

NSPKU News & Views

The National Society for Phenylketonuria (UK) Ltd

Summer 08 – Issue 124

Inside this issue...

Editor's Report

Letters

The Best Christmas
Party Ever!

Donations

PKU Pronto!

Dietitian's Report

SHS Filled Tomatoes

Fate Blueberry
Muffins



Seamus Thomas,
Daniel Clough and
Annabel Skidmore
at this year's NSPKU
Conference

It's PKU Land!

www.nspku.org

In Touch

The Council of Management

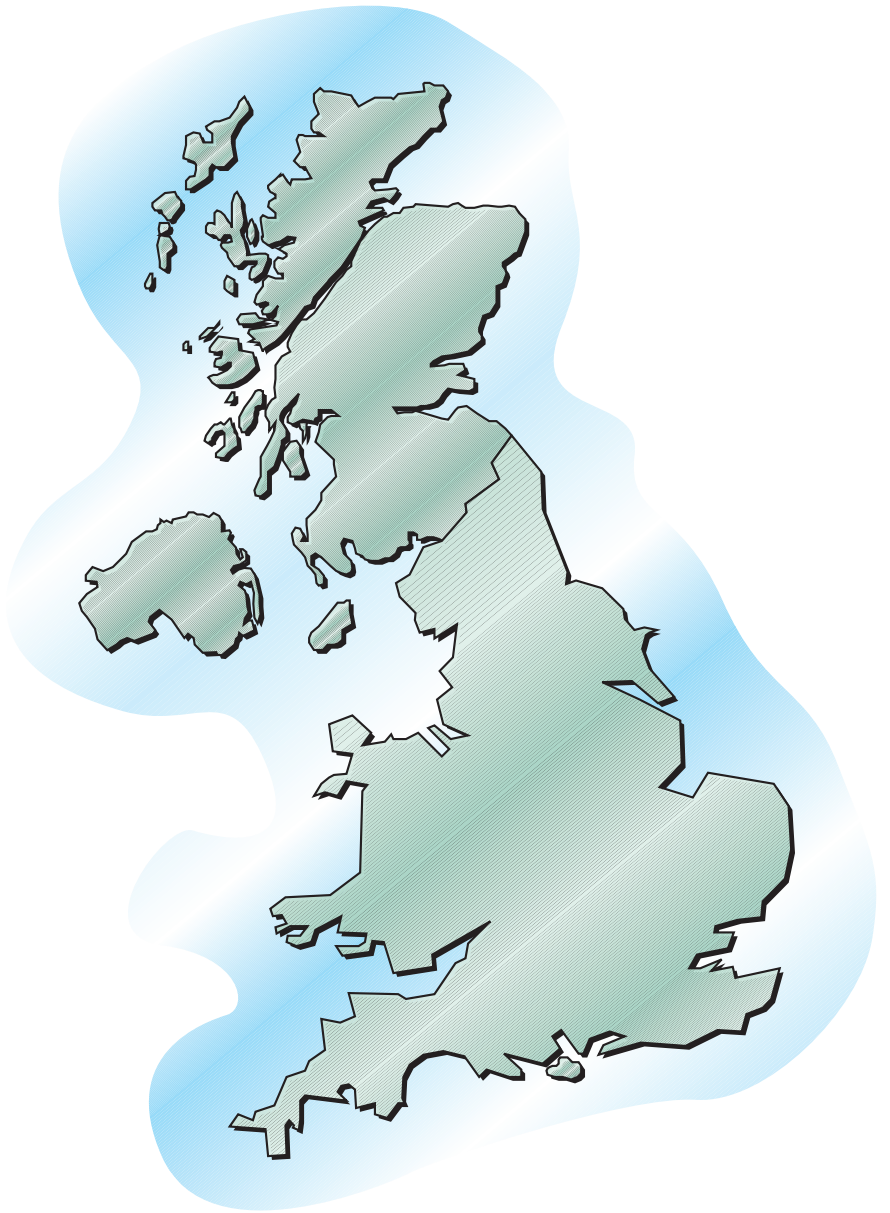
Telephone Helpline: 0208 364 3010

Recorded Information Line: 0207 099 7431

Address: PO Box 26642, London N14 4ZF

E-Mail: info@nspku.org

Internet: www.nspku.org



Contents

- | | | | |
|---|------------------------|----|--------------------------------|
| 1 | Editor's Report | 11 | PKU Pronto! |
| 2 | Treasurer's Report | 13 | Fate Blueberry Muffins Recipes |
| 3 | Donations | 14 | Dietitian's Report |
| 4 | Letters | 17 | SHS Filled Tomatoes Recipe |
| 5 | Yippee – it's PKU-Land | | |



Editor's Report...

