily accessed and analysed and are stored securely with authorised access only.

In addition, we organised a series of meetings about the registers, with groups representing metabolic and laboratory clinicians as well as with the NSPKU and CLIMB who represent the interests of patients and their families. They all expressed strong support for the PKU register and felt it should be continued as it would be highly valuable for research into the longer term outcomes of women and men with PKU and their children as well as the outcome for children who are on a 'diet for life' which was only introduced in 1993.

Modernising the register

However, we realised that the register needed modernising, not least because the 1998 Data Protection Act means that now we need to ask people consent to hold their information whereas most of the register data was collected before that law was passed. So we have been developing a plan to do this with the help of PKU doctors and nurses, as well as the NSPKU and CLIMB. As a first step we had to get the approval of the London Multicentre Research Ethics Committee. We have now received this and will be contacting all the individuals whose data are held on the register through their hospital doctors. If patients are not being seen regularly at a hospital, we will contact them where possible through their general practitioner.

If you have PKU and were born before 1994

If you have PKU and were born in the UK before 1994 we want to contact you.

When you hear from us you will be asked to decide what you would like to happen about the information we hold on the register. There are three choices – you can

- Ask us to keep your identifiable information and give us your up-to-date contact details so you can receive information about future research studies.
- Ask us to keep only enough of your identifiable information to allow us to follow your health through information routinely held by the NHS but not to make any further direct contact with you.
- Ask us to remove all your identifiable information (for example names and addresses) from the register and not follow your health or make any further direct contact with you

Your choice will not influence the care you receive from your doctor and the health service. We will be sending out information packs to patients and families through their clinicians this autumn and

winter. Children aged 12 to 16 years will also be able to give their consent and, in the longer term, we will seek consent of children once they become adults. Children and adults with special needs may need the help of their parent or carer to give informed consent.

Children born from 1994 on

If you are a parent of a child with PKU who was born in the UK after 1994 then we want to contact you.

We are currently working with the screening laboratories and the clinics to identify these children who are unlikely to have been notified to the register. We want to be able to follow them up in the longer term in much the same way as we have done for children born before 1994. This means we will be writing to all PKU children born from 1994 onwards through their doctors to ask their parents for consent to include their information on the register.

We are hoping to have reached everyone with PKU, no matter when they were born, by the end of 2006. If by then you have not received an information pack and then please do not hesitate to contact us, or your current PKU doctor, nurse or dietitian.

Future research

Doctors and scientists will be developing some research studies based on the register. There is a lot of interest in learning more about the progress of children who were continued on life long diet when this became policy in the early 1990's, as well as updating our information about the children of mothers with PKU. These kinds of questions are ones that the NSPKU and other organisations have told us matter to those with PKU and their families.

The NSPKU and CLIMB are represented on a steering group*** that oversees the register, as is the British Inherited Metabolic Diseases Group and the UK Newborn Screening Laboratory Network. All proposed studies need the approval of this group as well as ethical approval to go ahead. Even then, if you are approached, you will always have a choice about whether to take part or not.

If you have any questions or concerns about the information in this article then please send an email to PKURegisters@gosh.nhs.uk or telephone 0207 829 7883 a free phone number will be available shortly. **The full information pack about the registers and consent forms will be sent to you directly by your hospital clinician or GP over the coming months.**

The NSPKU strongly support the PKU register and is also available to provide support and information about PKU. News and progress reports about the PKU register will be made available through The NSPKU website, News & Views, CLIMB's newsletter and the UKNSPC website.

We are very grateful for your support in this important work which is being carried out to ensure that research can continue to the benefit of future generations of children with PKU and their families.

Alison Munro
Research Nurse

On behalf of the UK Newborn Screening Programme Centre

Useful websites:

www.newbornscreening-bloodspots.org.uk
www.Climb.org.uk
www.nspku.org

*** The PKU registers steering group members were:
Dr Don Bradley, Laboratory Director, Wales
Mr Steve Hannigan, Executive Director, CLIMB
Dr Philip Lee, Metabolic Consultant, London
Dr Hilary Leslie- Laboratory Director, Northern Ireland
Dr Peter Robinson, Metabolic Consultant, Scotland
Mr Dave Stening, Chair person, NSPKU

Now you can choose Breakfast, Lunch and Dinner



NOW AVAILABLE
ON PRESCRIPTION

GREAT TASTING MEAL SOLUTIONS WHATEVER THE TIME!

