NSPKU

News&Views

The National Society for Phenylketonuria (UK) Ltd

Issue 113

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PKU in Korea

Details of the 2006 Family Conference Inside!

In Touch

The Council of Management

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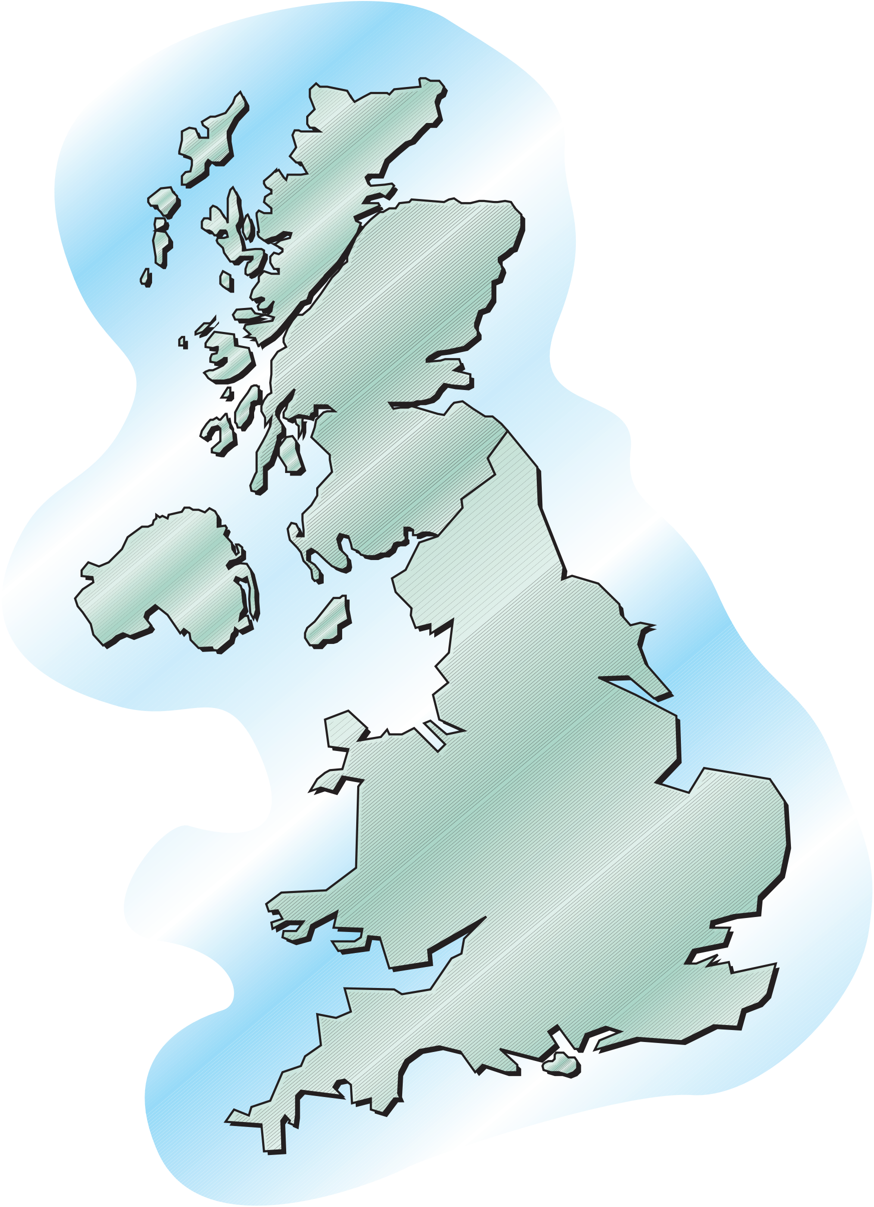

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Editor's Report...

I hope you all enjoyed the warm summer weather over the last few months. Our toddlers have spent as much time as possible completely naked running around the garden! I haven't followed suit you'll be relieved to hear but do seem to have spent a lot time drinking chilled rose wine. I know, I know, it's a tough job….

Whilst quaffing more than my fair share of pink drinks, I've also been attempting to introduce lots of salads and summer fruits into our little boys' diets. They keep telling me they prefer chips and ice lollies, I keep pushing the courgettes and berries. This issue, I've given you a recipe for PKU Pesto Sauce which my 3 year old adores but yesterday, when faced with a plate of stir-fried vegetables he told me he hated the colour green and turned with his back to the table, "I like 'Shrek' Mummy but I do not like green". I tell you this just in case anyone out there is under the impression that my children are bizarre vegetable-eating, sugar and salt shunning little angels. They ain't but I'll die trying to make them so!

This issue too, I'm really excited about an article that we've very kindly been allowed to reprint from the Korea Herald. It's fascinating and moving to me to think that just because we live thousands of miles apart and look so very dissimilar, a group of Koreans have in some respects, the same genes as us. In these paranoid times when difference seems to be something to be scared of, I really feel it's timely to remember that the human race is far more alike than different. I'm concerned I may sound dramatic, but I do believe that in a strange way, PKU reminds us of our connection to all humanity.

Kiri Thomas.
Editor

NSPKU
The National Society for Phenylketonuria (United Kingdom) Limited

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Treasurer's Report...

This is an exciting time for me as Treasurer. You may remember that in my last report I mentioned that we would be analysing some of the committee's roles to try and make more of our time. When I became Treasurer 6 years ago (can it really be that long?), I was rather daunted by the role. I spent the first year panicking that I wasn't capable, the second year coming to grips with the job and the third reasonably happy that I finally knew what I was doing.

Over the last couple of years I have become increasingly aware that I have been only half fulfilling the role of treasurer. I spend so much time involved in the day to day admin of the job (paying in cheques, paying bills, keeping general accounts) which means I have very little time to get really stuck into the big jobs such as checking out investments and insurances, preparing budgets and cash-flow forecasts. Basically I have no time to make the best use of the Society's funds.

Hence the reason for my excitement! I have spent the last few months investigating the possibility of passing much of my day to day work to a book-keeper. We are now hopefully very close to our goal and in the final stages of preparing to pass on some of my work-load. The only down side of this is that I'm now back to square one panicking again that I am not capable of this redefined role. I shall just try to remember what one of my old bosses said to me many years ago (you may have read the book, and indeed have the T shirt) "feel the fear and do it anyway".

Julia Bailey
Honorary Treasurer

Chairman's Report...

This copy of News and Views will have landed more heavily on your doorstep than usual. In this issue you will have the new dietary information booklets and I know that you will be looking through these eagerly to see what is new. There are a number of prescribable and supermarket foods which are included for the first time. Some of these are there because of the amino acid analysis we undertake each year. We try to analyse 10 new foods so that we can keep bringing new foods into the diet and so help to keep it interesting and as normal and easy as possible. Let Eleanor know if there is anything you would like to have on the list this next time around.

