NSPKU News&Views
The National Society for Phenylketonuria (UK) Ltd
Issue 117

Inside this issue...

Editor's Report

Letters

Doug's Holiday

A Friend In Need

Buying and Selling for PKU!

Springboard Firewalk

PKU Pronto!

Dietitian's Report

Fate Samosas

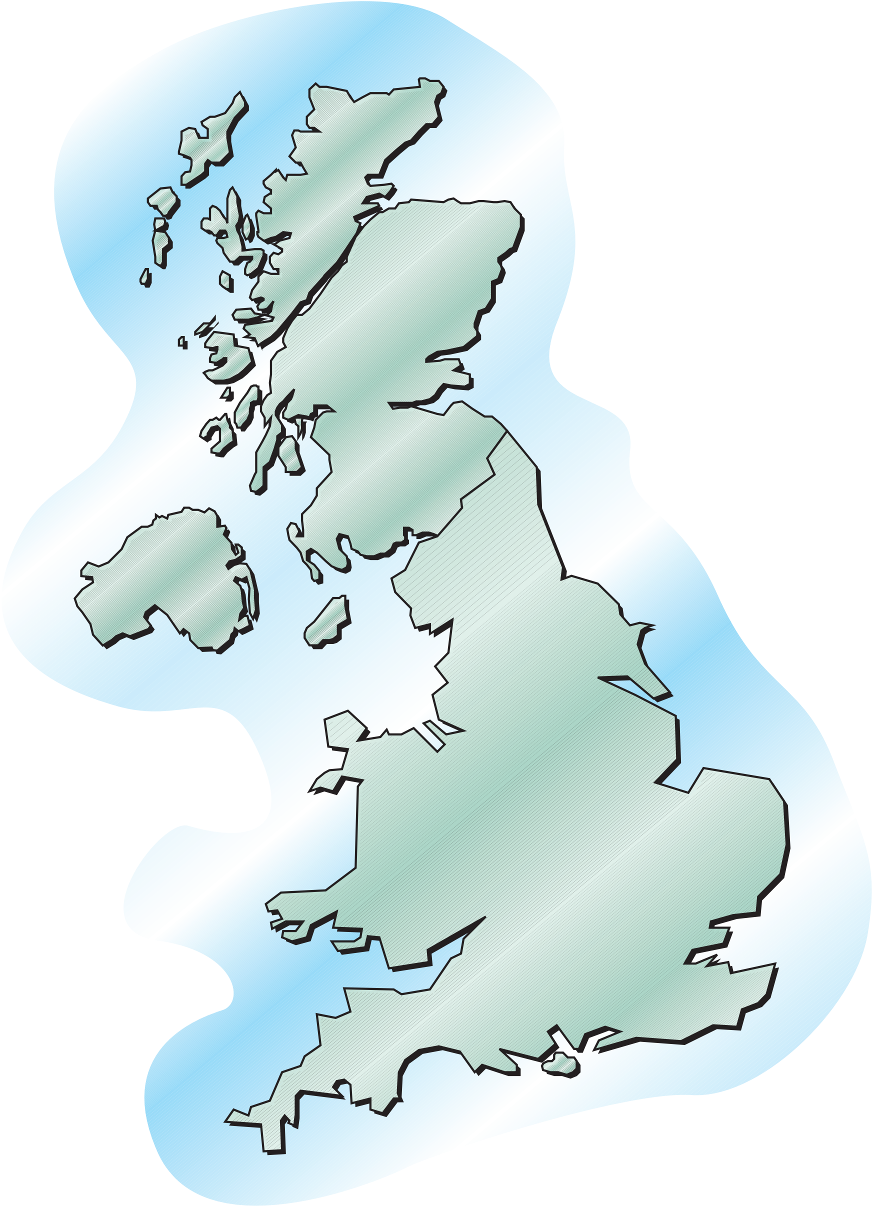
PKU in the Sun – a warming story for the winter months

HELPLINE 0208 364 3010

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

2 Treasurer's Report

Donations

3 Letters

5 Support Groups

6 Doug's Holiday

8 Springboard Firewalk

Buying and Selling for PKU!

9 A Friend In Need

10 'I'm a Helper'
'Get Me out of Here!'

11 PKU Pronto!

13 Fate Special Foods Recipes – Samosas

15 Dietitian's Report

Editor's Report...

It's the jolly season again! I must say, I absolutely adore Christmas and don't have a lot of truck with the Scrooges of this world. Whatever age you are, whatever religion, I think Christmas is a great opportunity to take a complete break from work and hang out with our families and friends. I cannot say I am averse to a present or two, but it's the parties and special meals with relatives that make Christmas for me.