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

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

For lunch or an evening meal: Pasta Shells in tomato, pepper and herb sauce, or Pasta elbows in cheese and broccoli sauce.

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

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

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 or visit the website for more information or with your

dietary suggestions.

Firstplay Dietary Foods

produce low protein

foods especially for

your diet.



Always consult your dietitian before trying something new.

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

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

Barnsley Fun Day



Great fun was had by all who attended the low protein cookery day in Barnsley on the 20th of May. The aim of the day was to help show children and their families how a low protein diet can be interesting and varied and to encourage the children to get more involved with the management of their diet and medication.

There were 3 workshops, planning a holiday, healthy eating and a "hands on" cookery session. The workshops helped to further educate the children and families about their condition and its management. People enjoyed having the opportunity to discuss their diets and to share their ideas.

In the cookery workshop the children prepared their own 3 course meal, a mango and pepper salad, five-minute stir-fry and a low protein sundae. The children also practiced weighing out their protein exchanges to accompany their meal. For some it was their first experience of preparing foods and to try their hand at cooking.

We thank VitaFlo who ran the cookery demonstration using recipes provided by Yes We Cook That.com. Low protein foods were also kindly donated by FATE Special Foods; a Victoria sandwich cake, apple and cinnamon muffins and lovely fluffy rolls were made by myself and my colleague Elmarie; SHS provided pasta which I turned into a low protein pasta salad and cookies; PKFoods cookies, pasta spirals and bread; Promin's imitation rice and cous cous also went down a treat.

Eleanor Weetch, the Dietitian from the NSPKU Society kindly ran the holiday workshop and informed everybody on the weekend break held at Edale Activity Centre.

Sarah Adam, senior specialist paediatric dietitian ran the workshop on how to achieve a healthy balanced diet when protein must be restricted. Using picture aids the children were asked to identify what foods were to be avoided, what required measuring and

what foods could be counted as free. The children then had to put their own balanced meal together. We discussed the frequency of blood phenylalanine monitoring and the ideal amount of phenylalanine that should be in blood.

A low protein lunch was then provided for everybody and included a sweet potato and okra curry, vegetable extravaganza, low protein casserole, grapefruit and pineapple smoothies and a summer fruits smoothie.

The children and parents seemed to thoroughly enjoy themselves and all the feedback was very positive, comments were: 'brilliant, good tasting the food', 'really really fun, more cooking please', 'informative and interesting', 'helpful to meet other people and learn about foods not tried before', 'to learn new things', 'meet people in a similar situation and learn more about PKU'.

A raffle raised £40 pounds for the NSPKU and there were prizes for everyone.

A big thank you also goes to the other dietitians who helped, Sharon Lowry and Leslie Robertson (who was Chief photographer and time keeper), the dietitians from Sheffield Children's Hospital, Allyson Terry, dietitian from Alder Hey Children's Hospital in Liverpool and my colleague from Barnsley, Elmarie Van Aswegen.

I hope to organize a similar event next year.

Sarah Adam

Senior Specialist Paediatric Dietitian



Pat Portnoi retires from SHS

In our last issue, we learned that Pat Portnoi, SHS dietitian had retired. Eleanor told us about the award she presented to her. In this issue, we thought it would be nice to share with you the thoughts and memories regarding her career. Who knows, maybe a young reader may be inspired to follow in her footsteps, it certainly sounds like an exciting and rewarding path to follow!

I must first say how pleased and surprised I was to receive this award. It has been a pleasure to work with PKU over the years, and I know that the award goes to all those at SHS who have worked alongside me.

I worked as a dietitian in the NHS for 4 years before joining SHS in 1981. I had moved to Birmingham with my first husband and was looking for a job as a dietitian. There were none in the area, but SHS had a vacancy and so I joined them. "good experience for a year" I thought, and never looked back! Joining SHS was like becoming part of a family. In those days it was a small family- owned business, and there was already a history in metabolic disease and PKU with old products such as Albumaid XP (remember that). I joined as a sales representative at first, soon became an area manager, and then moved to a job as marketing manager. I particularly enjoyed working with the metabolic products, and soon became known for this, travelling widely and meeting many doctors and dietitians in the UK. The number of dietitians at SHS grew, with the development of the R&D department, sales team and nutritional services. At this stage SHS was quite small and I was involved in all product areas and not just PKU. My friend and colleague Pat Wallis joined SHS at the same time as I did, and she was based in head office. She helped develop the in-house nutritional service at SHS and provided me with much help when I was out of the office.

