

Inside this issue...

Going on holiday
with a PKU child

Letters

Protein Substitutes
Home Delivery

PKU Pronto!

Fate Recipes

Dietitian's Report

Eleanor quenches our thirst!



**See inside for loads more
new products to try**

In Touch

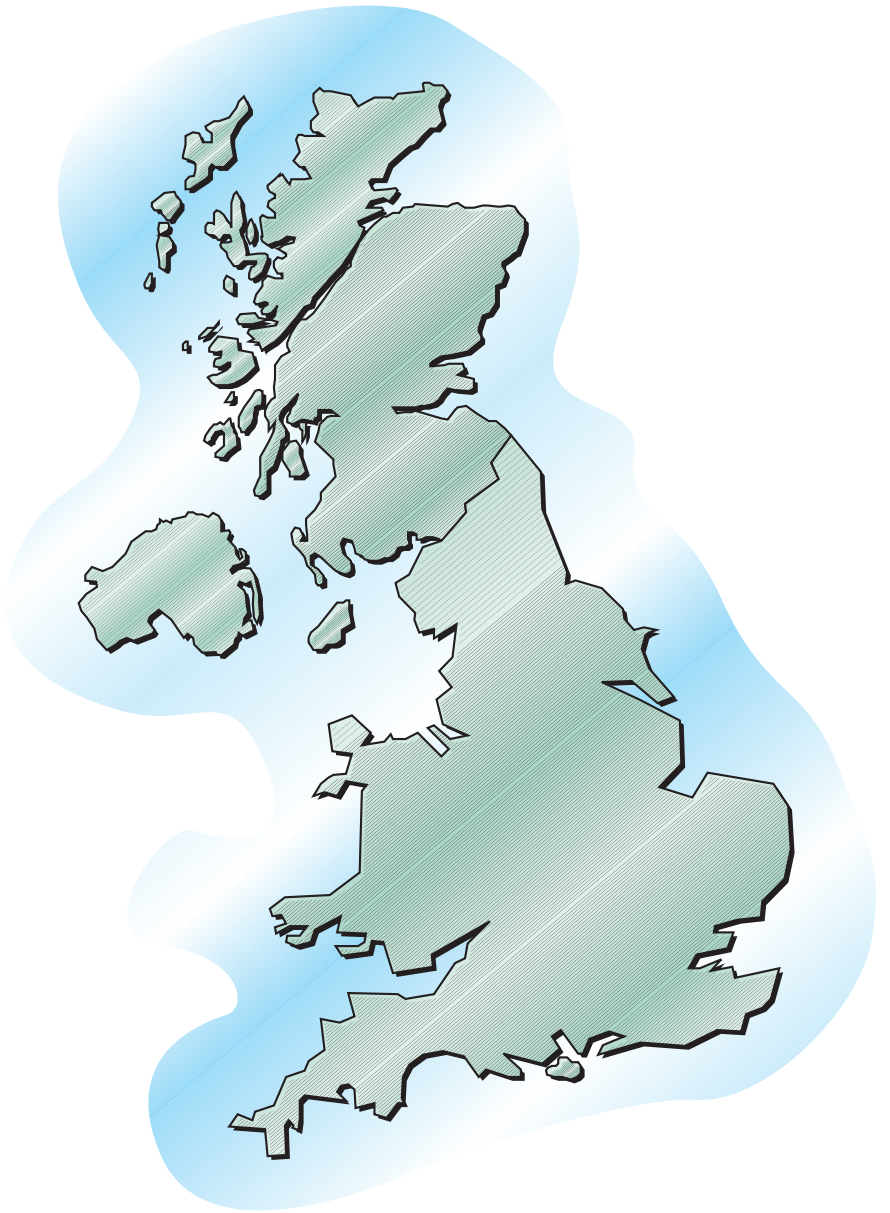
The Council of Management

Telephone Helpline: 0845 603 9136

Address: PO Box 26642, London N14 4ZF

E-Mail: info@nspku.org

Internet: www.nspku.org



Contents

1	Editor's Report	9	SHS recipes
2	Treasurer's Report	10	Going on holiday with a PKU child
	Thanks to our sponsors	11	PKU Pronto!
	Donations	13	Fate Special Foods: Fate Mango and Strawberry Cobbler
3	Letters	15	Dietitian's Report
6	Support Groups and Contacts		
8	Home delivery services for Protein Substitutes		

Editor's Report...

Well, since this is a summer of droughts, thank goodness for Eleanor's article packed full of information about PKU-friendly drinks. At least we can all sit comfortably with refreshing beverages in hand as we watch the lawn dry out!

Kim Ovard's piece with advice on PKU holiday-food is a great help too. Eleanor pointed out that her recommendation regarding amounts to bring is a smart one. Pack as much as you would normally use in the holiday period. You won't need three extra boxes of pasta just because you're on the Costa del Sol! That's really pertinent for me as I always feel compelled to pack loads of extraneous PKU items just in case the plane crashes and we end up marooned, Lost-style. I must remember that as important as the PKU diet is, in the rather unlikely event of such a catastrophe, I'll probably have more on my mind than Seamus's exchanges....

I'd like to say a huge thank you to Anita MacDonald also for her article about Home Delivery. Many of us struggle as we schlep from GP's surgeries to chemists with prescription requests and this free-of-charge service is one that could really make a huge difference in helping to make the diet that bit easier to live with. Anita has worked very hard in developing this facility and I think you'll agree it's been well worth it.

So, droughts and dessert-islands aside, enjoy your summer holidays and please, do write and tell us how you got on!

Kiri Thomas
Editor



The National Society for Phenylketonuria (United Kingdom) Limited

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

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

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

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

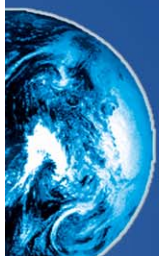
Helpline: 0845 603 9136
Email: info@nspku.org
Web Site: www.nspku.org

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

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

find
us
on
the
web
at:

www.nspku.org



Donations to.

