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Conference 2010

37th Annual Conference



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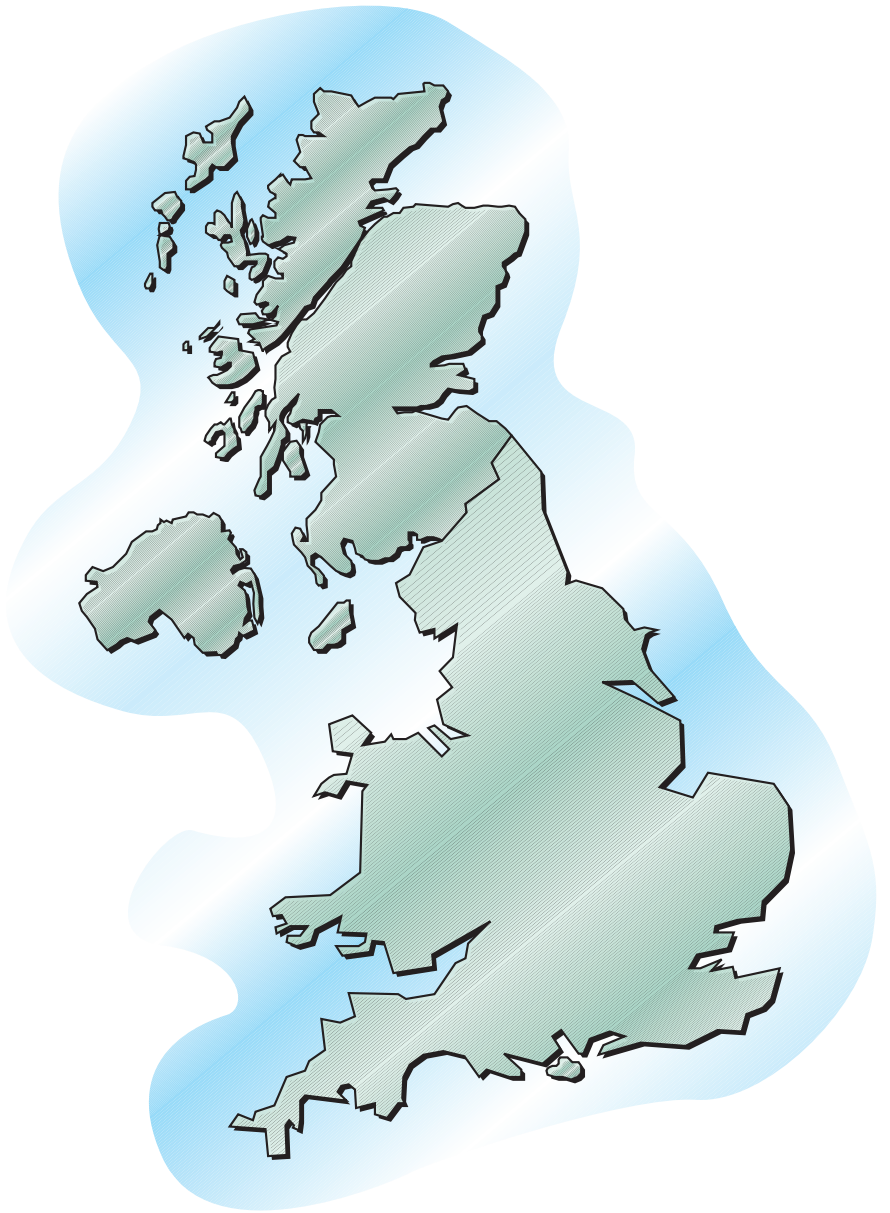
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Letters

News & Views, 23 Barnfield Cottages, Arundel Road, Fontwell, West Sussex BN18 0SE
Email: editor@nspku.org

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

Dear News and Views,

My son, George is 12 years old and has PKU. In George's spare time he enjoys playing the drums and often gets together with his best friend ,Craig, who plays the guitar for a "jam".

My partner, Fraser, who we live with plays the bass guitar in a local band called "idlehand2" and in January we held a charity night in aid of the NSPKU and raised £500.

As a surprise, Fraser and the band invited George and Craig to perform a track with them. They played in front of 150 people. This was the first time they had ever done this and obviously it was very nerve racking for them and they were nervous, but they were brilliant and made myself and everyone who knows them that were there very, very proud of them.