I soon started travelling with SHS, my first visit abroad being in 1985 to Sweden to discuss Maxamaid XP at a Swedish dietitians' conference. I remember discussing tyrosinaemia with the

consultants and one of our new special products was born. Soon I was travelling all over the world for SHS - Europe, USA and Australia at first. SHS was growing with new distributors being set up, or new subsidiaries. As nutrition became more recognized, and more dietitians appointed, so the product range at SHS grew, with a commitment to disease specific nutrition. Wherever possible SHS would try to produce a special product if there was a need for it. If this meant a product for just one child, then that would be done, if it was technically possible. Some of these "special" products later went on to become very important, others always remained small. All these developments were not just done by me of course- it involved every one at SHS, from the R&D, registration services, production, customer care to the nutritional services and sales department. This award goes to everyone at SHS who has helped over the years!

New product development was a key. We always felt it important to update products and to make them as palatable as possible so there was always an emphasis on this. Ideas often came from individuals or health professionals but we worked hard to keep them updated and to make products taste better. And to produce educational materials to help.

During my time at SHS I helped set up various meetings such as the Adult PKU Study Day in London, working first with Maggie Lilburn and David Brenton, and more recently with Paula Howard and Phil Lee. I also started a study day for health professionals, which has become an annual event, held in March each year. This is on various metabolic disease topics, but always has a half day session on PKU. It has been really interesting to see this meeting grow over the years and it is now in its 19th year with over 300 people attending.

I became a director of SHS in 1990, and also a director of one of our subsidiaries SHS Australia, and held that position until SHS was sold to Valio (a Finnish company) soon after. The family owners (The Scholefields) had reached retirement age, and felt the company needed new owners to help it continue growing. At this stage I decided I wanted to continue to develop the nutritional marketing aspect and continued as metabolic products manager. The new owners let SHS continue to develop in the same vein, but helped with access to some new markets. I remember 2 visits to Russia in the early 1990's, when communism was just cracking, and seeing the treatment of PKU. At the time there was a special school in Moscow for those with PKU, and they would attend during the week



and go home at weekends. Fruit and vegetables for special diets were hard to find, and the protein supplement was made in the USSR. It smelt really awful so they made it up in a fume cupboard, before dispensing to the children! I knew we could provide better products – easier to take. I visited once with Dr Isabel Smith for a Russian medical conference, and had a fascinating glimpse of Moscow. I also remember an ESPKU conference in Poznam (which Eleanor also attended) which was equally interesting, with food being a bit limited! One of my memories of this trip is Anita MacDonald having her passport stolen and helping to get a new one for her at the UK embassy in Warsaw.

I continued to travel widely both in the UK and abroad, spending much of my time away from home. However in 1994 I remarried and soon family followed- James and then Sarah two years later. I was an older mother (both were born when I was in my forties), so I went part-time at SHS now working 3 days a week. I still travelled a bit and did a lot of juggling child care. It was however very tiring so I took the opportunity to become the dietitian to the galactosaemia support group (about 1 day a week) and cut down my hours at SHS correspondingly, when possible.

SHS continued to grow and in 1996 was acquired by Nutricia, who have continued to help the company grow. It has helped provide contacts and subsidiaries all over the world so that the SHS range is now available in so many more countries. Development of PKU and other metabolic services in South America and the Far East and China has meant PKU is now very much an international problem. Many UK health professionals have assisted by speaking at meetings and conferences in these countries, and I am sure will continue to be asked to do so!

I decided to retire from SHS last year, having had breast cancer diagnosed the year before. This is now treated and behind me, but it made me decide to spend more time with my children and husband and opt to work from home. I continue with the galactosaemia support group and am also doing a little bit of consultancy work for SHS. One of the projects I am still involved with is the Untreated PKU trial. I have been part of the steering group set up to get a trial organized in this area, and having worked on this with my colleagues for over 6 years (including Eleanor and Phil), and wanted to continue with the steering group until it is finished. I am

particularly pleased with my involvement with this as it took so long to get going!