Having said that, for anyone with dietary restrictions, Christmas, Diwali or any big celebration can be difficult. In PKU Pronto, I offer one small party solution in the form of a dip that is as delicious as it is protein-free! For our 5 year old son, PKU is really not a hardship, at the moment at least, as he's never known any other way of eating. I do feel for those PKUs who have spent time off diet and then for whatever reason need to go back on it. The pre-conception diet is especially strict and of course especially important. In this edition, we have an article about 2 women with PKU babies who, through a support group in Essex, met up and became best friends. Wouldn't it be lovely if some women on the pre-conception diet could also meet and talk about the highs and lows of trying for a baby whilst keeping phenylalanine levels super-low? If you don't have a support group near you, you can always send a letter in to us, we'll publish it and try and get a response. In fact, to get the ball rolling, Heidi from Wiltshire who is on a pre-conception diet, has contacted us about meeting other PKU families. Read her notice in the Support Group section.

A summer holiday story may not be very seasonal, but I think you'll find your heart well-warmed after reading about Douglas Perry's trip away earlier in the year. Douglas, who has untreated PKU, was able to go on this trip only because of the help his carers, Lee and Frank, provided. At this time of year, it's worth remembering all those fabulous carers who do far more than what is required for their untreated PKU clients. It's good to see too that even with numerous disabilities, Douglas has the spirit to get a kick out of his vacation, just like anyone else!

Whatever you get up to these winter holidays, make sure you have a wonderful time and see you at the conference!

Kiri Thomas
Editor

NSPKU
The National Society for Phenylketonuria (United Kingdom) Limited

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

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

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find us on the web at: www.nspku.org

Treasurer's Report...

I can't believe it's year end again, where does the time go….the kids are well into the new school year, Christmas adverts have started on the telly and the auditor is pestering me about the accounts, the only good thing about this time of year is that I got an extra hour in bed this morning!

It's been a quiet few months for me, nothing particularly exciting to report. I have started looking at some on-line fundraising ideas. My new home page is everyclick.com (hopefully you'll be able to find out more in this issue) with the amount of surfing I seem to do I think I may single handedly fund the NSPKU next year!!

Keep an eye out for information in this issue on where you should be sending your payments, it's all change again I'm afraid. Our book-keeper Vicki King is now taking over the administration of donations so if you're thinking of sending us some money you can find her address on the inside cover. If in doubt as to where to send money contact me and I'll point you in the right direction (Eleanor regularly does….I think it's because she's blonde!)

Julia Bailey
Treasurer

Where do I send my money?

Confused? Then read on......

Vicki King
Donations
Invoice Payments
Miscellaneous payments

Lucy Welch
Publications payments

Mike Bailey
Merchandise payments

Please make all cheques payable to: NSPKU

All addresses and phone numbers available on inside page.

Donations

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

Donations over £30 from 1st July to 30th September	£
Neil Wilton	1,476
CSO Apache (Technip Offshore UK Ltd.)	900
Ann & Tony Fowler	810
Diana Murphy	310
Kiri Thomas	100
DML Running Club via Cathy & Iain Darby	86
Cathy & Iain Darby	321.50
Mr J. Morgan	77
Anne-Marie Naylor	250
Legal & General Assurance	2,125
(Brings total to date to £5,917.17)	
Mrs Ann Richards	335
John & Sharon Skidmore	1,024
Mr & Mrs RA Woodall	510
In memoriam:	
In memory of Albert 'Rod' Walkman	250
In memory of Violet Mold	625

Donations to.

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

If you are sending a donation or a subscription payment please send it to:
NSPKU, PO Box 26642, London N14 4ZF

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

Please send only cheques or postal orders
NOT CASH

Letters

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

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

Dear N&V,
We are very pleased to be able to enclose a cheque for £20.

Our eldest daughter Page (non PKU) attends 1st Birchington Rainbow Unit. The girls held a talent show earlier in the year. Not only did they put on a fine display of singing, dancing and piano playing, they also raised £60 for charity. The children wanted the money to be shared between three different charities, one of which is the NSPKU.

Our youngest daughter Emily is 22 months old and has PKU, so we are very pleased that this was one of their chosen charities.

Yours,
Mr and Mrs Burne.

Page and her Rainbow Unit

Dear N&V,
Please find enclosed a cheque for the sum of £2,000 for the NSPKU. This has been donated by the Andover Golf Club.

My brother Dickie White is this year's captain and his chosen charity is the NSPKU. Over the year, Dickie has organised certain charity events at the Golf Club and all donations received have been split between his and the Lady Captain's charity.

Enclosed is a photograph of Dickie and Vodaphone representative, Mrs. Cindy Blannin who presented the cheque on behalf of Vodaphone (Newbury) UK Foundation.

Dickie's year as captain finishes in December, so hopefully there will be another cheque for the NSPKU at the end of the year. Dickie's nephew Jamie has PKU and that is why he chose the NSPKU as his charity.

Yours,
Angela Haick and Dickie White.

Dear N&V,
Please find enclosed cheques for the NSPKU which total £335.