Unfortunately two crackers we had analysed and which were found to be suitably low enough in phenylalanine to be taken freely have suddenly been discontinued. These were Walker's Crackers in Black Bean and Spring Onion flavour and Thai Lemon Grass and Coconut flavour. This is really disappointing and I know that Eleanor and other dietitians have written to Walkers to plead our case to try to get them re-introduced. It might help if you could also write to Walkers and I include the address below. We can but try and consumer power can be effective.

The Managing Director,
Walker's Snack Foods ltd.,
P.O. Box 23,
Leicester
LE4 8ZU

The other publication in this bumper pack is 'Joe's Story'. This is the long- awaited booklet to help the young to understand PKU. Joe is the youngest son of the Reverend Gary and Mrs Lynn Schofield. He has PKU and it is his story. You may remember we ran a competition to find a good story and the Schofield family were the winners. We are very grateful to them for producing such a delightful little booklet for us. I would also like to thank John Tuck, a former chairman, who arranged all the lay-out and Elaine Nipper, the artist, who both gave their time freely. We have a super addition to our publications! Happy reading!

Finally, I want to tell you about the London Adult Study Day. It is on November 12th in rooms just off Regent Street in London. There is a lot to learn and enjoy by going to one of these days. It is free but you need to contact Mrs Paula Hallam for details and booking in so that you will be fed!

Mrs Paula Hallam,
Senior Dietitian,
National Hospital for Neurology and Neurosurgery,
Queen Street,
London
WC1N 3BG

email paula.hallam@uclh.nhs.uk

Letters

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

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

Dear News and Views

Please find enclosed £200 donated in remembrance of David Gell, granddad to Luke Gell born 18th April 2001, with PKU.

This money was given by friends in Cyprus where he last lived. Further donations were sent directly to the NSPKU by friends and family from the UK and the Isle of Man.

Yours,
J.A. Gell

Editor's Note: An extra £280 has been very gratefully received by the society in David's memory.

David Gell & his grandson Luke

Dear News and Views,

We held another Mid Summer Notes concert on Saturday 18th June and again it was a tremendous success. The weather was perfect and the event took place in our village of Barford in a beautiful garden setting. Hannah is doing very well and is at school now. She's gorgeous as you will see from the picture!

I enclose a cheque for £200 for the NSPKU with our love and gratitude for all in the Society. Caroline and Ned have so much support from you all: it's wonderful!

With very best wishes to you,
Shirley Osborne.

Dear News and Views,

Please see the attached photo of 3 exhausted females and 2 joyous PKU kids! The photo is of: Alison (cousin to Carys) Margaret (mum to Carys) and Pauline (mum to Lee) with Carys Hopkins & Lee Kerr (both PKU) in front. I think we were saying "that's it done for another year!" when that photo was taken!

I am sending you some cheques today totalling £1373, which we have raised between the 3 of us. It was a great day for all, if a bit hot! We would like to thank all our family, friends and work colleagues who helped us raise the money. I must say too that both Alison and I beat last year's time and Pauline did even better. This was her first run and she didn't manage to get much training in but she still finished in 68 minutes. Well done Pauline, same time, same place, next year! That also goes for any other Glasgow mums who want to raise some funds for NSPKU.

Yours,
Margaret Hopkins.

Alison (Carys's cousin), Margaret (Carys's Mum) and Pauline (Lee's Mum) are congratulated after their run by Carys Hopkins and Lee Kerr, both PKU

Letters

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

Dear News and Views,

Please find enclosed a cheque and banker's draft for £646.74. The money was raised for the NSPKU during the Belfast Marathon on 2nd May 2005. I currently work for the Northern Ireland Civil Service and have PKU. I decided to ask four of my colleagues to run in the relay event of the marathon to raise funds for the NSPKU. I have enjoyed reading the Newsletter over the years and am amazed at the ever improving style of the information presented (some of our older copies are just plain paper with black and white writing highlighted with green!) Many thanks for all your support and useful dietary tips, please continue the excellent work,

Barry McEvoy

Belfast City Marathon 2nd May 2005,
Back Row: Barry Mc Evoy, Martin Agnew
Front Row: Leah Sloan, Julie Andrews, Michelle McGoldrick

Dear News and Views,

Please find enclosed a cheque for £100.00. This is the proceeds of a Christmas Raffle that I have once again organised at my place of work, Bessels Leigh School.

In fact this is the tenth year that I have organised this raffle and would like to thank all staff, parents and friends of Bessels Leigh School for their continued support to our cause.

All the raffle prizes each year are kindly donated by my colleagues at Bessels Leigh and members of my family for which I am eternally grateful.

News and Views has been our lifeline over the years and I always look forward to receiving our copy. Our daughter Amy, now 18, continues to blossom. She works as an Administrator at our local newspaper office and passed her driving test before Christmas. These are all milestones that we thought unsurpassable before Amy was first born but with the help of doctors, dietitians and News and Views everything in ours and Amy's life is rosy.

Thanks to all the members of the C.O.M. for all your hard work on our behalf.

Yours sincerely,
Maureen Arnold

Dear News and Views,

Please find enclosed a cheque for £760 for the NSPKU. On Sunday 12th June, we held a garden party for friends and family who very kindly donated the above sum.

Our 4 year old daughter Kate has PKU. She has 3 brothers who are non-PKU. As a family, we want to thank the NSPKU for their constant support. Kate is an active little girl who leads a very normal life.

Thanks again to all our friends for a great day. We are grateful too that the constantly changing weather didn't keep anyone away!

Yours,
The Selbie family.

All the Selbie Children

Fun at the Selbie garden party

SHARING EXPERIENCES

Having PKU, being on diet and treatment can be a bit of a "bind"; however, if you didn't want anyone to know you wouldn't have to mention it. You look no different to anyone else; you behave just like your friends (good and bad in equal measures!) The only time it becomes obvious is when you go out to eat. Unfortunately eating out today is not a special treat, it is very much part of everyday living. Do you have to explain every time you go out, I can't have this, I can't have that or do you avoid eating out for the sake of explaining? Not having PKU myself, I can only imagine what it must be like but I'll never really know.

Each year at Guys, the metabolic team arranges a teenager's day out. Our aim is firstly to bring young ladies and gents of a similar age together as it is mostly the case that until these events, they will not have met with any other person who has PKU. We plan a day of fun and activity with a subtle undertone of education - what teenager would volunteer to spend time learning about their condition voluntarily!

We learn in this informal setting, views, opinions and difficulties experienced with living with PKU, which probably would not be revealed through a formal clinic setting. It is hoped with this shared information we can discuss practical ways of working through problems. Discussions were raised during our table top quiz and whilst baking the best chocolate cake.

Each year we discover that the groups all appear to know a lot about their diet and treatment, they know exactly how to measure exchanges etc. What they all seem to find difficult, is how to tell friends. Most are not concerned at disclosing to friends about their condition, what they find difficult is explaining exactly what PKU is!

This is hardly surprising, I suppose, my family often ask what my work involves. I struggle with an explanation to generalise metabolic conditions. If I used the word Phenylketonuria, I expect they would fall asleep by the time I finished the sentence. My parents tell people "Jane works with children who can't eat most foods." I get cross when they put it like that, what must our children and families feel having to explain things daily?