There are so many projects I have been working on over the years at SHS, and I have so many friends and colleagues who I am pleased to have worked with both in hospitals and in the company. As I keep saying, this award goes also to everyone at SHS who helped me, including those who have left and are now working elsewhere!



It has been a pleasure to work with PKU and to attend the NSPKU conferences, and I plan to keep involved in the future. Meeting those with PKU has always been so important. The NSPKU has always been a model society, and I have so often handed out leaflets and talked about the society in

my travels abroad- showing what can be done by the individuals themselves. With the internet, communication has improved dramatically now, but 15- 20 years ago each country was very much on its own, and the NSPKU was a role model.

It will be interesting to see where PKU is in the future-perhaps the diet will be a thing of the past! When I joined SHS over 25 years ago I was informed that in 10 years time gene therapy will have 'cured' PKU. Well it is still here now but who knows?

Home and Away with PKU

“Jane, an adult with untreated PKU tries out the PKU diet on holiday!”

“When we first talked about the trial, the staff here weren’t sure about what Jane would be allowed to eat and what she could not eat on the trial. Would she have enough to eat? Would she miss some of the foods she loves? What would she eat instead? And some of foods she could have lots of seemed to be completely the opposite of those healthy foods we encourage Jane to have!” recalls Jane’s home manager.

“As it has turned out we have not had as many problems as we feared. By doing some forward planning and with support from Lesley (who has always been contactable by phone), we have found ways to offer variety in the meals given and to avoid over-consumption of nutritionally poor foods.

“In fact, the staff did a grand job coming up with meals based on her special foods (such as a meat free “meat” pie, lasagnes, veggie bakes, and even a birthday cake made with her PKU flour.

“A big challenge we faced was how Jane would cope when she went on holiday. Jane has always believed that a holiday abroad was the only type of holiday to have (she is not on her own there!) and we were worried that going abroad would present us with some REAL issues! But Jane’s keyworker and another member of staff (who would be supporting Jane and another service user on their holiday) sat down with the PKU food “bible” and discussed the issues that could arise and how we could deal with them.

Jane’s keyworker describes what they did next. “We contacted Lesley for some advice about taking the amino acid powder through customs and she provided us with a letter to prove it was a nutritional supplement and nothing more sinister. So once this was done we booked the holiday (a self catering last minute deal to Kefalonia), packed Jane’s suitcase with all we would need to take with us (including her milk, rice cakes, the supplement drink, Jaffa cakes, Weetabix, Ready Brek and crisps). Once on the island we were more than able to plan and sort the meals within the boundaries of the diet, we counted the exchanges of each meal then planned the next following this. This did not infringe on the holiday at all and we got used to planning the meals as we went along, and Jane had a wonderful holiday where she did not miss out at all. Jane enjoyed her rice cakes with mayo and slices of tomato, salads with olives, chips and small ice creams. As Jane’s keyworker I was concerned that the diet would restrict her enjoyment of the holiday but I would say that with a little bit of thought,

planning and a drop of common sense, it can be done, was done and was a great success.”

Back home, Jane and the staff continue the success story. As the care home manager says, “We have now just started the second 6 months and feel very comfortable with the foods and are looking forward to the results at the end. All the staff who support Jane have enjoyed the last 6 months, and even though we’ve been challenged at times, it will be worth it if it has an impact on Jane’s quality of life. Even if it does not, we have at least supported Jane in an attempt to improve her quality of life.”



PKU Pronto!

I must admit that this issue's recipe is not the most glamorous one I've dreamt up. However, what we're after in this column is recipes for when you're tired, hungry and quite possible desperate! I do worry that there is a bias too in this column for kiddie-friendly meals and I am aware that the PKU diet is for life not just childhood. Still, when we're staaaarving and in need of something to eat NOW, sophisticated dishes are probably not what we're hankering after. So, now that I've explained myself, let's get on with *Rice, Peas* and *Peppers!*

Yet again, this recipe has two of my favourite features – it can include exchanges or not and can be tinkered with to feed the non-PKU contingent. My kids Hoover it up – with ketchup of course! I could eat a massive bowl of it myself in front of Coronation Street, but then I've always been a classy chick....

This is more of a method than a recipe so I'll just describe how I make it.

