NSPKU News & Views
The National Society for Phenylketonuria (UK) Ltd
Issue 111

Josh's Story

Vacancy for NSPKU Conference Organiser!

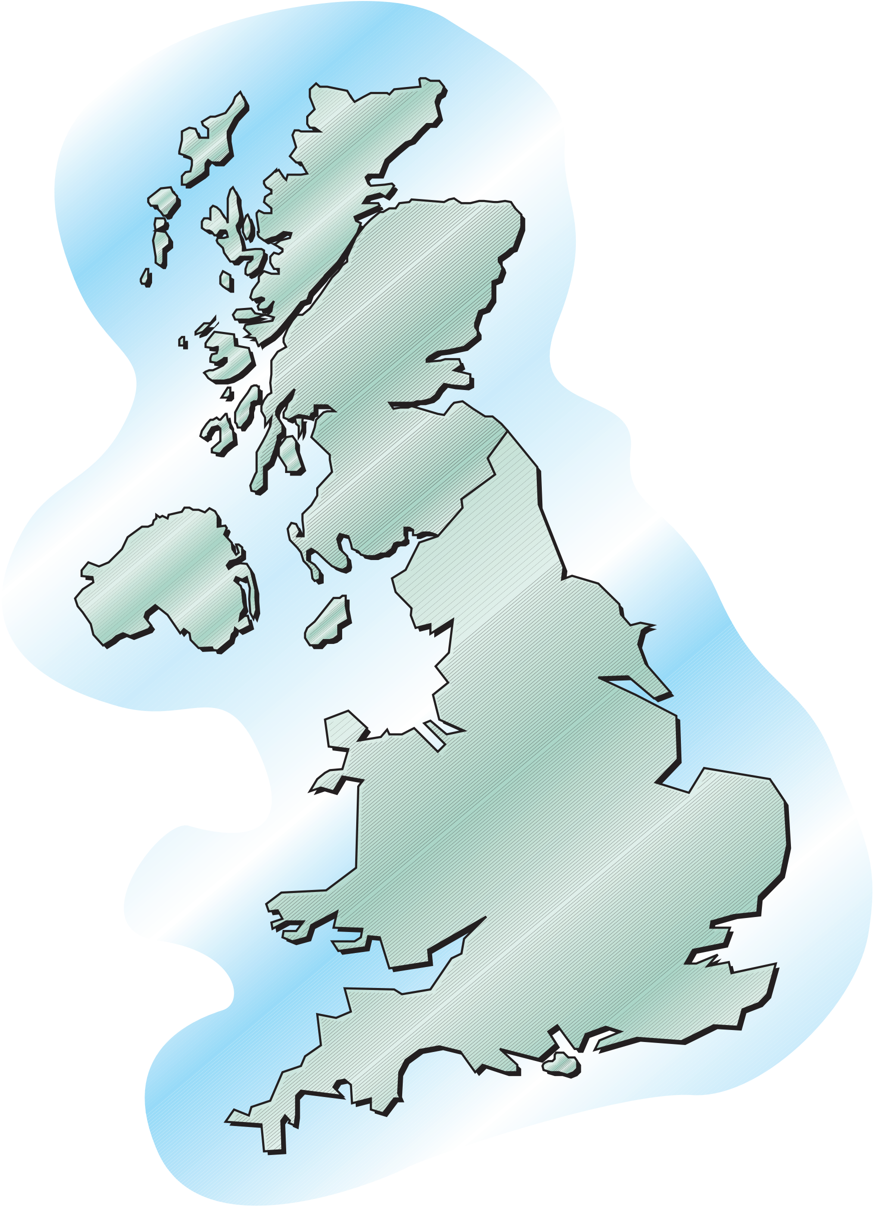
see inside for details!

www.nspku.org

In Touch

The Council of Management

Telephone Helpline: 0845 603 9136
Address: PO Box 26642, London N14 4ZF
E-Mail: info@nspku.org
Internet: www.nspku.org



Contents

Editor's Report...

A New Year and a new editor for News and Views! Pete Bramley is a hard act to follow but I will certainly try my best. Pete's done a great job for the magazine over many years. I will try very hard not to undo all your hard work Pete!

One other change you may notice in this issue is the inclusion of a new column called "PKU Pronto". It's designed to give quick meal ideas as opposed to recipes and, as in this issue, may incorporate new ways of getting those exchanges down as well as "free" food. If you have any thoughts for next issue's column, please email me at the address on the inside front cover. Come on, you know you want to….!

News and Views has lots of readers and each one of you has a unique story to tell about how and why you became part of the PKU community. This issue, Paula Garret tells her family's story and it's a moving and uplifting one I'm sure you'll agree. I really feel strongly that we all benefit from hearing about the different ways everyone copes with PKU.

Paula's family is doing well but not everyone could tell such a positive tale. It can be invaluable for anyone struggling with the diet to hear that they are not alone in finding the whole business close to impossible. Personally, I love to hear about other parents shouting in an unreasonable manner to innocent toddlers. It makes me feel, how can I put it, yes, normal! So please, write in and let us know how well or badly you're getting on. If you're doing great you'll be an inspirational support and if you're feeling despondent and fed up, then, in a strange manner, you'll be lending a hand too. Also, many problems can be solved or at least alleviated so ask for help – you might just get it!

Speaking of living in a helpful society, I would just like to give a thought to all those families torn apart in Asia. My family and I are thankful every day that we live in a country where PKU is treated by competent professionals and for free. The events of Boxing Day reminded me to be thankful that I have a family at all.

Happy New Year and please keep contacting us with your news, recipes and thoughts. A last thought, Mike Bailey who organised our conference over the last weekend in February, would really appreciate some feedback. He'd love to improve the conference in anyway that you, the punters, need or want. So please, please let him know – contact details on inside cover.