This year one of our volunteer helpers is a patient who came on sixth form work experience. She has atypical PKU and keeps in touch with the PKU clinic on an annual basis. The experience gained from both the teenagers and Amy is that they share life experiences and learn from one another. Amy does not require diet; she has never had to take supplement, however her phenylalanine levels remain slightly elevated. They do not exceed the recommended range to require dietary management but she knows that when the time comes for having children, she will need both the care of an obstetrician and a PKU specialist centre to give her baby the best chance of being born fit and healthy, unaffected by the harm a raised phenylalanine can cause. Potentially Amy may require a similar diet during conception and pregnancy.

By volunteering to help out on the day she was able to experience youngsters getting on with life even though they have classical Phenylketonuria. The teenagers themselves were interested in Amy's condition, learning about different aspects of PKU they had little awareness of. Introducing one another as a group makes it far easier to explain whys and hows of a condition better than any text- book. We could discuss exchanges, why some people were on more exchanges than others, why Amy didn't need diet but would always remain in some contact with a metabolic service.

Amy's work experience was to look at a career in nursing, which I'm pleased to say she thoroughly enjoyed as she got the chance to visit many of our paediatric departments at Guy's. We didn't put her off and wish her every success with her A-levels so that she can pursue her chosen career.

The afternoon activity this year was bowling, we had many laughs, some strikes and a number of complete misses, (not mentioning any names.) Last, but not least, we finished the day with a meal at a restaurant where the youngsters could choose a selection of food and drinks from a menu prepared to suit their diets. No questions asked!

With family permission we send a summary of the day to our local newspaper. Being in London, it does receive a wide readership. Sending in the story, we talk about the "heel prick test" and the success of treatment, which hopefully raises awareness of Phenylketonuria to the general public.

Continued on page... 6

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All in all, we always have great fun; a lovely day out and we each go away with a little more knowledge than we had at the beginning of the day.

Post script
A typical Phenylketonuria is picked up on heel prick screening at birth. The discovery is that these patients have a slightly raised phenylalanine level. Over a period of a year or so, the blood is measured to look at the trend to see whether or not the levels remain unchanged.

In males, the slight elevation is insignificant and it is likely they will be discharged. For females however, this level remains insignificant until planning a pregnancy. A slightly elevated phenylalanine level will need close monitoring both during the pre-conception stage, (this is when contraception has been purposely stopped in order to become pregnant) and during the pregnancy. Elevated phenylalanine is harmful to a developing baby and can cause serious abnormalities.

Management involves very regular blood spot monitoring (at least weekly.) Adjustment to the diet may be necessary as well as the introduction of a protein supplement. Because of the possibility that ladies are likely to require treatment to ensure a pregnancy is unaffected by a raised phenylalanine level, it is wise for all females to maintain contact with their nearest specialist metabolic service if only to be seen once a year to maintain these links. Should you be a female reading this article knowing you do not meet with a metabolic team and have a raised phenylalanine level, go to your G.P and discuss with him/her your situation and ask for a referral.

Jane Gick
Specialist Metabolic Nurse
Guy's and St. Thomas's Hospital

DOES THE TAX MAN OWE YOU MONEY?

From April 2004 anyone who completes a Self Assesment tax return will be able to nominate a charity to receive all or part of any repayment due to them. All you have to do is enter the identification code for the NSPKU (NAR80ZG) from the Inland Revenue's list of charities on to your tax assessment form and they will do the rest. For more information either contact your local Inland Revenue Office or our Treasurer – Julia Bailey, (contact details inside the front cover).

NEW

NOW AVAILABLE ON PRESCRIPTION

Start your day with a Hot Breakfast

THREE GREAT TASTING HOT BREAKFASTS FOR YOU TO ENJOY

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

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

Simply mix with hot water. Promin Hot Breakfast is convenient and easy to make. Its an instant hot breakfast, you could even enjoy a bowl for your supper. Promin Hot Breakfast is a great addition to your kitchen cupboard. Available direct from Firstplay, see the contact details below.

Full analysis available on request.

PROMIN

Firstplay Dietary Foods was formed in 1993 to produce Promin Low Protein products from a small factory in Stockport, where we only produce low protein products. Promin Pasta and Promin Tri-Colour Pasta are now a well established brand and are available on prescription. Our pasta range available by prescription also includes Imitation Rice, Pasta meal and Lasagna Sheets they are also available by mail order. More recently interaction with PKU patients, parents and Dietitians has resulted in the expansion of the Promin range. New products have been designed to reflect the needs of a maturing PKU population leading busy hectic lifestyles.

Call us for more information or with your dietary suggestions. Firstplay Dietary Foods produce low protein foods especially for your diet.

Always consult your dietitian before trying something new.

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

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

DLA - A Reader's Thoughts

Editor's note: *Last issue's article about the Disability Living Allowance prompted some spirited replies! One reader wished to share her experience of DLA with News and Views but did not want to reveal her name. Her thoughts are below.*

I am almost 23 years old with atypical-PKU and have only been on-diet for 1 and a half years. Currently, I'm studying for my PhD

When I first arrived in university as an undergraduate, I did not think of myself as "disabled". It was only pointed out to me after a lecturer approached me about the word "Phenylketonuria" on my records, and referred me to the college disability advisor. She told me that I was eligible for Disability Living Allowance. I applied in my first year at university, was successful and I have been claiming each year since.

The disability advisor suggested that she help me fill in the form for my first claim, and this was incredibly helpful - life with things like weighing, measuring, tablets, and low-protein foods seems so normal to me...until you explain it to somebody else! As I told her about my lifestyle she was able to write things down that I would have otherwise overlooked.

For the first year, I was awarded the middle rate for personal care, but since then I have been awarded the lower rate for personal care. I never had any trouble with the application, and was surprised when I read of other PKU families who had not been successful with their application. Although I claim primarily on the grounds of being PKU, I have also had other health issues that I have always included at the end of the form, and perhaps this may have influenced their decision. However, I have just applied again for this year, so we'll see what happens this time!

NSPKU SPRING DRAW 2005 - PRIZE WINNERS

	Prize	Ticket No.	Name	
1	£500 CASH	23107	Mrs McFadden	Craigavon , N.I
2	Digital Camera	11024	Natalie Johnston	Strood , Kent
3	Personal CD Player	8058	David Bennett	Mirfield , W. Yorkshire
4	First Play Prize £50 M & S V/c	11522	J Crumpton	London
5	Blackpool Leisure Beach- Vouchers	25203	Mrs Smith	Mkt Harborough , Leicestershire
6	£25 H.M.V Vouchers	22669	Alison Russell	Sheffield
7	£25 Book Vouchers	2950	Mrs H Oliver	Worsley , Manchester
8	£25 M & S Vouchers	27723	Lynsey Dumayne	Northville,Cwmbran
9	£25 B.H.S Vouchers	8284	P.Bright London	
10	£20 W.H.Smith Vouchers	783	J Wilton Leeds	
11	£10 Morrison V/c	1992	Barry McEvoy	Joneboro' , Co. Armagh

Thank you to all who bought and/or sold Raffle Tickets on behalf of the Society , especially those who asked for more tickets .

