

*The National Society for Phenylketonuria (UK) Ltd*

# News & Views

On the Road  
to the European Conference

*website: [nspku.org](http://nspku.org)*

Conference 2002 Report • Dietitians Report • Letters • And much more ...

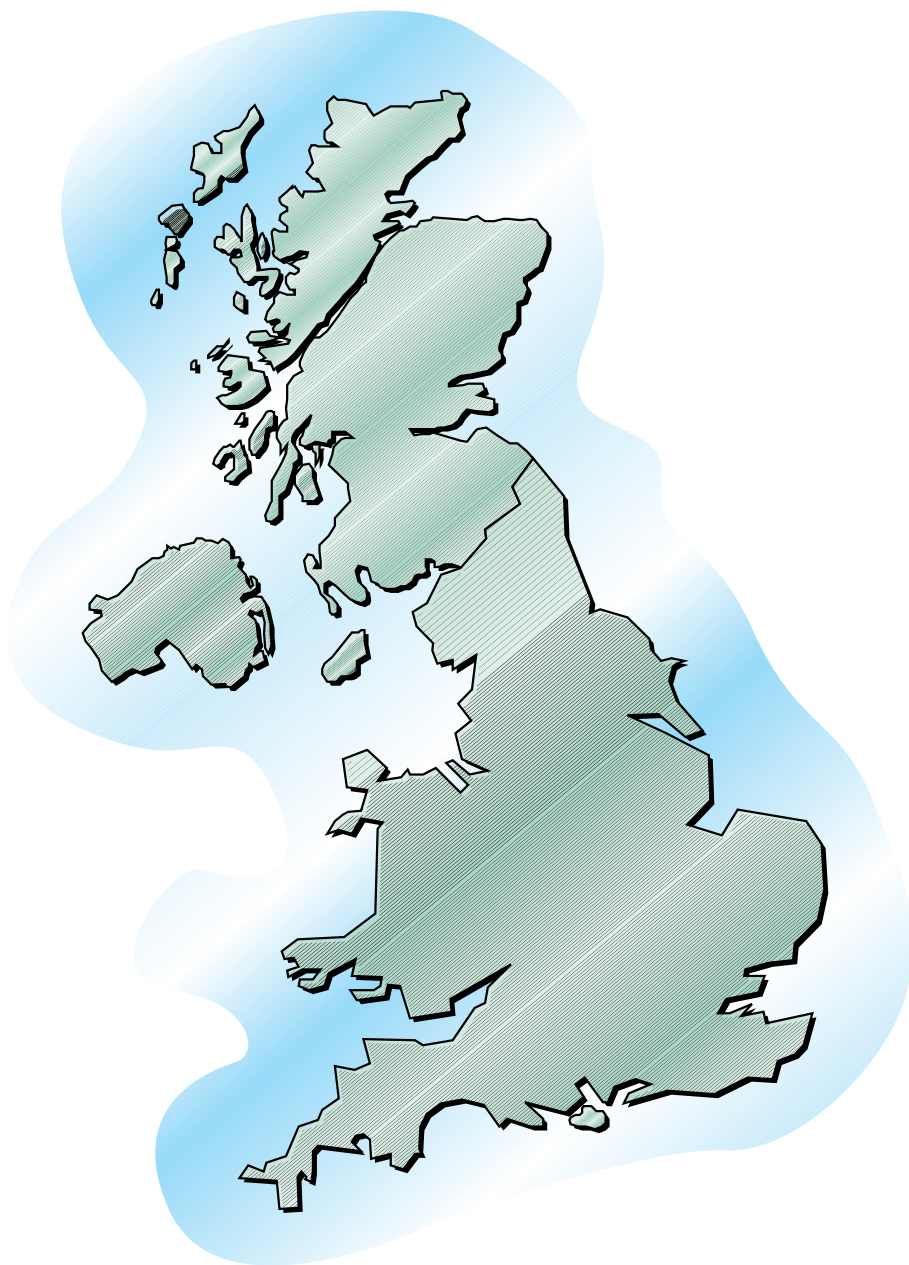
# In Touch

The Council of Management

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## Editors Report

Hello, Willkommen, Ciao, Bien Venue to News & Views 101. Slightly less of a headache than 100 which after the production of which, is how old I now feel. However, you may wonder what the European greeting entails.

Next year will be a different year for the Society. We will be holding two events next year, our AGM in March which is destined to be a one day affair and, another in October when we will be hosting the European Conference for PKU. Experts and families from all over Europe will be turning up and aching to share the information that they have with their fellow participants. This promises to be a fantastic event and will hopefully host upward of 500 guests.

For myself being fluent in 3 languages – English, Scouse and Supplementary and Futile Infantile Negotiation (arguing with kids) this will pose no problem on the interpretation front. Probably because AAAaaaaaaarrrrrrggghhhhhh!! Is universally linguistically transferable. However for you who intend to attend, brush up on your Esperanto as it will be sorely needed. Start saving so at least one of your family members can go to pick up on what a conference is all about.

If you need some fund-raising ideas, then this could be a project that you might like to aim for. It will cost at least one arm and possibly two legs as the UK has no formal system to subsidise the cost (unlike the European Social Fund) so this will be a big strain on Society funds albeit a very worthwhile one.

If you would like to fund-raise for this purpose please contact either Lucy Welch (NSPKU Administrator) or Julia Bailey (NSPKU Treasurer) whose contact details appear on page 2 of this publication – "In Touch".

So for now – Goodbye, Au Revoir, Arrivaderci and Auf Wiedersehn – apologies for interpretational antics

Pete Bramley  
Editor



## Treasurers Report

Well I have now completed (thanks to much help from Sara) my first year as Treasurer and with good behaviour should be up for parole in another two!

The conference as usual was a great success, not least in the funds raised for the Society. In just two days we raised in the region of £600 including the sales of publications and merchandise, guess the weight of the cake, the room raffle and most enterprisingly by Peter Stockton's face painting "dare". The latter actually received pledges of about £400 in the space of 45 minutes.....anyone who hasn't paid up **we know where you live!!**

I am hopeful that the next year will bring a few changes which will make mine and my fellow COM members jobs a bit easier, so watch this space.....

Julia Bailey  
Treasurer

✚ NSPKU ✚  
The National Society for Phenylketonuria (United Kingdom) Limited

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

Helpline: 0845 603 9136  
Email: nspku@ukonline.co.uk  
Web Site: nspku.org

Layout by **The Keystroke Mill**  
www.keystroke-mill.com

Printed by **Action Press**  
Tel: 01444 236204

## From your Chairman

It is my pleasure to bring the Society into the second centennial era of its publication of News & Views and especially delighted to be the first of the fairer gender to direct the Society in its aims and direction.

Most of you will know me as the past Treasurer and more of late as the Vice-Chair, a position occupied by Dave Stening whose worthy footsteps in which I follow and fulfil. I would like to thank Dave for his support in the transitional period into the "Driving Seat" and all COM and Lay Members who have supported my election.

Hopefully the Society will go from strength to strength and greater bonds between the membership, the Medical Profession and the food manufacturers/suppliers will be forged.