Kiri Thomas
Editor

NSPKU
The National Society for Phenylketonuria (United Kingdom) Limited

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

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

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

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

Treasurer's Report...

Firstly a very happy new year to all of you, I hope the year hasn't started as it means to go on 'cos all I've encountered so far is wind, rain and bills!

I am going to refrain from my usual topics of ways of raising funds or giving money to the Society, I feel that following the Tsunami in Asia there are many out there in greater need than us at the moment. It has reminded me however that for once I should be telling you about ways the Society can help you instead of the other way around for a change.

With the annual conference fast approaching I wonder if you are all aware that the Society has an Assisted Place fund for this event. This fund provides financial help for individuals or families to attend the annual conference. It can help with some or all of the cost of the conference fee (which includes meals and accommodation) and travel to and from the event.

Payments made are on a discretionary basis. Applicants to the fund are asked to provide details on how attendance at the conference will be of benefit. We also ask that other sources of funding are tried first, e.g. hospital funds, and that where possible a letter of support from a medical professional (dietitian, GP, health visitor etc) is obtained. We also appreciate any financial input, however small from the person applying for assistance.

Assisted places are awarded on a three year basis.i.e. anyone receiving an assisted place will then be unable to apply for help for the next two conferences.

The Society can also provide help in other situations such as grants to attend study days or other events. As long as we feel it will improve the life of a person with PKU and there is no alternative funding we will be happy to consider any request.

All claims for assistance are treated in the strictest of confidence. If you would like more information please feel free to contact me.

Julia Bailey
Honorary Treasurer

Orbituary

It is with great regret that we announce the tragic death of Andrew Weetch the husband of our dietitian Eleanor. Andrew was killed whilst out jogging during a break from his office at lunch time when he was hit by a lorry. He died the next day on 21st October 2004.

Andrew was a great encouragement to Eleanor in her work for the NSPKU. Not only did he encourage her to apply for the job when they had a young family but regularly put up with us sending her away to meetings and conferences all over the UK and the rest of Europe.

Andrew was a great believer in organ donations and would have wanted you to know that 40 people have benefited from his donations, and in addition, many others will benefit in the future as his lungs are being used for CF research. The family have asked you to take this opportunity to consider carrying an organ donor card and / or telling your next of kin that this is what you would wish.. More information is available by telephoning 0845 60 60 400 or www.uktransplant.org.uk

David Stening

NEWS & VIEWS 111
From Your Chair..

'Challenging jobs I have known whilst working with the Council of Management'

Well, this item started out as a brief description of the job of the chair but has turned into a goodbye message. Starting with the jobs though, there have been quite a few, ranging from packing the correct items in the correct parcels on a very busy pre-Christmas period as Merchandising Officer, to having to stop my knees knocking long enough to stand up in front of a very large number of people at last year's ES.PKU meeting, and then speaking! The truth is I, like many others, have lots of fears but believe they should not be allowed to stop me from doing anything that it is important for me to do. So at the conference I tried lots of things to get me through the scary bits, the main one being that I bought a bright red suit to wear. What purpose did that serve you might ask? It made me very easy to see, and that way it was impossible to just run away and hide when I was scared because everyone would see me scurrying for the door! It's a bit like the attitude of many of the adult PKU's I have been privileged to meet: they accept that having PKU is going to be hard work, difficult (challenging is a more positive word) and a real pain at times, but recognise that it's no good letting it rule what you do with your life. Yes it is very important to do what you have to do to keep well and yes that does need all-day, every day consideration, but it doesn't have to stop you doing the majority of the things that you want to in life.

I have worked on the COM for 9 or 10 years, a good memory for numbers and dates has never been one of my strong points. One thing I don't want or need is thanks because as is often the case when you make the effort to do something for others, I have benefited greatly. For example, before my time on COM I hadn't really touched a computer and needed an actual purpose, some work to do to encourage me learn; I hadn't ever attended a meeting let alone chaired one; I had never managed more than a household budget and kept our accounts, let alone taken on responsibility for a successful charity working as its treasurer, and although always one to have my say in small groups had never spoken a word in public let alone addressed a large room full of people. I gained the knowledge and confidence to go for a career changing job as a Road Safety Officer. Now I spend my days instructing groups of children, which I love, and talking with various sized groups of adults. Sometimes I don't even need the red suit to prevent me running for the door!

I am going to miss working on COM and having the opportunity to meet so many wonderful people. It doesn't take a genius to understand that we are all unique and will cope in similar situations in vastly different ways. That's what makes it so interesting and inspiring meeting others living with PKU, and also meeting those professionals helping us to do it successfully. Inspiring is definitely the word for some of them! I am leaving with so much left to do but there is, as always a first-class team in place, headed by Dave Stening, working hard for the NSPKU. Don't let that make you complacent or stop you from asking "What can I do for PKU's or the NSPKU?" We all have skills that could be of help and yes, I know we can be shy or reluctant to step forward and offer that help but I'm sure that when you do, the work will be rewarding.

One of the biggest pitfalls in writing an item of this sort is to start thanking individuals because there is always someone you forget. So although I do intend singling out a few people I am also going to say a huge thank you to everyone who has helped me during my years on COM, either personally or professionally. Thank you to the dietitians, doctors, nurse specialists, chefs and food manufacturers who have vastly improved the management and palatability of the PKU diet since I first came into contact with it 15 years ago. Thank you also to COM members past and present, the huge army of people who raise money, organise local support group activities, write items for News & Views or simply provide snippets of advice or information that I have been able to pass on to the benefit of others. I must single out Dave Stening for giving me a gentle push on many occasions, encouraging me to believe that I could do something when inside I was screaming 'No, not me'. Also Lucy and Eleanor with whom it has been an enormous pleasure to work. You may not realise the amount of work done expertly by them behind the scenes. Eleanor, as you know has been working for the Society for many years. She is well respected by her medical colleagues as well as our members, highly professional, and her knowledge and dedication shine through when you talk with her. Her practical and compassionate advice has helped support many families and in an unassuming and careful way she helps guide the work we do. Eleanor you and your

Continued on page... 4

Continued from page... 3

very supportive family have our gratitude and PKU families consider ourselves lucky to have you.