The total raised was just over £4,400 . The drop is undoubtedly due to the Society going over to the CAF address listing .

This was my last Spring Draw and I leave you all in the capable hands of Simon Murphy who , I am sure , will be a great asset to the Society .
Eric Lange 23 rd March 2005

PKU in Korea

Aussie diplomat brings hope to children with rare disease

Standing in front of families with children diagnosed with a rare metabolic disorder called phenylketonuria, Bill Brummitt, a 35-year-old Australian, addressed them in a trembling voice, probably for the last time.

"The whole experience with the Korean PKU group - it's been one of the best experiences in Korea," he told the gathering of Korean PKU families in Soonchunhyang hospital, in downtown Seoul, on Saturday.

Scheduled to leave Korea next month after a 37-month stay, Brummitt has been a messenger of hope and inspiration for PKU patients and their families. An economic counselor at the Australian mission to Korea, and father of daughters Naomi and Olivia, Brummitt is, most importantly, PKU positive.

Phenylketonuria or PKU is a rare genetic disorder of metabolism which is found in about one out of 80,000 to 100,000 new babies in Korea.

More than 100 people with the disorder, mostly children, have been identified in Korea since the first case was found about 20 years ago.

The condition is characterized by the absence or deficiency of an enzyme that utilizes the essential amino acid phenylalanine. Without this enzyme, phenylalanine from the food one consumes accumulates in the blood and body tissues, causing fairer skin and hair, and retardation. However, the condition can be treated with a high degree of success if diagnosed shortly after birth. The main treatment is adherence to a low phenylalanine diet for the remainder of one's life. The condition requires avoiding meat, dairy products and other protein-heavy food, leaving those with the condition eating essentially a vegetarian diet and special food items formulated to have little protein.

Brummitt was one of the first babies whose PKU condition was detected shortly after birth through a newborn screening system set up by the Australian government in the late 1960s. In Korea, a blood test for PKU is being made available for all newborns from this year, with the cost fully covered by the government.

Thanks to a special infant formula and diet that kept his phenylalanine rate low while providing enough of other kinds of protein that are needed by the human body, Brummitt appears as fit as any other man in his 30s, and is little enough affected by his condition that he can serve as a career diplomat.

Before coming to Korea in 2001, he hadn't been involved with any kind of PKU group activities in Australia. His encounter with the Korean PKU group, however, came in January 2003 with the birth of his second daughter, Olivia. Knowing that his condition can be inherited, he naturally wanted to have Olivia tested for the disease. When he was introduced to Dr. Lee Dong-won, a PKU specialist at Soonchunhyang Hospital, he received the happy news that she had not inherited the disorder, but also learned, to his surprise, that there are PKU sufferers in Korea.

Since then, he has actively participated in the PKU-related activities, hoping to help other people cope better with the conditions by sharing his own experiences and information.

"I was lucky to be picked up at birth. If born four or five years earlier, I might not have been picked up at birth. And I was lucky to have parents who really looked after me and made me stick to my diet. So for me this was a way to give something back," he told The Korea Herald after the PKU group's meeting Saturday.

In 2003 and 2004, he joined a summer camp for PKU families, bringing with him an unexpected package - financial support from the Australia-New Zealand Chamber of Commerce in Korea. The business organization promised to extend 5 million won in support for the camp annually.

"PKU shouldn't stop people from doing anything. You can live overseas, study anything you want to study, or do any job you want to do. PKU shouldn't stop children or their parents from doing anything," Brummitt says.

To recognize his assistance to the Korean PKU group, Minister of Health and Welfare Kim Geun-tae presented him with a certificate of appreciation last week.

As he prepares to return to Australia, Brummitt says he believes his connection with Korea will persist throughout his life, since his daughter, Olivia, was born in Seoul at Soonchunhyang Hospital, and because he wants to keep contact with the Korean PKU group.

"People think of PKU as a negative thing. But as you grow up, you come to understand even with PKU there are positive aspects," he said. "To me, the whole experiences I had with the PKU group in Korea - that was a huge positive of having PKU. It would've never happened if I hadn't had PKU," he said.

(milaya@heraldm.com)
By Lee Sun-young

(Reprinted by kind permission of The Korea Herald where it was first published in October 2004)

New Parents Learning more about PKU

Results of Newborn Blood Spot Screening

Phenylketonuria is suspected

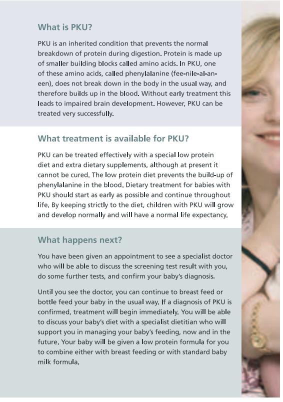
What is my baby's screening result?

When your baby was about a week old, your midwife took some blood from your baby's heel. The blood was used to test for some rare conditions, including phenylketonuria (PKU).

The screening test result suggests that your baby may have phenylketonuria (fee-nile-key-tone-you-ree-ah), or a related condition, although this result will need to be confirmed through further blood tests.

PKU is not a life-threatening condition, and if medical advice is followed, your baby will grow and develop normally.

This leaflet gives some information about PKU and what happens next.



What is PKU?

PKU is an inherited condition that prevents the normal breakdown of protein during digestion. Protein is made up of smaller building blocks called amino acids. In PKU, one of these amino acids, called phenylalanine (fee-nile-al-an-een), does not break down in the body in the usual way, and therefore builds up in the blood. Without early treatment this leads to impaired brain development. However, PKU can be treated very successfully.

What treatment is available for PKU?

PKU can be treated effectively with a special low protein diet and extra dietary supplements, although at present it cannot be cured. The low protein diet prevents the build-up of phenylalanine in the blood. Dietary treatment for babies with PKU should start as early as possible and continue throughout life. By keeping strictly to the diet, children with PKU will grow and develop normally and will have a normal life expectancy.

What happens next?

You have been given an appointment to see a specialist doctor who will be able to discuss the screening test result with you, do some further tests, and confirm your baby's diagnosis.

Until you see the doctor, you can continue to breast feed or bottle feed your baby in the usual way. If a diagnosis of PKU is confirmed, treatment will begin immediately. You will be able to discuss your baby's diet with a specialist dietitian who will support you in managing your baby's feeding, now and in the future. Your baby will be given a low protein formula for you to combine either with breast feeding or with standard baby milk formula.

Parents of babies with PKU often ask the following questions:

How do children get PKU?

PKU is an inherited condition due to an altered gene. It is not caused by anything parents did during pregnancy. Everyone carries a few genes that have become altered in some way and are passed on sometimes unknowingly in families.