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

If you are sending a donation or a subscription payment please send it to: NSPKU, PO Box 2664, London N14 4ZF

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

Please send only cheques or postal orders NOT CASH

Treasurer's Report...

Having spent my usual ten minutes staring into space trying to decide what to write about in my report I have come to the conclusion that this should be a bit of a review. This being the issue where we thank our sponsors and look back to what we have achieved (or not!) financially.

I think the main change this year has been the introduction of the book-keeper, Vicki. She has settled into her role really well and I already feel like I don't know what I'd do without her. We have changed our finance software to Sage which makes accounting much easier and will reduce our audit bill at the end of the year.

Unfortunately our income from donations and fundraising (such as the Spring Draw) fell this year. I think a lot of charities suffered following world events such as the Tsunami and Pakistan earthquake. On paper it looks as though our

expenditure has drastically increased this year however in fact it has remained largely the same. It is primarily the timing of payments being made and received across the year end period and the fact that we produced fewer issues of News and Views the previous year as well as the production of the pictorial guide that makes it seem a very expensive year.

Looking forward to our current year I have secured some very welcome sponsorship already (full details and thanks this time next year) and am looking for more! I am also hopeful that by the time you read this Eric Lange will have raised wad loads for his Marathon run and he will have inspired more of you to do the same in the 10k run. If not there's always next year!

Julia Bailey
Treasurer

Thanks to our sponsors and donors

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

- SHS who this year have provided £8,000 towards travel for our committee members to the annual ESPKU conference, subsidised PKU conference places, and the cost of printing our publications
- Vitaflo for £200 towards the pictorial guide
- Firstplay for £200 towards the Annual Conference

- Fate Special Foods for £200 towards the pictorial guide

We also have a number of generous members who contribute on a yearly or monthly basis via direct debit payments to the Charities Aid Foundation and by Give As You Earn schemes at work. We pass on our thanks to all of you for your continuing commitment to the work of the Society.

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

Julia Bailey
Treasurer

Donations

<i>Donations to 3/12/05 (£30.00 and over)</i>		£
W.A.J. Graham		100.00
Jo & James Green		383.00
Excel Recruitment Ltd.		461.00
Pauline Stubbins		200.00
Manx Masonic Fellowship		50.00
H.D.G. Evans		75.00
MIDAS – Manchester's Investment Agency		500.00
John Brook		30.00
Mono Equipment (via Leigh Harris)		1,250.00
Margaret Burns & Pat Fordham		50.00
Lesley Thomas		246.00
Mrs F.E. Leahy		400.00
Nigel Clarke		260.50
Mr C. & Mrs P Ashton		150.00
Camelot Foundation Employee Participation Scheme (via Marie-Claire Church/West Lodge School)		1,500.00
St Ursula's RC Junior School		100.00

Lloyds pharmacy Charitable Fund (via Gary Chattaway)	100.00
Christopher McElroy	80.00
Chartered Institution of Wastes Management	
N.E. Centre (via John Skidmore)	323.00
Joshua Joseph (via Caroline Graham)	500.00
Ms A.M. Jeyes	60.00
Cathy & Iain Darby	1,161.00
Hampshire Fire & Rescue Service (via Paul Murphy)	50.00
Anna Markey	100.00
Ellen Manning	470.00
Exeter Inn, Chittlehamholt (via Angee & John Cook)	808.00
Mullarch Limited	300.00
Darent Valley Round Table (via Wendy Cheale)	1,500.00
Sandra Bramley	60.00
Jo Green	383.00
Sharon Andrews	500.00

In memoriam:	
Given in memory of Garth Allen	280.00

Letters

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

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



Dear N&V,

Please find enclosed a cheque for £1,161 raised by our running club. We hosted a 5k Charity Santa Fun Run around Saltram House just outside Plymouth last December 10th.

We also enclose a picture of some of our fellow club runners who raced and our two children, Emily, aged 7 and Charlotte, aged 4 (PKU).

Yours,

Cathy and Iain Darby



Dear News and Views,

Please find enclosed a cheque for £60 which we raised by not sending Christmas cards this year. Please see also a photo of my daughter Alicia who is 4 years old with PKU. Alicia has been struggling to take her drinks of late and if anyone has any tips regarding this problem, I'd be eternally grateful. Alicia is pictured with our cat Molly who looks as if she can't wait for dinnertime!

Yours,

A.M. Jeyes.



Dear N&V,

On behalf of St. Ursula's Junior School, Romford, Essex, please find enclosed a cheque to the value of £100.00 which we would like to donate to the



NSPKU. The children of Year 6 held a special "Travel Day" on which they dressed in costume and prepared food from different countries around the world to sample. The monies raised have been sent to various charities suggested by the children. One of our pupils has PKU and the children would like to make a donation to your charity.

Yours,

Ursula Murphy,

Headteacher.



Dear N&V,

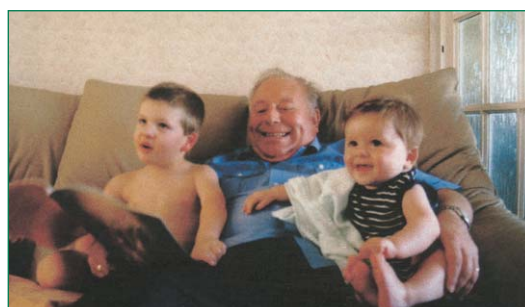
Please find enclosed various cheques which together provide £400 donated in remembrance of Rex Leahy, granddad to Samuel Leahy born 5th Feb 2003 with PKU.

We nominated the NSPKU in lieu of receiving flowers as Rex would have preferred to know that money was donated to assist the Society that continues to help his beloved grandson Samuel.