Lastly, a thank you to my own family, not just husband David who has helped me constantly but also Rosanna and Joshua, my mum and dad, mother and father in law, my sister and her family for helping on a regular basis. They have amused the children whilst I was at meetings and you may have seen them all manning the merchandise stand at conferences at various times. It has certainly been a case of my name being up front but all of them working hard behind the scenes and no way could I have done what I have without them. Oh, and finally to Simon and Pat Kimpton to whom I have moaned frequently for having got me into this in the first place, I would like to say thanks because this time on COM has enriched my life.

So, what started out with every intention of being a short goodbye, has been pretty long but for those of you who have stayed to end of my ramblings here is something you won't have seen before, some family photos. You can match faces to some of the names and if you want to see the rest (ie. COM) get yourself to a conference! We know ourselves the saving that has to done in order to come to a conference and annually review the amount of NSPKU funds used to make it easier for members to attend but if you can, take the opportunity to meet and chat with others in the same boat and let the children do the same and you will hopefully find it a very helpful and rewarding experience. See you there!

Sara Bartlett
Chair

SUPPORT GROUPS / LOCAL CONTACTS

Dear News and Views,
My partner Roger and I are parents to 5 month old twins Reece and Xander, both of whom have PKU. As you can imagine, the last few months have been an emotional rollercoaster. We have found it very difficult at times especially when they decide they are not hungry!

However, despite our G.P. not being very helpful, the dietitians and nurses at Guy's Hospital are all fantastic and always on the end of the phone. We can't thank them enough let alone imagine where we'd be without them today.

Having never heard of PKU, the past 5 months have been a whirlwind of doctor and hospital appointments, many tears and much laughter. I look to the future but still feel very anxious as to what lies ahead. I try to stay positive for the twins. Roger, on the other hand, is an absolute godsend. As well as being the perfect partner he is the best father and also a fantastic chef!

I have learnt that nothing is ever as bad as it first seems and we cannot thank the NSPKU and Guys Hospital enough for the help we have received.

We would love to hear from new parents or any families who would like to share experiences and advice, especially in the Sussex area.

Yours,
Vicki Croucher and Roger Kellie
6 South Undercliff
Rye
East Sussex
TN31 7HN
07780 508414 / 01797 224957

Editor's Note
Vicki wrote this letter some months ago and her twins are one now. She and the family are getting used to things but of course every new stage brings a fresh struggle – we can all relate to that! Vicki would still really love to have some contact from anyone in the South East so please give her a ring if you get a chance.

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,

I enclose a donation of £700 for the NSPKU. This money was raised by selling tickets for an "Austin Powers Party" earlier this year and by sponsorship for running as a relay team in the Edinburgh Marathon. The team consisted of myself, Alison Harper, Carol Sutherland and Dawn Skidmore. The party was a great success and great fun was had by all.

My daughter Olivia aged 9 has PKU and manages very well with her restricted diet, always maintaining her sunny disposition. I am very proud of her and also her younger sister Molly aged 4 who does not have PKU.

Yours,
Fiona Simpson.

Dear News and Views,

Please find enclosed cheques totalling £448.00. Jenny Beckett, mummy to Amy (4yrs) and James (3months) and my sister, died suddenly in September and we knew that Jenny would want friends to donate to the NSPKU rather than send flowers to her funeral.

Jenny was a wonderful mummy to Amy and James (both PKU) and loved them dearly. She is missed so much and will always be remembered. She successfully managed their diets and appreciated the support she was given by the dietitians at the Royal Manchester Children's Hospital.

Yours,
Ruth and Gary Dowd and Stuart Broadhurst.

Dear News and Views,

Enclosed is a donation of £30 from Mr. John Brook. This was saved by him by not sending Christmas cards this year.

Yours,
John Brook

Dear News and Views,

Please find enclosed two cheques totalling £100, raised through the completion of a sponsored triathlon.

Yours,
A. Roberts.

Dear News and Views,

Please find enclosed cheques to the value of £195 donated instead of flowers at the cremation of my mother Henrietta Cox. She was the proud Gran of my three teenage sons, Daniel, Stephen and Christopher all of whom have PKU. We had discussed the fact that people often named the NSPKU as their chosen charity on such occasions and that it seemed a more sensible use of friends' money than hoards of flowers. My mother fervently hoped that before long medical advances would make their dietary regime more "user friendly". I think she felt some sense of responsibility for their condition because her great nephew is also PKU and therefore, in retrospect she knew that she too was a carrier.

Yours,
Sandra Cox.

Dear News and Views,

We recently sold raffle tickets at nursery to raise funds for the NSPKU and are pleased to enclose a cheque to the sum of £56. One of our children, Cara Lee, has PKU and by working closely with her Mum we feel we are providing tasty, nutritious meals for Cara which look similar to those of her friends, Having Cara in our nursery has raised our awareness of this condition and given us the knowledge required to provide food from weaning through to pre-school age. Hopefully, by raising funds for the NSPKU we have also raised awareness amongst other parents.

Cara is a delightful little girl who is always smiling and is a pleasure to have in nursery. She is pictured here with some of her friends (in front with blonde hair wearing white t-shirt and jeans).