1. Chop up some **onion** and **pepper**. I reckon one onion feeds about 2 people as does one pepper. Crush some garlic – amount to taste.
2. Boil the kettle, then pour the **hot water** into a saucepan.
3. Remembering that 15g of raw **rice** equals one exchange when cooked, add required amount of long grain rice to the saucepan. You can of course use low-protein rice here instead in which case, you don't need to weigh it. Cook for 10 mins.
4. Meanwhile, in a small frying pan, heat some **olive oil** then fry the onion until soft. Then add the crushed garlic and chopped peppers. Take care that the garlic doesn't burn but cook gently until everything is soft.
5. In another small saucepan, boil up some water and cook some frozen **peas**. 25g equal one exchange after cooking.
6. When it's cooked, drain the rice. I always rinse it with more boiling water from the kettle at this juncture to keep it fluffy. Then, if you're using normal rice, weigh your required amount of exchanges and place in a bowl.
7. Drain the peas and weigh them as with the rice. Add them to the rice.
8. Mix the onion, garlic and peppers with the rice and peas. Stir through either a knob of butter or perhaps some garlic olive oil. Eat!
9. You could use courgettes here as well as or instead of the peas. Perhaps, fry some chilli with the onions? What about some mushrooms here too?
10. If you're hungry but don't have many exchanges left, you could always mix low-protein rice with normal long grain. You'd have to use two saucepans to cook the different types of rice of course otherwise you couldn't weigh the long grain rice properly. But it's only boiling water – not much of a pain to clean up!
11. **FOR NON-PKUs** – add grated cheese or indeed some leftovers shredded from the Sunday roast.

Kiri Thomas



Dietitian's Report

Let's Get Cooking!

Barbara Cochrane in Glasgow told me about a great web site dedicated to vegetables. It's called thinkvegetables.co.uk and there is such a lot of useful and inspiring information there.

It gives the vegetables in season (you can click on a month on a calendar and all the UK vegetables for that month are given). You then click on the picture of that vegetable for the month and it tells you and shows you what the vegetable looks like, how to choose the best quality, how to prepare, use and cook and gives recipes.

Some of the recipes are not suitable as they contain nuts or dairy products but in many cases you can either just leave out these ingredients or substitute something else as I have done in the recipe below.

The web site also gives the protein content of the vegetables but you can ignore this, as long as the vegetable is in the 'free' list you can use it freely. Although a vegetable may look to contain some protein the phenylalanine is low if it is in the 'free' list. Our amino acid analysis has helped us with this information.

This is what I found and have tried already I was so keen! We love sweet potatoes so I clicked on them. These sweet potatoes wedges are very similar to Eileen Green's recipe for them. Wedges are very popular and children like to eat with their fingers.

Cajun Spiced Sweet Potato Wedges

4 large Sweet Potatoes
3 tablespoons Olive Oil
3 Tablespoons Cajun Seasoning
Salsa or similar 'free' sauce to serve

What to do!

1. Preheat oven to 220/Gas mark 8. Slice each sweet potato in half lengthways and cut again to make 3 fat wedges.
2. Mix the oil and Cajun seasoning in a small bowl. Brush the mixture over the flesh of the sweet potato.
3. Transfer to a non-stick roasting tin and bake for 15-20 minutes.
4. Serve with Salsa or any free dip.



On the web site the recipe says use Tzatziki but this is yoghurt based so is not suitable.

Cajun Spiced Sweet Potato Wedges

I then clicked on courgettes because once they are in season they are cheap and if you grow them you know you can't keep up with them. I recently bought a hand-held slicing gadget and as you know with these things you want to slice everything in the fridge you get a bit carried away! I sliced some courgettes very thinly and put them in a mixed salad. This is what the web site had to say:-

Courgettes

How to use

Courgettes can be eaten raw or cooked. Finely chopped or grated raw courgettes and carrot can be mixed together and drizzled with French Dressing to make a classic simple salad. Courgettes can be fried in butter or steamed and served with lemon juice as a mouth-watering side dish. They can be included in tarts, pasta sauces and vegetables bakes and the main ingredient in the Mediterranean dish ratatouille.



Sliced in jiffy



Can't stop- see what I mean!



Courgettes fried in olive oil or garlic

Fate Special Foods recipes



Hello,

This time I thought I'd do my new version of an old favourite ~ Low Protein Scotch Pancakes.

They are quick and easy to prepare, and are very versatile.

Serve them hot or cold, at any time of day. Eat them simply on their own, with jam, or with sliced fresh fruit. This recipe makes about 20, so there'll be plenty for freezing.