The enclosed photograph is of Rex with his two grandsons. Samuel is on the right and his non-PKU older brother Matthew is on the left.

Yours,

Mrs. F.E. Leahy.



Letters

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



Dear N&V,
Please find enclosed a £10 cheque for the society. The money was raised as result of attending some swimming sessions approximately 3 months ago.

I am currently returning to the NSPKU and hope to attend the next regional conference.

I have just recently tasted the new PKU products which are delicious; the PKU crunch bars, the PKU burger mix and the gorgeous "Hot Breakfast" cereal. This has given me new inspiration for cooking PKU food and meals, which are quick and convenient.

I am a 33 year old PKU girl who has renewed faith in PKU food!

Yours,
Jane Nicola Reynolds



Dear N&V,
Please find enclosed our cheque for £1250.00 collected by playing a charity rugby match and running a raffle.

One of our employees, Leigh Harris, has a son who has PKU so his colleagues got together to raise this money. I hope it helps your cause a little. It would seem sorely needed.

I have enclosed a photo of the presentation.

Yours,
Jan Bevan
HR Manager
Mono Equipment
Swansea.



Dear N&V,
On 7th January 2006, Mrs. Pauline Stubbins had a "Bells and Bows" stage group reunion after 25 years. £200 was raised which she sent you in a previous letter. Kindly, she received a further £50 from a Mr. Kenny Roadcliff who attended the evening. This came from the Manx Masonic Fellowship to which he also belongs.

Pauline kindly chose the NSPKU as she is a close

friend of Jo Gell's, a previous Bells and Bows member who also attended the evening. Jo's grandson Luke James Gell (5 years) has PKU and is doing well.

We would like to take this opportunity to thank everyone for a lovely evening.

Yours,
Mr. and Mrs. M. Gell
(Luke's parents)



Dear N&V,
Please find enclosed a donation of £1,500 from the Camelot foundation.

My son Ben who is 5 ½, has PKU and attends West Lodge School in Pinner Middlesex. The money raised at the recent school fete there, was matched by Camelot as one of our parent fundraisers works for this organisation.

The picture is of Ben and his younger brothers Cameron and Toby, all with PKU and their new little sister Connie who does not have PKU.

Life can be so difficult with 4 children and PKU so we are delighted to forward this cheque to you as we really appreciate all the work the NSPKU does to make our life a bit easier. Thank you!

Yours,
Marie-Claire Church and all the family.





Letters

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



Dear N&V,

Pictured here is my brother Neil who took part in a sponsored slim. He named the NSPKU as his charity on behalf of our daughter India aged 7 who has PKU. Neil lost 40lbs in weight but gained £335 for the society from work colleagues, family and friends. We are very proud of my brother's achievement and as you can see our daughter India is very happy with her uncle too!

Yours,
Gail and Stephen Seavor.



Dear N&V,

I am enclosing cheques for £280 for the NSPKU. This money was raised at my husband Garth Allen's funeral.

Garth was a founding member of the society in the early 70s and was Fundraising Officer for a number of years. We attended most meetings which were then held all over the country. Garth also helped to set up the very first conference which was held in Blackpool. We were both very proud to see that the society has gone from strength to strength and helped so many PKU children.

Yours,
Glenise Allen.



Dear N&V,

Suzie Hanlan of Joshua Joseph has kindly donated £500 to the NSPKU as the result of an end of season sale. Joshua Joseph creates accessory collections



collaborating with up and coming artists and established designers from all around the world. I've enclosed an example of their design fabrics for you to see along with a photo of my three children,

The sale was more like a social event with about 100 people attending including many of our friends. Everyone was very supportive as they knew a contribution was being made to the NSPKU and most were aware that two of my three children have PKU.

Callum (12) and Holly (9) are both very well and happy. They are becoming more independent and cope amazingly well with the responsibility of their diet. They have a great attitude to PKU and just get on with it allowing us to have a normal family life. Unless you look at their food, it would be impossible to work out that my 6 year old is the one without the condition!



A big thank you to Suzie, Joshua Joseph and also Amanda Delaney for being so generous.

Yours,
Caroline Graham.



Support Groups

South Wales Support Group.....more info

In the last issue of News and Views (issue 115), we announced that the South Wales Support Group is closing since there is no-one to take over from Alun and Ifona Rogers. Following on from this, I would like to add that the balance of the Groups funds was donated to the NSPKU with the request that we would keep these funds available for a short term to anyone who came forward to revive the group.

On behalf of the South Wales Support Group this is now a last ditch plea. If you wish to revive this group for the people of Wales then please let me know. Otherwise, thank-you very much Alun and Ifona for your hard work over the years and for the donation to the NSPKU.

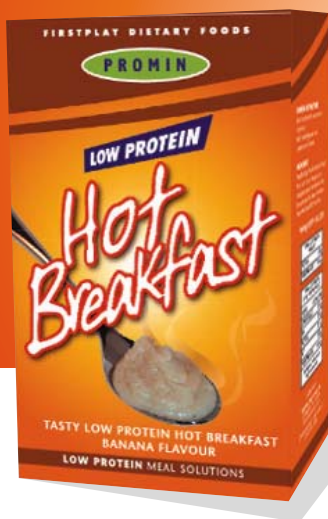
Julia Bailey
Treasurer

IT doesn't all end up in the bin!

The Chartered Institution of Wastes Management, North East Centre, held a charity raffle in support of PKU at their Christmas Luncheon in December held in York. PKU was the chosen charity in support of John Skidmore the North East Centre's Honorary Secretary whose youngest daughter Annabelle, aged 6, has PKU.

Waste collection vehicle and equipment manufacturers, academics, public and private sector waste professionals attended the event from across the North East of England. The raffle raised a tremendous £323 for NSPKU.

Now you can choose Breakfast, Lunch and Dinner



NOW AVAILABLE
ON PRESCRIPTION

GREAT TASTING MEAL SOLUTIONS WHATEVER THE TIME!