It was a great night and everyone had lots of fun. We hope to repeat this next year and who knows, in years to come, you may see George and Craig perform at Wembley!

Yours Sincerely
Nadine Joynton.

Dear News and Views,

I am just writing to let you know that I appreciated all the help that the National society for PKU gave, when you managed to offer an assisted place to Chelsea Ferbert, a teenager with PKU, at extremely short notice to you!

I have since met with her in school and she was full of, how amazing the weekend was, how much she had learned and the friends she made.

I can't thank you enough as this has had such a positive impact on Chelsea's life.

Everyone I spoke to and contacted was helpful from the initial contact to making bookings and emails,

Thank You,
Louise Tucker.
(School Nurse, Somerset Community Health)



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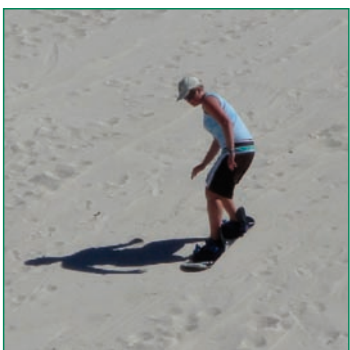


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PKU and ME

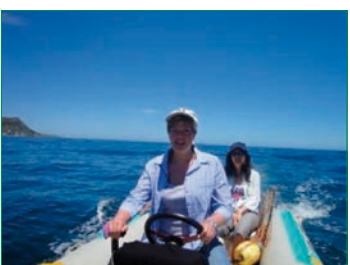
by Kylie Verster



Sandboarding in Hout bay



Feeding the birds



Driving the boat

Hi, my name is Kylie and I have PKU. I am 20 years old. I was born in South Africa in 1989 where there was no screening for PKU at birth. My GP noticed my pale hair colouring but did not think anything of it other than to say it was unusual for a baby to be born with so much ash blonde hair.

Apparently I appeared to develop normally till I was about 6 weeks old then I started getting very floppy, screamed a great deal and was very sick after feeds. Over the next 2 and a half years I was taken to a total of 9 specialists/therapists to try and discover why I was not reaching my milestones. Each time, mom was told that I was "just a bit slow", however she remained unconvinced. Eventually when I was 3 and a half, my gran found an Irish Educational Psychologist who diagnosed my PKU – the prognosis was not good. Mom, being mom, took me for a second opinion. This second lady told her that I would probably "be a vegetable" and the best thing would be to put me in a home for the severely retarded and get on with her life. Obviously this did not happen or I would not be here writing this article today!

For the next 3 years I was taken to speech, occupational and physical therapy and attended a special needs school for severely mentally handicapped children. My development slowly improved. Between my mom and grandparents and phone calls to Great Ormond street hospital my diet was sorted out as best it could be. I was put on 5 exchanges a day and a small amount of low protein food was imported from the UK as there was nothing available in South Africa – I hated my supplement!!!!



Me and my brother in 2003

By the time I was 7 years old, I was able to move schools and went to Vista Nova. This school was for children with Cerebral Palsy and moderate

learning difficulties.

In 1999 we made the decision to move to England as it was becoming impossible to get hold of even the smallest amount of low protein foods. Here we were introduced to the NSPKU where we made loads of friends and found the incredible support network it offers.

I remained in special schools for children with moderate learning difficulties and did ok.

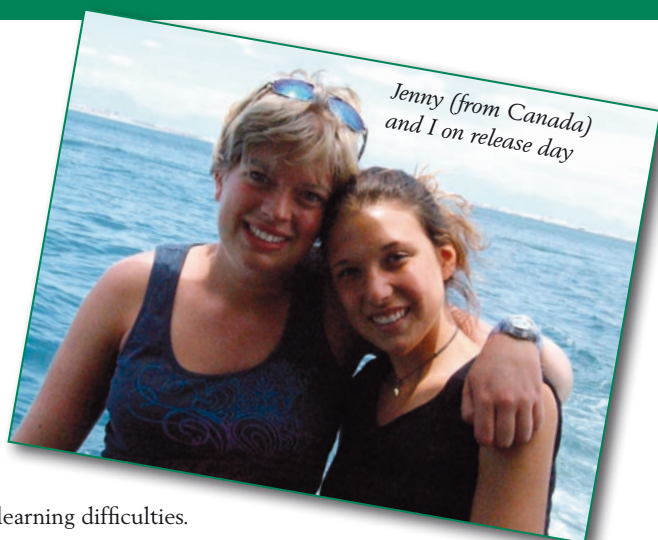
At 16 I went to college and discovered canteens!! I went through a 2 year phase of constantly cheating on my diet – nothing to extreme like eating meat etc, but I found I have a weakness for cheese, yoghurt, chips and chocolate! I did not weigh my foods and was desperate to be like everyone else, so I ate what I wanted when away from home and often threw my supplements away or hid it under my mattress so mom would think I had taken it. I tried to kid her that I was being strict, but she saw through me. We fought a lot. After about a year, I found myself in a very "dark place" mentally. I was depressed, suffered from severe mood swings and was generally very difficult to live with. My brother and mom bore the brunt of this.

