

# NSPKU News & Views

The National Society for Phenylketonuria (UK) Ltd

Issue 119

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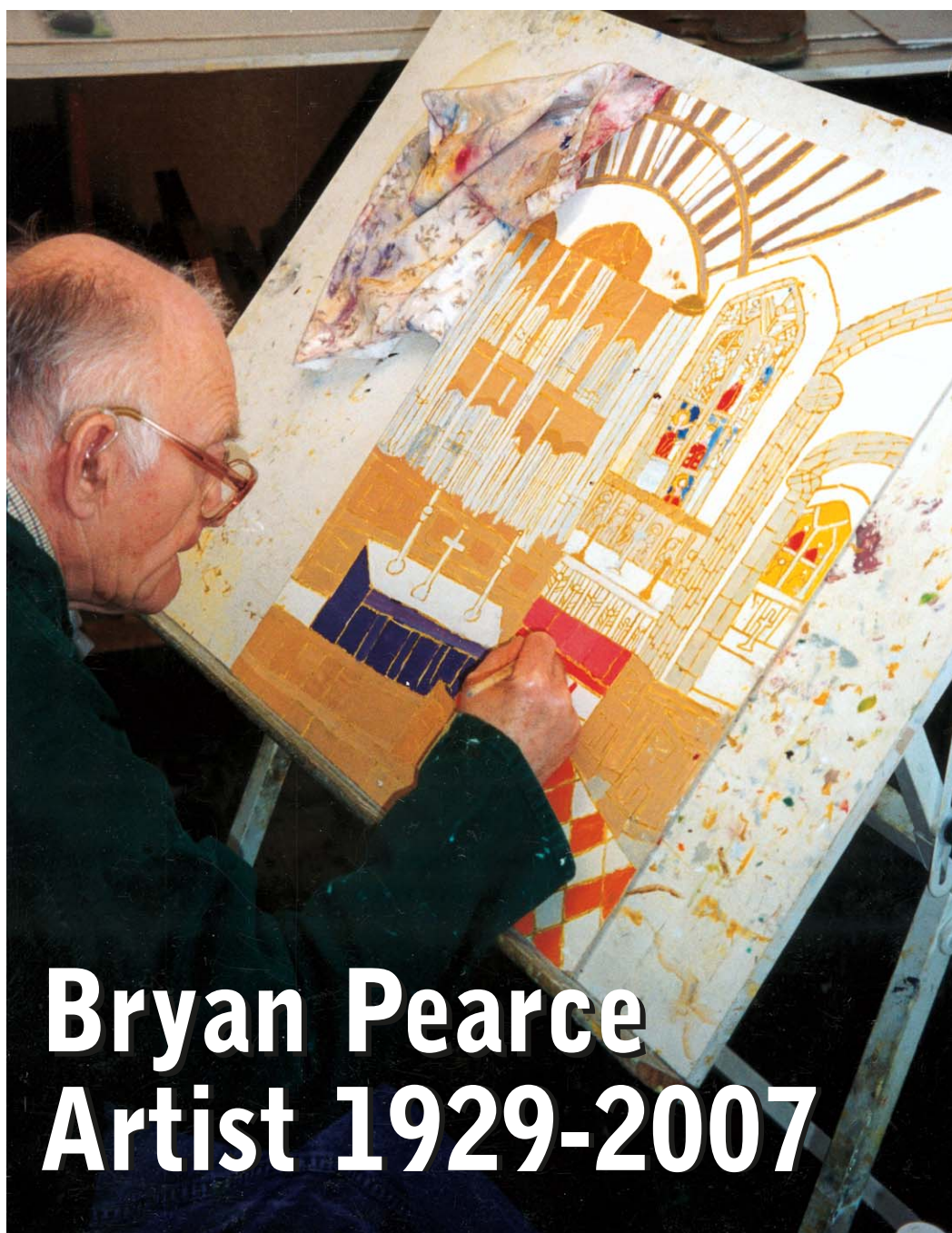
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ESPKU Conference  
Report

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Northern Ireland

Adult Study Day



**Bryan Pearce  
Artist 1929-2007**

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# In Touch

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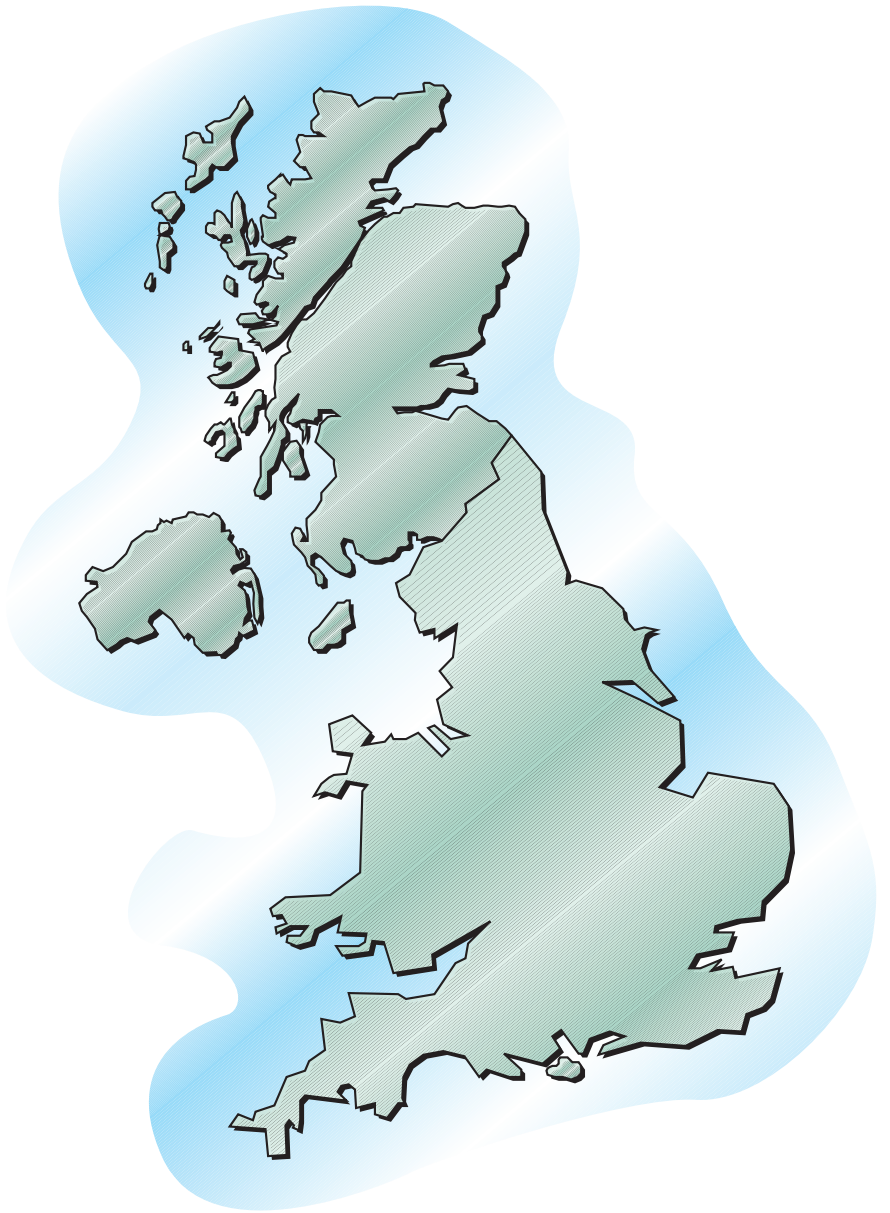
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## Editor's Report...