I look forward to giving and receiving input for us all to go forward

*Sara Bartlett*  
Chairman

## Donations

1st October 2001 – 28th February 2002

### (£30 and over)

The Squires friends and family	£2,400
Pam Mann	£100
Mrs M Maskym (incl matched donation from Beaverbrooks)	£1,200
Mr Chinnock and colleagues at Caerphilly Postal Delivery Office	£30
St Swithun's Church, Woodborough	£157.96
Jo Green KPMG	£500
Borax Europe Ltd	£141
Mrs HL Mann	£239
Thorntree Primary School	£44.47
I & VA Quinn	£800
LA & PJ Conway	£45
CS & E Henderson	£45
AM Roberts	£175
K Coleman	£274.50
John Cardy The Gas Shop	£50
Ellipit Group Ltd	£69.20
Maxine Eaton	£115
Bessels High School	£141
MJ Derrick	£52
VitaFlo(Int)Ltd	£59.60
Mr K.N. Young	£550
Gem Distribution	£152.50

### Gift Aided

Dennis Greasby & colleagues (incl matched from UBS Warburg)	£6,820
Mrs E Manning	£101.56
Mr & Mrs McGrath	£50
CJ Page	£410
AM McQuarrie	£60.00
Mrs WP Cheale	£1000
J Skidmore	£30
G Davison	£120
ST & J Skidmore	£255
J Skidmore	£221
JB Theobald	£85

### In memory of:

Mrs B Pryce	£144
John Manning	£420.31
Victor Bertie Humphries	£125

new website address!

nspku website is: [www.nspku.org](http://www.nspku.org)

# PKU Camping Weekend

28th June -30th June 2002

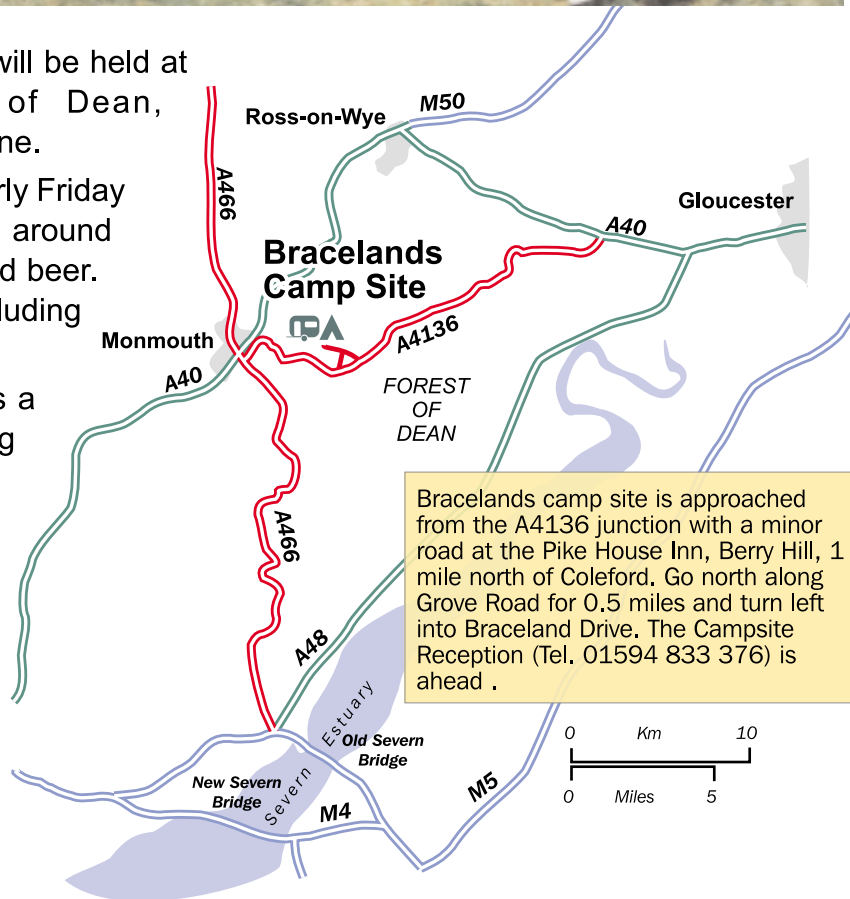
Forest of Dean, Gloucestershire



The annual NSPKU camping weekend will be held at the Bracelands campsite, Forest of Dean, Gloucestershire over the last weekend in June.

The first brave campers start to arrive early Friday evening, before too long they are sitting around gassing over mugs of hot tea or tins of cold beer. Saturday morning sees more arrivals including the "softies" who stay at local B&Bs.

Lunch at a local pub on Saturday raises a few eyebrows when families start weighing chips and checking the pop doesn't contain aspartame. The Saturday evening entertainment is too good to miss, a mix of smoke, warm beer and all sorts of food cooking on the barbie. This event is an excellent opportunity to meet other PKU families and to experience coping with



Visit to Clearwell Caves

PKU 'on tour'. The weekend is not exclusively for people with tents and caravans. Day visitors make up a large number of the party either just driving for the day or staying in a local B&B. The Forest of Dean is only a short drive from the M5 and M4 motorways, so make a date in your diary and come along for the weekend or just visit for the day. Remember the last weekend in June (28th to 30th June 2002).

**For more information contact :  
Ifona or Alun Rogers on 029 20890065**



*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.*

# Letters

News & Views, 48 Hazeldell, Watton-at-Stone, Hertford SG14 3SN  
Email: nspku.editor@ukonline.co.uk

## Dear News & Views

Please find enclosed a cheque for £800 for the benefit of the NSPKU. The money was raised from my completing the Glasgow half marathon in August in a time of 1hr 57mins 14secs. Suffice to say I was very glad of the 800 reasons to keep me going over the last 2 miles in the pouring rain.

My son Andrew is now 3 and has PKU and we as a family have benefited a great deal from the NSPKU, in particular from the Conference we attended at Gateshead which answered so many of our questions and concerns in Andrew's first year. He is thriving and now has a baby sister to keep him on his toes. (Photo below)



*The Winning Quinns*

Without the support of the NSPKU through the Conference, publications and web site our introduction to family life would have been a very different matter. This is our way of saying thanks!! I would like to thank all of those people who sponsored me for the race, particularly Andrew's grandparents and my colleagues at Standard Life

*Yours sincerely*  
Ian Quinn



## Dear News & Views

Please find enclosed a cheque for the sum of £420 - 31. This is half the amount of donations given in memory of Adam's much loved Grandad, John Manning, who died suddenly on 15th October 2001. The other half of the donations went to the Kings Nympton Methodist Church which he regularly attended throughout his life.

Adam is now 11 and has just started Secondary School, he has settled in really well.

Finally thank you to everyone involved in the NSPKU for their continuing hard work, providing helpful and friendly support always.

*Yours faithfully*  
Mrs E Manning

**Ed - Please accept our belated sincere condolences to your family - NSPKU - Council of Management.**

## Dear News & Views

Please find enclosed cheque for £274.50, which our son Daniel raised for the NSPKU by running the Junior Great South Run in November.

Daniel is 8 years old and has PKU along with his sister Taylor who is 3. He completed the 2 mile run in 18.53 minutes and is already out to beat his time next year! He is a Cub Scout and enjoys swimming and football. I have enclosed a photograph of him wearing his medal from the race and his sister who went along to cheer him on (*see below*).

We would like to take this opportunity to thank the NSPKU for all their invaluable hard work and support.

*Sincerely*  
Karen Coleman



*Taylor and Daniel Coleman*



## Dear Editor

Please find enclosed cheques to the value of £125 which were gratefully accepted in lieu of flowers at the funeral of Victor Bertie Humphries, Great Grandfather of Adam McGrath aged 8 years (Classic PKU).

Please carry on the good work and thank you for all your help.

*Yours faithfully*  
Christine Gyford (daughter of the deceased)

**Please accept our sincere condolences - NSPKU Council of Management**

### Dear News & Views

In support of his cousin Annabelle Skidmore aged 2, who is PKU Andrew Skidmore ran in the Great North Run that took place in the North East. Despite the gruelling challenge of the race he was spurred on by the Great North east public, who helped him achieve a personal best time of 1 hour 49 minutes and 55 seconds. A weary and tired body crossed the line, but it was all in a good cause as he raised £255 for the NSPKU.

Jon and Sharon Skidmore



### Dear News & Views

Please find enclosed a cheque for £425. This was raised by Evie McMichael School (Abbots Hill Junior School) for the NSPKU.

Sincerely

Sherryl McMichael



### Dear News & Views

On the 8th July 2001 a team of 14 from Umbro International cycled from Manchester to Blackpool to help raise money for 3 Charities. As one of the chosen Charities, I am delighted to enclose a cheque for £850. Yours was a chosen Charity by Mr Paul Masters (see photo – far right) from Umbro International whose daughter Chloe (4) has PKU.

