

## Inside this issue...

2005 Conference Date  
announced

Study day for adults  
announced

Profile of a  
Conference organiser

Letters from readers

News and information  
from our dietitian

## Maggie Lilburn's Retirement Party page 8



# In Touch

## The Council of Management

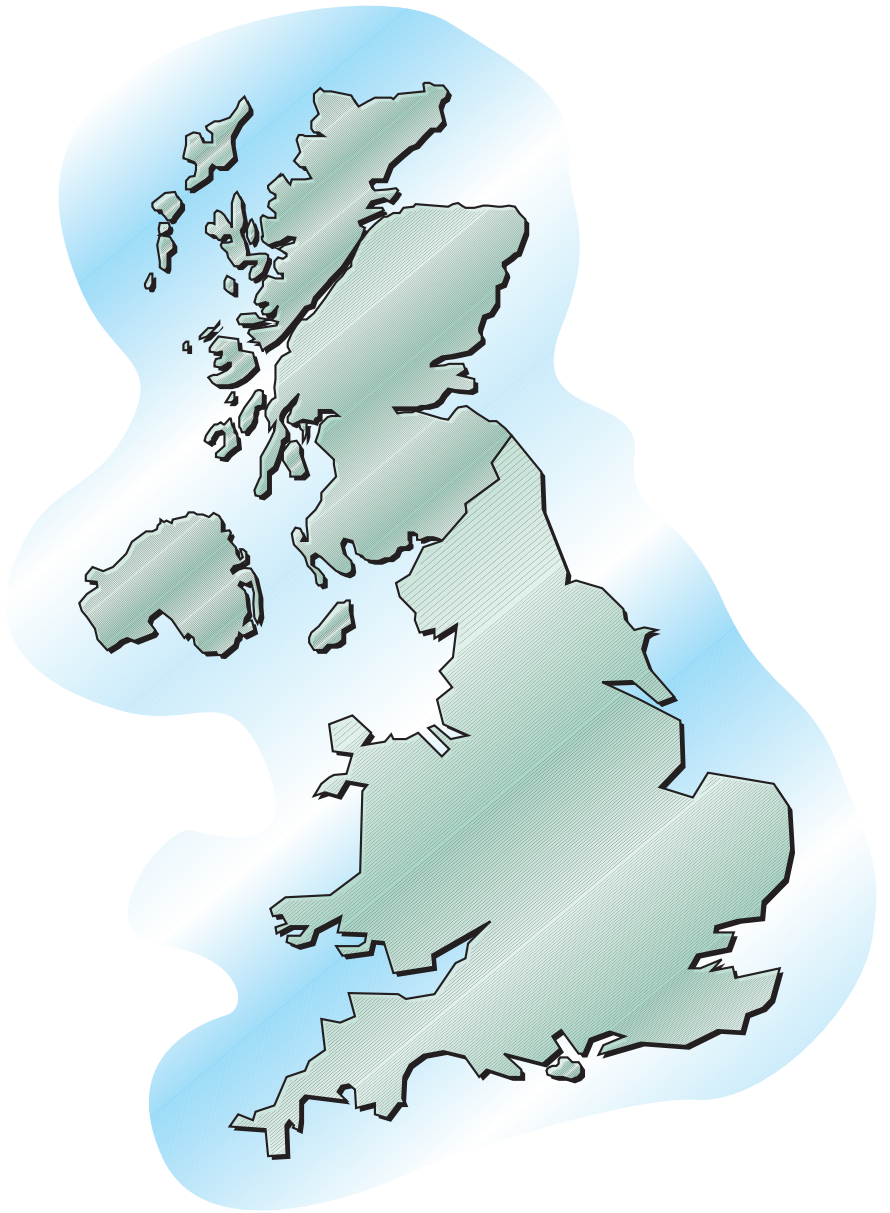
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# Contents

2	Donation	12	NSPKU Profile
4	Letters	14	Support Groups
6	Maggie Lilburn	17	Accounts
9	Study day for adults	18	Dietitian's Report



## Editor's Report...

Hello All

Dietary Management is probably the first thing that you wake up in the morning to as a PKU carer or parent. This includes dietary supplements, preparation and planning of how this fits into your day (notwithstanding the difficulties of application that this can entail!). The input that you have makes a huge difference to the well-being of your loved one. The Society is able to support you with the comprehensive array of literature it has compiled over the many years it has been in existence.

If you should require any assistance regarding Disability Living Allowance, the Society now has a comprehensive publication that is designed to help those that wish to apply for this benefit. It is not a mandatory benefit for PKU and many may not wish to apply for various reasons, however the advice is there for those members who require it\*.

Kind Regards

Pete Bramley

Editor

\*To obtain a DLA pack either download from our website [www.nspku.org](http://www.nspku.org) or contact our administrator on 0845 603 9136 or e-mail [info@nspku.org](mailto:info@nspku.org) for more information.

## Treasurer's Report...

I always find this report the easiest of the year as it is the one that I don't have to think of a topic! Slightly belated (that's the understatement of the century) this year as our dear Ed has been shirking his duties, it is time to present our financial report. We have now kicked Ed into touch and hopefully this will reach you sometime this millennium.

Details of our income and expenditure are available in this issue for your scrutiny but the gist of our financial activities are as follows:

I am pleased to report that this year our income exceeded our expenditure. The breakdown shows that income from publications and merchandise (fundraising) are down, however our ESPKU conference income and expenditure are not included in this year's accounts. This event represents a significant proportion of the year's sales which would account for this difference.