Well, we start this issue with a sad note as Bryan Pearce died in January. Most of us connected with PKU will have heard of Bryan as he was a gifted and renowned artist. For me, Bryan's life is especially significant for two reasons; he reminds us of the difficulties PKUs faced before screening and treatment were implemented in this country and yet he also reminds us that even lives touched by devastating disability have reason and purpose and equal importance to those lives lived impairment-free. Our own Eleanor Weetch and Rosemary Hoskin have written more about Bryan's life and work for us and it makes fascinating and moving reading.

We've also got lots of new recipes for you to try this issue along with some fun accounts of the Adult Study Day and the PKU Conference. It's nice to have a story from Northern Ireland too along with Eleanor's characteristically info-packed report. Happy reading and I hope to see as many of you as possible at the conference!

**Kiri Thomas**  
Editor

## ✚ NSPKU ✚

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## stop press...

### Car Boot Sale in aid of N.S.P.K.U.

Monday 9th April

The Kings Head, Belton, Great Yarmouth, Norfolk NR12 9JT  
Costs £5.00 per car.



# Donations

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

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	£
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Miss DL Winter	400.00
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Mr I and Mrs LD Thomas	220.00

## *In Memorium:*

In Memory of Mr Anthony Shaun Hurton	150.00
In Memory of Mr Francis Butler	179.00

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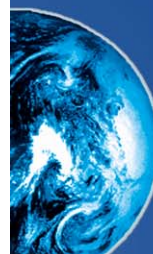
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# Earn money for the NSPKU while you search the Internet

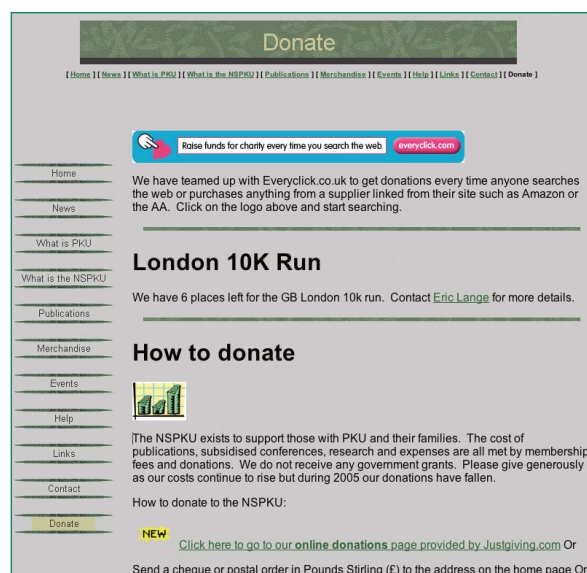
*Dave Stening, our Chairman has some more ideas for raising money!*

The NSPKU have teamed up with Everyclick.co.uk to earn money from Internet searching and purchases. There is no cost to you or the NSPKU but for every search you do, the Society gets a fraction of a penny. But as they say, every penny counts. For a purchase made via the site a referral fee is paid, typically of 2 – 5%

To use this just go to our donate page at <http://www.nspku.org/donate.htm> and follow the Everyclick link. Already over £5 has been raised in the first month.

## Join our Email mailing list

Cannot wait for the next News and Views? Keep up to date with the latest information by subscribing to our Email mailing list. Follow the instructions on our web site at <http://www.nspku.org/links.htm> and we will send you an email every month or so with the latest dietary information, events and announcements. Be amongst the first to hear about exciting new products and information.