Yours,
Sandra McAlenan
Manager Hazeldene Private Day Nursery, Southport.

Letters

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

Disability Living Allowance
Editor's Note
Next issue, we will be exploring the complicated subject of Disability Living Allowance (DLA) in more detail. I would be extremely interested in hearing all your varied views and stories regarding this matter, so please contact me if you can. In the meantime, here are two different stories about claiming DLA.

Dear News and Views,

I am the mother of Matthew who has PKU and is now 14. Matthew's condition is quite severe as he is on just 5 exchanges a day.

I have successfully claimed Disability Living Allowance (DLA) for Matthew since he was about 4. Initially it was for a period of 4 years, then for 2 years. At present, I have to apply annually. It is due to run out in April 2005.

It appears that as Matthew gets older, the Social Security Agency requires more evidence that he needs help and assistance. I am able to complete the application forms, but I would be very grateful for information from readers of News and Views as to the age to which DLA is paid. In particular, are there any children aged 16 or over in receipt of DLA?

This information would be of great assistance to me and would be useful for others as it could be drawn on in any appeal where it was argued that the child was old enough to manage their own diet.

I would be grateful for any information you or other readers could provide.

Yours,
Hilary Dobson.

Dear News and Views,

After reading the Editor's report on Disability Living Allowance in issue 109, I thought I would let you know my experiences of trying to obtain DLA for my son Bradley.

I first applied when Bradley was only a few months old. The application was refused and at the time I didn't appeal, possibly due to the stress of having a PKU baby and a 2 ½ year old (non-PKU). Then when Bradley was 10 months old, I was put in touch with Helen, whose son had just been diagnosed with PKU. We became friends and when she applied for the DLA and was awarded it straightaway, I decided to try again.

I was turned down, so I appealed and was refused again. I was told that if I appealed again and was yet again refused that I would have to go to a tribunal. This panicked me slightly but I was determined and Helen said she would go with me.

So, I appealed, was refused once more and had to go off to the tribunal. This was in Wakefield and Helen and I were questioned for about 10 minutes by 3 people (one of whom was a paediatrician). We were then sent out of the room to await the verdict. When we were called back in, I was told that they were awarding the middle rate to Bradley. Result!

So, I would like to say first of all, Don't Give Up! Yes the forms are a nightmare, but persevere; it's worth it in the end. Also, as I mentioned earlier, my friend Helen was awarded it first time so maybe I was just unlucky.

Secondly, I would like to say a huge thank you to Helen Scally as without her support and friendship I could easily have given up.

Yours,
Vicky Ellis.

Donations

Donations to 31/12/04 **(£30.00 and over)**

Mrs B. Whitnall	206.60
Joyce Bramley	30.00
Gift Aided	
Dave and Lin Stening	100.00
In memory of:	
Mrs A. O'Sullivan	331.00

Josh's Story

Paula Garret talks about coping with PKU when it's not the only long-term medical condition with which your child is diagnosed.

My husband Lee and I live in Wales with our daughter Georgia and son Josh who has PKU along with some other conditions which I'll explain about presently! We are a happy family but we've had to come to terms with many difficult issues over the last year or so.

I was working part-time in an electronics workshop when I found out I was expecting Joshua. A year before this, I had miscarried a baby so, when we found out another baby was on his way, we were thrilled but quite nervous. Because of this, the hospital scanned me regularly throughout the pregnancy. At my 20 week scan, the obstetrician noticed that Josh's head seemed a little small but assured me that there was nothing to worry about. Still, they continued with the regular scans right up to my due date and everyone kept telling me that the baby would be fine.

On October 30th 2003, my waters broke so I phoned the labour ward who told me to come straight in. Some hours later, I began to push and continued for two hours. When nothing happened and I was really feeling awful, my midwife informed my husband and me that I would need an emergency caesarean section. However, the doctor was stuck in traffic so I had to hang on, not pushing until he could get to the hospital. I felt I was in a living nightmare.

After two more hours, Joshua Lee arrived into the world weighing 7 lbs 14oz. He was lovely and had a mop of black hair just like his father. I was taken to the post-natal ward and thought after that nightmare delivery how lucky I was to have a healthy son.

The next day, a doctor asked if they could scan Josh's brain just to check everything was OK. I was quite relaxed about this although my husband Lee was really alarmed as they were just arranging this when he walked in to visit us. I assured him that everything was fine.

A couple of days passed and I began to collect my things, ready to bring our new baby home. At that point however, a consultant came to see me. He was concerned about the size of the baby's head – 33.5cm circumference. We took Josh home but couldn't relax. We knew something was wrong.

A few days later I had an appointment with the consultant who told me that our beautiful new baby had "microcephaly". I was totally bewildered and asked what this meant. The doctor explained that "microcephaly" meant small head size and that Joshua was going to have some learning difficulties.

We were devastated and couldn't speak for two days. Unfortunately, there was to be a second blow. We received the result of Josh's heel prick test; he had PKU. As soon as we heard this news, we drove Josh to the hospital to start him on the PKU diet. The dietitian tried to explain what the condition entailed but I couldn't take in one word.

A few weeks later, Josh had an MRI scan the results of which were sent to Alder Hey hospital for a second opinion. I understood that things were bad but thought I knew the extent of Joshua's problems. When I was asked to come in and speak to the Geneticist, I told my husband that he didn't need to miss work, I'd be fine on my own. Once again, I was wrong.

The doctor informed that our baby son not only had PKU and microcephaly but also a condition called semi lobar holoprosencephaly. This condition occurs when the brain is fused. In this case, Josh was born with 2 ventricles instead of 4. When I asked how this would affect Josh's life, the doctor told me he could have hormonal, breathing, pulse and temperature problems. She said that he would be prone to all kinds infections particularly those of the lungs. I think most shattering of all was the news that Josh may never walk or talk and could well have seizures.