They freeze well.

FATE SCOTCH PANCAKES - VERSION 2!

300g Fate All-Purpose Mix

30g Custard powder (not custard mix)

pinch salt

80g caster sugar

75mls oil

400mls water

Place the Fate Low Protein All-Purpose Mix into a jug, and stir in the custard powder, salt and caster sugar.

Using a baby's bottle, measure the oil and water and place into a separate jug.

Then pour about half of the liquid onto the dry ingredients. Using a fork or a wire whisk, quickly stir until smooth, thick and creamy, then add the remaining liquid, and mix until blended well.

Place a frying pan over a gentle heat. Do not add any oil.

Add 1 tbsp of the pancake mixture to the pan. Use the back of the spoon to gently spread the mixture to shape into a round pancake about 9 or 10 cms in diameter. Do this gently without lifting the spoon away from the mixture.

It is important that you do not have the pan too hot to begin with, as the mixture will cook before you have time to spread it!

Turn the heat up, and leave the pancake to cook for about 1 minute over a high heat, until the top is dry and the base is golden brown. Turn the pancake over and cook for a further 30 seconds or so. Place onto a wire rack while you cook the remaining pancakes. Serve hot or cold.



Dietitian's Report cont...

Another click on the mouse and more recipes come up.

Aspartame in drinks

Wendy Cheale got in touch with me to let me know that R Whites have just changed the recipe for their lemonade. It now contains aspartame and states on the label 'New Recipe'. This is a popular drink so it's annoying that it is now not suitable for the PKU diet. However, there are still lots of lovely drinks which are OK and you can download a list I researched recently which is on our web site at www.nspku.org



Now **not** suitable for the PKU diet

Fizzy drinks which are sweetened with aspartame will provide around 2 Exchanges per 330ml can so it is significant.

Conference Recipe

Several people who came to the conference in March asked me for the recipe for the **Sweet Potato Rissoles**. The chef gave me the proportions of the ingredients and I have converted this into the recipe but given the proportions for anyone wanting to make up larger numbers of rissoles (maybe for the barbeque).

Carrots 450g
Sweet Potatoes 300g
Onion 100g
Leeks 150g
Fresh Coriander

Method

1. Peel and chop the carrots and sweet potatoes into chunks and steam until soft.
2. Chop the onion and slice the leek and fry in a little olive oil.
3. Use some kitchen paper to dry the vegetables if there is runny juice.
4. Put the vegetables in a food processor to blend and season with a little salt and black pepper.

5. Add some finely chopped coriander – a few sprigs per person- or more if you like. The more fresh herbs you use the less salt you will need.
6. Shape into Patties and dust lightly with low protein flour.
7. Fry in hot olive oil turning occasionally. Serve Crisp.

If the mixture is too wet add crumbed low protein bread to bind it together.

Proportions of the vegetables to use:

Carrots 45%
Sweet Potato 30%
Onion 10%
Leeks 15%

Up-dated Publications

In this issue you will find two of our publications which have been updated – Packed Meals and Advice on Alcohol.

Packed Meals

This booklet contains so many ideas for packed meals but also for tea time inspiration and for lunch at home. I hope you will be inspired by the suggestions of things to try. I often take a packed meal with me for the train, bus or the car (or bike) as it means I can eat my own nice bread and I know it's fresh and it's what I like to eat when I want to eat it and saves money too! Good bread is the basis for a super sandwich so if you get this right you are more than half way to a great packed meal. Fate Special Foods and SHS both produce a booklet on breadmaking using a bread maker which helps to save time and makes a delicious loaf. If you contact them directly or via your dietitian you can obtain a copy.

Advice on Alcohol

This leaflet includes advice on even more alcoholic drinks and information about aspartame in these drinks.