## 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**

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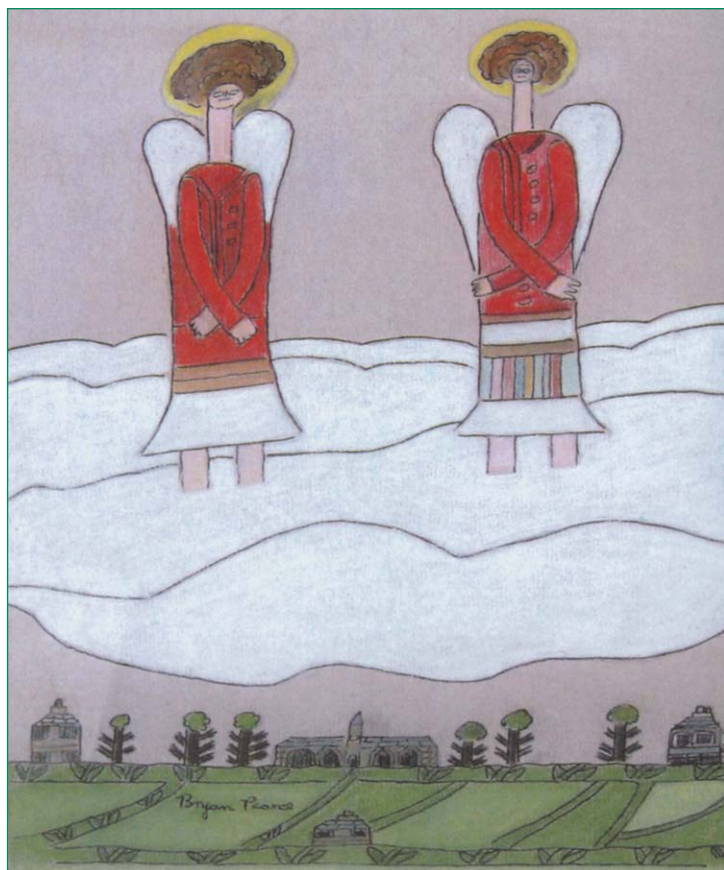
Yes We Cook That.com, 39 Leggate, New Cumnock, Ayrshire, KA18 4NG

# Bryan Pearce

21st July 1929 – 11th January 2007



'St Michael's Mount', 1971-1972, oil on board, 22 x 28ins



'Two Angels', 1987, conté, 11-1/2 x 9ins

Bryan Pearce was born in 1929 and became the foremost primitive painter in the UK. He was born before screening began or even known about and although damaged by lack of treatment his painting was his life and life-line.

He was encouraged to paint by his mother who, desperate to find something which would occupy Bryan, bought a painting by numbers book in Woolworths. Bryan loved this and his career developed through art school and from the encouragement of experts who recognised his talent.

Bryan's paintings have been exhibited at The Tate in London and St Ives and many other galleries. He was a prolific painter, painting 6 days a week, and mostly of his beloved St Ives and of still life. He was still painting up until Christmas but then a heart condition finally took its toll and he died peacefully at home on January 11th.

There is to be an exhibition of Bryan's paintings at Tate St Ives from February 3rd but if you miss this the gallery is worth visiting as I am sure there will always be something of Bryan's on show there.

I was privileged to be invited to Bryan's 75th birthday party in St Ives in 2004 where over 200 people attended all wishing to celebrate this remarkable man's achievements. It was a tragedy that he was born with PKU before screening began but he lived a long and happy life doing what he loved and surrounded by devoted carers who loved and respected him. It is a life to be celebrated.

# Rosemary Hoskin remembers Bryan

*The following tribute to Bryan Pearce was written by Rosemary Hoskin who attended his funeral on January 22nd. Rosemary visited Bryan every year. She wrote our booklet 'Dietary Treatment of the Previously Untreated PKU Adult', is a member of the team working on the untreated PKU trial and has worked tirelessly to improve the care of those born before screening began.*

Bryan Pearce, the internationally recognised Cornish artist who died on January 11th 2007, may well have been the longest living untreated PKU in the UK. His skill and success as an artist together with his truly lovely but blunt personality made him an exceptional individual who came to epitomise the character of St Ives in Cornwall. He lived up to the quotation on his mother's devotional pad on the day of his birth which said 'if you want to be original just try to be yourself, because God has never made two people exactly the same'.

His mother, herself a gifted artist, recognised that Bryan had a talent and made sure that he would be given every opportunity to express his gift but little could he have known that he would become such a sought after painter but also such a much loved character in his home town.

Picture a cold, drizzly, gale-swept January morning, the morning of Bryan's funeral in St Ives Parish Church. But as we sat there the weather mood changed and the soft winter sunshine transformed the atmosphere in the church to one of joy and thanksgiving, highlighting the beauty of this church where Bryan worshipped every Sunday and one which he had painted on many occasions.

The vicar, speaking to a packed congregation, said that 'he could paint and he was loveable'. The music and the addresses by Sir Alan Bowness, the art historian, and by David Bennett, were warm, moving and totally appropriate for the occasion, as was the general atmosphere amongst those present – and we all agreed 'he could paint and he was loveable' – a privilege to have known such a remarkably talented but totally unassuming man – perhaps made great by his disability, who knows.

There is an exhibition of Bryan's paintings at the Tate Gallery in St Ives from Saturday, February 3rd until 13th May 2007.

## Let's Learn about PKU – Age 12 to adulthood

Help for managing PKU for the older person has just been completed. It is again divided up into sections and this time subjects covered are:

- Trips and Holidays on a PKU diet
- Going out- Enjoying Yourself
- Becoming Independent
- Family Matters
- When it really counts
- Can't Cook – Won't Cook
- A Place of Your Own

If you would like a copy of this section please send a cheque for £3 made payable to NSPKU and send to me, Eleanor Weetch, at the address inside the front cover of the magazine.



# ESPKU

## Sarah Kimpton relates tales of her trip to the ESPKU Conference in Spain

Having won the competition to go to the ESPKU conference in Torremolinos and subsequently gone to Spain, the easy bits had finished and the hard work of writing my report on the weekend had to start.

I flew out from Stansted on the Wednesday. It was the first time I'd flown by myself but it all seemed to go alright. The only bit I didn't expect was the little train I had to take to get to the departure gate. Once I arrived at Malaga airport, I met up with John McKenzie, who had arrived a little earlier from Glasgow. We then took a taxi to the hotel in Torremolinos, it only took a few minutes.