We hope that this will go some way towards raising funds for this very worthy cause.

We wish you all the best with your fund raising in the future.

Yours faithfully

Margaret Weeks  
Head of Human Resources  
Umbro International Ltd



### Dear News & Views

Please find enclosed a cheque in the sum of £69.20, which has been kindly donated by the personnel at our Peterborough Head Office in lieu of sending Christmas Cards to all their colleagues.

We heard about the NSPKU from one of our employees who has a son with the condition and hope that our donation will benefit the Society.

Sincerely

Robinia Whitwell

For and behalf of the Elliot Group Ltd



### Dear Editor

Please find enclosed £550 from fund raising undertaken on behalf of the NSPKU by my family, particularly in N.Ireland, when I ran the London Marathon. My daughter Jessica aged 11, has PKU.

I am happy to be able to forward this contribution to the NSPKU.

Sincerely

K. Niall Young



Andy Skidmore



Paul Masters (far right) and Umbro International Peddlars!

### Dear Editor

Please find enclosed cheque for £120 which was raised by Strathmore Golf Club. This was one of the nominated charities chosen by last years 'Gents Captain' Peter tinker, grandad of Jordan, our 10 year – old daughter (PKU)

Yours sincerely

Dawn and Mark Tinker

## Contacts

My name is Kate Doherty I am 15yrs old and live in Canberra, Australia.

Address is -: 2 Jay Place Theodore ACT 2906 Australia.

Email:- [katie\\_doherty87@hotmail.com](mailto:katie_doherty87@hotmail.com)

I appreciate your reply so quickly and once again thanks for your help!

If you wish to make **Contact** with someone else to share your PKU experiences, write to **News & Views Editor**, 48 Hazeldell, Watton-on-Stone, Hertford SG14 3SN. Or Email [nspku.editor@ukonline.co.uk](mailto:nspku.editor@ukonline.co.uk)

# SHS recipe

**SHS**  
INTERNATIONAL

## VANILLA PANCAKES WITH MIXED BERRIES

Serves 6

### Ingredients

- 20g (3/4 oz) value butter, melted
- 200ml carton Sno-Pro Low Protein Drink
- 1 x 5mlsp (1tsp) vanilla essence
- 125g (5oz) Juvela Low Protein Mix
- 2 x 5mlsp (2 tsp) caster sugar
- 2 x 2.5mlsp (2tsp) cooking oil
- 300g (12oz) mixed berries, fresh or frozen
- Icing sugar



### Method

- Combine the melted butter, Sno-Pro Drink and vanilla essence.
- Place the Juvela Low Protein Mix and caster sugar in a large bowl, gradually beat in the Sno-Pro and butter until the batter is smooth.
- Preheat a non-stick frying pan and very lightly oil the base, place 1 x 15mlsp (1tbsp) batter in the pan and quickly shape into a round (approx 6cm/2 1/2 inch).
- Cook over a moderate heat for 1 minute, until small bubbles form on the surface, turn and cook the reverse side, until golden brown, keep hot.
- Repeat with the remaining batter, to make 18 pancakes.
- Serve 3 pancakes on a warmed dessert plate topped with a few mixed berries.
- Place a little icing sugar in a sieve and shake over the pancakes, to taste. Serve at once.

### Tips

The cooked pancakes may be frozen successfully – when cold freeze separately on a tray covered with greaseproof paper, when frozen remove from the tray and store in a freezer bag or airtight container. Defrost at room temperature for 30 minutes and reheat for a few seconds in a microwave oven, before serving with the mixed berries.



## Low Protein - Egg White Replacer

 Replaces  
approximately  
**100**  
egg whites

Available on prescription from December 2000

### Guidelines For Use

This product is an egg white substitute and can be used to make meringues and imitation cream, 1g is the equivalent of approximately 1 egg white. It is used as a solution at the following dilution 1g (1/3tsp) egg white replacer whisked into 40ml water (approx. 2tbsp boiling water and 1tbsp cold). Allow to cool. This is the minimum solution and can be scaled up accordingly.

Recipes available from SHS.



Solution Quantity Req'd	Egg White Replacer		Water Quantity	Hot/Cold Ratio (approx)
ml	gms	tsps	ml	tbsp
40	1	1/3	40	3 (2 hot, 1 cold)
80	2	2/3	80	5 (3 hot, 2 cold)
120	3	1 level	120	8 (5 hot, 3 cold)
160	4	1 1/3	160	11 (7 hot, 4 cold)
200	5	1 2/3	200	13 (8 hot, 5 cold)

For the dietary management of inherited metabolic disorders, renal and liver failure requiring a low protein diet.

**SHS**



*NSPKU will be  
hosting the*

***European Conference  
in October 2003***

*Details to be announced...*

## ***A cracking new product from SHS***

### **Low Protein - Herb Crackers**

The Loprofin Herb Cracker is a new, exciting addition to your low protein diet. A convenient savoury cracker, ideal for packed lunches or as a snack. Perfect dressed with salsa or used as an ingredient in a variety of recipes.

Contact the SHS Nutrition Services Department on 0151 228 1992 for a free recipe leaflet.



For the dietary management of inherited metabolic disorders, renal and liver failure requiring low protein diet.

**SHS**

# 29th Annual Conference Review



Pete Stockton gets in touch with inner self whilst daughter Bethany looks even more mortified!



Kids have their faces improved courtesy of the NSPKU



Danielle Skidmore - Conference Princess!

**For those of you who were wondering where the Conference booking form was as the New Year came and went. Here's your answer. News & Views 100 was a major project for us amateurs and the begging and pleading for everybody's input had gone largely unheeded. The publication looked like going out sometime in the next millennium such was the pedestrian pace of its output. Trouble was that the booking form was part of the Magazine.**

Mike Bailey – Head Conference honcho and Organising Supremo had long given up biting his nails and was working his way to his shoulder blades given that we now had just 6 weeks to make the whole thing happen – so we did a mail-shot which greeted us with an inundation of instant booking chaos as people jostled for the honour of staying in the primary Hotel.

And so all those months of preparation and collaboration between all COM members and especially Mike had culminated in our arrival at the comfortable and well turned out Swallow Hotel in the fine surroundings of Gateshead.

The Swallow Hotel in Gateshead has a curious setting. Close enough to Newcastle to be central, yet far out enough to be not close enough. Just go there. The level of care and comfort warrants it, but those who went there will know what I mean. Reports of the sister hotel, the Swallow Imperial, where the over-spill of our lovely delegates were staying, attracted similar rave reviews for the standard of accommodation. These conference die-hards made fair weather of the ferrying to and fro from one venue to another. We at the Swallow Gateshead salute you.

Friday is arrivals day and 280 weary guests bundled into the Hotel for the civic reception. Many thanks to our civic hosts of Newcastle who so kindly met the costs of the drinks, which was a considerable sum. The Mayor of Gateshead and his good lady wife welcomed us all to Newcastle and drank our health. We were all then ushered into dinner where chefs had toiled with ingredients they knew nothing about to produce fine PKU fayre.

Eric Lange did his super bit of fund raising and announced the winners of the spring-draw. Many thanks here to Eric who, with help from daughter Rosanna raised over £5,500 for the NSPKU. Many thanks also to all those who bought tickets and donated prizes.

Friday evening witnessed a disco whilst Debbie Denton (PKU Mum) provided the entertainment for the Saturday evening in her own inimitable cabaret style. Summary embarrassment was metered out to those foolish enough to stay within Debbie's grasp as she subjected poor souls to their first lessons in cabaret presentation.

Kids were treated to two trips. On Saturday they were escorted across the River Tyne via the new Millennium Bridge which spectacularly spans Gateshead to Newcastle. From there we went on to the new Interactive Life Centre in Newcastle which covered a variety of topics most notably Genetics – We know about Genetics don't we! On the Sunday they were whisked up to the Angel of the North, a massive sculpture that welcomes visitors to the North East. They then bowled their little hearts out and were awarded certificates courtesy of the NSPKU on the Sunday afternoon. Many thanks to all the helpers on the trips who had their nerves shattered and

patience tested to the limits – worthy companions indeed!