We went back to conference in 2008. It was there that I finally realised what I was doing to myself. I decided to try and get back on track. I met Clare Gibbings who inspired me to travel as she was planning to do. I knew there was no way I could go in the mental state I was in with my levels being as high as they were.

It took a full year to sort myself out. I lost the weight I had gained, counted my exchanges properly and took ALL my supplements – my moods improved dramatically and I became a much happier person.

During that year, I completed a course in animal care and decided to go to South Africa in October 2009 to work with penguins. My family rallied round and together we made it possible for me to go.

We spent a lot of time planning and ordered extra prescriptions of pasta and supplements. We sent 3 parcels of pasta, flour, tablets etc out to my aunt in Cape Town in July 2009 – only 2 arrived! We made up the shortfall by removing clothes from my suitcase and filling it with food instead.



Climbing Table Mountain with my aunt – we walked up and took the cable car down!

Armed with letters from my dietician and a copy of my prescription, I sailed through the "nothing to declare" queue at Cape Town International airport on 15 October 2009.

There followed the most amazing time. I spent a week with my aunt who helped me prepare freezer meals and we shopped for as many "low exchange" foods that we could find. I then went to my host family in Blaauwbergstrand where I shared a room with a girl from Canada. We became great friends and are in regular contact via MSN. My diet was reasonably easy to maintain and my host mom was fantastic.

SANNCCOB is a fabulous place. The centre rescues and rehabilitates sea birds, mainly penguins, who have been abandoned as chicks or injured by pollution. I learnt so much including how to prepare "fish shakes" and intubate the chicks to feed them. I worked with the vet in theatre and generally helped with the cleaning of pens.

I felt incredibly privileged to go out on "release day". It was wonderful to see some of the birds I had helped released back into the sea just near Robben Island.

On my days off I went back to my aunt who really made my stay memorable. She took me to a cheetah centre where I got to stroke the cubs – boy they purr loudly! I went sandboarding on the dunes in Hout Bay and drove the boat in False Bay on the day we went crayfishing.

I also made contact with friends I had made when I was little and went to the twins 21st birthday party. Nicola and Amy, along with Steffie had made up my best friends while at Vista Nova.



With "Phyllis" the lamb at Butser Farm 2009



LOVED the cheetahs



I came home on December 15 2009 – tanned and very happy!

I am currently working and saving to go back to college in September to do a course in outdoor education as I love anything adventurous.

I can honestly say that PKU need not control your life as long as you control your diet. You can go as far as you like, just control your diet and blend it in with your lifestyle.

We are unique and there is nothing wrong with that!

Kylie Verster



Horse riding in the woods in Cape Town

Special Tummies



Little man Sean Hanlon is three (and a half), because at his age a half makes all the difference. His parents have told him that he has a special tummy. Sometimes it's good to have a special tummy; after all Sean gets to go away on special weekends with his parents and spend time with other little children who have special tummies as well. In a few years' time, he won't even want his mummy around and will go on fun outings with the bigger boys; and this will only be the beginning as he'll soon be traveling the world attending similar meetings as an adult patient or maybe as a scientist with new ideas for better treatment – all is possible for Sean who has PKU.

Sean may have chosen his special tummy in heaven but he also wisely chose the right parents who'd know how to take good care of it. He's the first son of John and Caroline who are slowly teaching him the responsibilities of having PKU, and Sean is already showing signs of understanding. One evening, during his bedtime prayers, John asked Sean if he knew why God gave him a special tummy. Sean thought about it for a while and then answered "because God must have a special tummy too".

Dr. Christineh N. Sarkissian, Ph. D.