My husband's parents, Marjorie and Terry Richards had a party recently to celebrate a 60th birthday and also their Ruby Wedding Anniversary.

Instead of gifts, they requested that donations be made to the NSPKU instead as our youngest daughter Hollie, has PKU. A big thank you to Marjorie and Terry and to all those who made donations.

The enclosed photograph is of Marjorie, Terry our daughters Libby (6), Hollie (2), myself and my husband.

Regards,
Mrs. Richards.

The Richards family celebrating together

Dear N&V,
We are delighted to once again be able to send a cheque to you. This time it is as a result of our golden wedding party where we asked our guests if they would donate to the NSPKU instead of giving us presents. We raised £510.00.
Our grand daughter, Nicola Bramley, has benefited in many ways from the NSPKU as have other adults and children. We have watched the charity grow and go from strength to strength over the last 12

Letters

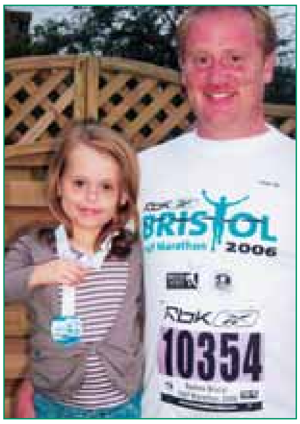
News & Views, 4 Kenilworth Avenue, West Didsbury M20 2LJ
Email: editor@nspku.org

years and, like many others, are grateful for the work they do.

Regards
Barbara & Roy Woodall

The Woodalls celebrate 50 years together

Dear N&V,



Madeline and her Dad Neil after his run

My name is Madeline Bryant and I am 6 years old and I am very special because I have PKU. My Daddy loves me so much that last year he decided to train to run the Bristol Half Marathon to raise money to try and help doctors to get me and other children better. Please find enclosed a cheque for £217.50 which is half of the money my Daddy raised. My Daddy's company Exel Logistics have offered to match his sponsorship and double the figure to £435.00. I have enclosed a photograph of me with my Daddy and his medal after he had finished the race. I would love it if you could put this in the News and Views Magazine with a little note to thank Daddy for me and tell him that I love him too. I hope this money helps some of the children with PKU to get better or eat some more different food.

I love reading News and Views and hope to see my Daddy's picture in there soon – I am so proud of him.

Thank you very much,
Madeline Bryant.

Dear N&V,

I cycled the 102 mile distance from Redcar to Rotheram, raising £240 for the NSPKU. The journey took 7 ½ hours and while the weather was warm at first, my arrival in Doncaster was greeted with a downpour of rain!

I'd like to thank everyone who sponsored me, it is very much appreciated.

Mick Clarke

Mick and friend at the finish

SUPPORT GROUPS...

Hello from Swindon, Wiltshire!

My name is Heidi Sudworth and I am PKU aged 25 on a pre conception diet, I also have a 14yr old sister Hannah Edwards also on PKU diet. My mum and Dad are Miriam and Eric Edwards. I have 2 non-PKU brothers.

My mum and I would like to hear from anyone from Swindon and surrounding districts in Wiltshire that are PKU or are related to a person with PKU and who would like to meet up. We'd like to discuss the possibility of starting a support group in Swindon for PKU families. If anyone is interested please either write an email to **heidikat4@yahoo.co.uk** or telephone (01793) 522272 after 7pm.

Doug’s Holiday

There are lots of people out there with untreated PKU and it’s delightful to hear that with help from some dedicated carers, they’re enjoying life, inborn error of metabolism or not! Here’s a sunny story to warm us up this wintertime!

My name is Lee Ward and I work in a registered care home near Reading in Berkshire where we support 6 gentlemen with various learning disabilities. One of the men we support is Douglas Perry, who is now 37 years old. Douglas has PKU which was unfortunately diagnosed late.

Frank Cullenaine and I have worked at the home where Douglas has lived for a number of years and we have seen Douglas through some very difficult times. At present Douglas is really well in a sociable mood and his diet is stable. He is on 30 exchanges a day.

Douglas has recently returned from a holiday to Majorca and we would like to share his good news story with you.

Frank, Douglas and I started the journey on Mon 18th September when we went and stayed in a hotel near Gatwick. We had a couple of drinks in the bar and something to eat before getting an early night. The flight was 0700 the next morning and we felt that if we stayed near the airport Douglas would get a bit more sleep and cope with the journey better.

We got up at the crack of dawn and went to the airport and because of Dougie’s disabilities we went to the front of the queue to check in. The staff at Gatwick airport were very helpful, getting us a buggy to take us down to the departure gate and getting us on the plane first. This was Douglas’s first time on an aeroplane and we did not know how he would react, but once the engine started Douglas started making happy purring noises and looking out of the window. When breakfast arrived Douglas did not miss out. We took his breakfast on the plane with us, (the article in the NSPKU News & Views Issue 116 “ Going on holiday with a PKU child” came in useful).