Now that our children are a little older, we decided to stay for the full weekend at the NSPKU conference this year. What a good decision! The kids just loved it and Martin and I really enjoyed our weekend off from cooking and clearing up! The hotel was fabulous and even baby Fintan had his first splash in the beautiful pool. If there are any readers out there contemplating attendance at the conference next year – don't think just book! We met babies, kids and teenagers, mothers and fathers, untreated adults - all with PKU and all their families too. Every aspect of PKU life was represented and everyone was made to feel more than welcome.

Very importantly, a weekend stay in a hotel can be very expensive for anyone, especially families. So, please remember that the NSPKU subsidises the weekend for everyone and that there are funds available for those who can't afford that. Please, please ask for help if you need it. I know it can seem embarrassing to ask, but bear in mind that most families don't have the expense and stress that PKU can bring. The Society exists precisely for that reason, to help people with PKU and their families adjust to what can be a difficult way of life and the conference is a really important part of that assistance. By swallowing hard, asking for - absolutely confidential - financial aid and bringing your family to the conference, you're ensuring that, for example your daughter or son, sticks to their diet and has confidence in realising they're not alone. Now that was worth it, wasn't it?

If you need more convincing, Eleanor has written about the conference in more detail and Rebecca Munns has taken some lovely photos too. In this issue, we also have a lovely account of a PKU Christmas party from Aqsa Mahmood and Eleanor will have you ditching your bikini diet once you read her extensive list of PKU friendly sweets!

Finally, I'd like to thank Julia Bailey for all her work as Treasurer. She has worked very hard for the NSPKU and will continue to do so as Health and Safety Officer. In the meantime, Vicki King, whom you met a few issues back, will be taking over most of her duties as Julia explains in her report. Let's take this opportunity to thank all of those who volunteer at the NSPKU. I'm sure ours is not the only family who would find life with PKU much more difficult without the society's help. As it is, we have a healthy, happy boy with PKU who is involved in every aspect of school and social life. Well done the NSPKU!

Kiri Thomas
Editor

Cover Photo: Seamus Thomas, Daniel Clough and Annabel Skidmore at this year's NSPKU Conference

NSPKU
The National Society for Phenylketonuria (United Kingdom) Limited

Please address all correspondence to the
Editor, "News & Views",
10 Silverdale Road
Chorlton M21 0SH
Tel: 0161 4462396
Email: editor@nspku.org

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

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

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

Helpline: 0845 603 9136

Email: info@nspku.org
Web Site: www.nspku.org

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

Layout by **The Keystroke Mill**
www.keystrokemill.com
Tel: 01444 236035

Printed by **action**
Tel: 01444 236204

find
us
on
the
web
at:

www.nspku.org

Treasurer's Report...

This will be my last "Treasurer's" report for News and Views as I am in the process of handing over the bulk of my role to our extremely capable bookkeeper Vicki King. I decided a year ago that I wanted to step down from the role but the absence of a replacement made my escape difficult! Plan B was to smile very sweetly at Vicki and say "pleeeeeease" in my most charming manner. Fortunately that worked as plan C was to emigrate! Now that my workload has drastically diminished the role of Treasurer is under revision so watch this space....

I must say however that pleased (or more accurately relieved) as I am to be concentrating on the hopefully less taxing role of Health & Safety, I have thoroughly enjoyed my time as Treasurer. The role provided me with essential mental stimulation

in the years that I was an at home mum and I have learned so much over the last 8 years. My personal finances have improved considerably – don't panic! It's not because I've been embezzling! – but because of the knowledge I've gained over the years. And I hope that the Society has benefited in some way from my time in post.