Although expenditure has fallen only 3 issues of News and Views were paid for in the year and our funding costs were reduced, the rest of our costs remain broadly similar.

This year we plan to look at the future of the Society and where it is heading so we can identify what sort of funding we will need to achieve this. If you have any comments or suggestions on what you think the Society should be doing for its members please let us know.

Julia Bailey  
Honorary Treasurer



The National Society for Phenylketonuria (United Kingdom) Limited

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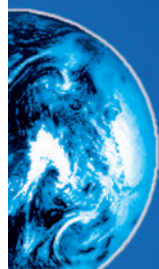
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## Donations

Donations to 31/03/04 (£30.00 and over)

Mr. E. and Mrs J.M. Corrigan	30.00
Mr. A.P. and Mrs L. Gibson	100.00
Chartered Institution of Wastes Management N.E. Centre (via J. Skidmore)	236.43
Leeds General Infirmary Christmas Party for PKU	45.00
Pharmacy Dept., Northern General Hospital, Sheffield	145.35
I.M.I. (Yorkshire Copper Tube) Workplace Trust	100.00
Mr. R.P.J. and Mrs J.M. Saunders	100.00
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### In memory of:

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Ann Richardson	225.00
Mrs Jane Davies	215.00
Lois, Gran Elizabeth	100.00
Irene Lillian Johnson	397.50
Barry Lawrence Poole	1207.15

# Annual Conference 2005

**Dates: 25th - 27th February 2005**

Venue: Hanover International Hotel and Club,  
Skipton, North Yorkshire.

# Thank you to all our supporters

Yes it's time for the NSPKU Oscars once again

We continue to be fortunate in receiving sponsorship from a number of food manufacturers this year, General Dietary, Firstplay Dietary Ltd, Fate Special Foods, Vitafllo International Ltd and Gluten Free Foods (also known as PK Foods) all provided sponsorship for the newly published illustrated guide. SHS international once again provided sponsorship for a number of projects:

£500	for the Baby exchange booklet
£2,500	for the dietary information booklets
£500	Edale
£1,800	Illustrated Guide
£700	AGM/study day 2003

On behalf of the Society I would like to express our thanks to them all. (I would also like them to know that I haven't forgotten their generous help with the ESPKU event but this will be noted next year!)

We also owe a debt of gratitude to our many regular donors, for example all those who make regular contributions via CAF and those who organise annual events. Whilst (thankfully) there are too many to name individually we would no less like you all to know how grateful we are.

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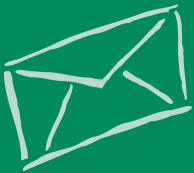
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# Letters

News & Views, 51b The High Street, Watton-at-Stone, Hertford SG14 3SX  
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,

Today I have put a cheque for £325.00 in the post to you raised by my colleague and friend, Mark Dinham, who completed his first 1/2 Marathon in Plymouth on 30th May in a time of 2 hrs 26mins. My husband and I are both keen runners and our part in this was to encourage Mark through a training schedule that would assist him in reaching his long sought-after goal. Our motive was the money he committed to raising for NSPKU. Our youngest daughter, Charlotte, fast approaching 3 years old, has classical PKU, hence our involvement.

Kind regards,  
Cathy Darby

Ps: I've also enclosed a further cheque for £30.00 as a donation from the Darby Family for the NSPKU T-Shirts that Sara kindly sent through to us before the race (Mark ran in his).

Editors Note: We appear to have mislaid the photograph supplied, we will try to print it in the next edition

Dear News and Views,

Please find enclosed a cheque for £100 raised for the NSPKU by Richard, Julie, and Chloe Saunders, and their family and friends. They all took part in a 12 mile sponsored walk around Lake Vernwy. Chloe, who has PKU and is aged 3, wore fancy dress! We are very grateful for the support and information we receive and would like to show our appreciation.

Yours,  
Richard, Julie, and Chloe Saunders.

PS Some of the money raised was shared with a charity for children with metabolic disorders in Shropshire and Wales.

Dear News and Views,

Please find enclosed cheques totalling £216.09. Our three-year-old son James, who has PKU, recently lost his Nan after a very sudden heart attack. Mourners were asked to donate to the NSPKU instead of giving flowers. We know this is what James's Nan would have wanted and are grateful that she had the chance to see James grow up to be a healthy, happy and very cheeky young man.

Yours,  
Stephen and Geraldine Smith.



Dear News and Views,

Please find enclosed a cheque for £41 raised from a Grand National sweepstake at Eversheds LLP Solicitors. The money was raised on behalf of my son Kian (10 months old and PKU) by Kian's Auntie Sarah Addyman who is employed by the firm. The employees of Eversheds also bought over £65 worth of tickets for the spring draw and hopefully will continue to support the NSPKU in the future.

Yours,  
Helen Scally.

Dear News and Views,

I am sending a cheque for £85 for the NSPKU following a Beetle Drive I organised in Barford on the 3rd April. My grand-daughter is Hannah Bridges who lives in Purley.

I usually organise "Mid Summer Notes" in the village in June, but this year there would have been a clash of dates hence the Beetle Drive! Next summer, we will definitely have another concert of music and poetry.

I am also enclosing a ticket and a picture of Hannah.