I fell apart. I managed to get myself back to our house and my husband came straight home from work. Friends and family rallied around that night but there were many, many tears. I just couldn't understand why this was happening.

A neurologist has subsequently told me that Josh's semi lobar holoprosencephaly should have been picked up during my pregnancy at Josh's 20 week scan. I do feel confused and upset that this was missed.

Nevertheless, the miserable fog began slowly to lift.

Continued on page... 10

NOW AVAILABLE ON PRESCRIPTION

they're a bit saucy!

TWO GREAT TASTING SAUCY FLAVOURS FOR YOU TO ENJOY

Promin Low Protein Pasta in Sauce Is a brand new fast food product available in two tasty flavours.

1. Pasta Elbows in a Cheese and Broccoli sauce.
Protein level 1.2g/100g Phenylalanine 30mg/100g
2. Pasta Shells in a Tomato, Pepper & Herb sauce.
Protein level 0.96g/100g Phenylalanine 20mg/100g

Pasta in Sauce

Simply mix with water in a saucepan bring to the boil and then simmer for 10 minutes. Promin pasta in sauce is convenient and easy to cook. It provides an instant meal solution for lunchtimes and tea times, you could even serve it for dinner with a side salad.

Promin pasta in sauce will soon become a necessary 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 also includes Imitation Rice, Pasta meal (available by prescription) and Lasagna Sheets (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.

Please consult your dietitian about how to count these meals in your diet as they contain phenylalanine.

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**

NOW AVAILABLE ON PRESCRIPTION TOGETHER WITH LASAGNE SHEETS & COUS COUS

Continued from page... 8

I lost my mother when I was young so have grown independent and, I think, quite strong. I decided I had to pull things together for the whole family. Incredibly, it seems that Georgia, our 7 old daughter who is coping the best with Joshua's conditions. We explained everything to her and she knows that her brother is very special. Georgia enjoys making up his Maxamaid, organising his medications and baking his PKU cakes.

Meanwhile Josh is now 15 months old and is doing really well. For a long time, he was on 6 exchanges which he took with XP Analog. He hated the Analaog but is now delighted with his sugary Maxamaid! I am proud and a little surprised to let you know that Josh is also a big fan of cabbage and Brussels sprouts! He is very alert, knows his Mum, Dad and Georgia and his favourite television programmes are "Big Cook Little Cook" and "Balamory". Josh has physio and occupational therapy regularly and the development team at Wrexham Hospital are working wonders with him. He is feeding well and has no fits. His special chair has been a real hit and he loves the frame he's been given to stand in. Josh has a new dietitian called Fiona White based in the Royal Manchester Children's Hospital. I am delighted because Fiona has lots of experience working with PKU children.

We believed that there was no support group for patients with holoprosencephaly but actually there is. It has been wonderful to talk to another family who can understand so much of what we're going through. In fact, we have now accepted the whole situation and just want to spend as much time together as a family as we can. After Joshua's diagnoses, I used to dread getting up in the morning. Now, I am a great believer that there is a reason for everything. Josh has come on faster and more dramatically than any of the doctors could have hoped. We are so proud of him and his wonderful big sister. You have one life so be happy with it! I also believe that with lots of prayers and love tomorrow's dreams come true!

PKU Pronto!

Right! Anyone reading this has to deal with the PKU diet either for themselves, a family member or a friend. However, we all lead busy lives and there's more to all of us than PKU! This column plans to help you out when you're in a hurry and want a PKU meal that tastes good, doesn't take forever and isn't chip based – again!

If anyone out there has a quick and easy PKU meal or snack recipe, I and the rest of the PKU community, would love to hear it. You can send it, email it, bring it round to me in person or resort to carrier pigeon, I don't care! Just please, give a hand to all of us doing our best to make the PKU diet as easy as possible. Your sandwich idea might be the answer to some harassed Mum's desperate prayer! (Please see the inside page of the magazine for all the editor's contact details – carrier pigeon instructions not detailed).

Now, I find that there are lots of great recipes around for "free" meals but many of us with younger kids know that often the problem is getting those exchanges down. This soup is quick, easy and has endless variations. Also, for those who want to eat something else for their exchanges, just use low-protein rice and the soup is freely allowed.

Only one of our sons has PKU – the other one doesn't. I'm relieved when I can make a similar meal for everyone and our PKU toddler loves to eat "the same" tea as his brother and friends. So, another great advantage with this soup is that it can be altered for non-PKUs, all you need to do is grate some cheese on top. You can use cheddar or parmesan or anything that's in the fridge and won't be greeted with a turned-up nose! Then serve the soup with low-protein bread or toast for the PKU contingent and normal bread for the others.

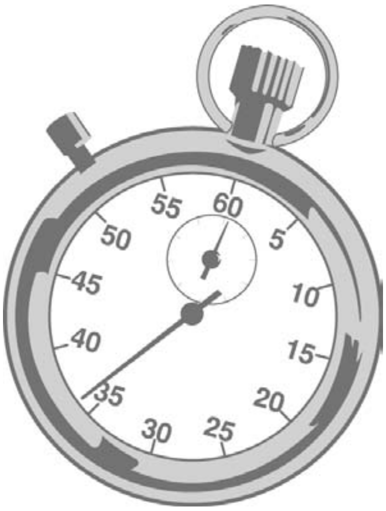
Now, here's how you do it.