A baby with PKU has inherited two copies of the same altered gene, one from each parent, which together cause PKU. When two people with this gene alteration have a baby, they have a 1 in 4 (25%) chance in every pregnancy of having a child with PKU. There is nothing the parents could have done to prevent their child having PKU.

What is life like for children with PKU?

Children with PKU are able to live full and active lives, just like any other children, as long as they keep to the special low-protein diet. To maintain a child's health it is important that the amount of phenylalanine in their blood is kept within acceptable levels. These levels are monitored carefully

Pre-Screening Leaflet Available in 11 Languages

English
French
Portuguese
Somali
Turkish
Bengali
Arabic
Urdu
Greek
Gujarati
Romanian

The UK Newborn Screening Programme Centre thanks members of the NSPKU for help in developing national policies and information for parents.

In the previous issue, Sara Bartlett discussed the work of the UK Newborn Screening Programme Centre, and how it has established new policies and standards for newborn blood spot screening in the UK. She has already outlined the new standards for screening and for early care of babies thought to have PKU. As members of the Parent Support Research Team, which is part of the Programme Centre, we are very grateful to Sara and other parents of children with PKU who have helped us develop these standards. Now we'd like to update you on the latest developments in our work that are of particular interest to parents of children with PKU.

New standards and guidance for health professionals

We have produced a comprehensive pack entitled "Newborn Blood Spot Screening in the UK" to help health professionals work together in meeting new standards for newborn blood spot screening. This pack comprises several different documents, including one about the new policies and standards, a handbook for health professionals, and information for parents. The pack has been widely distributed to health professionals, support organizations, and parents who have helped us to develop it. You can access the full pack on our website, www.newbornscreening-bloodspot.org.uk. Please follow the link to 'Resources'. From there, you will find separate links to each of the documents in the pack, which are available to download or read online.

New research-based information for parents

We have also developed a series of new information leaflets for parents: one pre-screening leaflet for all parents, and other 'results' leaflets for parents of babies whose screening results suggest that they are affected by one of the screened conditions. You can view all the leaflets by following our website link, as above, from 'Resources' to 'Parent Information'.

All our parent information leaflets are based on the best, up-to-date research evidence about newborn screening and communication, and the various conditions for which babies are screened. The detailed content and design of the leaflets were agreed through a series of discussions and consultations with groups of parents and health professionals, including midwives, health visitors, paediatricians, general practitioners and biomedical scientists.

New parent information about PKU

Two leaflets are of particular interest to parents of children with PKU. The first is the leaflet to be given to parents in late pregnancy and a day or so before the heel prick test, which has recently been distributed to health authorities in England, and is available in 11 languages. This leaflet explains why it is so important to have your baby screened, how the blood spot is taken, and how the results are given. It gives some brief information about the conditions for which babies are screened, including PKU. It explains that PKU is a serious condition, but highlights the fact that when babies are identified through screening, they can be started on treatment early, preventing severe disability.

The second is the leaflet for parents of babies whose screening test result suggests that they have PKU. We developed this leaflet specifically to give parents some brief but accurate information and support during the difficult, worrying days between receiving their baby's test result, and their first appointment with specialists. Some parents have told us that they felt left 'in limbo' at this time, and particularly needed some written information that was reliable and up-to-date.

The leaflet explains what PKU is, how it is treated, what causes it and what will happen next. It answers some of the questions that parents of babies with PKU often ask. It provides further sources of information and support that parents can trust, including, of course, the NSPKU, with full contact details. There is a lovely photograph of two happy children with PKU on the front cover of the leaflet, which we hope may help to reassure worried parents that their baby can and will thrive and enjoy life to the full!

The Parent Support Research Team is based at the Social Science Research Unit, London University Institute of Education. We work with other members of the Programme Centre team, who are based at Great Ormond Street Hospital and the Institute of Child Health. Our work is funded by the Department of Health. If you have any questions or comments on our parent information leaflets you are very welcome to contact us via the Programme Centre.

Dr. Katrina Hargreaves Dr.Jennifer Sinclair
Parent Information Research Officers

UK Newborn Screening Programme Centre
c/o Executive Offices
Great Ormond Street Hospital for Children NHS Trust
Great Ormond Street
London WC1N 3JH
Tel: 020 7829 7883/4
Fax: 020 7829 7881
Email: uknewbornscreen@gosh.nhs.uk

NSPKU 33rd Annual Family Conference Weekend 2006

Hinckley Island Hotel, Hinckley, Leicestershire

Friday 3rd to Sunday 5th March 2006

NSPKU

The National Society for Phenylketonuria (United Kingdom) Limited

Venue:

This years NSPKU Annual family conference weekend will return once again to the 4 star Hinckley Island Hotel (formerly known as the Hanover International Hotel). This hotel provides us with an absolutely stunning venue to hold our annual event.

Hinckley Island is one of the largest conference venues in the Midlands and with a major refurbishment programme currently in progress, we are all bound to notice the improvements.

Hinckley and Market Bosworth are areas steeped in local history and famous for the battle of Bosworth where Richard III died.

A diverse county, you will find that Leicestershire has a lively capital and delightful countryside. Gentle rolling hills are mixed with secluded valleys and surprisingly some of the most beautiful stretchways of waterways in Britain. Come and join us all once again and enjoy the facilities of one of the most versatile hotels in the area at great value.

Accommodation:

With comfortable and varied bedrooms your residential needs are definitely taken care of. All rooms offer what you would expect from a 4 star hotel. Comfortable, spacious bedrooms all with private bathroom, direct dial telephone, TV, hairdryer, tea & coffee tray and individual controlled heating. Add to this the hotel's leisure and business facilities, meeting rooms and you will wonder why you had not enjoyed all the benefits of the Hinckley Island Hotel before.

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:

349 en-suite bedrooms, 21 flexible self-contained meeting rooms, equipped business centre, Bodysense health & leisure club with 15 metre indoor swimming pool, sauna, steam room, spa and solarium. The Brasserie 209 restaurant or conservatory for a la carte dining, the Snooty Fox bar, newsagent, hairdressing salon, snooker and a range of shops.

There are also 600 car parking spaces.

(In order to maximise your chances of staying in the Hinckley Island Hotel early booking is recommended. This is a very well known hotel venue to NSPKU guests and high levels of bookings are expected). Please book as early as possible to avoid being allocated in an overspill hotel Thank you.

PKU Diet:

You will need to bring the PKU protein substitute and vitamins and minerals. The diet will otherwise be catered for from Friday evening to Sunday lunchtime inclusive.
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: Birmigham International airport - 20 minutes.
East Midlands airport - 45 minutes.
Rail: Hinckley Island station - 1 mile.
Road: The hotel is situated on the A5 and you will find us 300 metres south of the M69 junction.