It was a 2 hour flight and 1 hour transfer time from Palma airport. We received the same care at Palma that we received in Gatwick and the journey went without a hiccup. Douglas coped extremely well and seemed to enjoy the travelling. We arrived at the apartment around 12.00 (Spanish time) and Douglas soon familiarised himself with the layout of the apartment but after a coffee, decided it was time to catch up on some sleep! When Douglas woke up we went out for a meal and did some exploring of the complex and surrounding areas. Douglas soon let us know when he had had enough and wanted to go back to the apartment and we worked to Dougie’s pace.

The following day we went a little further afield and caught the bus to the next village. Douglas managed to eat one meal out each day and we cooked his own food the rest of the time. We made sure that we took free snacks with us when we went out so that he did not feel as though he was missing out. Douglas wanted naps during the day and did not want to stay out for any longer than 3 hours at any one time, so we decided that it would be better not to go on any of the organised trips and to let Douglas set the pace for his holiday.

On the second day we were sitting out on the patio and Douglas decided that it was too hot for him. He went to go into the lounge, on his way in he seemed to stumble. Frank shot up thinking that he was going to save Douglas from a fall, but Douglas sat down on the sofa and Frank tripped and fell chipping a bone in his foot! Frank was unable to walk so we ended up hiring a wheelchair for him. Douglas and I spent the rest of the holiday pushing Frank around in this. We did not let this affect the holiday and we found that Douglas was able to walk better by pushing the wheelchair. We went on walks every day exploring different local areas. We went on the beach, to the old town of Alcudia and in the evening watched various live shows at the different hotels in the area.

Majorca is an ideal place to visit if anyone has walking difficulties like Douglas as it is very flat. The manager at First Choice travel agents spent lots of time with us making sure that the destination met Douglas’s requirements and, despite Frank’s accident, the holiday was a great success. It was so nice to see Douglas enjoying new experiences and constantly smiling.

Douglas was diagnosed with PKU

late and as a result of this he has many physical and mental disabilities including tunnel vision, deafness, learning disability, non-verbal communication and walks on his toes. His mental health has suffered and Douglas has spent many hours in his room, not wanting to go out at all. If Douglas did venture out it would be for his meals and on a good day may be (with much persuasion) to go for a quick drive. On bad days Douglas would self-harm to the point of being hospitalised. The last time this happened was 2 years ago which resulted in Douglas having his medication changed, I am pleased to say that since this change Douglas has been getting better and better by the day.

He is now asking to go out to different places on a daily basis and his quality of life has improved tremendously. We are still aware that Douglas needs to do things at his own pace and that there is always a chance that he could go back to his old ways, but while Douglas is in this great frame of mind we are making the most of each day and Douglas never ceases to amaze us with what he will do next. Anyone knowing Douglas would appreciate what a major event going on holiday to Majorca has been.

Douglas has excelled all our expectations and is now living his life to the full.

Lee Ward 2006

A thank you message from Douglas's parents:
George and I were delighted with the success of this adventure and greatly appreciate Lee and Frank's dedication to our son and their courage in taking Douglas on this holiday in Majorca.

Those who are founder members of The NSPKU Society may perhaps remember Douglas as a small boy at the first Annual Conference held at Blackpool in April 1974. He looked like an angel with his blue eyes and golden curls but he was a lively handful!

Amy Perry
October 2006

Springboard Firewalk

As you know, we're keen on fundraising here at the NSPKU. Well, Claire Hawkins found a very unusual method of raising money when she literally walked on fire earlier this year! This time, she didn't donate the money to us but to another worthy charity but perhaps there's someone out there who's been inspired by her bravery and would like the NSPKU benefit….!

Claire talks here too about the positive influence PKU has had on her life and it's uplifting I'm sure you'll find.

"I decided to take part in this fundraising event after being talked in to it by two work colleagues! However it was a great event, drawing quite a crowd on the night! We went to a two hour motivational workshop beforehand to master the 'fear!' It was great fun and gave you a real buzz after to know you had just walked over hot coals as well as being able to raise money for Springboard in the process!

'Springboard for Children is a literacy charity providing vital support and specialist literacy teaching to children in the inner city. I began my time at Springboard volunteering first and then was employed by the charity after gaining my Diploma in teaching children with specific learning difficulties. After 7 fantastic years, I am as of September hopefully moving on to pursue a long term desire to train to be a speech and language therapist! It is with mixed feelings I leave Springboard but know this is the right next step.

I think having PKU has enabled me to empathise with the children I teach when they are struggling to grasp a new concept or becoming frustrated about the difficulties they have in literacy and the need to persevere through it all. PKU has taught me to persevere in many ways and never give up! Finishing at Springboard at the firewalk event was a great opportunity to give something back to the charity. I hope this will benefit many the children and families with whom we come into contact in our work, both now and in the future!"

Buying and Selling for PKU!