The talks, as always, provided the framework and foundation of the conference. In our experience, people come to conference for a myriad of reasons both personal and profound. But these reasons tend to fall into two categories – firstly the desire to learn and secondly the desire to mingle with the other individuals who support and care for sufferers of PKU. Both of these reasons, identities and the relationships between speakers and delegates personify the content of the conference. Hopefully people go away feeling that there is merit in the persistence of dietary management.

Speakers abstracts can be seen on pages 11 to 13 as usual the quality of the material was very high.

Many thanks to all of our guests who helped deliver such a successful conference and for their input. Also many thanks to our suppliers who operated trade stands in particular Steve and Linda Fletcher (Firstplay Dietary), SHS International, Vitaflo, General Dietary, Gluten-Free foods and FATE foods for being with us again and lending such support and

friendship to the conference.

A big thank you to the managerial staff at the Swallow whose slick professionalism instilled much confidence in all those who helped organise this event, in particular, Lynne Wilmott who just laughed at us for most of the weekend as we walked around the Hotel with our NSPKU banners trying to find better locations (and followed wearily by the Hotel maintenance staff).

Why is it the PKU food always seems so well prepared and presented at conference?

The presentation was superb, Eleanor Weetch had done the logistical version of the Marathon to arrive at this point. Just to make things more interesting for Eleanor there was no Head Chef which (strangely enough) seems to be a regular annual occurrence whenever she starts to assemble the menus ready for the conference! Hmmmmmm.

Finally many thanks to Joanne Clough who was unfairly singled out by an NSPKU press-gang to organise the Kid's Party which went with a real bang (it was only a small explosion). Thanks to her for all her hard work and to the army of helpers who inflated over 200,000 – ish balloons ready for the kiddie extravaganza. Also all power (but no street cred) to COM member Pete Stockton who had to endure his face painting debacle to raise funds for the Society – Hats off, make-up on.

Special thanks too to Anne Verster who waded through a floor of mini people along with creche facilitators, to pull together a very tight ship so far as childcare goes. Anne your card is marked!

Hope to see you at the next conference in 2003 in Hinckley where we will be playing host to the European Conference with visitors from far & wide. A true opportunity to meet and greet parents and professionals from around the Globe with one special thing in common. PKU.

## Why is it the PKU food always seems so well prepared and presented at conferences?

# Abstracts from the 29th Annual Conference

## Research and Developments in PKU

Maureen Cleary MB, ChB, MD, MRCP

Consultant Paediatrician with special interest in metabolic disease.  
Royal Manchester Children's Hospital

There are several areas of interesting research and development in PKU. These will be discussed by considering the following different areas of research:

- Developments in dietary treatment: The addition of long chain polyunsaturated fats to the amino acid supplement in PKU. The PKU diet is low on animal fats and therefore PKU children have lower levels of some important long chain fatty acids. There are several studies where the PKU amino acid mixture has been supplemented with long chain polyunsaturated fats.
- Measurement of brain phenylalanine using magnetic resonance spectroscopy. It is now recognized that the brain level of phenylalanine is different from the blood level. Some studies suggest that supplementing large neutral amino acids alone can alter brain phenylalanine level.
- The use of ammonia lyase capsules as alternative treatment for PKU. This topic will be updated with any new developments.
- Home monitoring for PKU. Although not yet available there are attempts at developing a home monitoring system for PKU where individuals with PKU or their parents would check the blood level at home and make the appropriate dietary changes. The extent of current research in this field will be discussed.

## Genetics & PKU

Linda Tyfield, Southmead Hospital,  
Bristol

The term Phenylketonuria or PKU is a biochemical description of a condition defined by phenylketones in the urine and high levels of phenylalanine in the blood (hyperphenylalaninaemia). An understanding of a basic level of biology would probably lead one to conclude that these biochemical effects arise from a defect in metabolism – a block somewhere that causes a damming effect and a spilling over of unwanted products into the urine. The word alone, however, does not hint at the different degrees of severity of the disorder or, indeed, at how any single affected individual has this disorder – i.e. that it is not acquired like an infection but inherited through the genetic material passed on from parents to offspring.

Genetic analysis – examining the single bases that constitute the gene – has provided some insight into why there are different degrees of severity of the condition. More than 400 different mutations have been described worldwide in the gene that is involved with PKU and although a few mutations are common, most are rare. Some are known to result in a more severe PKU whereas others are always associated with a mild form of the condition in which little dietary restriction of phenylalanine is required to maintain normal growth and development. Through mutation analysis it has been possible to trace the origins of the disease in different populations and to trace the migration of families through different geographical areas.

In this talk I will put 'genetic travel' into a perspective of space travel to illustrate the depths to which we travel inside the human cell in order to study individual genes. I will describe how different mutations have arisen independently in different

parts of the world and I will describe some unusual mutations that we have characterised recently in the UK population. I will show how computer modelling of protein structure is used to explore the effects of single base changes in the DNA.

## Diet, Fats and PKU

MacDonald A, Daly A, Asplin D, Chakrapani A, Rylance G,  
Birmingham Children's Hospital, Steelhouse Lane, Birmingham,  
B4 6NH.

### What are essential fatty acids?

Fatty acids are the building blocks of fats. The body can make some of the fatty acids it needs but there are two essential fatty acids, which cannot be made in the body. These are called **linoleic** (omega -6 family) and **alpha-linolenic acid** (omega -3 family). Humans have the ability to convert these fatty acids to other important longer chain fatty acids.

**Linoleic acid** is converted to arachidonic acid and remains in the omega -6 family. **Alpha-linolenic acid** is converted to eicosapentaenoic acid (EPA) and docosahexaenoic acid (DHA) and remains in the omega -3 family.

### What do essential fatty acids do?

Essential fatty acids are important in the normal functioning of all tissues of the body. Particularly:-

- The formation of healthy cell membranes.
- The proper development and functioning of the brain and nervous system.
- The production of hormone like substances called eicosanoids. (These chemicals regulate numerous body functions including blood pressure, blood viscosity, and immune responses).

### Which foods do these fatty acids come from?

The best sources of essential fatty acids are plants on land and in the sea.

- Linoleic acid** (omega -6 family) is found in seeds, nuts, grains and legumes. Good sources are corn oil, safflower oil, soybean oil, sunflower seed oil and peanut oil. Arachidonic acid comes from animal fats.
- Alpha-linolenic acid** is found in the green leaves of plants, including algae and in selected seeds, nuts and legumes. Flax, canola, walnut oil and soy oil are all sources of this fatty acid. The only sources of EPA and DHA are fish and shellfish.

The balance or ratio of omega 3 to omega 6 fatty acids is just as important as their quantity in the diet.

### Do people with PKU get enough essential fatty acids in the right balance?

There is evidence to show that people with PKU probably get enough **linoleic acid**. However, the balance between the intake of **linoleic** and **alpha-linolenic acid** may not be optimal i.e. people get plenty of **linoleic acid** but smaller amounts of **alpha-linolenic acid**. This may compromise the conversion of **alpha-linolenic acid** to the longer chain fatty acid EPA. In addition, the sources of the longer chain fatty acids e.g. EPA and DHA, are limited in low phenylalanine diets. There have now been a few studies, which show that the blood level of DHA is low in PKU.



All abstracts taken from 28th  
Annual Conference 2001  
Handbook



## How can we give more essential fatty acids in the right balance?

Traditionally protein substitutes in the UK have not contained fat. However, a protein substitute has now been introduced that contains both **linoleic acid** and **alpha-linolenic acid** in the recommended proportions. This is called Minaphlex (SHS). It is designed for children between 1-10 years of age. An international study (including patients from Manchester and Birmingham) showed that children who took the protein substitute with added essential fatty acids had better blood levels of both **alpha-linolenic acid** and DHA levels. It is hoped more protein substitutes will contain essential fatty acids in the future. A particularly useful source of essential fatty acids is walnut oil and this can be easily added to salad dressings.