Yours,  
Shirley Osbourne.







# Letters

News & Views, 51b The High Street, Watton-at-Stone, Hertford SG14 3SX  
Email: editor@nspku.org

Dear News and Views,

At the end of 2003, we decided not to send Christmas Cards. Instead, we made donations to a charity.

My son Ross (picture enclosed with sister Emily) is 7 years old and has PKU. This year therefore we made our donation to the NSPKU.

Please find enclosed our cheque for the sum of £250.

Yours,  
Jon Porter.



Dear News and Views,

Please find enclosed a picture of Vassos (12) and Christina (7) at a festival for children in December 2003. The festival takes place every year in Ayia Napa, Cyprus at the Central Square by the fountains.

Vassos and Christina are hyperphes. We are lucky as we have loads of fruit and lovely vegetables and our diets are well under control. Thanks to News and Views and keep up the well-organised News Letter!

Yours,  
Chriso Prodromou

PS the white foam on the kids is fake snow – we don't have snow in the neck of the woods so have to make do wit the fake stuff!

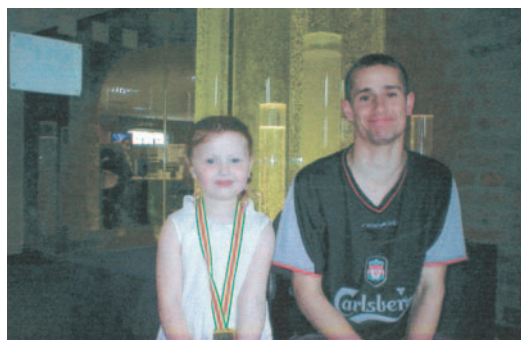
Dear News and Views,

Please find enclosed a cheque for £650. Our daughter India (5) has classical PKU and is pictured here with a friend Robert Cushion. Robert ran the London Marathon as part of the John Moores University running squad in April 2003. We thought this would be an ideal opportunity to raise funds on behalf of the NSPKU.

We would like to thank all our family, friends, work colleagues who gave in abundance to the sponsored event. Their generosity and support was both appreciated and overwhelming.

India is a wonderful little girl who is flourishing on her diet and is a credit to our family.

Yours,  
Stephen and Gail Seavor.



# Maggie Lilburn's Retirement Party



It was a great honour for me to go to Maggie's retirement party on March 31st. I have known Maggie for a long time and she has always been a great supporter of the NSPKU and a font of knowledge for me! Maggie always has time to talk, is always totally dedicated to her work and her patients and completely unflappable! She has done so much for people with phenylketonuria so our presentation of honorary membership of the Society could not be more deserved. It was when Dr Philip Lee spoke about the year Maggie started at University College Hospital as a dietitian in 1966 that most of us present really thought about how long ago that was. In those days we could play football!

I asked Maggie if she would write about herself for the magazine. She was somewhat reluctant to do this as she thought it wouldn't be interesting to anyone else but I found it fascinating and full of surprises. Those of you who know Maggie as your dietitian, work colleague or in any other capacity will, I'm sure, read with interest about her life and the development of PKU services.

On 1st March 1966 I arrived on the steps of University College Hospital (UCH) in London on the first day of my first job. I was warmly welcomed by the Chief Dietitian and started to feel more at ease until she said "Well you are going to be Metabolic Dietitian if that does not scare you too much"! An answer to this was clearly not expected since she immediately led me up to the Metabolic Unit, introduced me to some very important looking people and then disappeared.

This was certainly not what I had expected but I survived the first few weeks by hanging on to two rules:

- Take one day at a time. Focus on the job in hand and don't be distracted by what may, or may not, happen tomorrow.
- Don't be afraid to ask questions. You're not expected to know everything!

But how did I arrive at this point and what made me choose dietetics as a career?

Well, my Mother was one of the first people ever to train as a dietitian in Scotland. I have not told many people this because I did not want them to assume I mindlessly followed in her footsteps. In fact it sent me off in every other direction investigating different options. She was much too wise to try to influence me and I was much too stubborn to let that happen. I left school at sixteen and spent the next year studying physics and chemistry because for some reason which I never understood this was not taught at the school I attended. It also gave me time to consider what I really wanted to do.

I was already aware that what we eat has a marked affect on health but the fact that serious disorders can be successfully treated by radical changes in diet

was intriguing. So I started the four and a half years training. The first two years in Belfast, third year in Great Ormond Street Children's Hospital, fourth year back in college this time in Glasgow and the final six months in the Middlesex Hospital, London. During the final six months of practical training working as a student dietitian I found it frustrating that I seemed to be using only a fraction of all that I had learnt in my training. "There must be more to dietetics than this" I thought. Now, of course, I know there is!

The Metabolic Unit at UCH was founded by Professor Charles Dent who had a special interest in disorders of amino acid metabolism. However since these are rare conditions and at that time were mainly managed in children's hospitals Professor Dent focused on calcium metabolism and the Unit became a renowned centre for diagnosing and treating rare cases of metabolic bone disease.

It seemed ironic to me that I should get deeply involved in calcium metabolism on my very first job since during my training calcium and phosphorous metabolism was, to me, the driest of all subjects! How different things might have been had I not been more or less pushed into the job - but how grateful I am that I was!