Now to work! The audit has been done and the AGM is already a dim memory in the blur that was the conference. I am pleased to report another profitable year. Our investments have done amazingly well and donations remained at the same level as last year. Full details can be found in this issue.

Julia Bailey
Treasurer

Detailed Income and Expenditure Account for the year ended 31st October 2007

| | 2007 | | 2006 | |
|---------------------------------------|--------|----------------|--------|----------------|
| | £ | £ | £ | £ |
| INCOME | | | | |
| Membership fees | 10,578 | | 8,987 | |
| Donations and fundraising | 45,106 | | 41,631 | |
| Conference Income | 1,353 | | 677 | |
| Spring Draw | 7,196 | | 5,842 | |
| Bank and other interest received | 4,786 | | 3,308 | |
| Publications and videos | 4,217 | | 5,719 | |
| Advertising | 9,450 | | 14,400 | |
| Sponsorship | 20,450 | | 26,465 | |
| Outward Bound course | 3,945 | | 770 | |
| Other receipts | - | | - | |
| TOTAL INCOME | | 107,081 | | 107,799 |
| EXPENDITURE | | | | |
| Conference expenses | 7,954 | | 12,787 | |
| Spring Draw | 345 | | 809 | |
| Goods for fund-raising (net of stock) | 505 | | 5,703 | |
| Newsletter and publications | 19,302 | | 24,684 | |
| Telephone | 1,092 | | 1,286 | |
| Postage | 1,361 | | 1,626 | |
| Travelling expenses | 2,586 | | 1,894 | |
| Insurance | 1,847 | | 1,739 | |
| Stationery | 569 | | 835 | |
| Equipment and software | 170 | | 488 | |
| Depreciation | 319 | | 758 | |
| E Weetch fees | 15,330 | | 14,632 | |
| L Welch fees | 5,134 | | 4,252 | |
| Sundries | 30 | | 155 | |
| Committee meeting expenses | 4,736 | | 5,973 | |
| MAP meeting expenses | 629 | | 897 | |
| Advertising | 108 | | 175 | |
| ESPKU expenses | 1,214 | | 2,167 | |
| Sponsorship | 705 | | 2,112 | |
| Assisted Places | 576 | | | |
| Bank and finance charges | - | | 53 | |
| Outward Bound course | 6,270 | | 3,123 | |
| Audit | 1,410 | | 1,410 | |
| Membership Fees and Subscriptions | 523 | | 394 | |
| Research costs | 2,681 | | 623 | |
| Bookkeeping | 1,528 | | 971 | |
| TOTAL EXPENDITURE | | 76,924 | | 89,546 |
| SURPLUS OF INCOME | | 30,157 | | 18,253 |

THANKS TO OUR SPONSORS AND DONORS

We have once again been very fortunate with our sponsors and I would like to take this opportunity to give our thanks to:

SHS - who provided £16,000 to cover the costs of assisted places, the children's and teen's trips at last year's conference and for our ESPKU costs.

VitaFlo - who have provided a total of £6,000 towards the costs of Publications.

Our members have continued to be steady in their support this year and we would like to express our thanks to everyone who has supported the NSPKU throughout the year; especially to **Mary Cullen & Mallachy** who raised £5,000 in the Dublin City marathon; **Andover Golf Club**, the **Miskelly** and **Guest families** for their considerable donations and of course our own **Eric Lange** who once again ran the London marathon for us along with **Dave Williams** and **Allan Muir**. And last but by no means least those who provide us with regular donations by direct debit or workplace schemes.

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

Donations

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

| <i>Donations over £30 to end of March 2008</i> | £ |
|---|--------|
| Hart Common Pre School, Bolton | 559.40 |
| WAJ & EA Graham | 100.00 |
| Lady Carter | 30.00 |
| Hampshire Constabulary (Staff of Corporate Services Dept) | 47.74 |
| John and Marion Darby | 130.00 |
| Lloydspharmacy Charitable Trust (via Vicky Ellis) | 100.00 |
| Mirfield Parish Church Whist Drive Group | 40.00 |
| RK Reynolds, in memory of Julia Reynolds | 530.75 |
| Elliott French, in memory of his grandad, Dave Peters | 280.00 |

All PKFoods are now available on prescription

Chocolate Chip Cookies, Cinnamon Cookies, Orange Cookies, Flour Mix, Egg Replacer, Pasta Specials, White Sliced Bread, Crispbread, Cherry Jelly Mix, Orange Jelly Mix, Jammy Cookies, Jammy Biscuits, Jammy Ruskies

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



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.