Change in contact details for Juvela low protein products

With effect from 1st May 2001 any questions related to the Juvela range of low protein products will be handled by Juvela directly rather than by SHS international.

Juvela can be contacted either by

Phone Freephone 0800 783 1992
(Republic of Ireland 1 800 40 50 90)
e-mail low protein @juvela.co.uk

or by writing to Juvela 19 De Havilland Drive ,Liverpool,L24 8RN

Juvela will also now be responsible for supplying and marketing its range of low protein products. The products in themselves will not be changing and you will still be able to obtain them on prescription and through the SHS Homeward delivery service.

Juvela are committed to ensuring that consumers of their products are not affected by the handover of responsibility and would love to hear from current users in order to keep them informed of any future product developments.

Juvela already have plans for extending the range of low protein products available and if you have any suggestions please contact us.

John Phillips
Managing Director, Juvela

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All recipes developed, tried and tested
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Fate Low Protein Cake Mix
Fate Low Protein Chocolate Cake Mix



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direct order line : 01215 22 44 33. Helpline and general enquiries tel: 01215 22 44 34

Fate Special Foods recipes



Hello

This recipe was inspired by something we saw on the menu in a Chinese restaurant when we were on holiday. The restaurant was called 'The Jasmine' It was a really good place for us because they had quite a few dishes that were suitable for a low protein diet, and lots of others that could be adapted using Fate All-Purpose Mix. So, when we got home we made these vegetable balls. They are so easy to do, and just as good as the ones served in The Jasmine! They have a delicious fresh taste and texture.

They are really good served with a suitable sweet and sour sauce, or Fate Barbeque sauce.

The spice used can be varied, Cajun is our favourite, but you can use paprika pepper, curry spice or any other strong flavoured mixture.

They can be deep fried in oil or shallow fried. They freeze well.

FATE JASMINE BALLS

Method

Slice the spring onions into ½ cm pieces (use all of the onion, including the green tops) Chop the red pepper and the French beans into 1cm pieces..



Place the Fate Low Protein All Purpose Mix, baking powder, spice, salt and pepper into a bowl or jug. Stir.

Add the water and whisk with a wire whisk or fork until the mixture resembles a thick and smooth batter. This will take about 1 minute. Stir in the vegetables.



Dust the work surface with a little Fate All-Purpose mix. Take a tablespoon of the mixture and place onto the work surface on top of the Fate All-Purpose Mix. Then, dust your hands with a little more Fate All-Purpose Mix and gently shape into a smooth ball.



Either shallow fry in a little hot oil in a frying pan, or place into deep hot oil to cook. They will take about 5 mins to cook through and turn golden brown.

Drain on kitchen paper.

Serve them hot with a suitable Chinese style sauce, such as sweet and sour or Fate Barbeque sauce.

Ingredients

- 50g spring onions
- 50g french beans, fresh or frozen
- 50g red pepper
- 75g Fate Low Protein All Purpose Mix
- ½ tsp Baking Powder
- 2 tsp spice ~ we use Cajun or paprika.
- Salt and pepper to season
- 75ml water
- Extra Fate All-Purpose mix for shaping
- Hot oil for frying



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...and it's just
the start!

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... and if you have any ideas/ suggestions you want to share about **PROZERO** we would love to hear them too!



Here are just some of the recipes developed and perfected by Eileen Green, Fate Special Foods

CREAMS

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Custard
Brownies

SAVOURY SAUCES

Curry Sauce
White Sauce

DRINKS

Cappuccino
Milkshakes



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HOT
OFF THE
PRESS!

Summer Treat -

Panna Cotta with Crushed Strawberries and Mango

Serves

4-5 portions

Equipment needed

- Small saucepan
- Tall container or jug
- Hand held blender
- Suitable pots, ramekin pots, glasses or cups for serving

Ingredients

- 400mls **PROZERO**
- 50g unsalted butter
- 50g caster sugar
- 25g cornflour
- 1 vanilla pod or 5 teaspoons vanilla essence

To serve:

(for each portion)

- 4-5 fresh strawberries
- 2-3 teaspoons sugar
- 1-2 slices of ripe mango

Special Note!

If possible, use a vanilla pod rather than vanilla essence as this will give the best flavour.

Panna Cotta with crushed Strawberries and Mango

This is a low protein version of the classic rich, smooth and creamy Italian dessert; Panna Cotta. This recipe is freely allowed in your low protein diet.