Celebrating PKU was the theme running through the 7th annual charity day held in Normanton, West Yorkshire on Saturday 19th August with over 100 people attending throughout the day.

People with PKU, their families, friends, neighbours and visitors attended the event. Refreshments were provided for everyone, before they visited the "market place" where charity stalls offered fresh flowers, plants, nail painting, cakes, play your cards right, books, toys, posters, tombola, and even a children's entertainer. Food and drink were plentiful throughout the day and the weather held mostly fine despite all odds.

The day also raises awareness of PKU and helps families by "getting together" and sharing experiences on this special occasion.

Eleanor Weetch made another special appearance and even managed to have her nails manicured! Joanne Wildgoose, Leeds Dietitian, the Deputy Mayor and Mayoress from the City of Wakefield Council were also in attendance. It was also great to see Joanne Savage, Graham and Daniel who travelled up from Cambridge for the day.

A Grand Raffle was also held with 14 lucky prize winners were announced. Businesses and friends generously donated prizes.

Brisk trade was experienced throughout the day and there was a great atmosphere with everyone having an enjoyable time meeting new and old friends and renewing acquaintances at this annual event. A magnificent £1,010 was raised from all the fundraising and generous donations received in aid of NSPKU.

The Skidmore family

A Friend In Need

When their newborn babies were both diagnosed with a rare health condition, these two Mums met through a support group and became best friends.

Adam was diagnosed with Phenylketonuria (PKU) at two weeks old. It's caused by a build-up of protein in the blood and if left untreated can cause brain damage. He had a routine heel prick test and a week later, we got a call from Great Ormond Street asking us to go in to determine if he had the condition. To be told there was something wrong with him was devastating.
Emma, 28, Mum to Adam, 27 months

PKU is a rare condition; only 60 children in the UK are born with it each year. The only way to treat it is with a strict low-protein diet, which consists mainly of fruit and veg. It was terrifying to be told my baby had something so rare and that the chances of meeting a baby that also has PKU were small.
Tracey 41, Mum to Robert, 26 months

After diagnosis, I contacted my support group in Essex. They put me in touch with Tracey whose baby had just been diagnosed too so I called her.
Emma

I was pleased when Emma got in touch. We spent a long time chatting about PKU because there was no one else who really understood. We met up 4 months later though neither of us had a clue what the other looked like. We both hovered around looking for someone else with a buggy and a newborn, until we clocked each other.
Tracey

We were nervous and it felt strange at first as we sat there feeding our babies, talking about PKU and trying to get to know each other.
Emma

The support we get from each other is huge. We meet up once a week and talk on the phone every day. Adam is three weeks older than Robert and they're almost like brothers.
Tracey

It would have been a real struggle to go through it alone and we've come to rely on each other. We have to make the food from scratch with special PKU ingredients on prescription. Tracey and I swap recipes and when we make batches we give each other half.
Emma

Adam and Emma, his Mummy

We both have really close supportive families but it's so nice to have someone who totally understands how you feel.
Tracey

It can be difficult explaining why it's vital Adam sticks to his diet. If he eats something that's bad for him, I can call Tracey for reassurance.
Emma

We have known each other for two years now but it feels like a lifetime. We became close very quickly and Emma is like a sister to me. I feel emotional thinking about how frightened we were in the early days.
Tracey

You hear the words brain damage and that's all you can think about. We have to make sure that the boys grow up healthy by controlling what they eat. If we don't feed them correctly, they'll suffer. It's a responsibility but it's good to have Tracey there for support.
Emma

My husband and I went away recently and Emma looked after Robbie. I couldn't have asked my family as the diet is too demanding. She takes care of him sometimes while I'm at work and Adam loves being around his best friend.
Emma

Our husbands get on so we often meet up and have even spent Christmas Eve together. There's a one in four chance that if either of us has another baby it will be born with PKU. If this is the case, we'll know what to expect. Ours is definitely a friendship for life.
Emma

Robbie and Tracy, his Mummy

This article first appeared in ***Mother and baby Magazine*** *May 2006. The author was* ***Elin Tough.***

‘I’m a helper’ ‘Get me out of here!’

Anne Daly may not have eaten questionable kangaroo organs, but she and her posse had a challenging – and fun – time in Edale this year!

Taking 20 children minus parents on an outward bound trip in the middle of Derbyshire was one of our many challenges. The venue is Edale: a beautiful spot in the midst of the Derbyshire hills. It is so remote that not even our ever reliable ‘SAT NAV’ believed this place existed. However, after an hour or so of having a little detour (well in all honesty we were well and truly lost), the normal tranquillity of this little country village was soon replaced by the noise of screaming children and helpers as they tried the various perilous outward bound challenges.

The weekend began on Friday afternoon for this group of children with PKU who were all determined to have a great time. Some children knew each other before they arrived; some were meeting new friends with PKU for the very first time. The amount of energy and boundless enthusiasm was immeasurable. Initially activities were based around the Youth Hostel - with group - based team building tasks which enabled children to get to know each other really well. The end of the day even ended with a three legged fact finding mission which had to be seen to be believed!