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 2006 Residential Conference Fees:

Non-PKU Adult (15 years +)	**£150.00**
Non-PKU Child (under 15 years sharing with parents)	**£90.00**
Non-PKU Child (under 15 years in own room/sharing with another child)	**£135.00**
Single room weekend supplement	**£20.00**
PKU Adult (15 years +)	**£75.00**
PKU Child (under 15 years sharing with parents or in own room/sharing with another child)	**FREE**
All Infants (0-2 years)	**FREE**
Day Visitor Fees:	
Non-PKU Adult & Children Friday evening (dinner)	**£35.00**
PKU Adult & Children Friday evening (dinner)	**FREE**
Non-PKU Adult & Children Saturday or Sunday (coffee, luncheon & dinner)	**£35.00**
PKU Adult & Children Saturday or Sunday (coffee, luncheon & dinner)	**FREE**

Booking Conditions: All conference bookings MUST be made by (Monday) 6th February 2006.

Your NSPKU 2006 Conference Organiser is: Mandy Macedo
13 Govett Avenue, Shepperton, Middlesex TW17 8AA
Email: conference@nspku.org • Home Telephone: (01932) 230317 • Website: www.nspku.org

NSPKU 33rd Annual Family Conference Weekend 2006

Hinckley Island Hotel, Hinckley, Leicestershire

Friday 3rd to Sunday 5th March 2006

NSPKU
The National Society for Phenylketonuria (United Kingdom) Limited

HOTEL REF - NSPKU 2006

Name (Please enter first and last names)	**PKU** Yes or No	**Age at 03.03.06** (if under 18 yrs)	**Cot** Yes or No	**High Chair** Yes or No	**Childcare** (Creche for 6 yrs & under) Yes or No	**Room Type Needed** F=Family S=Single D=Double T = Twin	**FEE TO PAY**
Day Visitors – Days Attending (Please tick) ☐ Friday (dinner only) ☐ Saturday ☐ Sunday							
						TOTAL £	

Card payments: If you wish to pay by credit or debit card please tick the appropriate box -:

SWITCH ☐ MasterCard ☐ AMERICAN EXPRESS ☐ VISA ☐ CARD NUMBER: ☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Expiry date:.. Name of Cardholder:..

Signature:.. Credit card 3 digit security code (on reverse of card) ☐☐☐

Deposit Payments: Adults (per person - 15 yrs+)................50%

Children (per child - 3-14 yrs)...............50% Total Deposit Payable: £_______________

I enclose Cheque/PO (Do not send cash) to Hinckley Island Hotel for: £_______________

(Insurance cover is NOT included. Delegates should make their own arrangements)

*Full balance of monies should be paid to - "The Hinckley Island Hotel" on arrival at the hotel and additional extras on departure.

(Full conference fees will be payable in the event of non-arrival) **ALL PAYMENTS MUST BE MADE IN GB POUNDS STERLING**

ANY OTHER REQUIREMENTS :e.g. specific room request, wheelchair access, special diets (excluding PKU), cot, highchairs, extra nights accommodation or any other instructions that you wish the hotel to act upon etc:

....

....

....

CHILDCARE FACILITIES: Number of children – 0-1 years ☐ 2-3 years ☐ 4-6 years ☐

CHILDREN'S TRIPS: (Enter Numbers) - 7 + years ☐

TENAGERS ACTIVITY: (Enter Numbers) - 13 years+ ☐ (subject to final confirmation)

I AM ABLE TO ASSIST WITH SUPERVISION ON THE TRIPS: *(Please tick) ☐

Note:*Childrens' trips take place subject to adequate numbers of volunteer supervisors coming forward.

If this is the first time you have attended a Conference, please tick the box ☐

Signature:.. Date:..

Contact Address:..

....Contact telephone.. E-mail:..

Please send completed form and deposit payment to:

NSPKU 2006, c/o Alison Merritt - Events Manager, The Hinckley Island Hotel, A5 Watling Street, Hinckley, Leicestershire LE10 3JA

Telephone: +44 (01455) 631122 Facsimile: +44 (01455) 634536

Email: hinckleyevents@paramount-hotels.co.uk web site: www.paramount-hotels.co.uk/hinckleyisland

Data Protection Act: The information given here will be used solely to communicate with you. It will not be divulged to any other person or organisation.

Conference Delegate List: I agree to have my contact details published in the Conference delegate list available to all NSPKU guests on arrival. ☐YES

FATE
Special Foods ™

NOW AVAILABLE ON PRESCRIPTION
THE NEW WAY

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

THE VERSATILE PRODUCTS YOU'VE BEEN WAITING FOR:

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

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

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

EVERY PACK CONTAINS EASY TO FOLLOW RECIPES DEVELOPED BY EILEEN GREEN

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

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

Helpline and General Enquiries Tel: 01215 22 44 34

FATE SPECIAL FOODS ~ SPECIAL FOODS FOR SPECIAL PEOPLE

Fate Special Foods recipes

FATE APRICOT AND ORANGE MUFFINS

Hello
A while ago, I developed recipes for Raspberry Muffins and Apple and Cinnamon Muffins. Since then, I have had many calls asking for more! So, I've now got this one that uses 'ready to eat' dried apricots (the ones that do not need soaking). I also use unsweetened orange juice, the kind you get in a carton, this gives the muffins a lovely flavour and a moist texture.
They are perfect for any time of day. Have them for part of your breakfast with coffee, pack them for lunch or have them for pudding after dinner. Serve them hot or cold

Ingredients

200g ready to eat dried apricots
350g Fate Low Protein All-Purpose Mix
175g soft light brown sugar
1½ tsp baking powder
140g soft margarine
280 mls unsweetened orange juice

Pre~heat oven Gas 6, 200°C (400°F)

Method

First of all, chop the apricots into small pieces, and place them into a sieve. Rinse them under cold running water. Drain well.

Place the Fate All-Purpose Mix into a mixing bowl. Add the light brown soft sugar and baking powder. Stir.

Add the margarine and the orange juice, and using a wire whisk, mix quickly for 1 minute until well blended and smooth.

Stir in the well drained apricot pieces.
Divide the mixture between 12 large muffin paper cases set inside a muffin tin.

Bake in a pre~heated oven for 25–30 mins until risen and golden brown.

Place on a rack to cool.

The muffins freeze well.

PKU Pronto!

PKU Pesto

I hesitated before deciding on this recipe. PKU Pesto is not the cheapest option and it sounds a little pretentious I suppose. However, in its favour is the fact that it's remarkable easy and quick to make, keeps for a week in the fridge or longer in the freezer and all age groups enjoy it - from my fussy three year old to his 60 year old grandmother! Another plus factor is that it's one more choice for PKU children who like to eat the "same" food as their friends and family. You could easily give this dish to a non-PKU with some grated cheese and "normal" pasta. In fact, I tend to use a jar of ready-made pesto for my non-PKU son and keep the homemade pesto for my PKU child. I've often noticed that PKUs can, ironically, get a better deal when it comes to dinner time!

Ingredients
80 g of basil leaves
1 garlic clove
2 teaspoons lemon juice
5 tablespoons olive oil
Salt and pepper

The easiest way to make this is in a liquidiser or small bowl of a food processor. Just chuck everything in and whiz it up to a thick paste. If it seems a little thick, just add some more oil. Taste it and add more salt, pepper or lemon juice if you think it needs it. You can also make this by hand by chopping everything up really small and mixing it up in a bowl. The traditional way of making this would be to pound it in a pestle and mortar so that's another option. Any way you do it, it can be prepared in the time the pasta takes to cook.