I became fascinated by the work. I enjoyed the privilege of being able to treat patients as individuals not one of a group and also enjoyed being part of a team of doctors, nurses, biochemists, dietitian and diet cook, all working with the same aim but each with their own unique and essential contribution to make. For my part, I required certain skills/qualities - attention to detail; patience; ability to build a relationship of mutual trust with each patient and ability to motivate patients to do what was really totally unreasonable by showing them why it was necessary. After 18 months, despite really enjoying the work, I decided I was specialising before getting any basic dietetic experience so I made myself leave. I took a locum job at the Royal London Hospital and then went home to Ireland and set up a Dietetic Department in the local hospital with a lot of support and encouragement from the medical consultant.

This served to convince me that it was, after all, metabolic work I wanted to do and if I could not do that I would probably leave the profession.

In May 1970 I returned to UCH as Metabolic Dietitian and for those who say it is never right to go back I guess I must be the exception.

Gradually the research into metabolic bone disease was partially replaced by another speciality, inborn errors of metabolism of which PKU is one. We were asked by the metabolic team at Great Ormond Street Children's Hospital (GOSH) if we would take over the care of their older children. They wanted to transfer patients of 15 years and upwards, with PKU and other inborn errors of metabolism to our adult metabolic clinic. We were already looking after some adult patients with inborn errors of metabolism but this started a steady flow from

*Continued on page... 8*



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*Continued from page 6*

GOSH and other children's hospitals. We started with one small clinic per month. This has increased to seventeen large clinics per month. Other aspects of the clinic, besides the numbers attending, have changed. When our clinics started almost all our PKU patients had started diet late and many of them had already been taken off diet. They started diet late because they were born before 1969, the year screening of all new born babies for PKU was introduced.

They were off diet because the policy at that time was to relax the diet at 8yrs and stop it completely at 12 years of age. Doctors considered that brain development was complete and no further damage could occur by coming off diet and allowing the blood phenylalanine to rise.

Today we have approximately 350 PKU patients attending our clinic. The proportion of early diagnosed patients has increased to 75% and those currently on diet to 47%.

The policy in our clinic with regard to PKU diet in adult life is of course to encourage continuing on the diet. However the numbers of those on diet is constantly changing as we strive to do what is best for each individual at that moment in time.

Patients who were taken off diet in their teens or earlier may wish to, or be advised to, *restart* diet if they are experiencing symptoms that could be caused by high blood phenylalanine levels. There are also occasions when we have to advise a PKU patient to come *off* diet and eat entirely normally because the way in which they are doing their PKU diet is unsafe.

The most important point is that whether on diet or off diet all people with PKU continue to attend a PKU clinic.

For many years it was considered unsafe for women with PKU to have children.

It was Charles Dent, Professor of Human Metabolism at UCH who, way back in 1958, first described the abnormalities in children born to women with PKU. Nineteen years later, in 1977 we admitted our first maternal PKU patient and as many of you know this service developed and increased under the leadership of Professor David Brenton. We have now had 100 babies born to PKU mothers and the work continues to increase. This is an area that I have been very much involved in and have found both challenging and rewarding.

People sometimes ask if I found it daunting or even frightening managing a PKU pregnancy. I take it very seriously but if I got frightened I would not be much help to my patients! Remaining calm but at the same time being determined to get things right is an important part of care. The guidelines are clear and I work together with each patient, concentrating on achieving the best possible outcome. Frequent monitoring means it is possible to act quickly to keep the blood phenylalanine within a safe range, whilst frequent telephone contact (emailing and texting is not quite the same) to provide support, encouragement and, where appropriate, reassurance is vital.

In a relatively short time there has been an increase in understanding of PKU leading to changes in the way it is managed. Clinical nutrition companies are producing an ever increasing variety of low protein foods and protein substitutes to make the diet easier and more palatable, whilst researchers press on in their efforts to find an alternative to dietary treatment.

We can all look forward to what lies ahead. For me, although I retired in March 2004 exactly thirty eight years from that first day arriving at UCH, I have come back, part time, to do research.

Eleanor Weetch

# Study Day for Adults with PKU

Saturday 6th November, 2004

**Place:** English Heritage Lecture Theatre, just off Regent Street, London

**Time:** 9.30am to 3.30pm

**For further details and booking form contact:**

Diane Fogg,  
Conference Organiser  
SHS International Ltd.,  
100 Wavertree Boulevard  
Liverpool  
L7 9PT

Tel: 0151-228-8161

**Useful stuff you should know about this study day!**

This study day for adults with PKU is now an annual event. It's not stuffy or too medical or boring! In fact it is a great day out. The day is held in a really attractive reception room where coffee and tea and biscuits are provided on arrival. The lecture theatre, although in theatre style is very comfortable and not intimidating, except perhaps if you are speaking! The day is open to any adult who has PKU, is a carer of an adult with PKU or husband/wife, partner. You do not have to be attending a London hospital, it is open to all.

The day consists of talks from professionals and adults themselves both on and off diet, a cookery demonstration and most importantly a wonderful lunch of both PKU and non-PKU food. Lunch time is really informal and a good opportunity to talk to others.

The day is sponsored by SHS International Ltd and is free to you.

So, what is holding you back? Why not come along and find out more about PKU and make some new friends. You never know, you might really enjoy it and it could change your life!