Instructions

1. Pour the **PROZERO** into a small saucepan.
2. Add the butter, caster sugar and cornflour.
3. If you are using a vanilla pod, cut it in half lengthwise and remove the tiny seeds from the inside with a sharp knife. Place the seeds and the cut vanilla pod into the small saucepan. If you are using vanilla essence instead, add this to the pan.



4. Place the pan over a gentle heat and stir well.
5. Keep stirring until the mixture starts to simmer and is thickened.

6. Take out the cut vanilla pod.

7. Pour the Panna Cotta mixture into a tall container or jug and use a hand held blender to blend for 30-40 seconds.

8. Then straight away, pour the mixture into small ramekin dishes.
9. Leave to cool, then chill in the fridge for 3-4 hours. The Panna Cotta should be set but still have a light and soft texture.



Serving suggestions:

Place the strawberries into a dish and roughly crush with a fork. Sweeten with the sugar.

Cut the mango into small pieces.

Turn the Panna Cotta out of the ramekin dish onto a plate (You may have to loosen the edge a little with a knife first). Decorate with the strawberries and mango and serve.



NSPKU 37th Annual Conference

Skipton, north Yorkshire

The 37th annual conference weekend, held in Skipton, north Yorkshire, was attended by over 70 with PKU plus their family and friends. It's a wonderful mix of learning, exchanging ideas and fun. The hotel, used for the third time, is family run and the owner welcomed everyone and hoped we would have a 'right good Yorkshire do'. We did. Delegates had travelled from Glasgow to Devon and from Finland, Canada and Holland. It's interesting to hear how things are done in other countries. The father of a PKU son from Finland (only 5 with PKU there) said that they count everything in the diet and on cold weather – it's been -38°C and even they have not known what to do with the snow. It was good to see such support, especially in difficult financial times and with increasing electronic communications, but there is nothing quite like face to face contact and the chat over a cup of tea or drink at the bar.

The talks are the focus of the weekend and this year they generated so much interest. Dr Anita MacDonald, from Birmingham Children's Hospital, spoke about weaning and infant feeding. This coincided with our latest publication 'Weaning a child with PKU'. It's a beautifully colourful and clear booklet and all the stars in it have PKU. Anita gave her ten top tips for weaning, all common sense when considered, but often under pressure or when starting something new confidence can be lacking and if the baby has PKU there can be more anxiety. It was straightforward and re-assuring advice. Anita is always conducting research and her latest work was in looking at babies' stool/poo/haeces consistency and frequency. The addition of prebiotics to the PKU milk resulted in a softer poo and helped develop the beneficial intestinal flora or bacteria. Getting off to a good start is so important.

Following on nicely from this was Dr Stephan Huijbregts from Lieden in the Netherlands. He reported on research in executive function in early treated PKU. Executive function is a measure of what we need in daily life; planning, organisation, reaching goals, how to be flexible, inhibition of normal impulses, memory and monitoring and correcting our actions. Some examples, always helpful when explaining anything to do with the function of the brain, helped us to understand these studies. Pictures of Big Bird, Bob the Builder and Belle did nicely. The natural reaction of a child is to shout 'Big Bird' when asked who it is but the children were asked to whisper (inhibitory control). The results of his work showed when levels were within range the executive function was good but it is the average over time (mean) which is very important. The phenylalanine on the day of the test was not as strong as the mean. When levels were high and there was then dietary intervention over two weeks to bring them down results were better and faster. So you can do something with short term intervention. Phenylalanine levels in the younger child are very important because they have more problems with executive function if levels are high. More complex executive function is needed as you get older so it is important to continue the diet and treatment after childhood. Further information can be viewed on the ESPKU web site (espk.org).

The psychology of coping with a strict dietary regimen can be complex and it is the understanding of why we do what we do which is helpful. Dr Kathryn Bond, principal psychologist in metabolic medicine at Great Ormond Street Hospital, seemed to connect immediately with the delegates and had the ability to put her finger right on the problems. Her words 'if you take control from someone they will try to get control in another way' helped explain the reactions of both toddlers and teenagers. Her advice on a few things:-

On independence – 'It's important to start early, involve them in their PKU and always keep nudging them forward'.

And 'You can't become independent without making mistakes'.

On feeling guilty – 'It's tempting to compensate for PKU but it's not helpful'. Compensating makes it more difficult later on.