I didn't really know what to expect when I got to the hotel. I'd been to a couple of European conferences in the UK before with my parents, but this was new territory for me. On the good side, I had been to the hotel about 9 years earlier on a family holiday so had a bit of an idea about the place. The rest of the Wednesday was spent just finding more out about the hotel and meeting up with a few friends from the UK.



The hotel is very large and has 2 good swimming pools, is next to the beach, has a load of pubs near it and (most important!) had a bar with a happy hour. There was also entertainment in the evenings. Most of the conference delegates didn't arrive until the Thursday and then the conference suddenly seemed to come to life with all sorts of people and languages around the hotel. The meals were full of fruit and vegetables the meals at lunchtime and in the evening were very similar. The PKU food started on Thursday, it was mainly bread, rice or pasta with some sauce.



On the Friday we had just one talk, which was about living with PKU and how to increase the attendance to the ESPKU conferences. On the Saturday there were two main talks; one a continuation of Friday's session, the other related to the Allied Disorders. Towards the end of the afternoon, there was a summary

talk, reviewing the things that had been discussed earlier.

Saturday evening had a party atmosphere as everyone relaxed and mixed with people from other countries to compare what it is like to live with PKU around Europe (and elsewhere).

One thing really struck me from talking to people at the conference. Nearly everyone except the UK count the Phe level in virtually all foods. In the USA, they use an exchange system like us, but count everything rather than having the free foods that we have. In Europe and the rest of the world, they count Phe (where 1g Protein = 50mg Phe), again counting all food. Both of these systems seem (to me at least) to be a lot more faff and much harder to keep track of during the day. I'm glad we do it the way we do in the UK – it's a lot easier to manage and we don't seem to suffer from poorer dietary control here. I'm on 12 exchanges which would be 600mg Phe. I don't think I'd like to be in a situation where I've had 387mg Phe today and then have to add 65mg to it – it just seems like a lot more work.

On Friday and Saturday I spent some time shopping. Everything is much cheaper there so I did some early Christmas shopping. Also I was impressed by how many sports tops they had for sale but I didn't find one my size! Unfortunately I didn't get to learn very much Spanish or any other languages because everyone can speak English so well.

On the Sunday, it was a matter of packing ready to go back home. All went well with the flight back. My parents met me to take me back to university in Norwich and it was only when I got into the car that I realised that I had left a huge bar of chocolate in the fridge in my hotel room. It was supposed to be a present for my boyfriend! However my parents seemed pleased I had remembered their present. I made lots of new friends and hope I can go again next year to see them all and learn some more about PKU.

Sarah Kimpton

## ESPKU Meeting

The next annual meeting of the ESPKU is to be held in Torremolinos Spain from October 19th to 21st.

Further details about prices and programme will be posted on our web site as soon as we hear more.

Eleanor Weetch



# Fundraising in Northern Ireland

*This issue sees yet another inspiring fundraising story, this time from across the water. Mary Cullen recounts her family's fantastic journey to raise £10,000 for charity. In fact this story even made it into the Cullens' local paper The Impartial Reporter. The NSPKU is absolutely delighted and grateful to all involved.*

Malachy and I have three busy little boys, Riain 6, Tiarnan 4 (PKU) and Ciaran 22months.

In May Malachy ran the Belfast City Marathon and said never again! At that time, I was expecting Tiarnan and had never heard of Phenylketonuria, so it came as a big shock when our new baby boy was born in August 2002 and diagnosed with this rare condition. Tiarnan is now 4; he loves playschool and copes really well with his diet. Our biggest problem is trying to get 8.5 exchanges into him each day.

Since the diagnosis, it was always our ambition to raise money for PKU and although he never said, I think secretly Malachy always wanted to run another marathon. In July 2006, we were out for a meal with our good friends Patricia, Frank, Evelyn and Gerard and the conversation came round to running. By the end of the night the three lads had talked each other into running the Dublin City Marathon at the end of October and had arranged to start training that Monday morning!

And so it began...running Sunday mornings and two mornings during the week at 6am before going to work. I guess the three families put their lives on hold for a couple of months as "Marathon fever" took over. But we also had good fun meeting up on Sunday afternoons to decide our charities and plan our fundraising events. We come from a tiny village called Garrison in County Fermanagh and because PKU is so unheard of, we decided to put another charity, McMillan Nurses (Fermanagh Branch), along with the NSPKU.

Our first event was a Table Quiz at the local pub followed by a Poker Classic the next week. We put sponsor cards in all the local shops and businesses and collected spot prizes; everybody's generosity was overwhelming.

Then came Marathon Weekend! With the training all done and eight children farmed out for the weekend, the six of us headed to Dublin. The 26 miles were gruelling but the boys got there in the end with three wives cheering them on at as many positions as possible. Frank finished in 4hrs26mins while Gerard and Malachy (the oldies) finished in 4hrs 47mins. A well-earned pint of Guinness (or two) was then consumed at O'Donoghue's pub to celebrate their achievement.

There were stiff and sore legs for a few days but a full recovery was made and the following Saturday night we held our final fundraising dance and presentation of cheques in our local Community Centre. Again we had a wonderful response and when all the monies were totted up we made it up to an even £10,000. We were thrilled to present a cheque for £5,000 to each charity. A McMillan Nurse was there to accept their cheque and Laura Elliott, the mother of a foster child with PKU accepted the cheque on behalf of the NSPKU. A letter was read out from the NSPKU signed by the chairman Dave Stenning. It was a very proud night for the six of us, our four months of hard work felt so worthwhile. Malachy and I would like to thank our four great friends for helping us raise this money for the NSPKU, we feel it is such a wonderful charity which helps Tiarnan and all the other little boys, girls and adults with PKU. We also want to thank the doctors, nurses and dietitians at the Royal Victoria Hospital, Belfast for all their advice and support over the last 4 years. Without them, we would never have got this far.

Mary Cullen,  
Co. Fermanagh, Northern Ireland.