Eleanor Weetch
Society Dietitian



NOW AVAILABLE ON PRESCRIPTION *THE NEW WAY*

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

THE VERSATILE PRODUCTS YOU'VE BEEN WAITING FOR:



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



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



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

EVERY PACK CONTAINS EASY TO FOLLOW RECIPES DEVELOPED BY EILEEN GREEN



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

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

Helpline and General Enquiries Tel: 01215 22 44 34

FATE SPECIAL FOODS ~ SPECIAL FOODS FOR SPECIAL PEOPLE

Curried Dip

Ingredients:

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

* Check NSPKU Handbook for a suitable brand of mayonnaise

Method

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

All PKFoods are now available on prescription



UNIT 270 CENTENNIAL PARK CENTENNIAL AVENUE ELSTREE BOREHAMWOOD HERTS WD6 3SS

TEL: 020 8953 4444 FAX: 020 8953 8285

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

NSPKU 34th Annual Family Conference Weekend 2007

The Rendezvous Hotel, Skipton, North Yorkshire

Friday 2nd to Sunday 4th March 2007



Venue:

This years NSPKU Annual family conference weekend will be held in Skipton, North Yorkshire. This hotel provides us with an absolutely delightful venue to hold our annual event. Escape from the pressures of city life to the picturesque North Yorkshire Dales and Herriot country and enjoy the facilities of one of the most versatile hotels in the area.

Stunning views of the Yorkshire Dales from the peaceful waterside setting and lots of real Yorkshire warmth. The Dales offer some of the finest scenery in England; wild, tranquil, timeless landscapes dotted with grand castles, bustling market towns and beautiful gardens. If you simply want to find a quiet country walk it is all here!.

The Rendezvous Hotel, Skipton is very accessible from all parts of the country.

Accommodation:

There is a great choice of bedrooms, from executive suites and family rooms to luxurious rooms for two, all offering you what you would expect from a top hotel. Comfortable, spacious bedrooms all with private bathroom, direct dial telephone, TV, hairdryer, trouser press, hospitality tray and individual controlled heating. Add all the hotel's business facilities and function rooms, and you will wonder why you had not enjoyed all the benefits of the Rendezvous Hotel before.

Supervision of Children:

Whilst the children will be supervised in the creche, 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:

75 en-suite bedrooms, training centre, 12 meeting rooms, The Mallard Bar, The Baby Swan Restaurant, 120 car parking spaces, playzone nursery, indoor swimming pool, children's pool, whirlpool spa, steam room & sauna, solarium, gymnasium, 2 squash courts and health & beauty salon.

(please note that due to the limited number of bedrooms available, a number of overspill hotels very close by to the Rendezvous Hotel, Skipton will be used to accommodate our guests. In order to maximise your chances of staying in the Rendezvous Hotel, Skipton, early booking is recommended. Guests who stay in other local hotels will conference and take luncheon & dinner in the Rendezvous Hotel, Skipton)

PKU Diet:

You will need to bring the PKU amino acid 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.



Around and About:

Air: Leeds/Bradford airport – 30 minutes.
Manchester airport – 1 hour 15 minutes.

Rail: Skipton station – 1 1/2 miles.

Road: The hotel is situated on the A629 Skipton to Keighley road 1 mile south of Skipton town centre.

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 2007 Residential Conference Fees:

| | |
|---|-----------|
| Non-PKU Adult (17 years +) | = £165.00 |
| Non-PKU Child (4-16 years) | |
| Sharing with parents | = £35.00 |
| Own room/sharing with another child | = £70.00 |
| Non-PKU Infants (0-3 years) | = £15.00 |
| Adult single room weekend supplement (17 years +) | = £15.00 |
| Adult with PKU (17 years +) | = £82.50 |
| Child with PKU (4-16 years) | |
| Sharing with parents | = Free |
| Own room/sharing with another child | = Free |
| Infants with PKU (0-3 years) | = Free |

Day Visitor Fees:

| | |
|---|----------|
| Non-PKU Adult & Children (coffee, luncheon & dinner) | = £15.00 |
| Adult & Children with PKU (coffee, luncheon & dinner) | = Free |

Booking Conditions:

All conference bookings and fees MUST be made by 31st January 2007.

Your NSPKU 2007 Conference Organiser is: Sarah Lawson

45, Balmain Road, Kenton, Newcastle-upon-Tyne NE3 3QQ • Home Telephone: 0191 271 0464
Mobile: 07988 971321 • Email: conference@nspku.org • Website: www.nspku.org

34TH ANNUAL FAMILY CONFERENCE PRELIMINARY PROGRAMME OF EVENTS:

(DAY 1) – FRIDAY 2ND MARCH 2007

- 1230 hrs - NSPKU 34th annual family conference weekend registration desk officially opens in the hotel
Please note that no PKU/NON-PKU arrangements will be made for luncheon today
Remainder of afternoon at guests' own leisure
- 1700 hrs - Welcome civic drinks reception in the main conference hotel
- 1815 hrs - Welcome dinner will be taken in the main hotel only
- 1945 hrs - *Evening entertainment programme the main hotel:* NSPKU 2007 spring draw, DJ & discotheque, Pub Quiz and Overnight hotel

(DAY 2) – SATURDAY 3RD MARCH 2007

- 0700-0845 hrs - Full English breakfast will be served in the main hotel and overspill hotels
- 0830 hrs - Professional nursery/playgroup in the main hotel (infants & children under 8 years)
Children's outing: *IMAX Bradford, the interactive museum for photography, film and television (children over 8 years will be taken out this morning with adult carers)*
- 0900 hrs - NSPKU 34th Annual Family Conference weekend 2007 opening introduction in the main hotel/
Mr David Stenning – NSPKU Chair
- 0915 hrs - Research – PAL – research into enzyme treatment for PKU – Dr Christineh Sarkissian
- 1000 hrs - Maternal PKU – Dr Sue Bewley
- 1045 hrs - Morning coffee/tea break & biscuits (PKU food manufacturers exhibition open)
- 1115 hrs - Getting off to a good start – Anna Brazier, Psychologist
- 1145 hrs - Personal experience – travel, leaving home
- 1300 hrs - Luncheon will be served in the main hotel only
- 1400 hrs - Cookery demonstration with SHS
- 1700 hrs - Children's PKU party in the main hotel – Disco, DJ and Magician to be held in the hotel's Nightclub
- 1730 hrs - 2007 NSPKU Annual General Meeting in the main hotel
- 1915 hrs - Final dinner in the main hotel only
- 2100 hrs - *Evening live entertainment act in the main hotel:* ABBA TRIBUTE DUO/Overnight hotel

(DAY 3) – SUNDAY 4TH MARCH 2007

- 0700-0845 hrs - Full English breakfast will be served in the main hotel and overspill hotels
- 0830 hrs - Professional nursery/playgroup in the main hotel (infants & children under 8 years)
Children's outing: *Embassy and Bolton Abbey Steam Railway – take a ride on an old fashioned steam train! (children over 8 years will be taken out this morning with adult carers)*
- 0915 hrs - Weighing Research / Biomarin Trial, Dr Anita MacDonald
- 1000 hrs - Short Presentations – Maternal PKU Audit – Di Asplin/Brook St. Advice & Experience at Guy's – Jane Gick/ Pregnancy – Charlotte Tourgout
- 1045 hrs - Morning coffee/tea break & biscuits (PKU food manufacturers exhibition open)
- 1115 hrs - Workshops: Di Asplin/Charlotte Tourgout – Maternal PKU/Jane Gick – New Families & issues Arising/Dietitians – Supermarket Sweep
- 1215 hrs - Feedback session for workshops
- 1230 hrs - Luncheon to be served in the main hotel

PLEASE NOTE THAT THIS IS A PROVISIONAL PROGRAMME OF EVENTS AND IS SUBJECT TO CHANGE, PLEASE KEEP CHECKING WEBSITE FOR UPDATES WWW.NSPKU.ORG

Yes We Cook That.com

Specialist Dietary Foods

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

Vitaflo and Fresenius Kabi Working together to provide a home delivery service for you

Vitaflo are now delighted to announce the launch of
a home delivery service called



Vitaflo have teamed up with a company called
Fresenius Kabi Homecare to deliver your Vitaflo products directly
to your home each month.



By utilising their many years of experience in home delivery,
we can now offer a worry free and reliable means of obtaining
your Vitaflo products.



The service is provided free of charge from Vitaflo.



For more information or to register with this service,
contact your dietitian or doctor
or contact Vitaflo on

0151 709 9020



Fresenius
Kabi

Working together to deliver a better service

SHS **Homeward**

... more than just home delivery

- **Delivering SHS protein substitutes and milk substitutes directly to patients**
- **The first and only dedicated home delivery service for people with PKU (Phenylketonuria) and other inborn errors of metabolism.**
- **Clinically proven to aid compliance to diet[†]**

For more information call:

08457 623605



The Italian Job

Loprofin Pasta is just the 'Italian' job.

The Loprofin authentic low protein

Italian pasta range from SHS.



For more information on Loprofin Pasta please contact Nutrition Services on 0151 228 1992

SHS