On feelings- 'It's a broad band connection between you and your child. The child will pick up on anything immediately'.

This presentation generated much discussion and to reach a wider audience it was thought a section in News and Views on the psychological issues of long term treatment would be helpful.

New treatments, even cures, are hoped for and Dr Peter Galloway from Glasgow spoke about Kuvan (sapropterin) which has been shown to reduce phenylalanine significantly in milder cases of PKU. Response is measured by reduction in blood phenylalanine but in addition to this there is anecdotal evidence that it may have other benefits too but this has not been formally tested. This new drug is extremely expensive (100K per year for an adult) so funding is an issue but the NSPKU is supporting our medical experts' evaluation and guidelines for use.



Stars of the show are frequently those with the condition themselves and Clare Gibbings (age 20) was no exception. Clare took a gap year to work in a children's home in South Africa. She continued with her diet and explained the ups and downs of this whilst at the home and travelling for 6 weeks throughout Africa afterwards. Clare is now at Warwick university where she said her diet was much easier to do and low protein pasta is still top of her list. She said having PKU was no reason to stop doing anything and working in the children's home put things in perspective. About her up-bringing she said her parents and grand mother were very supportive and always encouraged her to do things for herself. The sooner you start this the better. It was the most up-lifting talk any new parent could have heard.

The PKU food is so important and the head chef, Dave, and his team pulled out the stops. We had 3 mushroom lasagne, marinated kebabs, stir fry in sweet chilli sauce- always at least 2 choices for each course. The low protein manufacturers always seem to have something new to display to make life better. We even had Duobar lollipop sheep – we were in Yorkshire after all and they made the event fun with competitions and great prizes. Their support is invaluable and they always rise to the challenge to make life better.



As always there were cookery demonstrations. FirstPlay Food's owner, Steve Fletcher, showed the versatility of his range even making a chocolate and red fruits pudding from his chocolate hot breakfast. He's not accustomed to cookery demonstrating but his down to earth approach was fun and encouraging. Eileen Green, from Fate Special Foods produced Black Forest Gateaux, soda bread, scones and cream (made with VitaFlo's new milk) and other delicious goodies. Delegates sat for 2 hours and no-one moved because they knew these treats were for tasting afterwards.

We had a quiz (Oh too hard Eric) competitions, raffles and a disco all with fantastic prizes. It was PKU land at its best so do come along next year and experience it first hand.

All the talks from the conference are on our web site at www.nspku.org



Pasta Twists With Green Vegetables

Method

1. Three-quarters fill a large saucepan with water, bring to the boil, add the pasta, oil and salt to the pan. Return to the boil, stirring. Reduce the heat slightly and cook for 8 minutes, stir occasionally to prevent pasta from sticking together. When the pasta is cooked, drain well and keep hot.
2. Meanwhile prepare the vegetables: cut the courgettes into ½ then ½ again to give thick 'batons', halve the asparagus tips, cut the leek into 2.5cm (1 inch) thick slices, trim and halve the beans.
3. Melt the butter in a saucepan, add the vegetables, cover and fry over a moderate to low heat for 2 minutes, add the stock and tarragon and bring to the boil. Reduce the heat, cover and simmer for 5 minutes, until the vegetables are tender. Adjust seasoning to taste.
4. In a small bowl blend the Loprofin Mix and Sno-Pro until smooth, stir into the sauce/vegetable mixture, bring to the boil stirring. Add the cooked pasta, tossing lightly until well combined with vegetables and sauce.
5. Transfer the pasta to a warmed serving dish, if desired garnish with fresh herbs, before serving.

Serves 2

Ingredients

- 150g (6oz) Loprofin Low Protein Pasta Twists
- 1 x 15mlsp (1tbsp) cooking oil
- 1 x 5mlsp (1tsp) salt
- 25g (1oz) economy butter
- 100g (4oz) baby courgettes
- 50g (2oz) asparagus tips
- 100g (4oz) baby leeks
- 50g (2oz) French beans
- 250ml (½ pint) home-made vegetable stock
- 2 x 5mlsp (2tsp) chopped fresh tarragon
- 1 x 15mlsp (1tbsp) Loprofin Low Protein Mix
- 4 x 15mlsp (4tbsp) Sno-Pro
- Salt and pepper
- 1 litre (1 ¾ pint) ovenproof dish

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Dietitian's Report

What's new in the supermarket?

