

NSPKU News & Views

The National Society for Phenylketonuria (UK) Ltd

Issue 127

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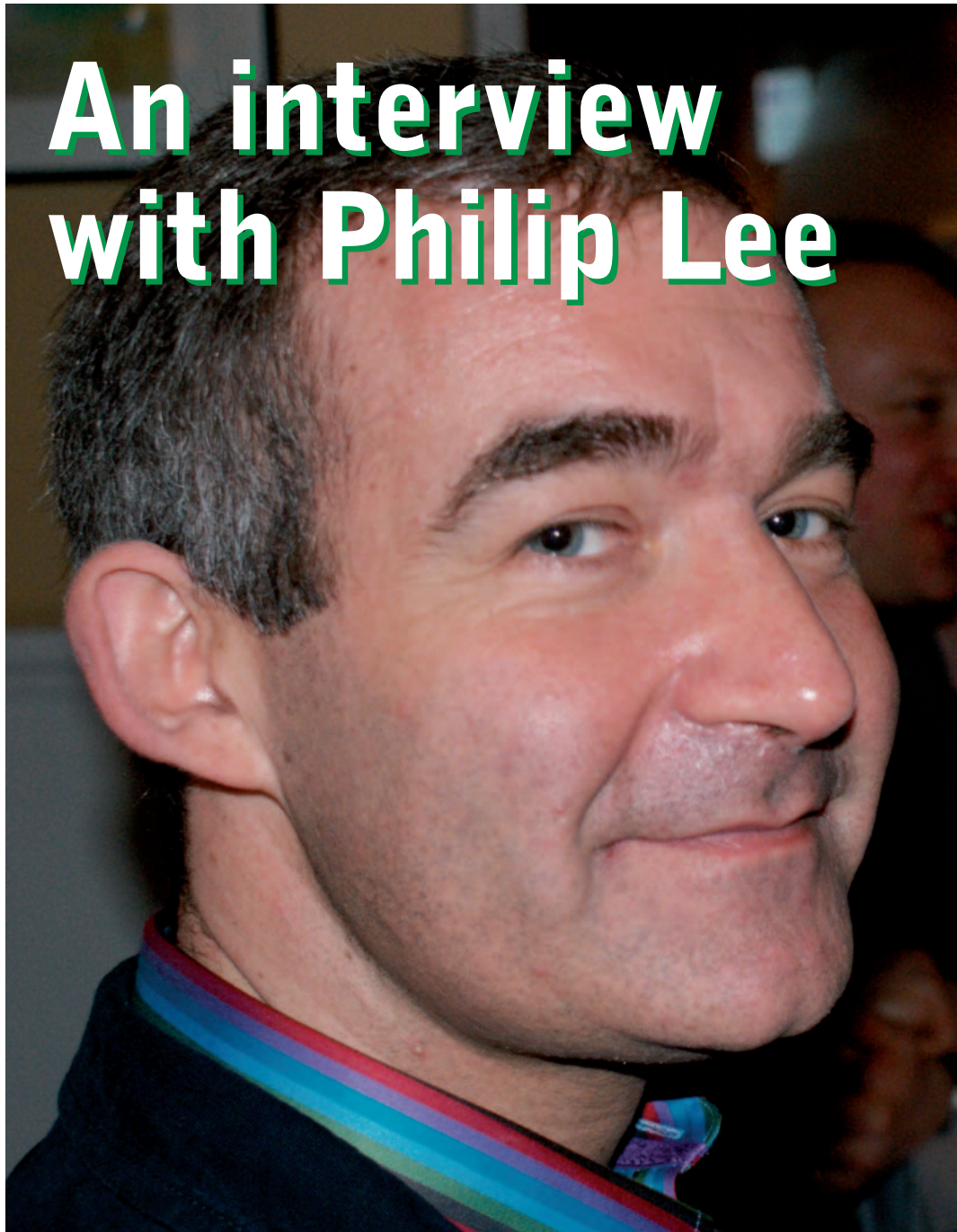
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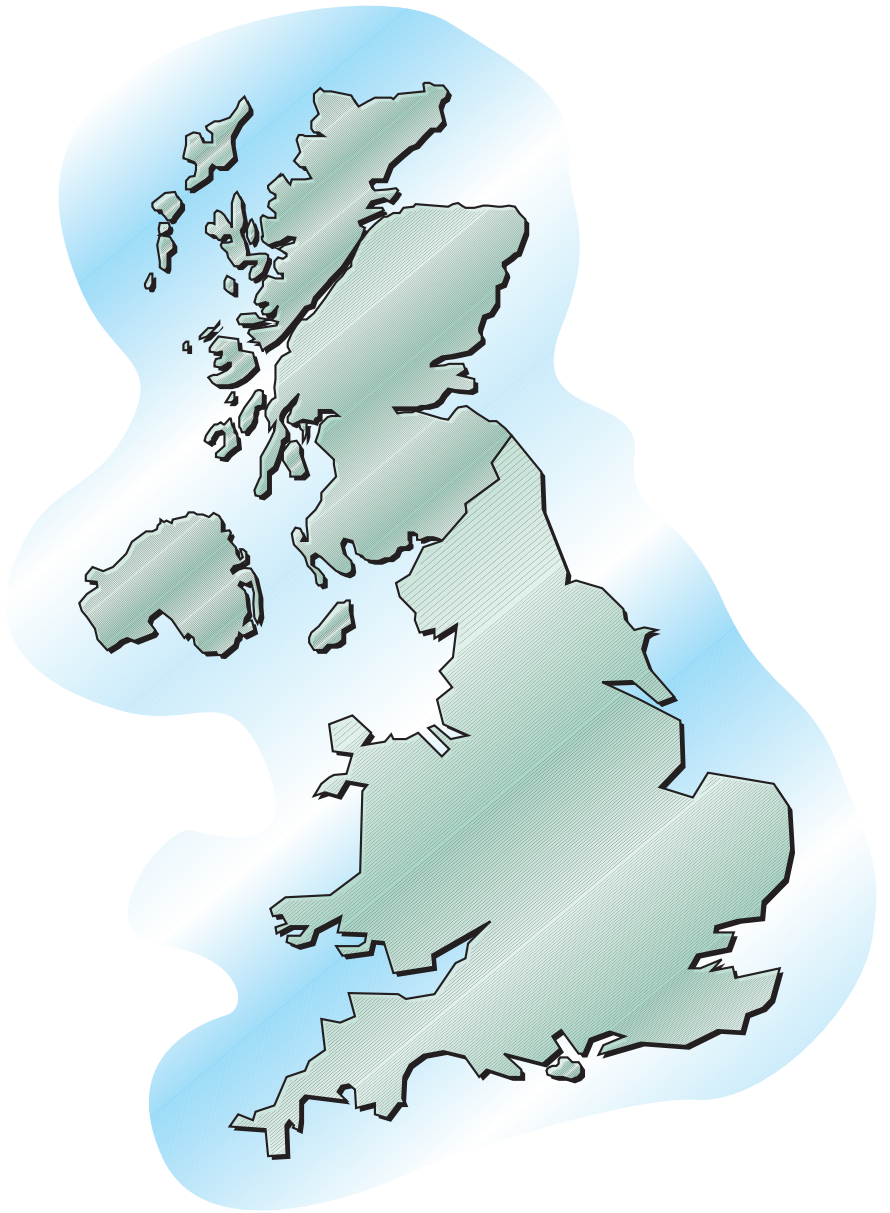
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Editor's Report...