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

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

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

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

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

PROMIN

Firstplay Dietary Foods was formed in 1993 to produce Promin Low Protein products from a small factory in Stockport, where we only produce low protein products.

Promin Pasta and Promin Tri-Colour Pasta are now a well established brand and are available on prescription.

Our pasta range available by prescription also includes Imitation Rice, Pasta meal and Lasagna

Sheets they are also available by mail order.

More recently interaction with PKU patients, parents and Dietitians has resulted in the expansion of the Promin range. New products have been designed to reflect the needs of a maturing PKU population leading busy hectic lifestyles. Call us or visit the website for more information or with your dietary suggestions.

Firstplay Dietary Foods produce low protein foods especially for your diet.



Always consult your dietitian before trying something new.

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

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

Home delivery services for protein substitutes

Anita MacDonald,
Anne Daly and
Vanessa Hopkins
Birmingham Children's
Hospital, Steelhouse
Lane, Birmingham,
B4 6NH

What is a home delivery service for protein substitutes?

Two dietary companies SHS Homeward and Homecare (associated with VitaFlo), have started a home delivery service for protein substitutes e.g. Minaphlex, PKU Gel, PKU Express Cooler and Lophlex) used in PKU. With your permission, each month they will organise a prescription directly from your GP, and deliver the entire protein substitute to your home at the same time each month. They will always ring you before your prescription is due to check the amount of protein substitute you need. The two home delivery services between them deliver all the protein substitutes available in the UK with the exception of Aminogran Food Supplement and Aminogran PKU tablets.

Why use a home protein delivery service for protein substitutes?

Protein substitute is a vital part of the dietary management of PKU. Without it, blood phenylalanine levels will quickly rise. Traditionally a GP will write a prescription for the protein substitute and a chemist then dispenses it. Although many GP's and chemists are very good, mistakes and delays do happen. Many of the protein substitutes share similar sounding names and packaging, so unfortunately mistakes are inevitable. We at Birmingham Children's Hospital trialled a home delivery service for one year in a group of patients after we had found a number of issues with patient supply of protein substitute through the traditional GP and chemist route.

The home delivery service proved very popular with patients and reduced dispensing errors of incorrect protein substitutes, time delays in receiving protein substitute, and reduced anxiety over protein substitute supplies.

1. Considering a home delivery service for protein substitutes?

If you think a home delivery service for protein substitute may help you, ask yourself the following questions. If you answer yes to any of them, then it is worthwhile discussing a home delivery service with your dietitian.

- Have you ever been given the wrong protein substitute?

- Have you ever had to wait for more than 7 days to receive your protein substitute?
- Do you ever struggle receiving the right amount of protein substitute from your GP?
- Do you ever have to ask your GP for repeat prescriptions more than once monthly?
- Do you have to collect your protein substitute from your chemist?
- Do you ever worry about obtaining your protein substitute?

2. How do I organise the home delivery of protein substitutes?

Firstly discuss this with your dietitian. He/she will do 3 things:

1. Ask you to complete a consent form to give the home delivery company permission to obtain the protein substitute prescriptions from your GP.
2. Complete a registration form which will outline your monthly protein substitute requirements for the home delivery company.
3. Inform your GP about the home delivery service.

As soon as this process has been completed, the home delivery service will contact you to organise your first home delivery, and will agree with you the delivery address and time. **It is a very simple process.**

3. Will the home delivery service deliver other products other than the protein substitutes?

The home delivery services are still in their infancy, but the long-term goal is that all products will be home delivered. However, even now, SHS Homeward is able to deliver their own vitamin and mineral supplements e.g. Paediatric Seravit, Phlexy Vits, and milk replacements like Liquid Duocal, Sno Pro, and Loprofin PKU drink. Homecare is also able to deliver Vitabite.

4. Have the home delivery teams had any training in PKU?

Specialist training on protein substitutes and other specialist products suitable for PKU has been given to the home delivery teams. All people involved in the home delivery service have received training to ensure they have some knowledge of PKU.

5. What do families think of the home delivery service?

When the home delivery service was trialled at Birmingham Children's Hospital, all the families receiving protein substitute via the new system said this service was better than before. They said it was reliable, flexible, and convenient and deliveries were usually complete. The process of obtaining

prescriptions appeared to be associated with less stress when compared with a comparison group of people who were still obtaining prescriptions from

their chemist.
(Results obtained from a controlled study).

Patient/parents comments about the home delivery service

chemist is a nightmare
-home delivery
is a far better option

saves time
and never run
out of products

made
life easier

stress free service.
Don't know
what we would do
without it now.....

pleased with
service...

...and final comments

A home delivery service for protein substitutes in PKU reduces prescription and dispensing errors. Particular attractions of this service include a consistent standard of service; the home delivery service taking direct responsibility for obtaining GP prescriptions; and a timely, reliable delivery. If you

already use a home delivery service for protein substitutes, please share your experiences through News and Views. Does it work for you? What other things could be introduced to make home delivery an even better service? We would love to hear from you!

SHS **recipes**

Curried Dip

Ingredients:

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

* Check NSPKU Handbook for a suitable brand of mayonnaise

Method

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

Kim Ovard Has written this very useful and timely guide for those of us taking young children with PKU on holiday. Indeed, many of these tips are useful for older people too so thank you Kim, for this very helpful advice.

Going on holiday with a PKU child

- Think about what your child uses in a week, this will help you decide on what you need to take.
- Make sure you **get a letter from your dietician** this letter will allow you to take the products into the country (it is very rare you are asked for it).
- If you are going on a long haul booking a **night flight** reduces the amount of food required on the plane.
- Request a **Vegan Meal** with no nuts as this gives them the opportunity to pick at the meal and **on Virgin** you can actually get a PKU meal.