Dear News and Views,

Please find enclosed a cheque for £150. This amount has been raised by my colleagues at my place of work as well as by family members. Each year, instead of sending each other Christmas cards, a different charity is nominated to receive funds donated by all who participate. This year one of my team nominated the NSPKU to receive some recognition. I would like to thank them through your magazine. My work collages know quite a bit about PKU now as I regularly tell them what it is like to have someone with this condition in the family, this person being my six year old daughter Alicia. I have enclosed a picture of Alicia enjoying Christmas. Keep up the good work that you do!

Regards
Amanda Jeyes.



Dear News and Views,

The Best Christmas Party Ever!

On Sunday 6th January 2008, I was invited to the 20th Anniversary Metabolic Christmas Party. The party was held at the Centennial Centre in Birmingham. The invitation said that we could go dressed up as our favourite character, so I went along dressed up as a fairy.



Soon it was time for tea, and what a mouth watering catering arrangement that was!...It was catered for each individual child's dietary requirement.



After everybody had eaten, we all went back into the hall with bags of goodies and balloons falling out of our hands, and then...the most important guest of the party arrived...yes, that's right, it was Father Christmas! The bags of presents that Father Christmas bought along with him were unbelievable. Everybody was so excited and couldn't wait for Father Christmas to call their names out so they could go up to get their presents!

I found it hard to wait myself. It was a good while before my name was called, but soon it was and I was really excited, my mum came along with me as I walked up to receive my present...I couldn't believe it when Father Christmas handed over my present to me, it was just the perfect end to a perfect day.

It was the best Christmas ever!!!!

by Aqsa Mahmood
Age: 5 Years



As I walked through the beautiful decorated entrance with snow falling, which gave a real Christmas experience, I was greeted by Alice in Wonderland and her friends who took my name and gave me a badge. Wow, what a reception I thought!

I lead the way up through to the doors to the hall entrance and just before I went in I had my photograph taken, this really made me feel like royalty. Then the moment

arrived when I walked through the doors and could not believe my eyes...all credit definitely goes to the organiser of this party...the one and only Anita MacDonald!!!

There were Disney characters left, right and centre, music playing and lots of people offering to do different things, like face painting, balloon making, mehndi, nail decorating - the list just went on. I, of course wanted to try everything, and so I did!



Yippee – it's PKU-Land

These were the excited words of a little boy coming into the hotel for the PKU conference. I thought it summed up the feeling of everyone at our annual weekend.



Seamus Thomas, Daniel Clough and Annabel Skidmore

The NSPKU conference is a time for the cook of the family to put his/her feet up and let someone else take over. What luxury! We had record attendance at the conference this year with nearly 90 with PKU and ages ranging from babies to those I used to refer to as 'young adults' but even they are getting older these days. We used to start the conference with a drinks reception attended by the local mayor and mayoress but we didn't do that this year. We really wanted the weekend to be informal and relaxing and nice as mayors and mayoresses are those chains are a bit intimidating so it was a bit like having a party with everyone you know there – no outsiders to have to be on best behaviour for tonight.



Non-stop chatter!



Small Group Discussions



Julia Bailey and friends



Everyone settling in!

The food is of major importance and the food companies are so generous and helpful in supplying all I ask for and in quantity. There's always food left but it does not go to waste – families happily set off home surrounded by boxes of bread, pasta, pot noodles...did we put the children in the car? The chef, Bob, and his team worked hard to produce some great menus. I try to incorporate as many of the newly prescribed foods as possible and families own recipes too. We had SHS's new lemon cake hot with lemon marmalade sauce, new breakfast cereals and pastas, Fate Chocolate

pudding with golden syrup sticky bottom, couscous from FirstPlay which is not much used in the UK but eaten by the ton in Europe, stripy jelly from PK Foods decorated with delicious fruits.....so much to try in PKU land. The menus for non-PKU were also excellent but the chef told me if we went again he would do more PKU food "it's the PKU weekend after all" he said.