Well, I am sad to say that this will be my final report. I have really enjoyed my five years as editor of *News and Views* but it's now time to give someone else a go! I have recently gone back to part-time work and that, coupled with the demands of three small children, means that I don't feel I have the time to organise *News and Views* properly. The magazine deserves someone who can.

This job has helped so much in my understanding of PKU. I have had news of new supermarket PKU-friendly food straight off the press! I've read about research and breakthroughs, PKU in other countries and a myriad of fund-raising schemes. Most of all, I've been incredibly moved by the countless families who've written and emailed *News and Views* with their unique stories. I will miss that contact with the PKU community. That, to me, is what the NSPKU is about.

Everyone wants their child to be completely healthy and normal and children just want to be the same as other kids. A PKU diagnosis means those very simple desires must remain, to some extent, unmet. When we were first told of our son's condition, the loneliness and sadness we felt were almost more than we could bear. Doctors and dietitians helped us manage PKU practically but it was only by meeting other parents that we truly began to believe that we could have a normal, happy family life.

As our son has grown, the annual NSPKU conferences have given him enormous confidence.

He is thrilled every year to meet other children with PKU. We point out too, the adults with the condition. He's more interested in the kids' trips and parties now, but we know he'll remember the wonderful grown-up role models in the future. He is not alone, he is not the only one. The NSPKU exists so that no PKU family needs to feel isolated. While PKU is incurable, it can be managed so well that a normal life and life expectancy are absolutely achievable and the NSPKU helps families understand this.

There are, of course, those for whom a diagnosis came tragically too late. The society, far from forgetting them, provides support on how to cope with untreated PKU and can help put families in contact with each other. *News and Views* is the mouthpiece of the organisation so, as I pass on the baton, I am hopeful that this magazine will carry on doing what the society does best, giving friendship and hope to everyone touched by PKU.

Kiri Thomas,
Editor

P.S. Please DO NOT send any cheques to me. They are all extremely gratefully received but need to go to Vicki King, our Book-keeper. Her address is on the inside cover.

NSPKU
The National Society for Phenylketonuria (United Kingdom) Limited

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Donations

Vicki King, Tarkwa, 65 Cromwell Road, Ribbleton, Preston, PR2 6YD

Donations over £30 to end of December 2008

	£
Micky and Karen Doyle - Nijmegen Marches	1,250.00
Sandra Bramley - London British 10k Run	520.00
Di Palmer - Coast to Coast Walk	654.37
Lucy Burks - Half Marathon	604.50
William and Carol McCloy and family	1,335.00
William and Carol McCloy - memory of Martin McCloy	275.00
Dawn Kennedy & Kenny Thomson - Scottish Fresh 'n Low 10k run	150.00
Ladies Section - Bramall Park Golf Club	1,330.00
Lisa Selbie and family	150.00
Milltimber P7 Mums (via Lisa Selbie)	75.00
M & P Kennedy	30.00
Christine Clothier	30.00
Mr & Mrs J Darby	130.00

Donations over £30 to end of February 2009

	£
Miss E Buckley	247.09
S Farquhar	761.80
WA & EA Graham	100.00
Mr J Leetch, memory of Rosemary Elizabeth Leetch	735.00
Mr & Mrs J Darby	130.00

Note from our Chairman

Kiri is retiring as editor of News and Views after 5 years' commitment to this job. She has been a joy to work with and has put her own personal and kindly touch to the magazine in her editorials and her recipe ideas. She has given us some wonderful thought-provoking messages and has introduced some debate too which is good.