**Remember to book in with a booking form from SHS. They need to know you are coming so that catering arrangements can be organised.**

## HOW TO GET TO LONDON CHEAPLY

There is a new bus company called the Megabus which runs from the following cities and towns to London and costs just £2 return! I know that sounds unbelievable but it's genuine! You have to book on the internet, but if you haven't got a computer at home you can go to a library or you may know someone who could do it for you. There is a booking fee of 50p.

Web address: [www.megabus.com](http://www.megabus.com)

The bus travels to London from the following places:

Birmingham, Bournemouth, Brighton, Bristol, Cardiff, Chesterfield, Dundee, Exeter, Glasgow, Leeds, Leicester, Manchester, Milton Keynes, Oxford, Perth, Plymouth, Portsmouth, Ringwood, Sheffield, Southampton and Swansea.

Another way of travelling cheaply is to book on a train in good time. If you book at least 7 days in advance you can get some really good deals. From my station in Sheffield you can go to London for £15 return if you book early. I'm sure the same applies to most of the train lines, especially on a Saturday.

If you can't get into London soon enough for the start you can also stay in a Youth Hostel very cheaply. You don't have to be a youth because I've stayed in one! They usually do not have single rooms but there are twins, triples and bigger.

**Eleanor Weetch**



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Working closely with PKU dietitians and PKU patients Leanora Munn and Pauline Young of Yes We Cook That.com now have a menu of over 120 ready meals and snacks all suitable for PKU sufferers.

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 sufferers in the UK with the opportunity to purchase ready made meals, breads, cakes and sweet and savoury snacks at supermarket prices.

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# NSPKU Profile: Mike Bailey

## NSPKU Conference Organiser

Back in 2002, I was approached by the NSPKU committee to become the Conference Organiser for the Society. Here we are now in July 2004 and I am still the Conference Organiser!

I jest in good humour though, because the role has been extremely rewarding and challenging over the past 3 years and most importantly, has brought me into so much contact with many new families, medical professionals, food manufacturers, PKU adults and PKU children. I hear you all say, well then simply book a place as a delegate; that way you can enjoy all the same perks and save your-self a whole lot of time?. No, that would be far too easy! I personally enjoy the organisational challenge of running an NSPKU family conference event because they are very different to your classic style corporate conference event.

Whilst the majority of you are departing from the hotel at the close of the last NSPKU conference or AGM (Annual General Meeting), preparations have already started on the next year's NSPKU family conference event. In very simplistic terms, it's like washing up. No sooner have you finished but another bowl turns up. Sound familiar?

In deciding on a final hotel conference venue by a process of elimination, many factors are taken into consideration for all our NSPKU events. These can be no more complicated than its location and ease of access and parking for our membership, to more complex details such as conference meeting room space availability and layout, syndicate breakout rooms, exhibition space and overall bedroom capacity. Oh, one small detail I omitted was price! We as a Society, have always enjoyed absolutely exceptional value for money with our NSPKU family conferences; when you consider that we include 2 nights accommodation, welcome drinks reception, breakfast, luncheon and dinner each day, all the conference meetings with first class speakers, children's outings on both Saturday and Sunday mornings, kids party, a full entertainment programme and the opportunity to meet both old and new friends (Priceless!). Here's a good exercise, if you break down each of the elements individually, one can see very quickly the true value for money that we all receive. Food for thought perhaps. The shortlist of hotel properties is then presented to the senior officers and dietitian of the NSPKU committee by the conference organiser. A sight inspection visit is then conducted by the NSPKU to the nominated hotel/s and a final decision is taken on the hotel venue for the next NSPKU family conference event.

This is when the role becomes interesting, because over the next 6 to 9 months I have personally come to know it as the "gestation" period (Ooh, I can sound so posh at times!!!). This is the time when

many of the finer details for the NSPKU family conference weekend are being covered off and communicated to both the NSPKU membership and also directly with the hotel venue.

To give you a taster of just a few of these; they can be the preparation of the booking form and prices which appear in the News & Views publications, speaker liaison and their hotel / travel arrangements, also food manufacturer liaison and their hotel / travel / exhibitor requirements, bedroom allocation, conference meeting room arrangements and production, negotiating and finalising the children's outing venues along with coach transportation and preferred kids party format and of course the first class evening entertainment that we have all come to enjoy.

Of course, there is so much more detail that goes into an NSPKU conference event and whilst you may be interested to hear more about what it actually takes from an administration and logistics perspective, I could wax lyrical for the next few days (and I am sure that you would all like to be spared that thought?). I have always used a "critical dates planner" since taking on the conference organiser role which defines clearly week by week leading up to the NSPKU conference event the milestones that need to be reached in order to keep all the event logistics on course. In this way, I can remain totally focused at all times and can also keep right up to speed with the tasks being handled at the same time by other invaluable colleagues of mine on the NSPKU committee.

In thanking all the team on the NSPKU committee for their invaluable support and time that they have offered to me on past conference events, a few, need to be mentioned by name (Pete Bramley known affectionately to me as "stubby"), (Jo Savage known affectionately to me as "fluffy"), (Eleanor Weetch known affectionately to me as, well "Eleanor Weetch of course"! ) and lastly, my own long suffering wife Julia for having to manage the children Louis and Meryn at the NSPKU conference on her own for most of the time!. Sorry, Louis and Meryn I nearly forgot to mention you both (how remiss of me), but you give me so many hours of enjoyment and laughter in all my times of need.