Final Touches for the first of many gorgeous PKU and non-PKU meals

The talks had a psychology theme with Danuta Orlowska helping us to look after our mental health. She dislikes the phrases "positive and negative thinking" and prefers "helpful and unhelpful thought". She explained that some things may be totally beyond reason to be positive about for example you can't be positive about swimming the channel if you are not a good strong swimmer. We can give ourselves goals and targets but we have to be realistic too and not set ourselves up for failure. She described how unhelpful thoughts can set up vicious cycles in our heads and just because we have these thoughts does not mean they will happen. And, sometimes things do go wrong, but setbacks are normal.



Danuta Orlowska

Danuta recommended 2 books:

Manage your Mind: The Mental Fitness Guide by Gillian Butler and Tony Hope 2007 Oxford University Press. Price on Amazon about £7.

for children: The Optimistic Child: A Proven Program to Safeguard Children Against Depression and Build Lifelong Resilience by Martin Seligman (paperback – 17 Sept 2007)

Dr Peter Burgard from Germany also a psychologist made many really helpful and illustrated analogies for PKU living with life. I particularly liked the bank account comparison. You can't put something in without being aware you have to take it out and for a happy life we need to get the balance right. Blood levels are like this. Blood tests may cause temporary pain but Peter will ask the child if they go skateboarding or ride a bike or play football. Falling over is normal and usual and grazed knees are a consequence but does the child stop playing because of this little fall? The same with the blood test – a little pain, a big hug and off you go to play again.

Jo and Fiona O'Malley, brother and sister, gave a wonderful presentation of how support and small steps can change a life. Jo helped Fiona and himself to get their lives and bodies in better shape and they were so inspirational. The applause said it all.



Dr. Peter Burgard with Jo and Fiona O'Malley

Lesley Robertson presented the results of the Untreated PKU Trial and Carolyn and Janet who were involved in the trial came along to participate. It's been a huge amount of work but worth it with so much that is positive coming out of it.



Lesley Robertson

Dr Anita MacDonald, always looking at making life easier for everyone to manage the diet, talked about work she is undertaking to get low protein food delivered directly to homes. There are stories of wrong prescriptions, too many or too few items, no items, short shelf life and so on which can make getting prescribed food hard work. With Anita behind the scheme there will be change I'm sure.



*Anita
MacDonald*

On the practical side Barbara Cochrane, dietitian in Glasgow, organised workshops of what to do with vegetables and how to change a recipe. Everyone was asked to form a group of 6 or so but with no family members together. This was really so good for getting everyone to mix and talk about their own ways of doing things. We also ran a competition of guessing the number of protein exchanges on the plate (10 food items), weigh out an exchange of 3 foods and calculate the exchange from the protein label. Adults and children entered into this with great enthusiasm and Ann Daly, dietitian from Birmingham, helped us with it having done something similar in their clinic. The competition was marked and the winner announced but another year I think it would be more helpful for everyone to mark their own paper and for us to put out the correct answers by the food. Many people wanted to know how they had done and where they had miscalculated.



Eleanor Weetch and Barbara Cochrane



Dave Stening welcomes everyone to the conference



Still going strong

LOW PROTEIN MEAL SOLUTIONS

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,

sausages, 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.

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

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



Then there was the PKU fringe. Mona Taylor using SHS foods had made 150 cakes for the children (and adults) to decorate; hundreds of rabbit and chicken lollipops, shortbread butterflies and eggs to decorate and what imagination they all had. The cakes went into a pretty box all tied up with ribbons- there were some proud faces on that stand.

VitaFlo held a colouring competition and entries went into the treasure trunk or the princesses' castle for a prize and a tasting competition had a star prize of a Nintendo Wii.

Proud Go-Karters!

Not finished yet – there's the children's party with entertainer, outings off go-karting, disco, dancing, raffles and a quiet drink away from it all somewhere in the bar.