What seemed like only a few hours later and no sleep at all, we were dragged from our beds to have a new day full of non-stop activities including rock climbing, raft building and canoeing. On a very hot weekend day in July, even the muddy grey colour of the local tarn appeared like the most beautiful lake in the world when we all paddled in the cool water. After a delicious low protein tea, all prepared by the Edale resident chef and his team, we were out doors again for more climbing and balancing on the assault course before finally experiencing a little archery. The end of the day finished with a head count to make sure that we had not lost anybody, protein substitute time and this year we had a Birthday celebration and smoothie bar (non alcoholic of course!)

Although by Sunday our batteries were running low, the weekend pinnacle was yet to come with abseiling over a very large bridge. After much reassurance that we really, really could not fall, the children were slowly lowered over the bridge, only to get to the bottom and want to do it all again!

The weekend was truly a challenge in so many ways. Not only were so many fears conquered with style, the children had to be independent and take care of their own phenylalanine exchanges and protein substitute – with just a little help from the NSPKU helpers. Counting and weighing out their own exchanges, make up their protein substitute, drinking last drops, scraping protein substitute bowls, and trying new low protein foods soon became the order of the day. Many managed to take their own protein substitute without complaining once and arguably some took it in record time. Perhaps it should be Edale all year!

We had even one more challenge this year. One of our young charges broke her leg pre-Edale but still joined in with all the fun despite leg in plaster cast and all its trappings. Doing a three legged race with a wheelchair adds a new dimension to life. This young lady was determined to enjoy herself and it just demonstrated that nothing was impossible.

Special thanks to the Edale staff, who were exemplary: always patient and very reassuring. The resident chef did marvels with the food and the low protein pancakes and syrup disappeared in seconds. Edale was very much the land of no mobiles and fresh air, but so much was achieved in so little time and we now have another 12 months to recharge our batteries before the next weekend event.

EDALE 2007 July 13th to 15th
Contact Eleanor Weetch for a provisional place.

The NSPKU would like to express their thanks to the Darent Valley Round Table who raised £1500 towards this trip - a sum which almost covered all our costs. We are very grateful.

PKU Pronto!

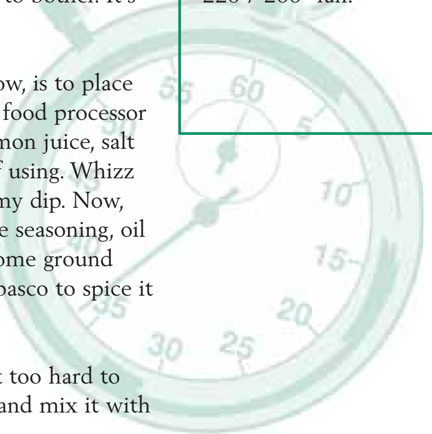
I'm a great lover of savoury snacks so I must say I really feel for those PKU women newly on the pre-conception diet who have to forgo protein-heavy dips like hoummous and tarasmalata. It's bad enough having to watch everyone down ice-cold beer whilst you sip tap water, never mind having to make do with carrot sticks as they gorge on cheesey morsels and crisps. Well, I've got something that to me, tastes not like a substitute, but instead a moreish, garlicky, delectable dish in itself. It's a Middle Eastern aubergine dip called ***baba ghanoush*** and it's lovely with sticks of "free" vegetables, fingers of low-protein toast or indeed, if you have some exchanges left, with crisps. It's easy to make and lasts for a few weeks in the fridge. We've had it in sandwiches instead of mayonnaise too and it was a hit for all our family, PKU or not. So whether you're a pregnant PKU woman who's just back on diet, or just a peckish person, I think this recipe will come in very handy.

Baba Ghanoush

Ingredients:
1 aubergine,
Juice of ½ a lemon
2 cloves garlic, crushed
2 tablespoons olive oil
Salt and pepper
2 tablespoons fresh coriander leaves, optional
Pre-heat the oven to 220°/ 200° fan.

Method:
Place the aubergine on the racks of the oven, allowing any juices to collect underneath. If you put the aubergine on a tray it will steam instead of roasting. Leave for about 30 mins until the skin is wrinkly and brownish, and the inside is soft when pierced with a knife.

Remove from oven and allow to cool until you can handle it. Cut off the calyx at the top. This is the stalk bit along with the leaves. Peel off the skin and discard it. Roughly chop the flesh. Now, you should really put the chopped aubergine in a sieve over a bowl to squeeze out excess juices but I have to admit, I'm quite lazy and don't tend to bother. It's up to you.