Gerard, Frank and Malachy, relieved after the marathon



The three marathon runners with their supportive families

# Adult Study Day

London November 4th, 2006



This was, it is thought, the 16th adult PKU study day organised by the metabolic team from the Hospital for Neurology and Neurosurgery in Queen Square, London and led by Dr Phil Lee and Dr Robin Lachmann. It's always an early start for me, coming down from Barnsley on a Saturday morning, but it really is not a day to be missed. This year the venue had changed to a very smart address in Belgrave Square at the Society of Chemical Industry. Although an imposing building the inside was warm, welcoming and practical for the different way, this year, of running the day. I was glad to see the chef was still the same as previous years though and he didn't fail to please all of us – lovely hot veggie dishes, lots of colourful salads and the puddings were well... irresistible.

I like to go to these days because as Dr Lee put it to me "it's good hunting ground for you!" The day was no exception. As is often the case, the speakers who manage PKU themselves are the most powerful and Fiona O'Malley (who has PKU) and her younger brother Joe (who does not) were truly inspiring.

Fiona told us about her life and how when her brother went to university she relaxed her diet so much to all intents and purposes was off it. She ate sausages, lots of baked beans and other foods high in phenylalanine so her blood levels soared and she put on a lot of weight. She felt very low, but was unable to get herself out of the depressing downward spiral she had got herself into. This is where brother Joe came to the rescue. Returning from university he was concerned to see how Fiona had changed both physically and mentally. Last year they both came to the London study day and heard a similar story to the one they were living and Joe, being a very positive and purposeful individual said to Fiona "It doesn't have to be like this".

They went home themselves inspired to change their lives. They started walking a bit, not too far or too long at first but just got out for 20 minutes and walked. They slowly increased this and at the same time got back into weighing exchanges, eating more fruit and vegetables and actually enjoying and taking an interest in the quality of the food they ate. Slowly, slowly the weight came down and so did the phenylalanine levels. What went up was self esteem and energy for life. Everyone around Fiona noticed how much more energy she had and how her outlook on life had become more positive. Joe lost over 4 stones and Fiona over 2 stones. They both looked great, buzzed with enthusiasm and left us all speechless when they had finished.

I have asked them both if they will speak at the 2008 conference. As Joe put it "who knows what

we will have done by then!" The hunter had found its quarry!

What a hard act this was to follow but Dr Lee managed to make a survey of PKU management worldwide interesting and thought provoking. Throughout the world levels aimed for are all a bit different and even in one country they do vary. Continuing research, monitoring and auditing of treatment is important. This way we achieve the best outcome and full potential is reached. This is why the PKU register is so important and I would urge you to help with this by providing as much information as you can. When the register's collection of data ceased in 1994 much valuable information was not collected. You may be approached to provide it now. Please do so because it was through information collected in the past that treatment is so successful today. You can do your bit to help those following you.

After coffee, biscuits and a chat in the lovely conservatory we went back to hear Dr Robin Lachmann on 'Highs and Lows' what effect does Phe have on me? What was of great interest was the staccadometer machine. Karen McKittrick, dietitian at Queen Square, was a bit surprised to see her face up on screen, size 5 feet by 4 feet wearing some rather amazing 'glasses'. These special glasses measured the reaction time to a light flashing in front. This time can then be linked to phenylalanine levels and provide a non-invasive non distressing way of monitoring neurological state. Dr Lachmann could not understand Karen's re-action to seeing herself on the big screen but I think all the women in the audience would have felt the same sense of relief when the slide show moved on!

This all got us quite relaxed and comfortable with one another and so the question panel which followed was lively and enthusiastic. Lunch followed and this was a good time to chat to everyone. It was quite informal – sitting, standing and tucking into a good meal – all generously sponsored by SHS International.

The afternoon format changed from the usual and everyone had the chance to join 2 workshops. We could choose between:

- Psychological/emotional aspects of PKU
- Low Protein Cookery- hands-on mince pie making
- Healthy Eating off the PKU diet
- Healthy Lifestyle on the PKU diet.

It was difficult to choose but I went for healthy lifestyle and psychological/emotional aspects of

PKU. In healthy lifestyle we learnt about what we could each do to improve general health as well as looking after the PKU. Weight gain is causing the same problems for those with PKU as the general population and the concerns about developing diabetes and heart disease as well as other problems associated with weight gain still apply. The combination of a diet for diabetes as well as PKU is not easy and can be avoided in most cases by exercise and watching the calories! We talked about all the ways this could be achieved.

The session run by Danuta Orlowska, the psychologist, was one of the best I have ever participated in during my time with the Society. We talked about various situations and how we would re-act, what the consequences of our reaction would be and how to help ourselves get out of negative thoughts. Danuta was so practical and

these life examples of behaviour were easy to follow. I think I need to ask Danuta to help us at a National conference too!

So, another great day. It would not have taken place without all the hard work of the metabolic team – Dr Lee and Dr Lachman, Avril, Karen and Francine (the dietitians), and of course SHS International Ltd who sponsored the day.

On the train home I kept thinking about all that had happened that day and I wondered if anyone had been inspired over something someone had said or done in the same way Fiona and Joe were last year. I can't wait to find out next year...please do it again London!!

Eleanor Weetch

# PKU Pronto!

We've received a request for some exchange ideas as opposed to free food. It's certainly an unfortunate irony that there can be as much difficulty consuming *enough* protein in the PKU diet as well as keeping to the non-protein foodstuffs! To help those of you who are struggling to get those exchanges in, I've listed the six exchange ideas we use the most whilst leaving out the mashed potato and chip options which although very popular are well known already! In keeping with this column's title, many are very quick and easy and those that are not can be made in advance and frozen. Please, send in any other ideas you have!

## Exchange Ideas

### 1. Milk

Our son takes Minaphlex as his protein supplement and we add 30ml of milk to each drink as an exchange. Seamus says he barely notices the difference in taste and 30ml isn't much to add even if you're finding it hard to get the supplement down. I find it easier to weigh the milk too – 30g = 30ml and this is also more accurate. This weighing technique is great for water and milk but be careful, it doesn't work for oil!