## Conclusion

In the UK, there are no current recommendations about adding essential fatty acids, particularly **alpha-linolenic acid**, to the diet. However, with increasing knowledge, this is likely to become a more prominent issue in the near future.

## Life with PKU

Katie Stevens

I'm Katie Stevens and I'm 24 years old. I have been on the Low Phenylalanine diet to varying degrees for my whole life. I am here from Australia on a working holiday for approximately two years.

I grew up in Sydney and was treated at the Royal Alexandra Hospital for Children. As I was diagnosed in the late seventies information about PKU and its treatment was relatively new and continually changing.

I was the first PKU patient that my doctor at the children's hospital had treated so he was learning at the same time we were. As I was growing up I was always promised that I could stop the diet "in a few years" but as more research came to hand I ended up staying on the diet.

Growing up on a special diet had bad points but it also had some very good points. Also during my lifetime I have seen many changes and advancements in the treatment of PKU.

When deciding what to do with my future my experiences growing up with PKU helped me decide what to do. I remembered seeing the dietitian at clinic and they would always suggest new things I could try which was always important when your diet is limited. I like the way that diet can have such a big influence on so many conditions as well as PKU. I thought being a dietitian would be quite interesting and I also thought that I might be able to empathise with people on special diets.

Having PKU has not stopped me from travelling. Sometimes it has been hard but also it has helped me to do more with my diet. I have been to the UK as an exchange student after school as well as travelling to Thailand with university. I have travelled around a lot of Europe and have more trips planned for the rest of this year.

This year I am living and working in the UK. I am currently doing locum work as a basic grade dietitian. Whilst I am over here I am hoping to expand my general dietetic experience but also find out more about PKU. Also I am here to do some more travelling as I mentioned earlier.

While I am here I would like to get some experience with the other side of PKU, the side of the dietitian rather than the patient.

My ambitions when I return to Australia are to work in paediatric nutrition and particularly inborn errors of metabolism. Also I have an interest in working in sports nutrition. I am also planning to visit the areas of my home and the rest of the world that I have not yet had time to explore.

## Towards PKU Independence

Carol Ferguson, Senior Dietitian  
Newcastle General Hospital

The Medical Advisory Panel (MAP) of the National Society for Phenylketonuria is aware that a significant number of PKUs reach adulthood without a firm understanding of PKU. Some adult PKUs have difficulty managing their PKU whilst busy with their work and social life.

In Great Britain we believe that "Diet for Life" is the treatment of choice for PKUs.

MAP members have therefore decided to develop strategies to help PKUs, of school age, gain a better understanding of PKU and to learn how to look after their PKU. If this can be achieved, then the adult PKUs will have a better chance of successfully continuing their PKU diet when living independent adult lives.

We have recently undertaken a survey in 3 PKU centers to assess the knowledge of PKU children about their condition and its management. We also found out how much of the PKU management the youngsters were themselves involved in. The PKU centres surveyed were Birmingham, Manchester and Newcastle. Young people (7-16 years) were surveyed.

I will explore some of the findings of this survey.

Following on from the survey we have set down a number of PKU self-management objectives for 7-11 year olds and 11-15 year olds. We envisage the objectives being used as goals which each PKU would work towards over a period of years.

We are now beginning the process of devising teaching aids/strategies that will help the PKUs achieve the various objectives with ease.

We hope that once the material has been developed and piloted it will be of help to PKU centers and PKU families. If successful, more PKU youngsters will develop self-management skills and the ability to cope with the difficulties associated with being 'different'.

## Healthy Emotional Development – How hard is that?

Dr S.E. Wressell  
Consultant Child and Adolescent Psychiatrist  
Flemming Nuffield Unit, Newcastle

Growing up is not easy. Children face new challenges at each stage of their development. At home, at school and with friends there are different social, emotional and psychological phases to negotiate. Growing up with a medical condition can make this more complicated, but children often surprise adults with their resilience and coping strategies. The talk will follow a child's emotional development from infancy to adolescence and highlight ways of building on the child's strengths to achieve good emotional health.

# Abstracts cont.

## Developing an Information Pack for Young People and Adults with PKU

Susan Durham-Shearer, Maggie Lilburn and Philip Lee  
The Charles Dent Metabolic Unit, National Hospital for Neurology and Neurosurgery UCLH NHS Trust, Queen Square London, UK.

Current recommendations suggest that people with PKU should stay on low phenylalanine diet long-term (1). There is now a "first generation" of adults remaining on diet or returning to diet after a break of perhaps several years. The need for specific services for adolescent and adult PKU patients has been recognised (1), however there is still a great shortage of both medical and written resources for this patient group.

In May 2000 a research project was started at the UCLH Metabolic Unit to produce an information pack designed to address the needs of adult PKU patients. A questionnaire and knowledge test was sent out to 177 patients attending the clinic. This was to gather information such as details of current dietary regime, personal experiences of dealing with PKU and suggestions for resource pack content.

72 patients both on and off diet completed the questionnaire. The most popular topics people wanted to read about in the pack were evidence for staying on PKU diet; guidance on dealing with healthcare professionals; explaining PKU to other people and "life-stories" from other PKU patients.

This information was used to design a small "filofax style" information folder covering a wide variety of topics. A separate pack for storing blood-test results and equipment was also created.

The pack will be audited using a sample group of patients to see if it has any effect on the management of their PKU.

The pack should be available to all users of the UCLH Metabolic Clinic after May 2002.

### Reference

1. Report of Medical Research Council Working Party of Phenylketonuria (1993). Recommendation on the Dietary Management of Phenylketonuria. Archives of Disease in Childhood, Vol. 68, No 3 pp426-427.

## MANUFACTURERS HINTS & TIPS

### QUESTIONS AND ANSWERS ON USING VITABITE

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**Vitabite** is a new and exciting low protein high energy chocolate flavoured bar. It comes in handy 25g bars and is available in convenient tubes of 4x7 bars.

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Yes. **Vitabite** is available on prescription through your G.P. in packs of 28 bars (4 x 7 bar tubs). Your pharmacist can order directly from **VitaFlo** on Free Phone Number 0800 515174 or through their local wholesaler.

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**Vitabite** can be used in many ways to add variety, fun and energy to your diet. It can be eaten as a bar, e.g. in your packed lunch, or melted, frozen, microwaved or grated. Melted **Vitabite** can be added to permitted cereals to make Crispy Cakes, to coat your permitted

biscuits or dip your favourite dried or fresh fruit to make tempting treats.

#### HOW DO I MELT VITABITE?

Melting **Vitabite** couldn't be easier. Break up into a bowl then either microwave for about 1 to 2 minutes or place over a pan of boiling water and stir until melted.

#### WHAT CAN I USE FOR EXTRA DECORATION?



To add more colour to your decorated biscuits etc. you could use permitted sweets such as Jelly Tots, Starburst Joosters or Super Cook products such as multi-coloured Sugar Strands and Silver Balls.

#### CAN I FREEZE VITABITE?

Yes. **Vitabite** is suitable for freezing - handy on a hot sunny day or what about dipping a permitted ice lolly into the melted **Vitabite** to coat and then keep in the freezer for a treat.

For further serving suggestions please look through the **Vitabite** leaflet enclosed.

We hope you enjoy these suggestions.