The final lead up to the NSPKU conference (4 to 6 weeks prior) is really when the role becomes its most pressured. Hair loss and colour changes, middle aged dementure, weight problems and neglect from family and friends are all key attributes that the conference organiser will have to endure at this time. During this time, lots of telephone calls and written correspondence are made to all the appointed suppliers involved with the NSPKU conference event, final mailings to all the delegates, speakers

*Continued on page... 14*





# The Italian Job



New Loprofin Lasagne sheets are just the 'Italian' job and are an addition to the authentic low protein Italian pasta range from SHS. Ideal for cannelloni as well as lasagne they do not need to be pre-soaked before cooking.



Each 75g portion contains:  
Energy 148kJ, 270kcal and Protein 0.3g  
of which phenylalanine 7.5mg.  
Available on prescription in 12 x 250g boxes.

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

## SHS

*Continued from page 12*

and food manufacturers booked advising them of all the final travel information and programme of events, constant hotel liaison, constant telephone calls to Eleanor Weetch (I spend more time talking to her than my own wife during this time!) and so on and on..... Then the NSPKU family weekend conference takes place and finishes and so, we go back to square one.

On a more serious final note, I have felt very privileged and proud to have been the NSPKU conference organiser for the last 3 years because the role is so rewarding. For me, my most lasting memory will always have to be organising the ESPKU (European Society of Phenylketonuria) conference at the Hanover International Hotel in Hinckley last October 2003, when the UK played host to over 100 of our dear friends and medical professionals from all corners of Europe. I was so pleased with all aspects of this weekend.

In closing, when I think hard about my own role within the NSPKU, it feels like organising a stage production where right from the choice of production selected through to the curtain down, you have been responsible overall for its success or failure. It's a daunting thought but at the same time, such a great feeling!

Lastly, a very big thank you to all you readers most importantly, because without you, there would be no NSPKU family conference weekend each year. Remember, always tell all your friends and patients about how valuable the annual NSPKU family conference weekend is and try and encourage them to attend next year's event!

See you all at the 2005 conference!

Mike

## Support Groups

On the inside cover of News and Views, details are provided of local support groups and contacts. You will notice there are quite large areas of the UK that are not covered by a support group or local contact and we therefore want to try to increase the number of support groups / local contacts for the benefit of Society members. The feedback from the questionnaires issued earlier this year identified that members wanted additional support groups / contact points where there is no regional cover in their area at present. We would therefore be interested to learn from anyone who is prepared to form a support group or act as a local contact point.

For further information please contact John Skidmore support group co-ordinator. Details on page 2



# Fate Special Foods recipes



## **FATE ORANGE AND STRAWBERRY GATEAU**

Hello,

This time I've got a beautiful cake for you to make. Deliciously light and perfect for summer. You just won't be able to resist it! I've made the buttercream with a lot less butter than usual which gives it a very light and creamy texture. Be sure to use pure orange juice in the recipe, the kind you get in a carton. Do not use fresh oranges, except for decoration.

You need to make two cakes, one for the base layer and one for the top, so that the cakes are the same size.

### **Ingredients**

#### **For the base layer of cake:**

1 x 250g Fate low protein Cake Mix  
65g soft margarine  
125 mls pure orange juice

#### **For the top layer of cake:**

1 x 250g Fate low protein Cake Mix  
65g soft margarine  
125mls pure orange juice

#### **For the buttercream:**

75g butter  
225g (approx.) icing sugar  
about 30mls pure orange juice

#### **For the top layer of cake:**

6-8 tbsp good strawberry jam  
approx. 400g fresh ripe strawberries  
1 fresh orange



### **Method**

Preheat oven Gas Mark 4 180 ° C 350° F

First, make the base layer of the cake. Place the Fate low protein Cake Mix into a bowl. Add the margarine, and orange juice. Mix quickly with a wire whisk for one minute, until well blended. Place in to a greased and lined round cake tin 8 1/2 inch x 2 inch deep (21 x 5cms). Bake for about 15 mins until risen, golden brown and firm to the touch. Turn out onto a wire rack to cool. Make the top layer of the cake in exactly the same way. Meanwhile, make the buttercream. Place the butter into a bowl, add the icing sugar and the orange juice. Stir well with a spoon until blended well, then change to a wire whisk to whip the mixture until light and creamy. If the mixture is very soft, you can add a little more icing sugar.

Peel the orange with a potato peeler; try to keep the strips as long as you can. Using a sharp knife, cut the strips into long thin strands. Place into a small pan, cover with water and bring to the boil. Simmer for 2 – 3 mins until tender. Drain, and leave to cool.

When the cakes are cool, spread the surface of the base cake with 2-3 tbsp strawberry jam. Slice about half the strawberries and place on top of the jam. Take the top cake and spread about 2/3rds of the buttercream onto the surface. Place buttercream side down on top of the base cake.

Decorate the gateau by spreading the remainder of the buttercream on the top surface. Sieve the remainder of the jam, and place it into a small piping bag and pipe lines in a criss cross pattern on top. If you prefer, use a small spoon and just spoon on lines of jam. Halve the remaining strawberries and place them around the edge of the cake.

Sprinkle the cool, strips of orange on top of the cake.

Store the gateau in the fridge.

The finished cake is not suitable for freezing, because of the fresh strawberries. You could make and freeze the baked cake layers, make the buttercream in advance and either store it in the fridge for a few days or freeze it. Then just defrost the cakes, and put the gateau together when needed.