She and her husband now have 3 little boys to look after and she is returning to her teaching and feels it is time for change.

I am sure you will all wish to join me in saying a very big thank you to her for her warmth and enthusiasm and for giving of her valuable time so freely. Thank you Kiri.

I am please to announce that Anne Vester has agreed to be the News & Views editor and I look forward to working with her on future issues.



Letters

News & Views, 10 Silverdale Road, Chorlton M21 0SH
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.

**Maddie and her Brownie Pack.
Maddie is lying down at the front.**



Dear News and Views,

My name is Maddie and I am 8 years old. I have PKU and am a member of the 39th Kingswood (Longwell Green) Brownies.. In November, my Brownie pack decided to hold a talent show and my Brownie Leaders decided to raise money for PKU.

We had lots of rehearsals and we all did a "finally" which was really funny as we had to wear our pyjamas. We sold programmes and on the back the Brownie Leaders photocopied information on PKU and attached a photograph of my family that had appeared in the local papers. We also had an interval and during this we sold cakes, biscuits, drinks and snacks and all of the money we raised I am now sending to you. We raised a grand total of £25. I am also sending a photo of my brownie pack so you can show your readers all their lovely kind faces. I would like to take this opportunity to thank them for their kindness and their talent and also to thank my Brownie Leaders for letting PKU benefit from this event. THANK YOU ALL.



Yours,
Maddie Bryant, Brownie and Special PKU person.



Dear News and Views,

We are very pleased to enclose cheques for the NSPKU totalling £1,330.00. This money was raised by friends and colleagues with whom we work on the FNF project at Devonport Royal Dockyard in Plymouth between August and December last year. The fund-raising activities were:

- Guess the weight of the crane jib competition which raised £100
- A 12 week sponsored diet by the DDLP team. This raised over £900 in weigh-in fees and sponsorship.
- A Christmas raffle which raised over £320.

The NSPKU was the nominated charity for these events as our youngest daughter, Charlotte, who will be eight this year has PKU. We would like to thank the NSPKU for the support we have received over the years since she was a baby and hope that this money will help you to continue your good work.

Yours,
Cathy and Iain Darby.



Dear News and Views,

Enclosed is a cheque for £106 which was raised from a raffle held at our annual family lunch.

Each January we have a family lunch instead of a Christmas party. We find this to be more relaxed and it's great to see everyone together. This year we tried out a new restaurant – Amore Restaurant Pizzeria. They were wonderful and could not have done more for us. Around 100 people came along from all over including Edinburgh and Perth. Judging from the chat, all had a great time.

The restaurant had only been open for a couple of months and I don't think they quite knew what they





Letters

News & Views, 10 Silverdale Road, Chorlton M21 0SH
Email: editor@nspku.org



Pub charity record

RYE'S Mermaid Inn has raised £1,680 for a charity which helps combat a rare condition that affects children.

Mermaid manager Judith Blinow said: "Every year at the Mermaid we raise money over Christmas and the New Year for various charities, but Christmas just gone. We broke all records raising money for the National Society of Phenylketonuria."

The condition is a genetic disorder that is characterised by an inability of the body to utilise the essential amino acid, phenylalanine.

The charity is close to home at the Mermaid as head chef Roger Kellie, and wife Vicki, have twin five year old boys, Reece and

Xander, who suffer from the rare condition.

Judith said: "Against all odds and with a tremendous amount of love and dedication from their parents, the boys have reached the age of five."

"The boys have never been able to eat and have to take nourishment from a tube."

"I have nothing but praise for Roger and Vicki."

"We would like to bring the charity more into the public eye and also thank everyone who helped us raise this tremendous sum."

Pictured is Judith with Vicki Kellie and the cheque which is being sent off to the National Society of Phenylketonuria.

were taking on when they agreed to help us organise lunch! They made a great job making pizza with low protein flour and the pasta dishes including the lasagne were very tasty.

We were very fortunate to have support from SHS International and VitaFlo International who organised the raffle and persuaded a couple of the teenagers to sell tickets. Thanks to them for providing the prizes and contributing to the event.

The restaurant is keen to ensure that families continue to feel welcome when visiting them and are happy to make up a menu using their own low protein foods. So, if anyone is visiting Glasgow and wants a super meal out, get in touch for details!

Yours,
Barbara Cochrane.



Dear News and Views,

I was very interested to read your recent letter from Mrs. E. Hellett regarding her son John who was born in 1965 and was "missed" for treatment even though the urine test was taken.

Our son Charles was born on Christmas Day 1963 and, as far as I can recall, received the "nappy test" as it was then known. I remember sometime during his second year mentioning to the clinic doctor that I did not think he was making sufficient progress and was told that I should not compare him with his older sister as girls very often made quicker progress in the early years. However, when he was two, the nurse arranged for Charles to be seen by the visiting doctor. He told me that Charles was indeed not where he should be in abilities but he could give no reason for this. Whilst leaving, the nurse rushed out and said he had a wet nappy – indeed he had. The upshot was that the test was positive and I found myself in hospital that day with Charles going through tests and the first lessons in the diet regime.

There were no special foods then, only tinned bread and substitute milk. The rest had to be measured by tablespoons e.g. one tablespoon of mashed potato constituted so many mgs per 100 of his daily allowance. I kept a large book and noted down everything he ate per day.

Further details would be too long and boring for you but he made progress and when he was 11 was taken off the diet as it was thought at that time that the brain would no longer be affected and was mature. Of course we now know that this is not always the case. Charles stayed at his special school and was able to find a job at 19, where he still works.