If you have any queries please ask your dietitian or write to **VitaFlo**. We would welcome any of your own suggestions which we could print in future editions of News & Views - a £5 token for any recipe ideas we print!  
**VITAFLO Ltd.**  
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Summers Road  
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# PKU Conference

Saturday  
25th May 2002  
12.30 to 5.30pm

The Education Centre  
The Birmingham Children's Hospital  
Steelhouse Lane  
Birmingham  
B4 6NH  
0121 333 9999

## What's Changed?

This year's programme includes: –

- A video about the first patient to be tried with dietary treatment.
- A talk about the early PKU diet.
- Some practical ideas about how to learn about PKU.
- What is MRS and can it be useful in PKU?
- Diet, what's new?
- And of course..... Eileen Green's Cookery Session

Unfortunately, due to new hospital regulations we will not be able to provide crèche facilities this year.

Please complete the attached form if you would like to attend.  
Further details will then be sent to you nearer to the day

## PKU Conference

*Birmingham Children's Hospital Saturday 25th May 2002*

Please complete and return this slip by 4th May so that we can send more information to you and be able to provide suitable refreshments.

Name .....

Address .....

*I /We would like to attend the above conference.*

Number of PKU adults ☐

Number of Non PKU adults ☐

Number of PKU Children ☐ Age ☐

Number of Non PKU children ☐ Age ☐

*Sorry, but we cannot provide any crèche facilities this year*

Please return this form to :- Mrs D Asplin  
Clinical Chemistry Department  
Childrens Hospital  
Steelhouse Lane,  
Birmingham B4 6NH



# Support Groups

## NEW VIDEO - PKU IS OKAY!

***A new video has been produced for 9 – 12 year olds with PKU.***

Young people face many questions and anxieties about PKU as they grow older. Should teachers or friends know about PKU? How is PKU explained? What about eating out with friends? Going on holiday? Choosing a career? Personal relationships?

All these questions and more are openly and honestly discussed by a group of young people with PKU. Each person has his or her own approach to coping with PKU and diet. But whatever the individual style, each demonstrates that a positive attitude enables them to overcome the extra difficulties of living with PKU.

Young people with PKU have taken part from all over the UK and there is not a health professional in view!

This video has been very generously sponsored by SHS. If you would like to see this video, please ask your local dietitian who can obtain one directly from SHS.

*In conjunction with Birmingham Children's Hospital*



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\* Subject to availability

# Fundraising Fest!

## Andy and Gina Guest gorge themselves on fundraising!

***First of all an introduction. We are Andy and Gina Guest, parents of Emily, aged 6 (non PKU) and William, aged 4 (with PKU). Both children suffer from chronic naughtyitis. William is something of a Houdini when it comes to raiding the kitchen. Our kitchen has more padlocks and bolts than the Tower of London.***

I am writing to inform you of the fund raising efforts of local people in Nottingham who know William, or are aware of him through contact with ourselves or his grandparents. Last summer the fundraising committee at the Nags Head public house, Woodborough, were deciding which charity to sponsor and asked local people to nominate. Williams grandad suggested the NSPKU, which they accepted.

The fund raising at the Nags takes the form of a quiz, which is held on a Tuesday night and runs for just short of a year. The questions are selected by the committee, Peter, Steve, Brian and Margaret. By sheer dedication and torment they have had us performing mental gymnastics which are often to no avail.

### **We are truly astonished by the generosity of people once they become aware of PKU.**

One September afternoon the landlady, Marilyn was serving a customer who had arrived for lunch and a pint. He seemed very interested in the NSPKU posters dotted around the pub and began making enquiries about it with Marilyn. The customer turned out to be Chris Mabbot, a Radio Nottingham presenter, who does a lot of work for charity in his spare time. Like most people he had never heard of NSPKU. Anyway, a charity night was arranged starring Chris and his team. The event included a fun quiz, raffle and an auction of donated prizes. These prizes included a tour of Radio Nottingham and a private box near the centre line for any Nottingham Forest home match. We all had a wonderful night: even though a few of us had to make fools of ourselves (without the aid of alcohol !) by being forced to sing "Three little maids from school are we". Not that we are in any way resentful !

The funds made were combined with the quiz fund. Still to be held is a

treasure hunt, rally and presentation night. The presentation night, with Chris Mabbot and his team, will be held on Tuesday, 24th June.

If anyone would like to attend please contact Marilyn or Alan on 0115 9654885 or myself on 0115 9563769 for directions.

As a result of the fund raising the local church, St Swithens, at Woodborough chose to donate their contributions from a Christmas carol concert. This was a very enjoyable afternoon which Emily particularly enjoyed. The sum of £156.96 was raised and we are very grateful.

In the meantime William was turned into a star both by appearing on East Midlands Today, our local news programme, and by being interviewed on

Radio Nottingham. Both items brought a great deal of awareness to his condition. I was even stopped in a restaurant and asked "Were you the lady on the telly the other day?" much to my brothers immense amusement for the rest of the night!!

As a result of seeing William on the television our local darts secretary rang up and asked if he could nominate the NSPKU for their annual fund raiser; the whole thing seemed to be snowballing from one thing to another! Thanks to the efforts of Dick Jerram and other members of Arnold Mens Darts League, £431 was raised.

Perhaps the most amusing thing happened to my dad, Mick Cox who is Group Operations Manager at Bristol Street Motors, when Jenny Evans and Kath Savage thought my dad should do some fundraising along with colleague Everitt Jones. Unbeknown to both parties it was arranged for them to be "arrested" by two policemen at work and then taken to Nottingham Castle. To their utter shock this happened and they were taken away with sirens blaring; armed with only their mobile phones and address books. Between them they raised £1500 for their release.

All this has come about through the hard work of many people and all is not finished yet. We are truly astonished by the generosity of people once they become aware of PKU.



*William and Emily Guest*



*Mick Cox and Everitt Jones do a spot of "Porridge" for a good cause!*



# Great Ormond Street Hospital

## Toddlers Party...

*Following the success of the toddler group (featured in News & Views 100) the PKU team at GOSH decided to hold a Christmas group. Over 30 families of children under the age of 5 who attend the hospitals PKU clinic came along to the morning. The group gave families an opportunity to mix swapping ideas and tips. The families have many different experiences of living with PKU so there were lots of ideas being passed around.*

Our new consultant Dr Andrew Morris was introduced to the families and hosted a question and answer session.

A "low protein shop" dietary display was set up featuring lots of foods for the festive season available in the supermarket. There were also lots of prescribable low protein foods to taste and samples

to take home. Many parents were surprised at the variety of foods on display and commented that they would not have tried such dishes at home. Marian, one of our Dietitians, has spent a lot of time making cakes and with low protein products. She was able to share suggestions to alleviate some of the difficulties experienced with low protein cookery.

Whilst the adults were busy sampling food the children had great fun playing together and making new friends. There was also a surprise visitor – Father Christmas came all the way from Lapland and gave each child a Christmas gift.

The families are all keen to attend future groups and the children are looking forward to seeing their new friends again.

*Alison Munro  
PKU Clinical Nurse Specialist  
Gt. Ormond Street Hospital*

*(Ed - The NSPKU Committee and Membership wish Alison well for her maternity leave and impending delivery!)*



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# Dietitian's Report

The simple things in life - bread, soup & "cheese"

## Breadmaking Machines - Exposed! - *report by Eileen Green*

I have said so many times, that I think the most important low protein recipe is Bread. There can't be many people in the world who don't eat bread of some kind every day.

The most simple plate of salad or vegetables can be transformed into a filling meal if you have decent, good bread to eat with it. In our house, we have bread on the table with every meal.

Even if you have absolutely no experience of bread making, low protein or otherwise, you will find automatic bread machines are easy to use and so convenient. There is nothing complicated about any of these machines.

As bread machines generally have become more popular, even quite fashionable to own, there is a greater choice of machines, shape and size of bread pan in the shops. Although the prices have come down a great deal, they still vary a lot, and can be anything from as little as £35 to £129 or more.

If you use a machine, the great thing is that you can have fresh, low protein bread all the time. You will no longer need to freeze your bread. (Although you should probably keep a spare loaf or two frozen for emergencies) or if you have a very small child, you could perhaps make a loaf, use one half of it, and freeze the other.