Plane Food & Drinks

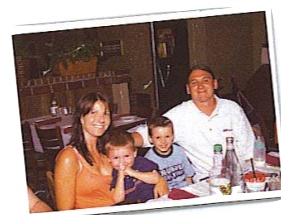
- A small **Ribena bottle** is easy to carry and fits nicely into hand luggage.
- (If a night flight) take **cereal** and a **small carton of PKU milk**, this is good for breakfast. Or if exchanges allow, a cereal bar.
- **Fruit flakes, school bars, raisins, repacked fruit** from Marks and Spencer's or any supermarket are a good choice, **crisps and crackers biscuits**, are all good snacks,
- If you are on a long haul flight, **tin shapes (Barney or hoops)** are approx 4 exchanges if all the tin eaten and can be heated up on the plane.
- **Snack pots** are a really good idea but you must peel back the lid slightly to allow the air to get out or they do explode on the plane.
- Children do not eat that much on the plane, they do prefer to snack.

Packing Food & Drinks

- A must is **High Juice** - it is very hard to find juice that is suitable, approx 2 bottles for a week, wrap them separately in carrier bags and pack in the suitcase.
- Pack enough **Lo-Profin Milk** for the week for cereal.
- Best pasta to take that cooks the quickest is the **Loprofin spirals**, must be placed in boiling hot water little salt and oil for about 10mins max. This pasta is free and can add vegetables to make tasty or even jar of tomato sauce which you can buy in most countries.
- If you take the **Promin pasta shells** which are multi coloured they take a long time to cook, so, you can soak them in the day and then when they are ready to cook it takes less time.
- **Broccoli or Tomato pasta** which are both 1 exchange each and each box has 4 sachets (you do not need to take the box, it saves space to remove out of box).
- **Long Spaghetti** is extremely quick to cook and one box will do at least 4/5 meals.
- If exchanges allow, **2 min noodles** are a good idea. (Remember to tell them to remove the wrapper 1st. In Turkey they boiled the whole packet with the wrapper still on!)

- If you have your own villa or self catering apartment you may find it a bit easier to allow the exchanges to be used while you are out and about and the free meals at night. This way they can eat chips and vegetables for lunch and have ice cream etc.

I have been to a various countries and never been refused any of the pastas to be cooked and always had a lovely holiday.



PKU Pronto!

How fabulous! Barbara Broadbent, whose 10 year old grandson has PKU, sent us in these great recipes. I can't wait to try them and am so delighted to put someone else's recipes in this column. Many thanks, Barbara.

Vegetables in Honey Mustard Sauce

Ingredients

- 150ml dry or medium dry white wine
- 6 tablespoons extra-virgin olive oil
- 4 tablespoons tomato puree
- 4 tablespoons chopped parsley
- 2 tablespoons whole grain mustard
- 2 tablespoons clear honey

Method

- Pre-heat oven to 190°C or 170°C fan.
- Mix all ingredients thoroughly in a casserole dish.
- Take 100g each of peeled and sliced courgettes and parsnips.
- Add vegetables to the casserole dish and ensure they are all well covered by the sauce.
- Put on a tightly-fitted lid, or indeed some foil.
- Bake in the centre of oven for about one and a quarter hours or until the vegetables are cooked through.
- Serve with mashed potatoes (exchanges) and or finely sliced spring greens (exchanges).

How delicious does that sound?

Oven roasted tomato sauce

Ingredients

- 20-24 tomatoes
- 2 large red onions, coarsely chopped
- 4 tablespoons olive oil
- 1 tablespoon balsamic vinegar
- 1 tablespoon caster sugar
- Salt and pepper
- A little crushed garlic, if you like it

Method

- Pre-heat oven to 200°C or 170° fan.
- Wash the tomatoes and cut each one across the middle. Arrange in flat baking trays, cut side up. You will probably need to use 2 large trays.
- Sprinkle the chopped onion onto the tomatoes.
- Drizzle the tomatoes with the olive oil and garlic if using.
- Bake in the oven for about an hour.
- Cool for 30 minutes then whiz with an immersion blender or in batches with a food processor. Place into a bowl and stir in the remaining ingredients.
- Freeze in batches, in foil trays preferably.

Barbara says you can also freeze the sauce in ice cube trays and then easily defrost a few cubes to use instead of gravy with things like pies of pasties.

Speaking of which.....

Individual Vegetable Pies

Barbara makes these in individual round foil dishes measuring 11cm across and 2.5cm deep. She

doesn't know the brand name but the serial number is CP12/12 so you might be able to track them down that way. The following recipe should make about of these pies.

Pastry

- 350g low-protein mix
- 175g block margarine
- A little salt.

Method

- Pre-heat oven to 200°C
- In a large mixing bowl, lightly rub the low-protein mix and margarine between your fingertips until it resembles breadcrumbs.
- Sprinkle with a little salt and place in the fridge to rest whilst you prepare the filling.

Filling

- 1 large red pepper, de-seeded and chopped
- 75g small cauliflower florets
- 75g French beans, topped and tailed
- 1x400g chopped tomatoes

Method

- Liquidise the chopped tomatoes in the food processor to make a smooth sauce.
- Put the red pepper and cauliflower in a large frying pan and cover with the tomato sauce. Heat and simmer for about 10 mins until the pepper and cauliflower are just cooked through.
- Simmer the French beans in a separate pan of water as they don't cook at the same rate as the other vegetables if simmered with them in the tomato sauce.
- The beans should take about 7 mins to cook until softened but not soggy. Cut them up into small pieces and mix with the other vegetables. Allow to cool.
- Take the pastry out of the fridge and mix with a few tablespoons of water until it sticks together and can be rolled out. Barbara recommends rolling it out in two batches.
- Using a saucer slightly larger than the foil trays, cut out 5 pie bases. Invert one of the foil trays and cut out 5 pie tops. You will probably have enough pastry left over to roll and cut out one more base and top.
- Line each tray with pastry.
- It's important that the vegetables are moist but not wet so you can either place a colander onto a bowl and drain the vegetables through it, or you could use a slotted spoon to remove the vegetables from the sauce. Ensure the pieces of cauliflower, pepper and beans are small enough to fit into each pie dish.
- Moisten the outer edge of each pastry base and after filling it, put a pastry top on each pie.
- Bake the pies on baking trays for about 25 mins.