Charlie, as he prefers to be called, is a lovely person and liked by all who know him. The doctors did say, that we would not know, until he was mature, how badly he had been affected by not being on diet for the first two years of his life. Indeed, his academic abilities

were diminished but his life skills are very good and he has a good brain in various areas. I myself wish the diet for life regimen had been thought of in his early years. Now, I cannot think he would be able to cope with it even though there is so much more help and many more palatable food available. I would be very interested to know if indeed there are different forms of PKU – severe or less so – as I feel Charles has been very lucky to become such a normal, self sufficient person. He only needs some help with any official papers of forms which need information, replies etc.

Yours,
Mrs. Hazel Andrews.

There are over 400 known mutations of PKU. The most common in the UK is the severe classical form (80% of the PKU cases) where there is no enzyme function but there are milder forms of the condition where there is some enzyme function.



Dear News and Views,

I have PKU and am a member of the NSPKU. I would like contact with other people with PKU. I would appreciate it if you could put me in contact with other people with PKU.

Yours,
Rory O'Hanlon, 6 Cloughmore Park, Rostrevor, Co Down, Northern Ireland, BT34 3AX

A Medical Query

Maureen Hutchinson recently contacted the NSPKU with a question regarding PKU and surgery. Our society dietitian, Eleanor Weetch, consulted Dr. Peter Galloway to get a comprehensive answer. This information may be helpful to other people with PKU undergoing operations.

We have a daughter age 22 with PKU. It is quite possible that later this year she will have to go into hospital for an operation and we have had two conflicting views regarding her phenylalanine blood levels at the time of the operation.

One dietitian has said that blood levels should be very low while a second dietitian is of the opinion that her current levels of 600 to 800 are quite acceptable.

Have any other parents been in a position where their PKU child has had an operation and their blood levels have been a material consideration?

With kind regards
Maureen Hutchinson

Eleanor's Answer:

It shouldn't matter that much. Whilst a temporary rise in Phe levels occur, it's average control that counts. For instance, Dr. Galloway had an adult with PKU off diet who was in ITU and he treated him the same as a non-PKU patient.

If a patient's PKU is very well controlled, he or she may just become more irritable if their condition is poorly controlled for a week or so.

Ultimately, if the patient is undergoing a simple operation, and will be eating within 24 hours, the advice would be to ensure the patient's dietitian worked with the ward to give them their protein substitute and low protein products before and after eating again. 10% dextrose with saline for fluid replacement may also be administered in order to give some energy during the day of the operation.

If this was a major operation where the person was well controlled and likely to be in ITU for a week not eating and unable to use nasogastric feeding, then a more complex solution may have to be considered.

If nasogastric feed was possible within 2-3 days, supplements could just be put down this tube.

However, Vitamin B12 levels should always be checked prior to an operation if not done within the last year and found to be well within the reference range.

It's important to note of course that these are general guidelines and that each patient should discuss their particular case with their own doctor and dietitian.

Interview with Philip Lee

– Consultant in Metabolic Medicine

The Charles Dent Metabolic Unit, Hospital for Neurology and Neurosurgery, Queen Square, London

Dr Phil Lee is very well known to patients and professionals in the UK and internationally. He has recently retired due to ill health and on January 15th a Festschrift took place to pay tribute to him and to give so many a chance to see him and his family and to hear presentations in the numerous areas of which he has interests.

On - this day the NSPKU presented Phil with Honorary Membership in recognition of his enthusiastic support for the Society and for all the important work he has done to improve the care of those with PKU.

I conducted an interview with Phil over the 'phone recently which he is very happy to share with you.

Your name is well known in the PKU world but how did you first get involved and become so interested?

It was working with Dr Campbell Davidson in the PKU clinic at Alder Hey Hospital in Liverpool in 1991 which gave me my first taster and then I did some research (not research in PKU though) at the Institute of Child Health in London. There I met Dr Isobel Smith, the very well respected specialist in PKU - but I didn't get really involved until my appointment as consultant at the Middlesex Hospital in 1997 working with Dr David Brenton. We worked together for a year before he retired.

Why did the unit move from the Middlesex to the Neurological Hospital in Queen Square?

There were several reasons for this. Having the metabolic unit next door to Great Ormond Street Hospital made it easier to build bridges between us and for the patients moving to the adult service next door, so to speak, meant it was familiar and easy to find.

There was also a time delay in getting blood results back from the lab when we were at the Middlesex; sometimes it could take 2 weeks, whereas having the lab next door at GOS it would only take 1 to 2 days.

Patients with a metabolic disease, and there are very many, frequently have neurological and neuropsychological problems because of the condition, so it made sense to be within a specialist neurology hospital. We often felt lost in a large general hospital.

So many now attend the clinic at Queen Square, what sort of numbers started there and how many attend now?

In the beginning there were about 150 and now it's 400 adults with PKU.

And staff?

There was just Maggie Lilburn and myself at first with Dr Brenton and then Eleni joined us as medical secretary. Now there are around 15 staff including nurses, dietitians, secretaries and doctors.

The transition from child care to an adult unit can be a difficult time. What do you think makes a smooth transition?

The key to this is the change from parent-centred to patient-centred care and getting the young adults to take responsibility and become independent. Ideally this should have begun before they move over into the adult sector. Familiarity is helpful and the clinical nurse specialist goes to meet them, shows them round the adult unit and sits in with them in the clinic at GOS before they move over.