So it's over for another year but next year's plans are being made already.....can it keep on getting better?

Eleanor Weetch
NSPKU Dietitian



Fabulous Cake Decorating!

Eileen Green's theme was celebrations which went from crispy garlic ciabatta, oriental parcels with mint raita, aubergine rolls, machine donuts, birthday cake and sticky coffee toffee choc mocha pudding – what a name! What a pudding! Inspirational as always.



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

Vitaflo offer a reliable and trust-worthy
home delivery service called



We offer a worry free and reliable means of obtaining

your Vitaflo products.



The service is provided free of charge from Vitaflo.

For more information or to register with this service,



contact your dietitian or doctor

or contact Vitaflo on

0151 709 9020

All new
products now
available on
Homecare



Fresenius
Kabi

Working together to deliver a better service

PKU Pronto!

Pea pesto is a quick recipe that is nice and summery and, as suits this column, very quick to make. Our whole family eats this “pesto”, non-PKUs have it with normal pasta and parmesan cheese, PKUs have it with low protein pasta. One other idea; we went to a posh Christening once where all the children were being given crostini or toast spread with avocado. I spread this on low-protein toast for Seamus instead – he loved it! Follow my instructions for weighing the pesto as you must remember that peas are an exchange but it's not hard! Sprinkle a plate of this with sunblushed tomatoes and you have a visual treat that's as good as what's on offer in any posh restaurant.

Ingredients

1 x tablespoon garlic infused oil
(available in all supermarkets)
150g x frozen peas, weighed after cooking, reserve
a little of the cooking water
Squeeze of lemon juice
Handful fresh basil, if you have it
Salt and Pepper to taste.

Place all the ingredients in a liquidiser or food processor adding a little of the reserved cooking water if the mixture seems too dry. You are looking for a moist paste. Taste and add more lemon juice, garlic oil, salt or pepper too if you think it needs it.

Now, using a spatula, scrape out the food mixer and weigh the entire mixture. Divide this amount by 6 and this number equals the weight of one exchange of the pesto. For example, your pesto mixture might weigh 180 grams. 180 divided by 6 is 30 so 30g of your mixture would give you one

exchange. You divide by 6, because you have used 150g peas in the recipe and 150g of peas equal 6 exchanges. When you get used to this, you might use more or less peas depending on how much pesto you want so adjust your sums accordingly.

I use 1 or 2 exchanges of this for a child's portion and keep the rest in the fridge labelled with the exchange weight on it. You could also freeze it in an ice cube tray making sure each cube weighs the equivalent of one exchange. What a quick supper that would be!

I know this probably sounds complicated but honestly, the whole pesto can be made and weighed in the time it takes for the low-protein pasta to cook!

Kiri Thomas
Editor



Seamus enjoying his pea pesto at Café Thomas!"



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

This recipe is so easy to do, and makes 12 large beautiful muffins. Frozen blueberries tend to work better in this recipe, but you can use fresh ones. I often buy fresh ones when they are cheaper and plentiful and just keep them in the freezer until needed. I like to use the smallest berries that I can find as they seem to have more flavour, and they 'burst' when cooking giving the muffins a more fruity flavour.

I also use unsweetened pure orange or apple juice, (the kind you get in a carton) to give the muffins a soft, moist texture.

They are perfect for any time of day. Try them as part of your breakfast with coffee, pack them for lunch, or have them for pudding after dinner. They are delicious served hot or cold.

FATE BLUEBERRY MUFFINS

Ingredients

325g Fate Low Protein All-Purpose Mix
150g soft light brown sugar
1 tsp baking powder
120g soft margarine
240 mls pure orange or apple juice
180g blueberries

Pre-heat oven Gas 6, 200°C (400°F)



Method

Place the Fate All-Purpose Mix into a mixing bowl. Add the light brown soft sugar and baking powder. Stir.

Add the margarine and the orange or apple juice, and using a wire whisk, mix quickly for 1 minute until well blended and smooth.

Stir in the blueberries.

Divide the mixture between 12 large muffin paper cases set inside a muffin tin.