The pies freeze well and the fillings can of course be varied.

Pasties

This makes 4 pasties and each one contains ½ exchange of potato.

Pre-heat oven to 200°C

Pastry

250g low-protein mix

125g block margarine

Method

- Rub the margarine and flour together to the breadcrumb stage as in the pie recipe above.
- Place in fridge to rest whilst you prepare the filling.

Filling

3-4 tomatoes

A few potatoes

1 large red onion

Some chopped parsley

Method

- Cut a cross in the top of each tomato, place in a large bowl and cover with boiling water for 1 minute.
- Carefully remove from the water with a slotted spoon and when cool enough to handle, remove the skins. Quarter each tomato, remove the hard core and put the flesh into a saucepan.

- Cook over a low to moderate heat until the tomatoes have gone mushy. Do this slowly so that they retain some moisture.
- Boil enough small potatoes so that you are able to weigh out 160g once they are cooked. The skins should peel off easily when they are cool.
- Peel and slice a large red onion and fry them lightly in oil until they are cooked through. Drain on kitchen paper.
- As in the previous pie recipe, use a little cold water to make the pastry stick together. Roll it out.
- Barbara uses a small saucer of 13cms diameter to cut out 8 circles of pastry. On 4 of the circles, put 40g of potato, some of the fried onion and a good spoonful of the cooked tomato so that the filling is moist but not wet. Sprinkle with chopped parsley. Place another circle of pastry on top of the filling. Moisten the edges of the pastry base and top and bring up the edges of the base to form a frill around the bottom of the pasty. Cut a cross in the top of each pasty to let the air out.
- Bake on a lightly oiled baking tray for 20-25 mins. *The pasties freeze well.*

Yes We Cook That.com

Specialist Dietary Foods

Freshly prepared PKU ready meals

Available near you*

Would you like...

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

Yes We Cook That!

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

Yes We Cook That!

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

Yes We Cook That!

To have all this at Supermarket prices?

Yes... it is!

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

Yes... we do!

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

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

Our menus are available through your dietician in some parts of the country or directly from Yes We Cook That.com. Our aim is to supply all PKU people with the opportunity to purchase ready made meals, breads, cakes and sweet and savoury snacks at supermarket prices.

*Available now in most of the UK and Ireland.

Phone Leanora or Pauline on 07773 342594

24 hour answering machine 01290 332 949

e-mail sales@yeswecookthat.com

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

Fate Special Foods recipes



FATE MANGO AND STRAWBERRY COBBLER

Hello,

This recipe is a for a really fresh tasting fruit pudding. It makes 4 good portions. The pudding looks best cooked and served in individual ramekins or other ovenproof dishes. Try to use those that hold around 250mls. (I've used some that I bought from Asda)

You can vary the type of fruit you use, and any combination ~ Just use anything that's allowed, but try the mango, you won't be disappointed!

Also, you can use pure apple or pineapple juice in place of the orange juice in the base and the topping if you prefer.

For the base:

- 1 medium fresh mango
- 8-10 medium sized fresh strawberries
- 4 tbsp pure orange juice

For the cobbler topping:

- 200 g Fate Low Protein All-Purpose Mix
- 50g block margarine
- pinch salt
- 1 tsp baking powder
- 60g light soft brown sugar
- 120mls pure orange juice

Pre-heat the oven Gas 5 190°C 375°F

First of all, prepare the fruit base:

Peel the mango and cut into small pieces. Cut the strawberries into quarters and place into ovenproof ramekin dishes in equal proportions. You should fill the dishes about 2 thirds full. Add 1 tbsp pure orange juice to each dish.

Then prepare the Cobbler topping:

In a mixing bowl, place the Fate Low Protein All-Purpose Mix. Add the salt. Rub in the margarine until the mixture resembles breadcrumbs. Add the baking powder and sugar. Stir well.

Measure the pure orange juice and add it to the bowl. Stir well using a large metal spoon until the mixture is smooth and creamy. Leave to stand



for 2-3 mins.

Place the cobbler topping into the dishes on top of the fruit.

Bake in a pre-heated oven for about 25 mins until the topping is cooked and golden brown. If you are unsure, use a skewer and push it into the centre of the topping. It should come out clean.

Serve hot or cold.

*The puddings can be frozen,
But make sure you protect the
dishes well.*



Dietitian's Report

What's New To Try?!

Quorn

Surprisingly Sizzling Smoky Bacon-Style Slices

So many were disappointed to learn that the bacon substitute called Streaky Strips was no longer available in the UK. It was the focus point of a cooked breakfast along with the tomatoes, mushrooms and toast. A proper cooked breakfast!

Well, I must thank Mrs Katherine Senior from Bath who told me about the **Surprisingly Sizzling Smoky Bacon-Style Slices**. We met down at the PKU up-date day in Taunton in March and as always at these interesting and fun days I learn something from you. This 'bacon' is more like back bacon and doesn't have the streaky effect but I've just cooked a rasher and I think the taste is excellent. You just fry the 'bacon' for 2 minutes on each side or you can grill them after lightly brushing with oil. The 'bacon' does crisp up like ordinary bacon too.

One slice provides 2 Exchanges but because the slices are quite wide you could cut them in half lengthways to provide just one Exchange. There are 8 slices in a pack and the pack costs £1.95. I bought mine in Asda.

You could make a low protein BLT, you could snip it on top of a low protein pizza or what about making a low protein 'cheese'? sauce for vegetables and then crumbling the 'bacon' on top? I think I'm feeling hungry already.....