This amount would coat pasta for 4 adults – that's about 400g pasta, weighed before cooking.

I tend to keep this in a jar where I use it within a week. Otherwise, I freeze it in an ice cube tray and find that 2 or 3 cubes is enough for my three year old with his PKU pasta.

Variations

- You could add more garlic if you like and if you're feeling adventurous, what about some fresh seeded chillies or a few sundried tomatoes in oil?

- Also, this pesto is delicious made with rocket instead of basil and you can get big packets of that in most supermarkets now.

- Don't just keep the pesto for pasta either. You could mix it with PKU rice or PKU couscous and add some fried or boiled vegetables like mushrooms or carrots. Of course, if you've got some exchanges left, you could measure out "normal" rice too, remembering that 45g of cooked rice equals one exchange.

- I've had great success as well when I mixed 1 tablespoon of the pesto with about 100g of soft butter. My son adores some of this spread on a PKU roll stuffed with fried mushrooms. I always feel good when my children eat fresh vegetables even if they are doused in oil and butter…..

So, it's a really quick, easy and useful sauce to make from scratch or to have on standby. It's not cheap but cheapness can't always be our main aim when preparing food can it?

One more thing, some people have expressed surprise that my toddlers like something that they consider "adult" but I think that it's always worth letting children taste as large a variety of foods as possible. The PKU diet is so restricted that I think it's a good idea to widen it as much as you can. You might be very shocked to find your children like pesto or olives or even chillies!

Dietitians Note:
I whole heartedly agree with Kiri's last paragraph. Try to introduce as much variety into the diet as you can.

Donations

<u>Donations to 30/6/05</u> **(£30.00 and over)**

Women's Institute Group (via Di Asplin)	135.00
Evershed's Solicitors	500.00
Neil Addyman	130.00
Ms H Scally	150.00
Lisa Guest	1177.00
Barbara Cochrane	52.00
Barry McEvoy	646.74
Welsh Support Group	797.16
Corporal B Hayes, Albrighton	150.00
Peter Rose	57.25
Peter Fleming	50.00
St Mary's Parish Church, Whist Drive Group, Mirfield	35.00
I.M.I (Yorkshire Copper Tube) Workplace Trust	100.00
Lisa and Frank Selbie	760.00
Bessels Leigh School (via Maureen Arnold)	100.00
DK & S Osborne	300.00
Gift Aided	
Barbara Broadbent	100.00
In memory of:	
Albert Crockett	165.00
David Gell	480.00

Dietitian's Report

MORNING STAR STREAKY STRIPS

These streaky strips which look like bacon are now unavailable in the UK. I contacted the distributors and they have sent me the following letter which explains the situation.

To: Morning Star Farms, United Kingdom
Customers, Importers and Preferred Consumers.

We regret to inform you that Morning Star Farms will no longer be able to produce the Streaky Strips and Back Bacon products.

These products have gained great acceptance among the English consumers and developed a strong and growing business over the years. However, we are not able to ensure our future ability to maintain GMO status in these products. In compliance with our commitment to selling only GMO free products in the UK, we have discontinued production.

We sincerely appreciate your understanding.

Blaine McPeak
General Manager
Frozen Food Division
Morningstar Farms,
U.S.A.

BLUE DRAGON BEAN THREAD NOODLES

These noodles are made from mung beans and the protein content of the noodles is very low. They can be allowed freely in the diet. You can use the noodles in lots of different ways. They are very fine and translucent and can be added to soups and stir fries. They can be deep fried and used as a garnish or an accompaniment to oriental dishes.
Make sure you get the bean noodles and NOT rice noodles which are much higher in protein.

CHEWING GUM

I have been in touch with Wrigley's about aspartame- free gum. They now do not produce one. There used to be Wrigley's Double Mint but this now contains aspartame.

But Skittles now make a Fruit and Sour flavoured gum both of which are fine in the PKU diet and can be taken freely. That's good!!

STRETCH ISLAND FRUIT LEATHER

This can be found in the organic section of the supermarket. The Apple and Mango flavour is so low in protein it need not be counted in the diet. There are other flavours but these are higher in protein.

MIKE AND IKE JOLLY JOES

These are chewy, tangy,fruit flavoured sweets from America. They are protein free.

MARIGOLD ORGANIC SWISS VEGETABLE BOUILLON CUBES

I wrote about these last time. They can be a bit difficult to track down but look in the organic section in the supermarket. These stock cubes are so low in protein you do not need to count them. They are useful for making soup, gravy or anytime you need some stock.

PROTEIN FREE BEER

Sara McDowell, dietitian in Leicester, told me about some gluten free beer which is phenylalanine free.

Greens Discovery Beer
Greens Explorer Stout
Greens Pioneer Lager

SPLENDA

This new sweetener, made by Tate and Lyle from sugar, does not contain phenylalanine. It is being used increasingly in drinks. Paula Whitehead from Cornwall told me about a Simpson's juice which is sweetened with Splenda. It comes in orange and apple and blackcurrant flavour.

I was listening to the radio whilst eating my lunch recently and in the past year Tate and Lyle have opened two new plants in America and one in

Singapore to cope with the demand for Splenda. Their profits have risen accordingly!!
So, keep looking out for drinks particularly as I am hopeful there will be more choice of suitable ones now.

HARTLEY'S

Make some thick fruit smoothies in little pouches. They come in different flavours; Five Fruit Feast and Apple and Strawberry and are pureed fruit with sugar. They do not need to be counted in the diet.

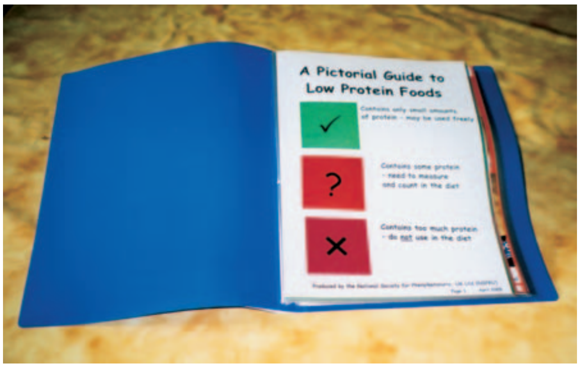
PICTORIAL GUIDE - SECOND EDITION!

The second pictorial guide is now available. It is bigger and better and a must for anyone following the PKU diet. Even if you are 'old hands' at the diet I'm sure you will find new foods to try in here. It contains pictures of all the foods available on prescription as well as supermarket own brands and brand named food e.g. Heinz. All the foods are set on a coloured background of red, amber or green depending on the protein content so it's easy to use.

It is useful to take to the chemist to make sure you are given the correct prescription, for friends to help them to provide the right foods, for yourself to take to the supermarket to make sure you pick up the right food, for grandparents and so on. It is helpful for children to learn from and for them to help you find things when you are shopping!