Tomato and Rice Soup

1. Take a jar of freely allowed tomato sauce for pasta e.g. Co-op Fresh Napolitana, Co-op Spicy Vegetable sauce, or Tesco Value Pasta Sauce.
2. Place this in a saucepan and add enough boiling water from the kettle to make a soupy consistency in which you can cook rice.
3. This will make quite a lot of soup. If, like me, you're serving one PKU along with some non-PKUs, remove 2 or 3 ladles of soup to a smaller saucepan. This will make the PKU portion. Now, to this, add 15 grams of long grain rice. Simmer gently for about 10 minutes until the rice is cooked and you've got a portion of PKU soup with one exchange. I would leave the saucepan lid on halfway to avoid too much evaporation. The larger amount of soup can be used for non-PKUs. It too should be simmered with rice and obviously non-PKUs won't need their rice to be measured. The non-PKUs can also have cheese grated on top of their bowls as described above. Serve with appropriate bread.

Variations

- I find for our toddler, less is more so I would only use one ladle of soup for him. In this case it might be better to cook the rice separately otherwise the soup might boil dry.
- Clearly, you can up the exchanges by adding more rice. You could add leftover cooked rice too – 45 grams of boiled rice is one exchange. Be careful with leftover rice however. It must have been put in the fridge very quickly after cooking and should be used within one or two days
- An even cheaper and possibly more nutritious method would be to make the sauce yourself. Fry one onion and a crushed clove of garlic in oil until soft but not brown. Add one tin of chopped tomatoes and simmer gently for ten minutes. You could also add finely chopped carrots and celery when frying the onions and garlic or even mushrooms or any "free" vegetable. There's your sauce!



NSPKU Annual Conference Organiser

The NSPKU is in need of some enthusiastic person to organise our Spring 2006 Conference. It's being held in Leicester as before and is to follow a tried and trusted formula. There will be loads of help from everyone on the Council of Management especially from Mike Bailey who is sitting by the phone waiting to take your call! The Conference is a really popular event and a rare chance for PKUs and their families to meet others who truly relate to their condition. This job won't be arduous and there'll be someone to hold your hand every step of the way BUT it really needs to be done. No organiser, no conference! So please come and help us. It's a worthwhile challenge and we actually think you'll have fun too!

Please contact Mike Bailey on
01995 641119
conference@nspku.org

Variety for Life from SHS

Biscuits
Breakfast Cereals
Breads
Egg Replacers
Milk Replacers
Mixes
Pasta

SHS continues to combine innovation with the latest research to design state of the art formulae for the nutritional management of PKU.

The SHS Loprofin and Juvela Low Protein product range offers a choice of tasty, convenient phenylalanine free protein foods and snacks designed for ease of use to people on a PKU diet.

- **Comprehensive product range**
- **Continued excellence in customer service**
- **40 years of experience in diet and PKU**

Contact the SHS Advice Line on 0151 228 1992
or visit our website at www.shsweb.co.uk

SHS Loprofin Low Protein

Juvela Low Protein

SHS INTERNATIONAL

SPECIALIST CLINICAL NUTRITION

SHS International, 100 Wavertree Boulevard, Liverpool L7 9PT.

FATE
Special Foods
TM

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

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

SHS International Ltd, 100 Wavertree Boulevard, Liverpool L7 9PT, United Kingdom. Tel: +44 (0) 151 228 8161 Fax: +44 (0) 151 228 2650 Internet: www.shsweb.co.u

Manufacturers hints & Tips

Scales

I was made aware of some really useful scales that are very small and easily fit inside a pocket, handbag etc. I received them last week and they are really neat and tidy and above all very convenient for taking out with you. The scales will operate up to a maximum of 250g and will cover most situations.

Please take a look at the website below - the scales cost £29.95 + postage.

Could colleagues also make the information available through the PKU clinics as appropriate.

The scales are available to view and order on-line at the following address www.scalesexpress.com

John Skidmore

Fate Special Foods recipes

FATE BAKED PEAR WITH CHOCOLATE CRUMBLE

This is a really delicious pudding and quick to prepare. The forest fruits I use are a frozen mixture of dark cherries, grapes, blueberries, blackberries and blackcurrants, bought in Sainsbury's and Tesco. These are so useful to have in the freezer as you can just take out the amount that you need. You can use tinned forest or summer fruit if you like, these work just as well.
The pears are baked with a little apple juice and extra forest fruit in the dish. This combines together to make a sauce for the finished pear crumbles.
The crumble topping is made with Fate chocolate cake mix. I find it easier to make up a full 250g pack of cake mix into a crumble mixture and store it in the freezer. It is then ready to use when ever we need it. You can use any kind of fresh pear, as long as they are ripe.

Ingredients

For the crumble:
250g Fate Low Protein Chocolate Cake Mix
100g block margarine or butter
For two portions:
1 large ripe fresh pear
3-4 tbsp frozen forest fruits
50mls unsweetened apple juice

Method

Pre~heat the oven, Gas 5. 190°C 375°F

First prepare the crumble topping:
Place the Fate chocolate cake mix into a mixing bowl. Add the margarine or butter and rub in until the mixture resembles fine breadcrumbs.

Then prepare the pears:
Cut the pear in half lengthways. Use a teaspoon to scoop out the core. Then use a small knife to cut out the stalk that runs up the inside of the pear. Place into a small oven proof dish.
If the pear halves won't lie straight without wobbling, cut a tiny slice from the back of each one.
Place about one tablespoon of forest fruits into each pear half. Then gently place about 2tbsp of chocolate crumble mixture on top. (Freeze the remainder for another day). Pour about 50mls apple juice into the base of the dish and add about another tbsp forest fruits.

Bake for 20 – 40 mins uncovered in the oven. Time depends on the size and ripeness of the pears used. (Insert a metal skewer into the pear to test) They should be soft but not mushy, and the crumble topping crisp. Serve hot with the juice and fruit from the dish.