- Make a white sauce using low protein 'milk' and then crumble in a small packet of cheese Quavers. A small packet of Quavers provides ½ an Exchange.



Plum Baby Super Foods

Again I have to thank Mrs Senior for finding these pots of baby foods. This is a new range of organic baby foods for babies from weaning. They come in

pots of 2 per pack. They're not available in all supermarkets but go to this website either to buy them online or to see if an independent shop near you stocks them:

<http://www.graigfarm.co.uk/babyfoodplum.htm>. Sainsbury's do stock them however.

The flavours I have on my desk are:

Sweetcorn and Carrot 40gms = 1 Exchange
Squash and Sweet Potato 90gms = 1 Exchange
Spinach, Parsnip and Basil 85gms = 1 Exchange
Parsnip, Apple and Pea 65gms = 1 Exchange
Mango and Banana 50gms = 1 Exchange
Blueberry, Banana and Vanilla Free

This range of baby foods is a bit more expensive than other baby foods but apparently they are lovely. These pots are not just for babies either! Mrs Senior said that the Spinach, Parsnip and Basil one is just like pesto and so you could stir it through hot pasta for a really Mediterranean flavour. Let me know what you think! Has anyone got any more ideas?



Marks and Spencer

Lemon Sauce

Barbara Cochrane brought this sauce to the conference. It's lovely lemon sauce which is good on vegetables. It's quite rich so you don't need a lot of it. 85gms = 1 Exchange.



Summer Fruits Compote

This is a delicious pot of summer fruits which would go well in a Meringue nest (nest = ½ Exchange) or with some sorbet.

Another idea I read for meringue nests is to put some lemon curd in them and then top with some squirty cream (don't forget to count the cream). This would then be like a lemon meringue pudding. Lovely!



John Lewis

Barbara Cochrane brought these sweet little chicks and nests to the conference. She found them in John Lewis and they are free. John Lewis also sell the Carbonnel and Walker sweets which are expensive but according to those who have had them are really good. The suitable ones are Crèmes Parisienne, Peppermint Creams and Crystallised Ginger. Maybe something for a special occasion! I saw the following sweets in Asda a few weeks' ago. Asda Sugar-free Lemon Drops
These are boiled sweets which are sweetened with sucralose. Each sweet is 8 kcals so if you are trying to lose weight and want something a bit sweet to suck these could be useful.



Sugar-Free Sweets

Sweet 'N Low

Sugar free sweets fruit medley
These are boiled sweets sweetened with Acesulfame K. Each sweet is 7 kcals so again useful if you are watching your weight.



Russell Stover
No Added Sugar Jelly Beans
Sweetened with sucralose.
All the above sweets are protein free.

Name it Labels

Mrs Christine Cardy read about this label company and sent me the cutting from the magazine. You can order labels with your own message on them. They may be useful to label protein substitute or a picnic box. The labels are colourful and waterproof.

To find out more about these visit the web site at www.nameitlabels.co.uk
Tel 01823-451281

Summer's coming - What can I drink?

I've been up and down the supermarket aisles to see what's around. The following list is not a complete list of everything but I hope will give you a good idea of the variety of drinks which are suitable. There's vast range now and I was pleasantly surprised at the lovely variety of flavours and presentations of drinks.

I find it interesting going to different supermarkets. I usually shop in Morrisons because it is the nearest to where I live but visiting Tesco's, Sainsbury's, Marks and Spencers and Asda opened my eyes to further choice. So, if you always use a certain supermarket it might be worth trying another one to see what's in there if you are passing. Variety is good and especially important if the diet is restricted. This applies not just to drinks but all the other types of food too.
Of course we all look out for aspartame in drinks and it is very important to avoid any drink sweetened with aspartame. A can (330ml) of drink sweetened with aspartame will provide about 2 exchanges.

You only need to avoid Aspartame and Aspartame with AcesulfameK.
Acesulfame K on its own is perfectly OK in the PKU diet.
Sucralose is also OK and I found a number of drinks with this sweetener. I think you will see this sweetener more and more as its popularity increases.

Squashes

Robinson's

High Juice 55% juice - Grape and melon, Apple, Cherry and Raspberry

Ribena, Vimto

Asda

High Juice 50%. All flavours currently 2 bottles for £2.

Dietitian's Report cont...

Sainsbury's

High Juice. All Flavours Currently 2 for £2.

Tesco

Hi Juice. All Flavours.

bottlegreen

Cordial – Elderflower, Ginger and Lemon grass,
Spiced berry (*this is a rather smart cordial!*)

Duchy of Cornwall

Organic Lemon Refresher

This one's a bit smart too. £1.49 a bottle so not too expensive

In hot weather you can put a plastic bottle of water in the deepfreeze half full. Fill with water in the morning and add a little squash and it will still be cold at lunch time. It helps keep the picnic cool too!



Fruit Juices and Smoothies

Pure fruit juices are all suitable. There are lots of flavours in cartons and bottles and pouches. All fruit juices can be diluted down with fizzy water or plain water if you like. This is just a small selection:

B2b

Peach and Passionfruit

Innocent - Smoothies for kids

There is one with coconut milk which is higher in protein. Best to avoid this one as the coconut milk may be concentrated. You can drink fresh milk from the real broken nut but the milk you get in tins contains the squeezed nut flesh too which makes it higher in protein. I don't know what they use for the Innocent Smoothie which is the reason for choosing the other flavours.

Princes

Whole range of fruit juices. Good mixes of flavours e.g. Orange, Apple and Passionfruit.
Tomato Juice is really nice with Worcestershire Sauce and an ice cube.



Fruit Juices with or without sugar and/or other things

Del Monte

Indian Mango and Papaya, Persian Pomegranate, Mandarin and Lychee

Appletizer

J2O

Good range of interesting flavours. Widely available in pubs too.