### 2. Bananas

We count bananas as an exchange which works very well for us as Seamus can have a healthy, filling snack and get an exchange in too! Talk to your dietitian however, as some centres allow bananas freely.

### 3. Potato Bread

We use Eileen Green's recipe from her very useful book Special Recipes. She recommends mixing 400g plain mashed potato with 200g low-protein flour and 50ml oil

and a little salt. If you divide this mixture into 10 (use your weighing scales to be accurate), each piece will then comprise ½ exchange. You roll each portion out flat and fry them on both sides in a hot, dry frying pan until golden. This only takes a few minutes. I tend to wrap the cooked potato bread in foil and freeze it. To defrost one piece at a time, I pop them in the toaster! My son adores this smothered with butter. We have even made spread homemade tomato sauce on top and made potato bread pizza – a great success!

So, while this recipe takes a bit of preparation, it's time well spent and means you can have some exchanges on the table in the time it takes to make a piece of toast!

### 4. Broccoli

Again, our centre does not count this but check with your dietitian. Our son lists this as his favourite vegetable but I admit not all 5yr olds would agree! 30g = one exchange so a few quickly steamed florets can be added to a low-protein meal to bulk up those exchanges.

### 5. Peas

If peas aren't popular, you could cook some frozen ones, drain them and whizz them in a liquidiser. 25g = one exchange so you could add 25g of the pea mush to individual portions of low-protein soup and pasta sauce thereby getting pea exchanges in on the sly!

### 6. Cheezly

This is a vegan cheese available in Tesco and depending on the variety, 30g = one exchange. This can be melted on low-protein pizza, used as a sandwich filling in low-protein sandwiches, or cut into fingers and dipped in ketchup, that last idea being a big hit in our house!



# **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<sup>†</sup>

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# PKU Doughnuts

*Eleanor Weetch received an interesting PKU recipe idea recently. It's only suitable if you have the necessary machinery but if you're thinking of purchasing something to liven up your PKU cooking repertoire, perhaps this will inspire you?*

Dear Eleanor,

For Christmas we bought our son Paul (PKU) and his wife Julie a doughnut maker. Here is my version of a PKU doughnut recipe for suitable for the machine. It worked quite well, but there is always room for improvement and adaptation!

Best wishes,  
Christine

## Ingredients

- 170g PKU flour (I used Juvela).
- 110g caster sugar.
- 4 tsp. baking powder.
- ½ tsp. salt.
- 170ml water.
- 2 tsp. egg replacer
- 4 tbsp. oil
- caster sugar for coating.

## Method

1. Grease and heat doughnut maker. Mix together PKU flour, sugar, baking powder, salt and egg replacer.
2. Stir together oil and water.
3. Gradually add liquid to dry ingredients. Beat well until smooth.
4. Fill each hole with a 10ml spoonful of batter.
5. Close lid and lock. Bake 2 mins.
6. Remove doughnuts and toss in caster sugar. Repeat with remaining batter.
7. The doughnuts can be covered with different sugars and toppings.

Best wishes,  
Christine Cardy

# Barbara Broadbent Comes up Trumps again!

*Regular readers will be delighted to learn that Barbara has forwarded us yet another delicious and interesting recipe to try.*

**Mushroom and Fennel Hotpot**  
Serves 4.

## Ingredients

25g/1oz dried shiitake mushrooms  
1 small head of fennel  
30ml/2tbsp olive oil  
12 shallots, peeled  
225g/8oz button mushrooms, trimmed and halved  
250ml/8fl oz dry cider  
25g/1oz sun-dried tomatoes  
30m/2tbsp tomato paste  
1 bay leaf  
Salt and ground black pepper  
Chopped fresh parsley, to garnish.

## Method

Place the dried shiitake mushrooms in a heatproof bowl. Pour over just enough hot water to cover them and leave to soak for about 15 minutes. Meanwhile, trim and slice the fennel.

Heat the oil in a heavy pan. Add the shallots and fennel, then sauté for about 10 minutes over a medium heat, until the vegetables are softened and just beginning to brown. Add the button mushrooms to the pan and cook for a further 2-3 minutes, stirring occasionally.

Drain the shiitake mushrooms, reserving 30m/2tbls of the liquid to add to the cooking liquid. Chop the shiitake mushrooms and add to the dish.

Pour the cider into the pan and stir in the sun-dried tomatoes and tomato paste. Add the bay leaf. Cover with a lid and simmer gently for about 30 minutes, until all the vegetables are tender.

Remove the bay leaf and season to taste with salt and pepper. Serve sprinkled with plenty of chopped parsley. Nice served with mashed or boiled potatoes (exchanges).



**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**



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then ask your chemist to telephone our direct order line : 01215 22 44 33**

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# Fate Special Foods recipes



Hello,

When I make up a recipe using the Fate plain cake mix, I often use pure fruit juice in place of water. Not only does it add a lovely flavour, but it makes them a deep golden brown. I like to use pure orange, apple or pineapple juice, the kind you get in a carton. It can also be used with the chocolate flavour cake mix as I have done in this recipe.

This pudding is very easy to prepare, and because it is cooked in the microwave, it is ready to eat in a few minutes.

Just an important note about the chocolate spread that I use for the topping: I've always used Tesco's own brand (50g for 1 exchange) BUT, they have changed the recipe and it is now only 35g for 1 exchange. However, they sell another one under the Tesco 'Value' range which allows 40g for 1 exchange, so I used this one in this pudding.

It just shows that labels need to be read and checked even if you have been using the same brand for years! Ask your dietitian if you are unsure.