Best wishes
Eileen Green ~ Fate Special Foods

Dietitian's Report

JACOB'S TUC SANDWICH

The protein content of these savoury biscuits is wrong. The protein per biscuit is labelled as 0.1g. It should be 1.1g protein per biscuit. Jacob's are aware of the mistake and the new packaging will provide the correct information.

A few families have told me about these biscuits and I am grateful to them. If you do find a food which seems to have an unlikely protein content when you look at the list of ingredients please let me know and I can check it out for us all.

KARELA

In the last issue of News and Views I told you about the new foods we have had analysed for phenylalanine content. One of these foods was Karela, an unusual looking vegetable, a bit like a small rough cucumber with spikes! It is quite bitter. It is often used in curries and stir fries and can be stuffed. The younger the fruit the less bitter it is but it takes longer to cook. The seeds are usually removed before cooking as they are a laxative, and the fruit is then rubbed with salt and washed to remove some of the bitterness. Karela can be classed as a free vegetable.

Eileen Green sent me a newspaper article about Karela which included the following recipe from the chef, Habib Mohammed, who runs a restaurant in Halesowen in Birmingham.

Karela Special

Ingredients:
2 onions
1 clove of garlic
2 teaspoons ginger
1 birds eye Chilli
1½ teaspoons of Gharam Masala
½ teaspoon Turmeric
Salt and Pepper

Method:
Chop the onions into small cubes and fry in one tablespoon of olive oil until brown.
Add karela, masala, turmeric, chilli, salt, pepper, garlic and ginger.
Slow cook all the ingredients until all the fat has come out of it and the extreme bitter taste has gone.

PAK CHOI

This is another free vegetable which we had analysed last time. It is much cheaper to buy in Chinese supermarkets or open air markets than in the ordinary supermarket. Look out for it and try it in stir fries.

BREAD MACHINES

Again, I must thank Eileen Green for letting me know about two bread making machines; one is great the other is not!

Argos
The new **Cookworks 11597** machine is no good for low protein bread. Eileen can't make low protein bread with it so what hope for the rest of us!

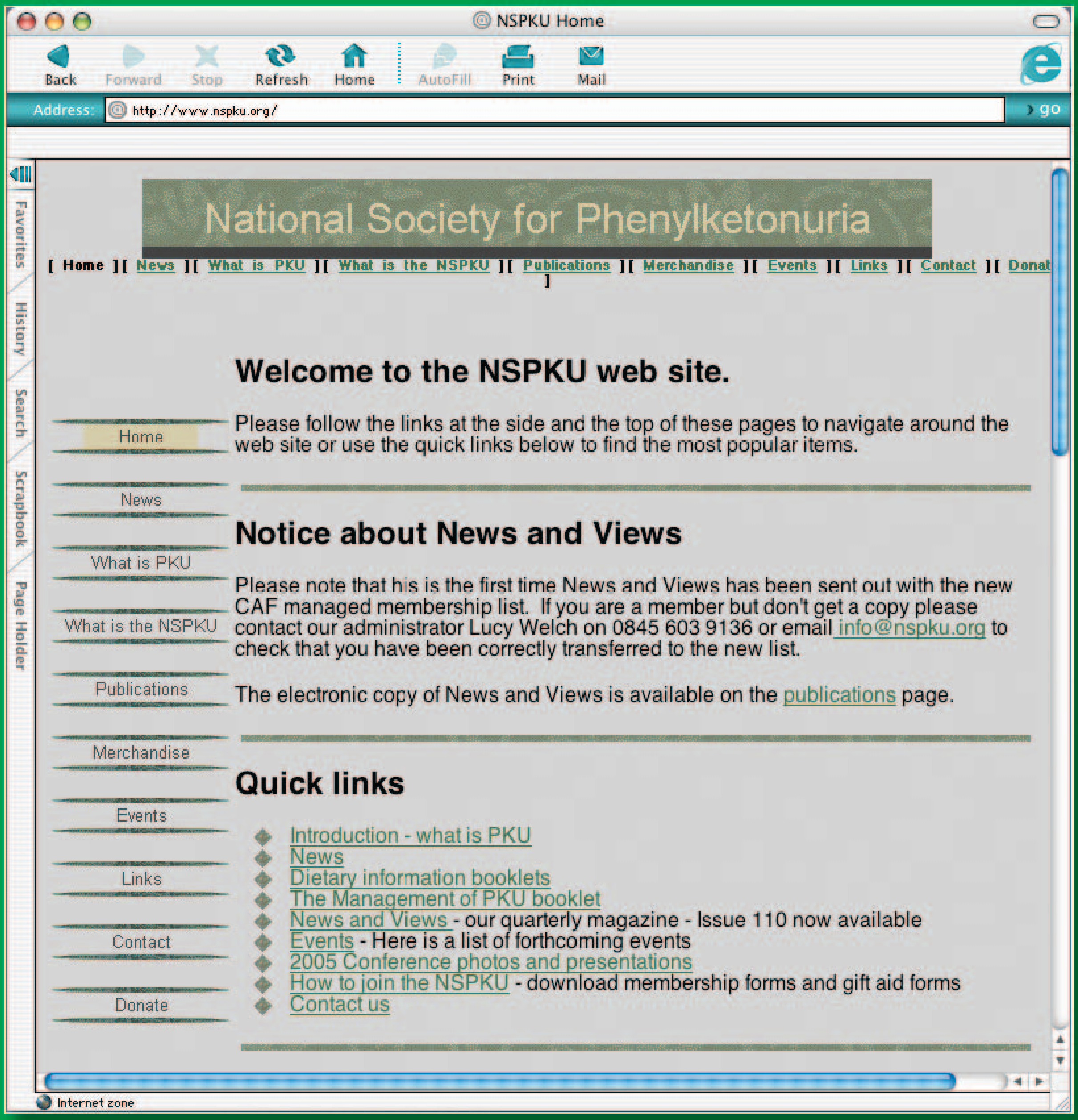
However! Good News now!