Either way, the easiest thing to do now, is to place the aubergine in the small bowl of a food processor along with the crushed garlic, the lemon juice, salt and pepper, olive oil and coriander if using. Whizz everything until you've made a creamy dip. Now, taste it and see if you'd like any more seasoning, oil or lemon juice. You could also add some ground cumin if you like or indeed some Tabasco to spice it up. Experiment and see.

If you don't have a processor, it's not too hard to simply mash up the aubergine flesh and mix it with the other ingredients.

Kiri Thomas

Fate Special Foods recipes

Hello,
This recipe is for the little triangular shaped pastry parcels which have become very popular. They can be filled with any vegetables and seasoned with any spices or herbs that are allowed. Here I have used a simple mixture of cooked sweet potato and onion, lightly flavoured with madras curry powder. They are very easy to make, and are delicious. The recipe makes about 8.

FATE SAMOSAS

Pastry~
150g Fate All-Purpose Mix
½ tsp salt
50g hard margarine
½ tsp baking powder
80mls water
Filling~
150g diced sweet potato, boiled until tender.
50g finely chopped onion
salt and pepper
1-2 tsp Madras curry powder, or other allowed spice mixture
Oil for frying

First make the pastry~
Place the Fate All-Purpose Mix and salt into a bowl. Rub in the margarine until the mixture resembles fine breadcrumbs. Stir in the baking powder. Make a well in the centre and pour in the water. Use a metal spoon to mix it until it forms a dough. Leave it to rest for a couple of minutes.

To prepare the filling~
Place the diced sweet potato (it must be cooled) into a bowl and add the onion. Season with salt and pepper and stir in the curry powder.

To prepare the Samosas~
Take the pastry and knead it lightly just a couple of times, on a surface dusted with extra All-Purpose Mix. Roll it out and cut it into large circles about 6 - 8 ins in diameter. (Use a small plate to cut around or use a saucepan lid)
Cut each circle in half.
Take one half circle of pastry and moisten the straight edge with a little water.
Fold the pastry to form a triangular pocket, overlapping the edge slightly. Press the moistened edge well to seal. Open the end and place about 2tsp of filling inside.
Moisten the edges of the top of the Samosa and press together to close.

Pour enough oil in a frying pan to just cover the base, and fry the Samosas just a few at a time for a minute or so each side until brown and crisp.

Note
The Samosas can be frozen, but it is best to lightly cook the onion first in a little oil in a pan, and cool before adding to the other filling ingredients. Freeze them after shaping. Defrost when needed, and fry in a little oil until brown and crisp.

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

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

Homecare

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

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

The service is provided free of charge from Vitaflo.

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

0151 709 9020

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Working together to deliver a better service

Dietitian’s Report

Eating Out – Brewers Fayre

I was delighted to receive some information from Jo Savage about her experience at the Brewers Fayre restaurant. Jo has a little boy called Daniel who has PKU and they were really impressed with the new menu on offer now.

Jo wrote:
When Daniel and I ate at Brewsters the new menu was so good that I just had to pop it in my handbag!

As you can see the Kids Combo from the mighty meals section is just great as a main meal. (I swapped the chicken for coleslaw. The apple I asked for whole and we took that away with us as Daniel wanted a pud.)

‘Dessert was just as impressive. Daniel had the fondue as he was ordering from the Mighty Meals, but I’m sure they wouldn’t mind taking an order for a smaller dessert such as the Fruit Dip. I checked the ingredients of the sauce and all seemed OK with me, so I allowed that freely. Daniel is very dubious of such things anyway and only had a little bit, more for the effect than taste. (With the Fondue you do have donut pieces. I’m afraid to say that yet again I did manage to gain out of Daniel having PKU, but he was only too pleased to share…honest! Obviously, I could have asked them not to be added if it was a problem.)

‘I was also impressed by the selection of fruit juices and of course the Del Monte lollies. We all love them!

‘I must admit I didn’t pay much attention to the adults’ menu but will try to see if that is as good for adults with PKU as the child one is. (I can’t even remember what I had to eat!)”

Dietitian’s note: *From the menu I can see that the choice of drinks is good too. There’s freshly squeezed orange, and freshly pressed apple and cranberry as well as Capri-Sun Orange and Buxton Natural Mineral Water.*