You were on the medical advisory panel of the NSPKU and that was very helpful to us, was it for you?

Yes. The NSPKU is a good model of how we can work together. It helps to break down barriers between medical professionals and patients and bringing people together is important for us to see how it works from the inside, and how we can tailor our advice and approach for the best.

You have been involved in a lot of research. What has been really helpful in practice and changed what you do?

Our research into maternal PKU made us change our target phenylalanine ranges. We are now much better able to advise couples on what is required for the best outcome of pregnancy.

The trial of diet for previously untreated patients was supported in part by the NSPKU. What are your thoughts on this research?

It was very valuable. It showed that you can do a randomised double-blind cross-over trial with diet in this condition. It was the longest piece of



research work I have been involved with, taking about 8 years from start to finish, but well worth it.

Sadly you have taken early retirement due to ill health. Would you be able to tell us about this?

I am a life-long non-smoker but was diagnosed with lung cancer following a persistent cough. I decided to take early retirement to be able to spend more time with my family and have control of my time.

Life has changed hugely but I know you are still very busy. What are you doing now?

I'm spending more time with my family. I set up a boys' football club some time ago as my son is a keen player. I am one of the managers of the under 13 year team and also referee and help organise them. There are now 10 different squads going from under 8s to under 14s. I have also taken up bridge again after 30 years and play twice a week. There are competitions which we always used to come bottom of but things are improving and we came 7th out of 16 teams recently!

I've also always been keen on photography so I've enrolled on a photography course and bought a proper digital SLR camera.

You have been through chemotherapy and countless procedures which must have been and still is difficult. Is there any advice you can pass on to help others coping with problems?

Keep a positive approach and be optimistic. There isn't another way. Take it day by day, value your time. I am also fortunate in having a wonderfully supportive wife and family.

I know you are a big Chelsea fan. What are your thoughts on the team manager situation?

I went to the manager's last match on Saturday (against Hull City) which is bizarre as I hadn't been to a game for a long time. It's all so short-term

nowadays but I think you have to give people a fair chance, I felt sorry for Scolari but then he did receive a big fat cheque as a send off....!

I am sure that you will all wish to join me in passing on our very best wishes to Phil and his family.

Eleanor Weetch

All PKFoods are now available on prescription

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... and play important roles in:

- Brain development
- Eye development
- Good for your heart too!

Also during pregnancy they play a very important role in the development of your baby.

How do I get them?

From your food. Fish is packed with **Omega-3**! You can find lots of **Omega-6** in oils, such as vegetable and sunflower oil!

But what about me - on my PKU diet?

Well as you know because fish is high in protein **you cannot have it** - you will always need to get your Omega-3 from somewhere else.

What about Omega-6?

You will have no problem in getting it from vegetable oils when you are older, but as a baby or a toddler you need to get your Omega-6 from another source!

How can Vitaflo help?

We have made sure that each of our protein substitutes either has it in or we have made you new products to take with your protein substitute - nothing could be simpler!

For more information about these products contact your dietitian.



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Dietitian's Report

New and Useful Foods in the Supermarket

Pesto

In the special diet section of my Morrisons I found a nut free pesto. It's made by a company called Florentino. It's basil pesto made with only basil, oil and other free ingredients and can be used to stir into hot pasta, spread on low protein toasted fingers with tomato, black olives, peppers or other free vegetables or use on pizza. You could also add a little to a tomato sauce for a real Mediterranean flavour.



Free and Easy – Dairy Free Cheese Flavour Sauce Mix

I spotted this sauce mix on the same shelves. You make the powder to a sauce with water or rice milk.

100ml of sauce = ½ Exchange

Use on baked potatoes, pizza, vegetables, low protein pasta for macaroni 'cheese'.



Oatly Oat Cream

This is a good substitute for cream. It's best to keep it in the fridge as this thickens it nicely.

Again I found this in the special diet section in Morrisons.

200ml = ½ Exchange
Count like SnoPro and Loprofin milk.
NB the carton is 250ml size.

Oatly 'Milk'

125ml = 1 exchange

Dole Fruit and Rice

These little puddings come in mango and pineapple flavour.

1 pot = ½ Exchange
Useful for a picnic box or as a snack.



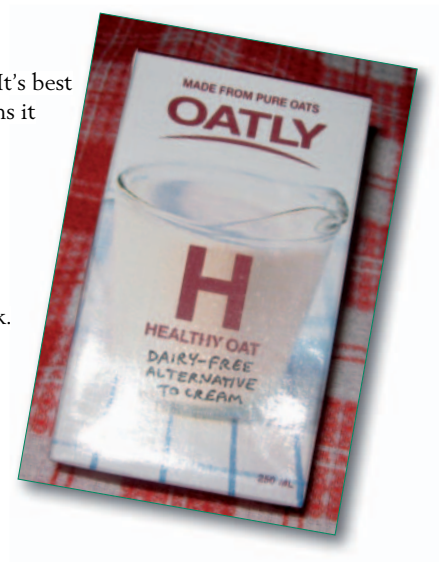
Stock Cubes and Powders

I have been looking at what's in the supermarket for making stock which is suitable for soups. You can use any vegetable stock cube or powder which when made up has a protein content of 0.3g protein or less per 100ml.

The following are examples of those which are suitable:

Marigold Swiss Vegetable Bouillon Powder
Marigold Organic Swiss Vegetable Bouillon Cubes

Kallo Just Bouillon Premium Vegetable Stock Cube
Kallo Organic Vegetable Cube



Dietitian's Report continued

Knorr
Vegetable Cube

Oxo
Liquid Vegetable Stock



Do you make soup?