Bake in a pre-heated oven for 25 – 30 mins until risen and golden brown.

Place on a rack to cool.

The muffins freeze well.



Dietitian's Report

Ice Cream

Grandessa from Aldi Stores

Premium Strawberry-Sensation

This is a strawberry flavoured ice cream and strawberry flavoured yoghurt ice cream with strawberry swirl (and it has a long name too!)

The first few ingredients listed are all free items such as strawberry puree, sugar, lactose (a sugar found in milk but has no protein) glucose syrup and the ingredients which contain some protein come further down the list. Ingredients are always listed in descending order of amounts. The ice cream has some protein but because the main ingredients such as strawberry puree and sugar are low in protein the ice cream is also low in protein compared with other ice creams.



Protein 1.1g per 100g so
90g ice cream = 1 exchange

Mibod

The company Mibod Health Foods provide a strawberry and blueberry drink in a pouch and Gummy Bears for the health food market. They are promoted for their 'free from' sugar, artificial colours and flavours. They are presently only available from vending machines in museums and schools, not yet in supermarkets. However, Barbara McGovern found the bears in a shop called Home Bargains in Newcastle – a discount shop. The bears are protein free and the drink is also protein free. The company hope to launch in supermarkets and will have a stand at the NEC Food Show in Birmingham from April 6th to 9th.

Gummy Bears

Little Chewy Bears – FREE

Juicy Jel – prebiotic drink

Blueberry and Strawberry - FREE



Crisps and Crackers

Taj Brand Crisps

These cassava crisps can be found in Tesco in the foreign foods section, NOT the crisp section. There are 3 kinds of the crisps – Salted, Unsalted and Chilli and Lemon Flavour. The Taj company have now got some cassava sticks too and all of these mentioned are FREE. At the conference I put them out in bowls at the drinks' reception and they disappeared very quickly. The crisps are quite firm so they are really great with a salsa dip or mix mayonnaise with a little curry powder or paste or what about my favourite taste of the moment – sweet chilli dip?



ASDA Crispy Cracker Selection

These tapioca and cassava crackers are in the Good for you Range, being quite low in calories at 76 per bag. The flavours are Thai Style Sweet Chilli, Sun-Dried Tomato and Herb and Hickory Smoke Barbecue flavours. The protein contents are as follows:

| | |
|---------------------------------|--------------|
| Thai Sweet Chilli | 0.2g per bag |
| Hickory Smoke Barbecue Flavour | 0.2g per bag |
| Sun-Dried Tomato & Herb Flavour | 0.3g per bag |

They are **NOT FREE** because they do contain coconut milk powder, milk cream powder and wheat flour and the protein above is per bag not per 100g. An item can be allowed as a FREE food if the protein is 0.3g per 100g or less for sweets, crisps, puddings, sorbets. These

crisps fall into that rather awkward category of not being free but you would need a lot for a whole exchange.

Count them as 2 bags for ½ exchange

Chewing Gums

I am again grateful to Barbara McGovern for sending me a big selection of different chewing gums and bubble gums. Not so long ago there were virtually no chewing gums which did not contain aspartame but those days are gone!

Sainsbury's

Basics Sugar Free Whitening Chewing Gum. FREE

Marks and Spencers

Sugar Free fruit and mint chewing gums. Sweetened with sucralose. FREE

Leaf

Spaghetti Gum and Tubble Gum. Both of these gums are Free for the PKU diet. The Tubble Gum looks like a tube of toothpaste!



Roll up

This bubble gum comes in a little round tub and the gum is on a roll. I couldn't resist opening the tub up and yes, trying it. I am now sitting here like a real journalist thumping out the information and chewing away!

Also by Leaf but under the Red Band name

Chewy Mint Gums and Chewy Strawberry Gums – both sugar free and no protein so FREE in the diet.

And Sweet Enoughs are not really a gum but a chewy sweet in lemon and orange flavour. Also FREE.



Dietitian's Report continued...

Leaf Sweets

We are all familiar with Chewits in Orange, Strawberry, Blackcurrant, Fruit Salad and Extremely Sour Apple but the company do quite a number of other sweets which are FREE.