I have thoroughly tried and tested a number of different machines, makes and models. Each machine comes with a hand book, and some of them mention making bread for different diets, but I found that the advice varied such a lot, and anyway, none of them applied to Low Protein Bread. So, when testing these machines, I just started from scratch and tried different ways with each machine.

### ***These are the general points that I have found:~***

- All modern bread machines are basically the same. They all mix, prove and bake a loaf of bread. They have a removable baking pan, with a separate mixing paddle that fits in the middle of the base. On some machines, you have a choice of crust colour. This can be set to come out anything from a light golden to a dark brown. Although some machines give darker results than others.
- The size of the baking pan varies on some machines. Although there is not a great deal of difference. If like us, you need quite a lot of bread, it would be worth choosing a larger model. Although many families have a smaller machine, and just use it more often.
- Another consideration is the shape of baking pan. Quite a few machines now have wider, more shallow pans that produce a more traditional shape of loaf, what I would call "farmhouse" style, whereas most have taller, narrower shaped pans. I have tested machines with both shaped pans and get the same good results.

- Some machines will offer a bigger number of programmes, the average being about 10 or 11. For Fate machine bread, you do not need any of the more sophisticated programmes. In all the machines that I tested, I found that the Basic, Basic Rapid or Normal cycles worked the best. (These usually take anything from 2 hrs 35 mins - just over 3 hrs) and these are on all machines.
- Most machines have a timed programme where you can set it to start working at a later time but this is unsuitable for the Fate mixture, simply because the low protein mixture starts to prove and rise straight away, hours before the machine starts the programme.
- If I need a fresh loaf for early morning, or when returning home in the evening, I just load the machine and leave it to bake as normal. The loaf will be fine left in the machine after baking. Sometimes the loaf will be a bit softer at the base because of all the moisture from baking, but after a short while on a wire rack, it soon dries off and is perfectly OK.
- I also found that the various whole-wheat programmes did not give such good results. This is because the machine has a rest and heating session right at the start, before it begins to mix the bread. This caused the bread to be half risen even before it was mixed properly.
- Some machines are advertised as having a Rapid Bake programme, where they produce a loaf in around an hour. I found that these were a bit hit and miss, and the bread came out a little bit heavier. Although I have spoken to someone who uses a Rapid Bake machine, and then when it has finished baking, uses an extra programme which just extends the cooking time by another 30 mins. I was told this is very successful.
- Sometimes a loaf will have an uneven top because of the way the machine mixes, especially those that have the taller baking pans. I usually cut this top off into a thick slice and it is eaten in chunks. Also, the paddle leaves a small hole in the middle few slices, so they may be unsuitable for sandwiches, but I usually sort these out and use them for toast. Remember, if the paddle is still in the base of the loaf when you turn the loaf out, just leave it in the bread until everything is cold. This way, you will avoid making a bigger hole.
- Machines only bake whole loaves, they do not bake rolls, baguettes or different shapes of bread. Although there is a dough programme on all of the machines this usually takes around 1 hour 40 mins. You still have to take the mixture out, shape it into rolls and then prove and bake them.
- DO NOT OPEN THE LID WHEN THE MACHINE IS WORKING. A great deal of heat will be lost, and the bread will not cook thoroughly, and will be spoiled. If you want to try a recipe such as Fate Machine Fruit bread, or other

flavoured breads, put all the extra ingredients such as fruit or spice, in at the beginning, so that you do not have to open the lid. Unlike ordinary bread, Fate mixture is quite soft, and the added fruit or other ingredients will not be crushed.

- The outside measurements of different machines varies a lot, and some are quite bulky. The weight also varies. This is something to consider if you go on holiday etc. When we took a machine with us on holiday to Spain, we carried it in a sports bag as hand luggage on the plane, and it was easy to carry. (Don't forget an electric adapter)

## Bread Recipe using FATE flour

The recipe to use is exactly the same recipe you use for all Fate low protein bread and rolls, etc. that's 500g (1 pack) Fate All-Purpose Mix, sachet yeast, (enclosed in the pack) 2 tsp salt, 120mls oil and 450mls warm water.

After that, all you need to think about is the size of baking pan your machine has, and the programme that will work best.

However, most machines will NOT hold the full amount that the recipe makes, so, after making up the Fate mixture, you just put in the amount that the baking pan will hold. An easy way to calculate how much to use, is to first measure how much water the pan holds. If it holds more than 2 litres and 700mls of water, you need all the mixture EXCEPT 150g. If it holds less than 2 litres 700 mls, you will need all the mixture EXCEPT 200g.

(Do not worry, you won't waste the left over mixture, I'll tell you what to do with it at the end of the recipe\*\*)

Remember to measure the water and the oil accurately. It is best to use a baby's feeding bottle.

Also, make sure that you add 2 full teaspoons of salt.

## Ingredients

- (500g Fate All-Purpose Mix (full packet)
- sachet of yeast (enclosed with pack)
- 2 tsp salt
- 120mls oil (I usually use sunflower oil)
- 450 mls warm water.

## Method

- Place the Fate Low Protein Mix into a bowl. Add the sachet of yeast and the salt. Stir well.
- Measure the oil and the warm water in a separate jug, and pour it all onto the dry ingredients. Using a wire whisk, start mixing quickly to get everything blended together. The mixture will be runny at first, but after about 30 seconds, it will begin to thicken. By this time, the mixture should be smooth and free from lumps. There is no need to mix it further.
- As soon as the mixture is free from lumps, it is ready to go into the machine.

Do not put all the mixture into the machine. If your machine holds more than 2 litres 700mls of water, take out 150g of the mixture, and put the rest into the machine. If your machine holds less than 2 litres 700mls of water, take out 200g of the mixture, and put the rest into the machine.

- Set the machine to give you the programme you want, then press start. On most machines I have found that the Basic, Basic Rapid or Normal cycles give the best results. Most machines have a count down timer, so that you can check the progress.

**Do not be tempted to open the lid until the machine has completely finished.**

- When the bleeper signals the end of cooking, switch off the machine, and remove the bread pan. Gently shake the bread out onto a wire cooling rack. If the mixing paddle is still in the base of the bread, leave it in until the bread is cold, then remove it.

If you want fresh bread for the following morning, or when returning home in the evening, just load the machine and leave it to bake as normal. The loaf will be fine left in the machine after baking. Sometimes the loaf will be a bit softer at the base because of all the moisture from baking, but after a short while on a wire rack, it soon dries off and is perfectly OK.

- When the loaf is cool, wrap it well to store. To slice, it is much easier if you use an electric knife.

Like all fresh homemade bread, it is best eaten within about 3 days. I usually store it in a large food or freezer bag.

\*\* The mixture that is taken out, can still be used in many ways: *Either* : **1.** Stir the mixture for an extra 30 seconds, then put it onto a baking tray, then dust your hands well with extra All-Purpose Mix, and pat it out into a rough circle for a pizza base. This can then be frozen as it is, or left to prove in the usual way and then frozen. Defrost it when you need it, top with suitable pizza topping and bake in the usual way. Or: **2.** Freeze the mixture as it is, in a lump. When you need it, just defrost it, stir it for about 30 seconds, then use it to make a low protein pizza base or pitta bread. (Full instructions of shaping and cooking are in the pack of Fate All-Purpose Mix)

### Bread Recipe using Juvela Flour SHS International Ltd JUVELA Low Protein Breadmaking in your Breadmaker

This recipe is suitable for use with most Automatic Breadmakers

#### Basic Recipe

##### Ingredients:

- 300ml (12floz) water
- 1 x 15ml (1 tbsp) vegetable oil
- 350g (14oz) JUVELA Low Protein Mix
- 1/2 x 5ml sp (1/2tsp) salt
- 1 x 5ml sp (1tsp) dried yeast (measured from sachet supplied with mix)

##### Method:

- Place the water and vegetable oil in the bread pan. Add the JUVELA Low Protein Mix, salt and yeast and place the bread pan in the breadmaker. Select the WHOLEWHEAT programme, *although generally longer, this slower programme is beneficial when making low protein bread.*
- Once the paddle starts to mix use a rubber/plastic spatula to incorporate any Mix from the sides of the pan.
- When baked, leave the loaf to cool slightly before removing the pan. NB. The paddle may stay in the loaf. Take care removing as it will be hot!