Panasonic FD252 Bread Making Machine
This machine is excellent. You can use a whole packet of flour mix, no premixing is required and it makes fantastic low protein bread.

The machine is well made with a heavy bread pan so it is solid and of good quality. The paddle which acts as the kneading tool is a lot slimmer than most and it will just leave only a narrow split in the loaf. Let the bread go cold first before trying to remove the paddle.

At the moment it is on special offer at £60 from electrical stores and John Lewis and is available on the internet at £70. This machine is more expensive than some others but from the sound of it, it is a good machine which will last and will reward you with wonderful bread. I do think that if you have got some really good bread you have the basis of a really good meal!

Check out Our Website for the latest information



National Society for Phenylketonuria

[**Home**][News][What is PKU][What is the NSPKU][Publications][Merchandise][Events][Links][Contact][Donat
]

Home

News

What is PKU

What is the NSPKU

Publications

Merchandise

Events

Links

Contact

Donate

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

Traditional Vegetable Lasagne

Ingredients

- 2 x 15mlsp (2tbsp) olive oil
- 1 clove garlic, crushed
- 75g (3oz) shallots, chopped
- 50g (2oz) celery, sliced
- 75g (3oz) carrot, diced
- 65g (2 ½ oz) cauliflower, roughly chopped
- 40g (1 ½ oz) broccoli, roughly chopped
- 25g (1oz) courgettes, diced
- 400g can chopped tomatoes
- 3 x 15mlsp (3tbsp) dry white wine, optional
- 2.5mlsp (½ tsp.) dried mixed herbs
- ½ vegetable stock cube
- 50ml (2floz) hot water
- Salt and pepper to taste
- 9 sheets **Loprofin** Low Protein Lasagne
- 1 x 15mlsp (1tbsp) fresh chopped herbs, optional

Sauce:

- 2 x 200ml cartons **Sno-Pro** Low Protein Drink
- 25g (1oz) butter
- 25g (1oz) **Loprofin** Low Protein Mix
- Salt and pepper to taste

- 25cm x 17.5cm (10inch x 7inch) shallow ovenproof dish
- Oven temperature: 200 C/400 F/Gas Mark 6

Method

❶ Heat the olive oil and fry the garlic, shallots, celery and carrot in a covered pan, over a moderate heat for 3 minutes, stirring occasionally.

❷ Add the cauliflower, broccoli and courgette and cook for a further 3 minutes.

❸ Stir in the chopped tomatoes, white wine, herbs, stock cube and water, bring to the boil, reduce the heat cover and simmer 5 minutes, stirring occasionally.

❹ Prepare the sauce: pour the **Sno-Pro** into a pan, add the butter and heat gently until melted, whisk in the **Loprofin** Low Protein Mix.

❺ Bring to the boil, stirring briskly to achieve a smooth sauce, adjust seasoning to taste (if desired stir in one of the suggested flavourings, below).

❻ Spoon about a quarter of the vegetables over the base of the ovenproof dish. Cover with a layer of **Loprofin** Lasagne sheets, breaking them to fit.

❼ Repeat with two more layers, finishing with vegetables, then cover with sauce.

❽ Place the Lasagne in a preheated oven for 25 minutes, until the top is golden brown. If desired sprinkle with chopped fresh herbs, before serving.

Serves 3

Serving suggestions and optional flavours

Serve the Lasagne with a crisp salad.

Optional Topping Flavours - Stir one of the following into the **Sno-Pro** Topping, before spreading over the layered sauce and pasta, prior to cooking.

1 x 15mlsp (1tbsp) chopped fresh parsley or fresh herb of your choice
17g packet Cheese Flavoured Quavers, crushed

NB: the Lasagne may be made in individual portions.
If freezing 1 or more of the portions, the lasagne can be prepared in 3 x 12.5cm x 10cm (5inch x 4inch) foil containers. Cook for 20 minutes and ensure that the cooked Lasagne is completely cold, before sealing and freezing.

French Toast

French toast works well as a snack and is a good filler for children when they come home from school

Ingredients

- 1 tsp Loprofin Egg Replacer
- 3 tsp Loprofin PKU Drink
- Small knob of margarine or butter
- 1 slice low protein loaf
- Sugar and cinnamon to serve

Method

❶ Blend together the Loprofin Egg Replacer and Loprofin PKU Drink until smooth

❷ Heat the butter or margarine in a frying pan.

❸ Dip the bread in the "egg" mixture making sure that both sides are covered

❹ Fry on both sides until golden brown

❺ Serve hot sprinkled with sugar and cinnamon

All PKFoods are now available on prescription

Chocolate Chip Cookies

Cinnamon Cookies

Orange Cookies

Pasta Spirals

Crispbread

Cherry Jelly Mix

Orange Jelly Mix

Egg Replacer

White Sliced Bread

Flour Mix

aminex Cookies

aminex Biscuits

aminex Rusks

UNIT 270 CENTENNIAL PARK CENTENNIAL AVENUE
ELSTREE BOREHAMWOOD HERTS WD6 3SS
TEL: 020 8953 4444 FAX: 020 8953 8285
Website: www.pkfoods.co.uk Email: info@glutenfree-foods.co.uk

NEW

Fasta Pasta

Available on Prescription for Phenylketonuria

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 (½ an exchanger per pot)

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

SHS

SHS International Ltd, 100 Wavertree Boulevard, Liverpool L7 9PT, United Kingdom. Tel: +44 (0) 151 228 8161 Fax: +44 (0) 151 228 2650 Internet: www.shsweb.co.uk