**Best wishes**  
**Eileen Green ~ 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**

# Accounts

## The National Society for Phenylketonuria (United Kingdom) Limited Detailed Income and Expenditure Account for the year Ended 31st October 2003

	2003		2002	
	£	£	£	£
<b>INCOME</b>				
Membership fees	9,777		9,659	
Donations and covenants	31,683		31,865	
Contribution and sponsorship re Conference	543		7,050	
Lottery	6,059		5,633	
Bank and other interest received	2,119		2,882	
Publications and videos	1,864		2,757	
Advertising	8,850		3,150	
Fund raising	983		1,911	
Sponsorship re international conferences	—		3,133	
Sponsorship re publications	6,377		3,000	
General sponsorship	—		1,500	
Outward Bound course	1,050		1,064	
Donations re research	—		50	
Other receipts	180		126	
<b>TOTAL INCOME</b>		<b>69,485</b>		<b>73,780</b>
<b>EXPENDITURE</b>				
Conference	484		8,876	
Lottery	1,440		2,113	
Goods for fund-raising (net of stock)	(458)		842	
Newsletter and publications	22,012		24,472	
Telephone	1,693		1,726	
Postage	1,758		1,726	
Travelling expenses	8,288		8,905	
Insurance	1,571		1,329	
Stationery	600		290	
Equipment and software	916		1,891	
Depreciation	439		—	
E Weetch fees	13,732		11,897	
L Welch fees and expenses	2,948		3,056	
Sundries	327		434	
Committee meeting expenses	588		1,016	
MAP meeting expenses	121		85	
Dietician's meeting expenses	—		80	
International conferences	—		1,522	
Bank and finance charges	59		418	
Outward Bound course	2,479		2,330	
Audit	1,131		940	
Legal and professional	50		—	
Research costs	1627		—	
Grants	595		3,570	
<b>TOTAL EXPENDITURE</b>		<b>62,400</b>		<b>77,698</b>
<b>(DEFICIT)/SURPLUS OF INCOME</b>		<b>7,085</b>		<b>3,918</b>



# Dietitian's Report

## ANY NEW FOODS WHICH YOU HAVE FOUND?

Don't forget to let me know of anything you have found in the supermarket which could be useful. It is always helpful for me to have the packet so that I can check it out and know what I am describing!

## ROBINSONS FRUIT SHOOT DRINKS

It used to be easy to recognise the aspartame-free drinks in the Fruit Shoot range because they had green tops. Robinson's have now changed the way of distinguishing the sugar-containing drinks from the sugar-free ones. It's not so easy to recognise now and although I have written to the company about this it is unlikely to change.

**Fruit Shoot Sugar-free drinks containing aspartame**  
A narrow, differently coloured strip on the outer edge of the pack now distinguishes the drinks containing aspartame. The strip says No Added Sugar.

The separate bottles in the packs also have aspartame in the ingredient label and the warning notice 'Contains a source of phenylalanine'.

NB There is a bigger range of sugar-free than those which contain sugar.

## BOOTS ENERGY DRINKS

Barbara Cochrane, dietitian in Glasgow, told me about some energy drinks and a gel which can be used in the PKU diet. These products are aimed at the athletes amongst us!

## FRUITY SMARTIES

These are made by Nestle and are a bit like Skittles with a crispy outside and chewy centre. They are free in the PKU diet.

## TREAT ISOTONIC

An anytime hydration drink and energy drink. There are several flavours. Made by Taut (UK) Ltd., Manchester Street, London  
Presentation: 500ml pouches

**Lucozade Sport Orange Carbo Gel**  
Presentation: 45g tube

## JORDANS

### All Fruit Bars

These bars come in two flavours; Apple and Strawberry and Apple and Passion Fruit

Apple and Strawberry 2½ bars for one exchange

Apple and Passion Fruit 1½ bars for half an exchange

These might be nice in a lunch box.

## HARIBO

Haribo wine gums do not contain any protein and so are free for the PKU diet. There are not many gummy-type of sweets which are free, so look out for them.

## TRAVELLING AND INSURANCE

John Skidmore and family take out world-wide travel insurance for the family. PKU is specified on their schedule but is included fully.

John told me that Halifax travel insurance is no problem and even cheaper if you bank with them. Asda travel insurance is also no problem; they used them recently.

## PREVIOUSLY UNTREATED PKU TRIAL

Patients have now started on the trial. Allayne Amos, who is the research psychologist, has produced a newsletter for carers, family and those involved in the trial.

Suitable patients are still being recruited to the trial. Please contact me for further information and help.

Eleanor Weetch  
Society Dietitian



# Dietitian's Report

## FIRST GLACE



This is a non-dairy 'ice-cream' made from oats which the manufacturers claim is as creamy as normal ice cream.

First Glace Oat Ice-Cream (soon to be named as Oat – Supreme) is available in four flavours: Classic Vanilla, Strawberry Sensation, Chocolate Supreme and Vanilla Chocolate Fudge.

Classic Vanilla, Strawberry Sensation and Vanilla Chocolate Fudge

All the above flavours 140gms for 1 exchange

Chocolate Supreme

85gms for 1 exchange

Oat Supreme Lite

150gms for 1 exchange

Vanilla Cornish Style frozen dairy dessert

This 'ice-cream' is made from oats and according to the manufacturers it has a rich taste and mouth-feel you would expect from a high fat Cornish ice-cream but is low fat, low calorie and dairy free.