Fruits of Nature

Organic Apple Juice

Has a screw cap so could be re-filled.

Pouch Drinks

Capri Sun

Pouch with a straw. Good value in Asda 20 drinks for £3 - that's 15p per drink.



Tesco

Orange Juice and Blackcurrant Juice Drink
10 pouches for £1.69

Small Bottled Drinks with Push Down Caps

All the following are in solid colour bottles and look attractive so you can use them again and could be useful for mixing and taking protein substitute.

Robinson's Fruit Shoot

The Green-capped bottles.

Sainsbury's for Kids

Lower calorie drinks

Orange Still Juice and Apple and Blackcurrant

Currently £1.58 for 6

Asda

Juice Squeeze Tropical Fruit Flavour and other flavours £1.14 for 6

**Flavoured Waters**

There are lots of these now. They come in still and sparkling.

The following are all low calorie ones.

Marks and Spencers

1 litre bottles Still Water orange and other flavours

Sparkling water – Elderflower and other flavours.

Take care there is one elderflower drink with aspartame.

500ml bottles in the cool cabinet

Spring Water with Strawberry and Aloe Vera and other flavours.

Danone

Shape Flavoured Spring Water – Raspberry and Strawberry

**Water****Disney**

Welsh Natural Water - £1.43 for 6

Trendy cartoon bottle – can be re-used and might help encourage water drinking. Can be re-filled and I would at this price!

On the subject of water I always put a jug of water on the meal table and a glass for everyone. It really encourages us all to drink more water and as the family find it an effort to get up to get anything else it goes down well and it's cheap! You can add a few slices of lemon or some funny shaped ice-cubes. This might also help you to drink it more! One dietitian I know calls it tap juice! It is important to drink enough in hot weather. The urine should be straw coloured or lighter but not dark.

**Tea**

There are a lot of flavoured teas now. The fruit teas are very nice and make a change.

Lipton

Ice Tea – Peach and Lemon

Nestea

Ice tea and red fruits

**Something a bit sophisticated!****Ame**Grape and Apricot, Orange and Grape
Raspberry and Blackberry**Shloer**

Sparkling drinks - Red Grape, White Grape and Cranberry, White Grape and Elderflower

Alcoholic Drinks

There are a number of alcoholic drinks which contain only a trace of protein and therefore can be

Dietitian's Report cont...

drunk without counting them as phenylalanine exchanges in the diet. They are the following:

Wine

Red, white and sparkling – sweet, medium and dry
There are also a number of non-alcoholic wines which can be taken without counting too.
Fortified Wines
Port and sherry.

Spirit

Gin, whisky, rum, brandy, vodka and Pimms.
Take care that any mixers, either bottled or on tap, do not contain aspartame.

Vermouth

Sweet and dry.

Cider

Dry, sweet and vintage cider

Bottled Shandy

N.B. Bottled shandy is classed as a soft drink as the alcohol content must not be above 0.5%. Shandy made in a pub is stronger. See next bit about 'Drinks containing significant phenylalanine'.

Alcopops and Alcoholic Fruit Drinks

e.g. Hooch, Source
NB Some alcopops may contain aspartame. This will be declared on the label.

Ginger Beer

Is a soft drink and does not contain beer. It may contain aspartame. Check the ingredients label.

Liqueurs

Cherry brandy and Curacao

Drinks containing significant phenylalanine.

The following alcoholic drinks contain some protein and should be counted as follows:

Beer - All beer, brown ale, lager, pale stout and stout extra. 1 pint counts as 1½ exchanges

Guinness

1 pint counts as 2 exchanges

Strong Ale – Barley Wine Type

250 ml counts as 1½ exchanges

Pub Shandy

1 pint counts as ½ exchange

Cream Liqueurs

e.g. Bailey's Irish Cream, Cadbury's Cream Liqueur
30ml counts as 1 exchange (as a guide a small liqueur glass holds 20ml)
Advocaat contains egg yolk so should not be taken.

Pop or carbonated drinks

Irn-bru

Coca Cola

Sprite

7up

Dandelion and Burdock

Lucozade

What I couldn't find was a squash to dilute which is very low in calories and without aspartame.

Does anyone know of such a squash? Please let me know so that I can tell everyone!

PS. Next question up for discussion is:

My child/teenager finds it really hard to explain what PKU is. What do you say about it? How do you explain it to a stranger? Let me know how you handle this one.

Presentation of Honorary membership to Pat Portnoi



It gave me such great pleasure to present an honorary membership to Pat Portnoi from SHS International at the company's metabolic study day in London on March 10th. I think that all the professionals and many of you, both the families and adults, will know Pat well. For as long as I can remember Pat has always been a part of the PKU world and throughout that time has always been enthusiastic, totally professional and dedicated. In addition to this she is a friend to many of us. She is always smiling and any meeting with her is memorable.

It was wholly appropriate to make this presentation (the first time we have given this award to someone in industry) in front of a large international professional meeting and the applause really said it all.

Eleanor Weetch
Society Dietitian



NOW AVAILABLE ON PRESCRIPTION *THE NEW WAY*

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

THE VERSATILE PRODUCTS YOU'VE BEEN WAITING FOR:



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



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



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

EVERY PACK CONTAINS EASY TO FOLLOW RECIPES DEVELOPED BY EILEEN GREEN



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

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

Helpline and General Enquiries Tel: 01215 22 44 34

FATE SPECIAL FOODS ~ SPECIAL FOODS FOR SPECIAL PEOPLE

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

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



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



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



The service is provided free of charge from Vitaflo.



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

0151 709 9020



Fresenius
Kabi

Working together to deliver a better service

SHS **Homeward**

... more than just home delivery

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

For more information call:

08457 623605



The Italian Job



Loprofin Pasta is just the 'Italian' job.

The Loprofin authentic low protein

Italian pasta range from SHS.



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

SHS