## FATE CHOCOLATE AND ORANGE SAUCY MICROWAVE PUDDING

For the sauce:

1 exchange suitable chocolate spread  
50mls pure orange juice

For the cake:

1 x 250g Fate Chocolate Cake Mix  
65g soft margarine (the type in a tub)  
125mls pure Orange juice

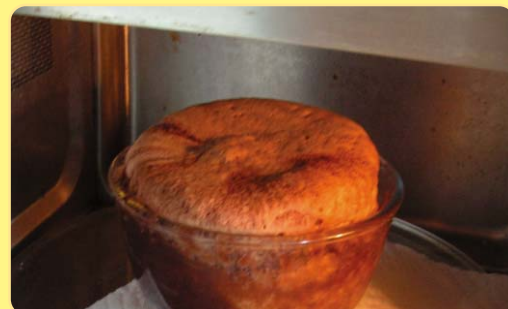
Weigh the chocolate spread and place it with the 50mls orange juice into a microwave-proof pudding basin (about 1 litre capacity) Put it in the microwave for about 30 seconds to warm through. Take it out and stir it to make a smooth sauce.

Place the Fate Chocolate Cake Mix into a mixing bowl, add the margarine, and the 125mls Orange juice. Mix quickly with a wire whisk for 1 minute.

Place into the pudding basin, on top of the chocolate sauce. Do not mix or stir in.

Place into the microwave, on full power for about 4½ mins till risen. Allow to stand for a few minutes before turning out.

Serve warm. Any left over can be frozen, just defrost and reheat in the microwave until piping hot again.





## ***Quick Vegetable Risotto***

### ***Ingredients:***

350g (14oz) 'free' vegetables  
2 x 15mlsp (2tblsp) olive oil  
100g (4oz) Loprofin Low Protein Rice  
Approx 325ml (13 floz) homemade vegetable stock, hot  
1 x 15mlsp (1tblsp) tomato ketchup  
Salt and pepper to taste

### ***Method:***

1. Peel and trim the vegetables, cut into bite sized pieces.
2. Heat the oil in a large frying pan, add the vegetables and stir-fry for 1-2 minutes.
3. Add the Loprofin rice to the pan and stir-fry for a further minute.
4. Add the stock and tomato ketchup to the pan and stir well, bring to the boil.
5. Reduce the heat, cover and simmer for 15 minutes. Stir frequently during cooking to prevent the rice sticking to the frying pan.
6. During cooking check that the stock is not reducing too much, add a little extra if the risotto becomes too dry. Adjust the seasoning to taste, before serving.

Serves 2.



# Dietitian's Report

## New Dietary Information Booklet 2007 - 2008

*In this issue you will find the latest dietary information booklet. I have changed the way the diet information is produced because of the improvement in nutrition labelling and the more cost effective ways of using our web site to convey some of the information.*

I have stopped writing a separate exchange booklet of manufactured foods. It was a very time consuming and expensive piece of work to do and also nearly all foods now carry the protein content on the label. In the new booklet you will see how to calculate the exchange value for your self and a selection of useful items have been put on the NSPKU web site. There is a handy protein calculator card in your booklet so that you can work weights for an exchange out easily.

The Baby Food Exchanges and FREE baby foods are also on the NSPKU web site; [www.nspku.org](http://www.nspku.org)

You will also notice that some foods have moved in the booklet and there are some exciting new entries!

You should always consult your dietitian about any changes in your own or your child's diet. If you are not sure how to work out exchanges from the example please ask your dietitian to help you. She/he will be happy to help you work through some different examples.

### Amino Acid Analysis

Each year we try to analyse some new foods for their phenylalanine content. Our diet is so much more varied than it used to be and if your choice is restricted you don't want to limit yourself unnecessarily. It's good to try new things so the diet is not boring, and to join in with everyone else as much as possible. Of course there are many foods which are so high in phenylalanine it is not practical to include them but the last analysis of foods we had done (and thank you for all the support you give the Society) has enabled some changes which I think you will enjoy.

### What can be taken freely?

#### Green Beans

It was a South African dietitian who asked me "What is the difference between green beans, runner beans, French beans, flat beans, fine beans, Bobby

beans, round beans, dwarf beans and stringless beans?"

The answer is they are all free. We had several different beans analysed and you can treat them all the same. So runner beans (whichever you thought this one was!) used to be in the "take only one small portion a day" section but it has moved.

**All green beans are free!**

So that solved that one!



#### Fruit Crisps

Apple crisps and other fruit crisps (Humdinger do some) are also free. These are nice for the lunch box. As well as those pictured Marks and Spencer's do some too.



#### Cassava and Tapioca Crisps

These are also free. Both tapioca and cassava flour are very low in phenylalanine so we expected the crisps made from these plants to be free too and they are. The Taj Brand I bought in Tesco and the Indonesian Crackers in Waitrose. These are great for parties, the lunch box and to dip in a tomato salsa or suitable dip. (try mayonnaise with a little curry powder or tomato puree)



# Dietitian's Report cont...

## Cassava Chips

(also known as Yucca chips)

You can find these in the frozen section of Indian supermarkets. Cassava (Yucca) is very low in phenylalanine and can be taken freely. Try them! They could be a 'free' alternative to potato chips.

## Marks and Spencer

### Chewing Gum

There are 3 chewing gums (sugar free) which are being sold in Marks and Spencer which are free of aspartame and can be taken without counting in the diet for PKU. They are all sweetened with sucralose.

Menthos Airplus

Very Berry

Coolmint

I found them at the checkout and when I read the ingredients I had to try very hard to stop myself shouting out loud and telling everyone in the store what a great find this was!!

## Foods which need to be counted

### Sugar Snap Peas and Mange Tout Peas

Sugar snap peas and mange tout peas contain too much phenylalanine to be allowed freely BUT not enough to make them an exchange. So we have put them in the section "take one small portion a day" and it need not be counted. *Good news for the stir fry!*

### Vegetable Crisps

These are crisps made from mixtures of parsnip, sweet potato, beetroot, carrot or as just one vegetable e.g. Sweet potato or plantain.