It should be counted in the diet as follows:

150gms provides 1 exchange

The above 'ice-creams' are only available in health food shops. The company will let you know of the nearest shop to you which sell it or they can speak to your local shop on your behalf and get it stocked.

Contact details for First Glace:

Tel: 01494-431-355

Fax 01494-431-366

Email: [chris@first-foods.com](mailto:chris@first-foods.com)

## WEIGHING ICE-CREAM

You will see on cartons that the nutritional value is given per 100mls. This is often the way ice cream manufacturers give their values. Approximately 100mls of ice cream will weigh 50gms. So, do take care. If an ice cream is stated in protein per 100mls you will need to double the protein content for 100gms of the ice cream.

Take the following as an example:

Vanilla ice cream 1.5gms protein per 100mls  
So there would be 3gms protein in 100gms  
Therefore 35gms ice cream provides one exchange  
If you are not sure about this ask your dietitian.

## RHM CENTURA FOODS - BISTO

Bisto Best Roast Granules

Onion  
Beef  
Chicken  
Turkey

A parent asked me about the suitability of these gravy granules in the PKU diet. They are all suitable when made up as directed and need not be counted to a limit of 100 mls per serving.

I have also recently been asked about stock cubes and powders. Please use the following guidance for these.

If the stock cube or powder, when made up as directed, contains 0.3gms protein per 100mls or less then you can use up to 100mls of the stock without counting it in the diet. If you are using stock cubes or powder to make soup a serving will be more than 100mls so you will need to count it in the diet. For example 500mls of stock (with a protein content of 0.3gms per 100mls) will provide 1.5gms protein or 1½ exchanges.

A support worker looking after a patient with PKU told me that Knorr Lamb stock cubes were the lowest in protein that she had found. The protein value is 0.3gms per 100mls made up.

Does anyone know of any stock cubes or bouillon powder with a lower protein value than this? Please give me a ring or email me and I can put the information into the magazine.

**NEW**

# *Fasta Pasta*



at lasta...

Ideal for modern day living the unique new Loprofin low protein Snack Pot from SHS is a quick and simple to use convenience food.

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



... low  
protein  
snack pot

Each 47g pot contains: Energy 694kJ, 165kcal, Protein 0.9g  
of which phenylalanine 23mg (1½ an exchange per pot).

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

**SHS**

# NSPKU *Direct*

## Help support NSPKU!

We now sell a wide range of merchandise, please use the form below remembering to state the size and colour (state a 1st and 2nd choice) where applicable. For postage and packing prices, see table below. Please fill in the form below and return to Lucy Welch at the address shown.

Lucy Welch  
NSPKU  
PO Box 26642,  
London, N14 4ZF  
Tel: 0845 603 9136



## Order Form *NSPKU Direct*

Product	Size	Colour	Price	Quantity	TOTAL
Adult Sweatshirts ( <i>Red, Black, Grey, Navy, Wine</i> ) <i>S. M. L. XL. XXL</i>		1ST CHOICE: 2ND CHOICE:	£12.00		
Adult Poloshirts ( <i>Red, White, Navy, Jade, Grey, Wine</i> ) <i>S. M. L. XL. XXL</i>		1ST CHOICE: 2ND CHOICE:	£9.00		
Children's Sweatshirts ( <i>Red, Black, Grey, Navy, Wine</i> ) <i>3-4, 5-6. 7-8, 9-11 years</i>		1ST CHOICE: 2ND CHOICE:	£8.00		
Children's Poloshirts ( <i>Red, White, Navy, Jade, Black, Dk Green</i> ) <i>3-4, 5-6. 7-8, 9-11 years</i>		1ST CHOICE: 2ND CHOICE:	£6.00		
Ballpoint Pens x 9			£1.50		
Sticky Bugs			60p		
Rubbers			80p		
Wallets			£3.75		
'Bryan Pearce' Greeting Cards ( <i>sold individually</i> )			60p		
Mug 'Probably the Best Diet in the World!'			£3.50		
Christmas Cards - <i>Round the Christmas Tree</i>		10 PER PACK	£3.00 pk		
Christmas Cards - <i>Tree Stars</i>		10 PER PACK	£3.00 pk		

NAME: \_\_\_\_\_

+ P&P  
(see below) £

ADDRESS: \_\_\_\_\_

**TOTAL REMITTANCE** £

POSTCODE: \_\_\_\_\_

TEL: \_\_\_\_\_

☐ I would like to make a donation of £: \_\_\_\_\_

**Please make Cheques and Postal  
Orders payable to 'NSPKU'**

**Send completed form to:**

Mrs Lucy Welch  
NSPKU  
PO Box 26642,  
London, N14 4ZF

### P+P COSTS:

Order value up to £2.00	50p
Order value £2.01-£6.00	£1
Order value £6.01-£10.00	£2
Order value £10.01-£20.00	£3
Order value over £20.01	£4

*Photocopies are acceptable*



*All PKFoods are now available on prescription*



*Chocolate  
Chip  
Cookies*



*Crispbread*

*Pasta Spirals*



*Cinnamon  
Cookies*

*Cherry Jelly Mix*



*Orange  
Cookies*



*Orange Jelly Mix*



*Egg Replacer*



*White Sliced Bread*



*Flour Mix*



*aminex Biscuits*



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