Del Monte Lollies are FREE

Smoothie pops are also available at Brewsters and are “free” on the PKU diet

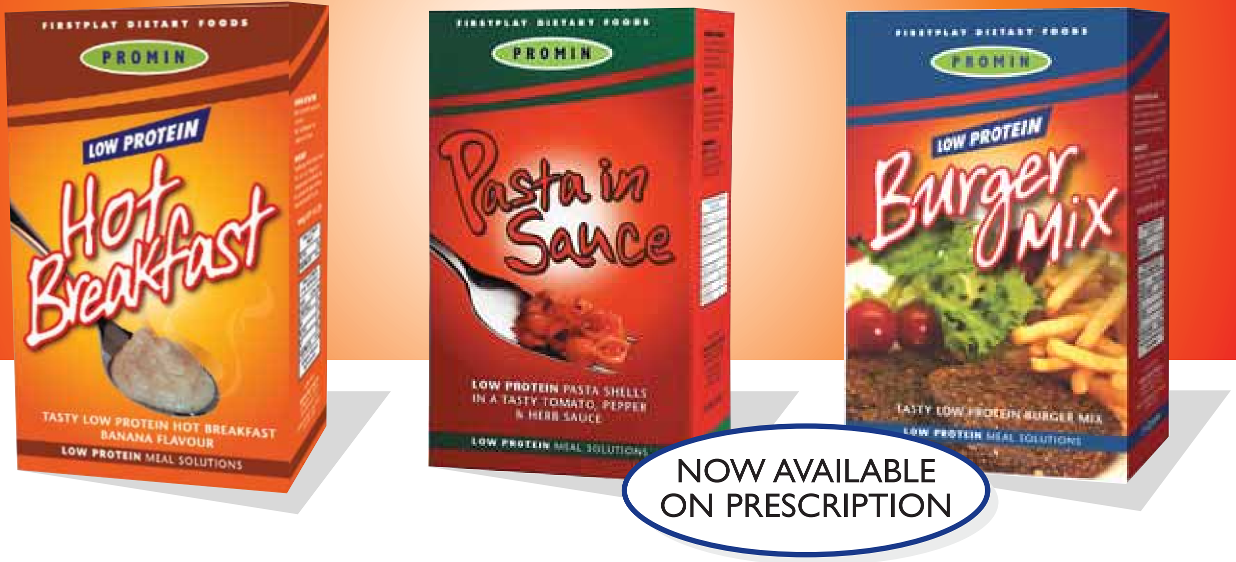
Marks and Spencer

In the last issue of News and Views I included a list of suitable drinks for the PKU diet. In that list were some from Marks and Spencer which contained sucralose. I have just heard that Marks are removing aspartame from all of their drinks and they will be using sucralose instead. They could not give a date when all will be changed but please look out for a larger range of suitable drinks in store from now on.

Chewitts

Michele Smith, the grandmother of a little child with PKU, rang me last night about some new ranges from Chewitts. They are producing individually wrapped sweets with a theme. There are Vampire Fangs now for Halloween and other topical treats will follow. The sweets are protein

Now you can choose Breakfast, Lunch and Dinner



GREAT TASTING MEAL SOLUTIONS WHATEVER THE TIME!

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

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

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

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

PROMIN

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

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

Our pasta range available by prescription also includes Imitation Rice, Pasta meal and Lasagna Sheets they are also available by mail order.

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

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

Always consult your dietitian before trying something new.

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

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

Dietitian's Report cont...

free but of course always check the label for protein content in case this changes.

If a sweet contains 0.3gms of protein per 100gms or less then it does not have to be counted in the diet.

Cheezly

When I was in Asda yesterday I noticed that they have started to sell Cheezly Mature White Cheddar Style. This is the first time I've seen it in this supermarket. It cost £1.89 for the pack.

25gms of Mature White Cheddar Cheezly is 1 Exchange.

Let's Learn About PKU

This learning file of games and activities is the result of years of work from a team of dietitians, nurse specialists, play therapists and patients of all ages. The aim of the file is to teach the child about PKU and its treatment so that they can begin to successfully manage their PKU for themselves. Self-confidence and independence comes with knowledge, regular teaching and patience.

All the games and activities have been evaluated on children with PKU from all over the country to make sure they are age appropriate and work!

The treatment for PKU is complex and often hard to explain to children. They probably want to know about the following:

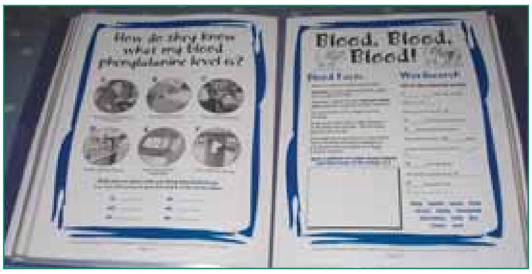
1. Why they have PKU (when no one else in their family may have it)
2. How to be independent
3. How to manage away from home
4. Why they have to take protein substitute
5. Why they need to avoid high protein foods
6. How their body works
7. How to take blood correctly (and why they have to take blood)
8. How to deal with peer pressure

The file is divided into 5 sections:

What is PKU and learning about the body
Food and Diet
Blood Monitoring
Genetics
Coping with PKU

Each section will stand on its own and is subdivided into different activities. Some of the activities require aids you will need to make for yourself but full instructions are given and they are not difficult to prepare. You can adapt the games to suit your own needs and those of your children with PKU.

If you would like a copy of the file please send a cheque for £30 made payable to NSPKU to me at the Barnsley address. The Society is not making any profit on this file and when you receive it you will see why! It's really good value for all that has gone into it.



Eleanor Weetch
Society Dietitian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