Velvet Crunch Crisps



These are tapioca and cassava flour crisps which come in 2 flavours. Unfortunately the Thai Chilli Flavour contains aspartame but the Cheddar Cheese and Spring Onion Flavour do not.

The bags weigh 20g and contain ½ Exchange per bag and 83 calories so for those watching their weight that's quite a bit less than normal crisps.

Mexican Taco Trays



These taco trays are made by the Discovery company who do a whole range of Mexican food items. The trays are only ½ exchange each and would be a novel way of serving all kinds of savoury meals. You could fill with stir fry vegetables, Cajun sweet potato chips or squash or salad mixes. It's the tray which would make it all so different and appealing.

Pure Soya Thick Slices



These are the vegan equivalent of Dairyalea slices. You could put these on low protein toast or in sandwiches or melted onto cauliflower, broccoli or potatoes or on top of a low protein lasagne.

Each slice is 1½ Exchanges.

Tesco Value Squeezy Chocolate Flavour Ice Cream Sauce

This chocolate flavour sauce is low in protein and would be good not just on ice cream but also on pears, with some low protein cake or hot sponge pudding, banana split (using the SHS dessert mix) or anything else you like to have with a chocolate sauce.

Protein is 1 exchange for 100g and this is about half the tube which is a lot. 50g (that's 2½ tablespoons) of the sauce would be ½ Exchange.



Nesquik and Sipahh Straws Strawberry Flavour

These flavoured straws can be used for protein substitute and milk substitute to make a fun and nicely flavoured drink. At the moment only the strawberry flavour is suitable, the chocolate is too high in protein, but there may be more flavours coming our way from Australia. You should be able to find them in most supermarkets including Aldi which the Sipahh company specifically mentioned to me.

Haribo

At the conference the children who went to the party made up their own party bags filled with a selection of Haribo sweets. These very attractive sweets were brought down from Newcastle by



Barbara McGovern and have been checked for protein content which is 0.1g per 100g (except Rotella which is 0g protein per 100g) so they can be classed as free in the PKU diet. The sweets are labelled as suitable for vegetarian diets (no gelatine in them).

The sweets which are suitable are:-

In Bags (labelled suitable for vegetarians):-

Funny-Mix 160g bag – all these sweets are free including strawberry shapes.



Jelly Beans 175g bag

These are available in Tesco, Morrisons, Holland and Barratt and many other supermarkets and shops.

In large boxes – can be bought as individual sweets:-

Giant Apples

Giant Oranges

Giant Strawberries – not the small strawberries called Strawbs

Rotella

Starfish

Freaky Fish

Jelly Beans

Barbara bought the **large** boxes in Makro, a wholesale store. Other wholesale stores include Booker and Hancocks and many other cash and carry outlets. Individual sweets are widely available. Probably just as well as they are very more-ish!

A bit of history....

I have just read that the name Haribo was chosen by Hans Riegel who was a young baker/confectioner in Bonn, Germany in the 1920's. He started by making sweets in his own kitchen which his wife then delivered by bicycle. He later set up his business in Bonn using the name HARIBO;

HA for Hans; RI for Riegel and BO for Bonn.

Aspartame

I was catching up on my dietetic journals on a long train journey last week and came across the following article.

FSA (Food Standards Agency) Calls for Volunteers for Aspartame Study

The study will not look at the safety of aspartame as that has been established, but will focus on people who have reported bad reactions. The pilot study will then inform a larger study that is being planned by the European Food Safety Authority and results should be published early in 2011.

The study appears to have been stimulated by anecdotal evidence. These are separate incidents which people have reported claiming a reaction to aspartame. Andrew Wedge, the FSA's chief scientist, said "Truly anecdotal evidence is not evidence in the scientific sense, it's observation, it's often subjective and the effects seen may be due to a number of factors all varying at the same time. Observation can help us towards understanding certain issues, but it is a first step towards a testable hypothesis, not an end in itself. Therefore, anecdotal reports do sometimes deserve closer examination, especially when a number of unrelated people are reporting similar things. As a science-based organisation, the Agency pays close attention to scientific evidence, but sometimes the anecdotal reports we receive are persistent enough to make us feel we need to take a closer look at people's concerns."

Aspartame is a sweetener to be avoided because of PKU (it is made from phenylalanine and aspartic acid) but it will be interesting to learn what becomes of this researchI'll let you know!

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