Is it something you have thought of as too difficult or time consuming to do?

Well, I'd like to try to change your mind because home made soup is cheap, filling, tasty and good for you.

There are some excellent stocks which come as cubes or powders which are within the protein range allowed without counting, and stick blenders make the job really easy and quick with little washing up to do.

What proportions should I use?

Remember the one one one one rule.

One Onion

One pint (550ml) stock

One pound (500g) vegetables

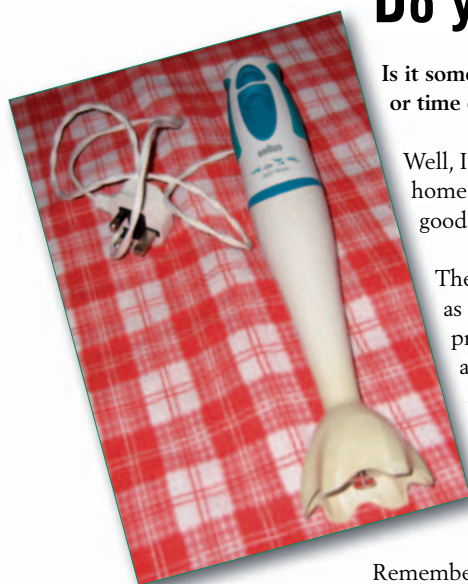
One walnut sized piece of butter.

So what do I do?

1. Melt the butter gently in a largish saucepan
2. Add a chopped up onion and soften for 5 minutes, stir it now and then. Don't get the heat too high as you don't want it to brown, only soften.
3. Add a pound (500g) prepared vegetables e.g. celery, leeks, carrots
4. Soften these for 5-10 minutes with the butter and onion.
5. Add 1 pint of stock made up as directed on the packet.
6. Simmer gently with the lid off for about 20 minutes or until the vegetables are soft.
7. Add a little salt and pepper to taste.
8. Go in with the stick blender and liquidize it all. Do not lift the stick out of the soup as you liquidize or you will have soup everywhere.
9. Serve in warm bowls with warm low protein bread or little croutons (fry low protein cubes of bread in butter for a few minutes)
10. Add 20ml of single cream (½ exchange) to make the soup nice and creamy.

Ideas to try

- For mushroom – add a chopped garlic clove to the onion
- For celery – add a ½ teaspoon of celery seeds
- For cauliflower – add ½ teaspoon of chilli flakes
- For parsnip – add ½ teaspoon of curry paste
- For butternut squash – peel, de-seed and roast the squash in the oven (180 for 30 mins) until soft. Add 1 teaspoon cumin seeds to the stock.
- For carrot – add 1 good handful of coriander (you can use the stalk too) and a squeeze of lemon. Cream or crème fraiche is good with this soup. Count as exchanges depending on amount used.



Double, single cream and Crème fraîche.

Double cream 60ml = 1 exchange
Single Cream 40ml = 1 exchange
Crème Fraiche – check label on protein pack for value.

Potato also adds body to a soup but remember to count it as exchanges.

Soup freezes very well too.

Diet Information Booklet 2009/10

Important changes to this edition.

The way **Broccoli, Brussels Sprouts and Cauliflower** are counted has changed. All of these vegetables have similar phenylalanine levels but up until now have been counted differently. In order to be consistent, and as a result of research and experience, they have all been moved to the section 'Restrict to one normal portion per day' – **this means that you can only choose one item per day from this list** but you do not have to weigh.

The cut off level of protein for **margarines** which are freely allowed has also been raised from 0.5g per 100g to 1g per 100g.

Vegetable stock powders and cubes with a made-up protein content of 0.3g per 100ml or less can be included without counting.

During pregnancy control has to be very strict and some of the advice may be individualised.

Our amino acid analysis last year enabled us to add some new foods to the diet either as free foods or exchange foods.

New Free foods

Dragon Fruit
Potato Flour (do not confuse with instant potato flour like Smash)
Okra

Gellan – a gelling agent used in sweets and jellies, so useful to know it's not like gelatine which is high in phenylalanine

Controlled food (but no need to weigh) - Limit to one serve a day

Whole Hearts of Palm

Try on pizza, in a stir fry, add to salads or serve with mayonnaise.

Exchanges

Passion Fruit 40g = 1 exchange
Kale 35g = 1 exchange
Vine leaves 30g = 1 exchange

Other things to note:

Items on prescription: SHS international Ltd

New pastas

More breakfast cereal flavours

Dessert mixes

Cake mixes

And coming in March – unflavoured snack pot and a crispbread in handy packs

FirstPlay

Taranis Lemon Cake

Sausage mix – new flavours

Burger Mix – new flavours

Dessert Mix – new flavours

Pasta and sauce – new flavour



AVAILABLE ON PRESCRIPTION:

Fate Low Protein All - Purpose Mix

Fate Low Protein Cake Mix

Fate Low Protein Chocolate Flavour Cake Mix



"As a mom with two daughters who both have PKU, I fully understand the low protein way of life. I have developed these mixes and many recipes to help everyone make great low protein food."

Eileen Green



**Ask your Doctor to prescribe Fate mixes,
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 recipes



Hello,

My recipe this time is one that is a must for Easter. The buns are made with a generous amount of dried fruit, and flavoured with a generous amount of ground mixed spice, just like all good hot cross buns should be!

It makes about 9 or 10 hot cross buns.