On the plate are:

- Sugar Coated Strawberries
- Sour Watermelons
- Mint Fondants
- Crazy Faces
- Fruitinettes.



All of these have a protein content of less than 0.3g per 100g so they do not have to be counted.

Well I had to try these too of course! Writing my section this time has been really fun for me..... wonder what treats I can find for next time (with your help of course).

Edale Outdoor Activity Weekend

The outdoor activity weekend is taking place again this summer from **July 18th-20th**. I've had a lot of enquiries and it is always popular, many asking to come back for the third time. The age range is from 9 to 13 years, boys and girls.

Cost is £78.50 per child which is half of the true cost as the NSPKU subsidises the weekend. We are very keen that children with PKU have the opportunity to come to this active and fun holiday and we can help with costs for those who need it.

Please contact me about a place for your child as soon as possible. Your child will learn a lot and most importantly have a lot of fun too.

Eleanor Weetch
Dietitian

A few words from our Conference Photographer, Rebecca Munns!

Being a teenager having PKU can be quite challenging as I struggle with getting my levels right. That can be hard. However, I wouldn't change it for the world!

I like having PKU as I've met lots of friends through having it. Also, I am individual in my school because I am the only person there that has PKU! I especially love the conferences because I get to see my friends and I get to try new PKU foods or substitutes.

I found that taking images for the News & Views was a brilliant experience as I got to feel what it would be like to be a real photographer. I took photography for my GCSE's as I love taking pictures in my spare time and it is a hobby as well as a subject at school.

Filled Tomatoes

Ingredients:

2 large tomatoes (approx 250g/10oz)
65g (2 ½ oz) parsnip, coarsely grated
25g (1oz) butter
Finely grated rind ½ lemon
Large pinch dried mixed herbs
Salt and pepper, to taste
25g (1oz) Loprofin Low Protein Herb Crackers,
finely crushed

Oven temperature:

200°C/400°F/Gas Mark 6

Method:

1. Slice the tops off the tomatoes and carefully scoop out the pulp, seeds and juice. Chop the pulp, reserve the juice and discard the seeds.
2. Fry the grated parsnip in the butter, for 4 minutes, over a moderate heat, covered. Stir in the tomato pulp, lemon rind, herb's, seasoning and 3 ½ x 15mlsp (3 ½ tbsp.) herb cracker crumbs. Reheat for 1-2 minutes, stirring.
3. Divide the filling between the tomato shells, packing the mixture well into the cavities.
4. Place the filled tomatoes in a shallow ovenproof dish and pour 2 x 5mlsp(2tsp) tomato juice over each, sprinkle the remaining herb cracker crumbs over the filled tomatoes.
5. Bake in a preheated oven for 15-20 minutes, until the tomato shells are just tender. Serve hot with Loprofin pasta.

Serves 1

For more great tasting recipes, visit

www.lowproteinliving.co.uk

Yes We Cook That.com

Specialist Dietary Foods

Freshly prepared PKU ready meals

Available near you*

Would you like...

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

Yes We Cook That!

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

Yes We Cook That!

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

Yes We Cook That!

To have all this at Supermarket prices?

Yes... it is!

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

Yes... we do!

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

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

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

*Available now in most of the UK and Ireland.

Phone Leanora or Pauline on 07773 342594

24 hour answering machine 01290 332 949

e-mail sales@yeswecookthat.com

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



SHS Homeward
... delivered direct to your door

The one-stop-shop

We have now made it even easier to get hold of your favourite SHS low protein foods



SHS Homeward provides a home delivery service for all your SHS metabolic products including low protein foods. There are no tie-ins, no minimum contract and it is available now, completely free of charge.

- You no longer need to make time to visit the chemist to pick up large orders. We will deliver your amino acid substitute and your low protein foods directly to your door.
- We will contact your GP directly and manage the monthly pick-up of prescriptions for your all your SHS products.
- Your order will arrive on a scheduled day each month to the location of your choice.

For further information contact the Co-ordination Team on:

08457 623 605

A full list of the products available can be found at:

www.lowproteinliving.co.uk

SHS Homeward
... delivered direct to your door

This service is available in Northern Ireland