These can all be taken as 50g = 1 exchange

You are possibly wondering why they can't be free as they are all free fresh vegetables. When vegetables are fried they lose a lot of their moisture and the vegetable becomes more concentrated in its nutrients. It is at least twice as high as the fresh version and we all know how much easier it is to eat



quite a lot of crisps! It is why the weights for one exchange of potatoes varies with how they are cooked. They lose lots of water when fried so:

Boiled Potatoes	80g = 1 exchange
Roast Potatoes	55g = 1 exchange
Chips	45g = 1 exchange
Crisps	15g = 1 exchange

For the technically minded, the more surface area there is the more moisture the vegetable will lose and the more concentrated the nutrients become.

### Crispy Seaweed (Blue Dragon)

This is quite high in phenylalanine but it is very light.

So 20g = 1 exchange  
(the picture shows 20g of seaweed)

The Blue Dragon packet of crispy seaweed pictured contains 55g of seaweed so 20g is nearly half the packet. You would probably only need ½ exchange (10g) on your Chinese stir fry. (We did analyse seaweed sheets but they came out much higher in phenylalanine so are not suitable)



### Quorn Smoky Bacon Style Slices

These 'bacon' style slices are made from mycoprotein which is a member of the fungi family (like mushrooms). It is not real bacon!

½ slice of 'bacon' = 1 exchange

The 'bacon' slices are quite wide so you can cut a slice in half length ways and it looks like a streaky strip of bacon.

You might like to use this exchange as part of a breakfast with tomatoes, mushrooms, low protein fried bread.

So try some new things. Let me know of anything you would like to have analysed next year and we can start another list going.

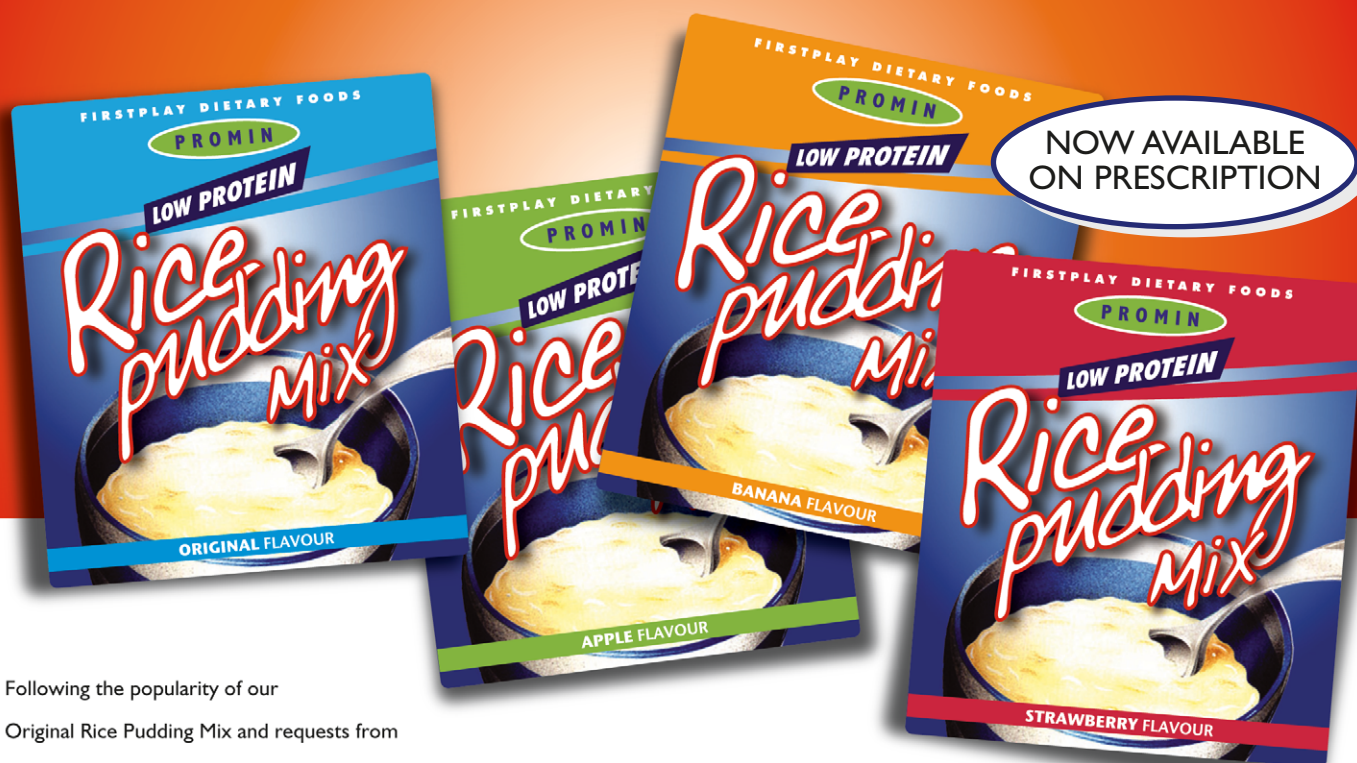


If you would like to do some fund raising each analysis costs about £120 but what a benefit it can be to so many.

Eleanor Weetch  
Society Dietitian

# Three NEW! flavours added

**NEW**  
NOW AVAILABLE ON PRESCRIPTION



Following the popularity of our Original Rice Pudding Mix and requests from customers we have added three NEW flavours: Apple, Strawberry, and Banana.

All the NEW flavours come in packs of four and are available on prescription.

With more meal solutions being added to the Promin range you can be sure there's a great tasting 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.

A recent addition 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. Visit our website for more details and a full analysis on all our

products. [www.promin-pku.com](http://www.promin-pku.com)

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. The range also includes Imitation Rice, Pasta meal and Lasagna Sheets. By talking with PKU patients, parents and Dietitians new products have been developed to reflect your needs. Please call or visit the website for more information and keep sending your recipe suggestions.

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



**PROMIN**

Always consult your dietitian before trying something new.

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

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