You will find an order form in this News and Views. *(see over)*

Eleanor Weetch
Society Dietitian



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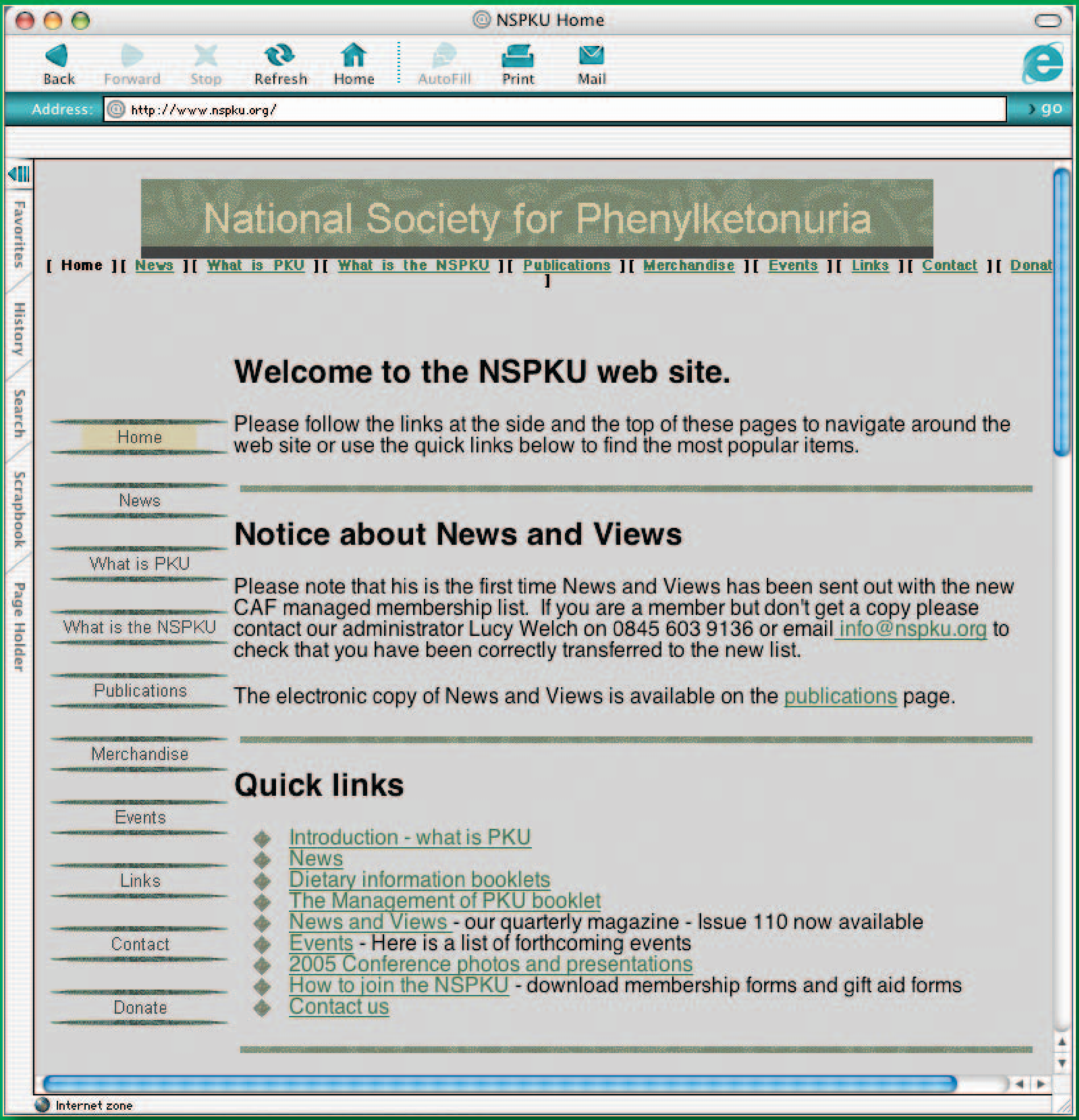

Welcome to the NSPKU web site.

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

Notice about News and Views

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

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

Quick links

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

www.nspku.org

For your free easy to use novelty mould
and recipe suggestions contact Vitaflo on:
0800 515174

Recipe suggestions are also available on our website
www.vitaflo.co.uk

Vitaflo
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Chilli & Pepper Pasta

Ingredients

- 75g (3oz) Loprofin Low Protein Penne
- 1 x 15mlsp (1tbsp) cooking oil
- 1 x 5mlsp (1tsp) salt
- 75g (3oz) red pepper
- 75g (3oz) yellow pepper
- 75g (3oz) green pepper
- 1 red chilli (approx 25g/1oz)
- 2 cloves garlic (skin on)
- 2 plum tomatoes (100g/4oz flesh)
- 6-7 fresh basil leaves
- 3 x 15mlsp (3tbsp) olive oil
- Salt and pepper
- Extra basil leaves for garnish

Method

❶ Three quarters fill a large saucepan with water, bring to the boil, add the pasta, oil and salt to the pan. Return to the boil, stirring. Reduce the heat slightly and cook for 8 minutes. Drain thoroughly.

❷ Meanwhile, place the peppers skin side up, on a baking sheet, cutting if necessary to ensure they lie flat

❸ Deseed the chilli and place skin side up on the baking sheet with the peppers, Halve the garlic cloves and place skin side up on the baking sheet. Place the baking sheet under a preheated grill for a few minutes until the skins have blackened.

❹ Transfer the peppers, chilli and garlic to a polythene bag, to sweat for a few minutes.

❺ Halve and deseed the tomatoes and place under a preheated grill for 2-3 minutes until the skins shrink and can be removed easily.

❻ Remove the skins from the peppers, chilli, garlic and tomatoes, process briefly or mash the vegetables, with the basil leaves and olive oil, to give a chunky sauce.

❼ Transfer the mixture to a saucepan, add the cooked pasta, place over a moderate to low heat for approximately 5 minutes, until bubbling and heated through. Serve immediately, if desired garnish with fresh basil leaves.

Serves 1

NEW

Fasta Pasta

Flavours Now Available
Curry and Tomato & Basil

at lasta...

Ideal for modern day living the unique new Loprofin low protein Snack Pot range from SHS.

Quick and simple to use convenience foods.

Just add boiling water and you have succulent pasta in only a few minutes, ideal as a snack or as a part of a main meal.

... low protein snack pots

Available on Prescription for Phenylketonuria

Each 47g pot contains: Energy 694kJ, 165kcal, Protein 0.9g of which phenylalanine 23mg (½ an exchange per pot).

For more information on Loprofin Snack Pots, please contact our Nutrition Services Department on 0151 228 1992.

SHS

SHS International Ltd, 100 Wavertree Boulevard, Liverpool L7 9PT. Tel: +44 0151 228 8161 Fax: 0151 228 2650 Internet: www.shsweb.co.uk

The Italian Job

Loprofin Pasta is just the 'Italian' job.

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Italian pasta range from SHS.

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

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