Method

Preheat the oven Gas 6. 200°C 400°F

Place the Fate Low Protein All-Purpose Mix, yeast, salt, demerara sugar and spice into a mixing bowl. Stir well.

Measure the oil and water into a separate jug, and pour it all at once onto the dry ingredients. Using either a balloon whisk, or an electric mixer, immediately start mixing quickly to get everything blended together.

It will be runny to begin with, but after 20-30 seconds, the mixture will begin to thicken.

Mix for about 1 minute, until the mixture is smooth and silky. Then, using a large metal spoon, stir in the dried fruit. Take a piece of cling film and place it onto your scales. Sprinkle it with a little All-Purpose Mix. Using a large metal spoon, weigh a piece about 120g in weight. You do not have to be too precise, just so long as it is within about 10g. (This will ensure that the buns on the same tray will take the same cooking time and also they will look very professional when baked) Using the cling film to help you, transfer the mixture into your other (dusted) hand and gently pass the mixture from one hand to the other, just once or twice, so that the surface is smoothed, and a round bun shape is made. **REMEMBER** As long as you have a little Fate All-Purpose mix on your hand, the dough will not be sticky. Continue with the rest of the mixture.



Place the buns onto a greased baking tray. Leave room between them to rise. Place the baking trays into a large polythene bag, tie the ends up, trapping enough air so that the polythene is lifted well above the buns. Leave in a warm place to prove until double in size.

Then prepare the mixture for the cross, ~ Place the Fate All-Purpose mix into a small bowl or jug. Add the water and oil. Mix with a fork until smooth. Leave aside until the buns are risen and ready to go into the oven.

Then, put the 'cross' mixture into a small piping bag and pipe a cross onto the top of each bun, or if you prefer, use a small spoon and dribble the mixture in the shape of a cross onto each of the buns.

Straight away, place the buns into a pre-heated oven for about 30 minutes until golden brown.

Meanwhile, make the sugar glaze ~ put the caster sugar and water into a small pan and bring to the boil. Then turn down the heat and simmer for about 3 minutes only.

As soon as the buns are baked, remove from the oven, and brush the surface with the sugar glaze. Remove to a wire cooling rack to cool. The hot cross buns freeze well.



Ingredients

For the buns:

500g Fate Low Protein All-Purpose Mix
sachet yeast(enclosed with mix)
75g Demerara sugar
pinch salt
1½ - 2 tsp ground mixed spice
250g mixed dried fruit
50mls oil
420mls very warm water.
A little extra Fate All-Purpose mix to shape

For the cross:

30g Fate Low Protein All-Purpose Mix
50mls cold water
10mls oil

For the sugar glaze:

30g Caster sugar
30mls water



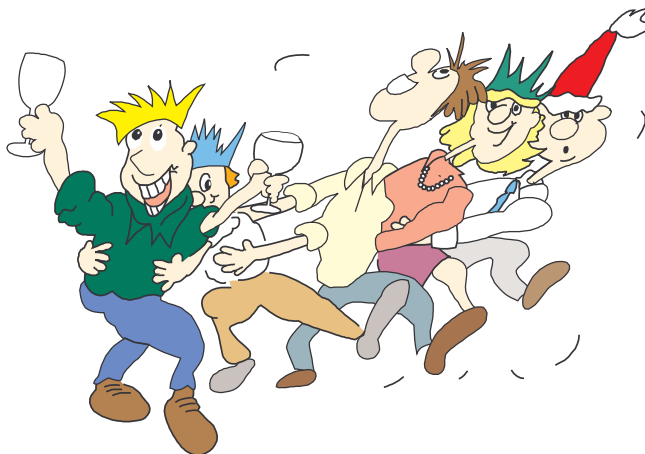
Christmas Party

Following the success of the conference and holiday weekend in Torquay, the Rainbow Hotel are planning a **PKU Christmas Party Weekend** Friday 18th December to Monday 21st December.

The cost will be £75 per adult and £10 per child (sharing room with 2 adults). This is inclusive of 3 nights' accommodation, breakfast and evening meals including PKU food, entertainment and the use of the leisure club.

This is excellent value but can only be achieved if they receive sufficient interest.

For further information please contact the hotel on 0870 7704131 or K.Smith@rainbow-hotel.co.uk



Baby News...

John McKenzie and Sarah Lawson's baby Ruby Elizabeth was born at 10am on 29th October weighing 5lb 3oz. Mother and baby doing well. Ruby does have PKU.



NEW
NOW AVAILABLE ON PRESCRIPTION



Family favourites for the Barbeque

Promin burgers are now available in two flavours, Original and Lamb & Mint and Promin sausages in three flavours, Original, Apple & Sage, and Tomato and Basil so all the family can enjoy the barbeque

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 which is great for people on a restricted diet as it minimises the risk of contamination. Our original low protein and gluten free pasta range, includes Promin Pasta and Promin Tri-Colour Pasta, now a well established brand and are available on prescription. The range also includes Imitation Rice, Pasta meal, Cous Cous and

Lasagna Sheets. By talking with PKU patients, parents and Dietitians a great range of tasty products have been developed.

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 and now Spirals in a spicy Moroccan sauce

A recent addition is our great tasting Burger Mix, you can easily shape it into burgers,

meatballs or even dinosaurs for the kids! - they taste great with chips or mixed with some of our pasta. Finish with Rice pudding - 3 flavours available or a Chocolate and banana dessert, there's a strawberry and vanilla one too. Please call us or visit the website for more information and keep sending your recipe and meal suggestions.

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

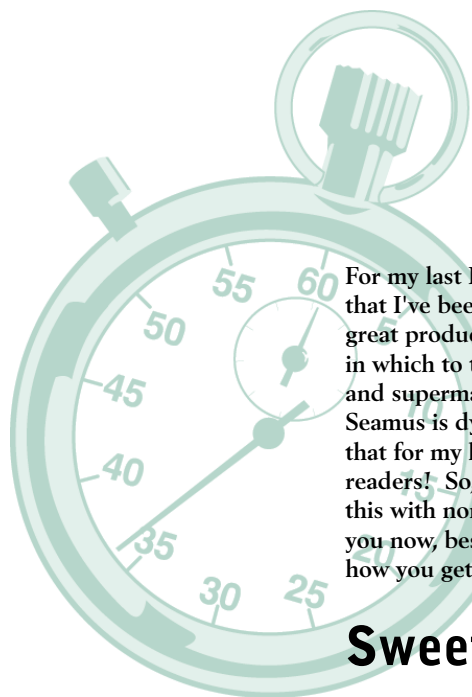


Always consult your dietitian before trying something new.

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

PKU Pronto



For my last Pronto column, I thought I'd suggest a recipe for you that I've been unable to try myself! Eleanor has recommended a great product called Oatly cream and I have in mind a great dish in which to try it. My only problem is, our local Health Food Store and supermarket have been out of stock for the last couple of weeks. Seamus is dying to try this, as am I, but I think it's quite fitting that for my last recipe, I'm passing on the responsibility to you the readers! So, I'll give you the recipe and assure you that I've tried this with normal cream and it's been absolutely delicious. Over to you now, best of luck, and please, please let News and Views know how you get on!

Sweet Potato Pie

Ingredients

1kg sweet potatoes
25g butter
100g onions, sliced very finely into rings
625ml Oatly Cream
1 level tsp garam masala
Large pinch nutmeg
1 clove garlic
salt and pepper

Method

1. Preheat the oven to 180°C
2. Peel potatoes carefully and cut into 5mm slices.
3. Rub the sides of an ovenproof dish with some of the butter and cut the rest into small cubes.
4. Mix everything else together and place in the preheated oven for 1 hour or until the potatoes are soft and the top is brown.
5. Serve with a cucumber salad dressed with lemon juice and oil.

This is not a dish cooked and served in 10mins, but it can be prepared hours ahead and just plonked in the oven an hour before you want to eat. Also, it's as nice warm as it is hot so is very forgiving if dinner is delayed.

NB Exchange Information. Since 200 mls of Oatly cream = ½ exchange, this whole recipe totals just over 1 ½ exchanges. It's meant to feed 6 but this is very variable. If you do stick to the serving size suggested, one portion would equal ¼ exchange and 2 portions ½ etc.





Hot Cross Buns

Ingredients:

1 pkt/500g **Loprofin** Low Protein Mix
 1 sachet dried yeast (encl. with Mix)
 50g (2oz) caster sugar
 2.5mlsp (½ tsp) salt
 5mlsp (1 tsp) mixed spice
 50g (2oz) economy butter, at room temperature
 100g (4oz) mixed dried fruit
 200ml carton **Snopro**
 145ml (5floz) boiling water
 Cooking oil

Topping:

3 x 15mlsp (3tbsp) **Loprofin** Mix
 2 x 15mlsp (2tbsp) caster sugar
 3-4 x 5mlsp (3-4tsp) water

Glaze:

1 x 15mlsp (1tbsp) caster sugar

1 Swiss Roll Tin approx. 30 x 22.5cm (12 x 9 inch), greased

Oven temperature: 200 C/400 F/Gas Mark 6



Method:

1. Combine **Loprofin** Low Protein Mix, yeast, sugar, salt and mixed spice in a large bowl.
2. Cut the butter into small pieces and thoroughly rub into the dry ingredients, stir in the fruit.
3. Reserve 3 x 15mlsp (3tbsp) **Snopro** for the glaze, combine the remainder with the boiling water, add to the dry ingredients, kneading together to form a soft not sticky dough.
4. Dust a work surface with Low Protein Mix and lightly knead the dough for about 2 minutes, until smooth. Cut into 15 equal sized pieces.
5. Knead and shape the pieces of dough into balls, approximately 5cm (2inch) diameter and arrange slightly apart on the Swiss Roll tin
6. Evenly brush each dough ball with oil.
7. Loosely cover the balls with cling film and put the tray in a warm place for, approximately 25-30 minutes, until the dough has risen, doubled in size and the balls are touching each other.
8. Whilst the buns are rising, make the topping – place the **Loprofin** Mix and caster sugar in a small bowl, stir in sufficient water to give a thick smooth paste, spoon into a piping bag fitted with a ½ cm (¼ inch) plain tube.
9. Carefully remove the cling film and with a sharp knife, lightly mark a cross on the top of each bun. Pipe a cross of flour paste in the indentation on each bun.
10. Place the tray in a preheated oven for 15-20 minutes, until the buns are lightly browned and sound hollow when tapped underneath.
11. To make the glaze – stir together the **Snopro** and caster sugar, brush over the hot buns.
12. Cool on a wire rack, serve warm or cold.

Makes 15 buns

Tip: The cooked buns can be frozen successfully, but allow to fully defrost and 'refresh' in a warm oven for a few minutes before serving, or microwave for 10-15 seconds.

For more great tasting recipes, visit

www.lowproteinliving.co.uk



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