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## Machines Tested *by Eileen Green*

*Here is a list of the machines I tested. I have placed them in order of the ones I liked the most. I recommend the first five.*

- 1 **Cookworks. Price £39.99** Made by the Alba group, exclusively for Argos stores. I love the shape of loaf it made. This has a good "farmhouse" style shaped baking pan. A basic, no frills machine, but it makes really good bread. It is the smallest, lightest machine, one of the easiest easy to transport for holidays. I use number 3 programme, 2hrs 35 mins. It holds less than 2 litres 700 mls. Tel number ~ 02087 873111.

- 2 **Hinari HB 164 and HB 174** Price £49.99 in white, £59.99 in silver. Made by the Alba Group. Both good reliable machines. Has a tall bread pan. Holds just a little more than 2 litres 700mls. I use Basic Rapid Programme, which takes 2 hrs 35 mins.

I've had an Hinari 164 for more than 3 years, and bought another about 10 months ago. It had the same model number, only the numbers on the programmes had been changed around. The 174 machine is the newer model, although 164 is still available. Available at some Tesco stores, Makro or a mail order company : JD Williams. Tel. 0161 238 2000 or for customer services: 0870 6033 603. You could also telephone Alba plc for stockists, on 02087 873111.

- 3 **Morphy Richards Standard, 48210 Stainless steel. £89.00.** Available in Argos. Really large, tall, pan. Holds 3 litres 300mls. It easily holds the larger amount in the recipe. Good reliable machine, makes good bread. bread usually comes out a darker colour, even though it does not give you a choice. Perhaps not a machine for people who don't like really dark crusts.

Also, it is one of the bulkiest machines, so probably not a good choice if you travel a lot. I use the Basic Rapid programme 4, it takes 2 hrs 40 mins. I've been using an earlier version of this machine 48200 for over 4 \_ yrs, and it is still making good bread.

- 4 **Morphy Richard Icon . Number 48221** I paid £45.00, but it was a discounted price, they are usually more like £55 - £60 Widely available. I've seen them in Asda, Curries and Comet. The outside is made from stainless steel, and looks good, but it shows every finger mark. This has a tall pan, holding about 2 litres 500mls. Best used on the Basic White Large 1.5lb Dark setting 3, which takes 3hrs 10 mins.

- 5 **Morphy Richards Fast Bake 48230** About £60. 00 I bought it at Argos, but they no longer stock it. Available at Comet, Curries and Powerhouse. Not too successful with the fastbake, but much the same for all other programmes. Just like other Morphy Richards machines, Use the programme 2 or 3 for best results.

**There is a telephone Helpline for Morphy Richards ~ 08450 777700.** They will tell you the stockists for your area. I was also told that all the Morphy Richards machines are basically the same. They all have all the same basic programmes, but the machines have different added features. i.e. cool walls, fast bake, or slightly larger baking pan.

- 6 **Kenwood BM200** with Rapid bake around £119.00. Available from Argos, Comet, Co op. Tall pan shape. (They took off £40.00 in the January

sale). I used the number 2 and 3 programmes and had good bread, but, it was probably the most disappointing machine of them all. Not because of the bread that it made, the bread was OK. It was because of all the money I spent.! It seemed to me, that it was made of very thin metal, and compared to all the others, I thought that it wouldn't be able to take much work !. I had the feeling that someone was just trying to cash in on the reputation that Kenwood has. Also, it was advertised on the tele over Christmas, and I wondered if that was why they charged so much for it. Or is that just cynical old me again?  
**Kenwood Customer Careline ~ 02392 392333**

- 7 **Breville Home Bake** around £69. from Argos. A really upside down machine. By that , I mean, it seemed to do everything completely the opposite of the other machines. The heating element is integrated around the top rim of the pan, and I thought with all the putting in and taking out, it was bound to get damaged. Also, because the heat was mainly at the top, the top third of the loaf was a golden brown, but the bottom two thirds remained white. This meant the loaf was very soft. The machine has only 4 programmes, and the basic rapid cycle took 4 hrs, which was the longest programme on there!. I baked successfully on the Basic Medium programme, and chose a dark crust. It took 3 hrs 31 mins. Overall the loaf turned out lovely, it has a very large pan, with a very good farmhouse shape. but the crust was very soft and not at all brown apart from around the top rim where the element had been. The inside of the bread was very smooth.

The outside of the machine is small, and it has a nice rounded shape. A nice looking machine, probable a lot more attractive than a lot. I found it extremely noisy, at times annoying.  
**Breville have an advice line ~ 0161 652 1211**

- 8 I also tested **Prima ABM 3** - Now discontinued, but may still be available, hopefully as a bargain. I really liked this machine. A smaller, light machine. Probably would have been at the top of my list if it had still been available. I was told the Prima ABM 7 is the replacement. **Prima telephone number for further information is ~ 01132 511500**

- 9 **Prima ABM 8** - Around £79.00 from Curries, This is a new twin paddle machine, one paddle larger than the other, and I thought it made the loaf uneven as the larger paddle seemed to push the dough over to one side producing a lop sided loaf. I thought this machine was going to be really good, especially after I liked the Prima ABM 3 so much. I had to try a lot of programmes before I got a good result. The thing that I fancied about this machine was its size and long shape of pan. It would hold virtually all the mixture. Disappointedly, almost all programmes started with a rest and heat session before starting to mix, "to get all ingredients at the correct temperature for kneading" and was unsuitable. The only programme that I had a decent loaf with was the rapid cycle, which had only a three minute heat and rest. This was OK.

*If you would like further information or would like to talk about anything in this Automatic Bread Machine Report, please contact Eileen Green on 01215 22 44 34. There will be a further report in future News & Views as new makes and models are being introduced all the time.*



## Soups

### Carrot, Ginger and Honey Soup

#### Nick Nairn's Recipe

*You will probably remember in the last issue of News and Views there was a report from Barbara Cochrane on a wonderful cookery day they held in Glasgow. The day was made all the more special as they had a TV celebrity chef there called Nick Nairn. Nick Nairn is regularly on TV and also runs some very exclusive restaurants. At the cookery workshop day Nick rustled up a carrot, ginger and honey soup and gave out some very good tips on soup making. I can do no better than reproduce Nick's information and recipe which he prepared that day.*

*I will add one thing (can't help it) and that is that I think a home-made soup with some lovely bread takes some beating. It is nutritious, filling and cheap and seems suitable for anytime of day except perhaps breakfast!*

The variations are endless so don't get stuck in a rut!

#### Serves 6

80g unsalted butter  
150g onion, thinly sliced  
20g root ginger, peeled  
600g carrots, peeled and grated  
1 tablespoon clear honey  
2 teaspoons maldon salt  
1 tablespoon lemon juice  
5 turns freshly ground pepper  
900ml boiling water

- Melt the butter in a large saucepan. Add the onions and stir well to coat. Don't let the onions go brown.
- Using the flat edge of a heavy knife, crush the ginger (this releases the oil). Add to the onions and let them sweat for 10 minutes.
- Now add the grated carrots, the honey, the lemon juice and seasoning. Stir well. Pour in the boiling water and bring to the boil. Simmer for 45 minutes. You may have to add a little more water during this time to allow for evaporation.
- Remove the pan from the heat and liquidise the contents (with a hand blender or in the liquidiser) until smooth and creamy.
- Check the seasoning and serve.

If you are making the soup ahead and you want to freeze it, allow the soup to cool before pouring it into a sealable tub and putting it into the freezer. If you're not freezing it, the soup will keep well for up to three days.

**Nick tells News & Views readers...** I love soup. I find it a very comforting thing, both to make and eat. Especially with slices of freshly baked bread slathered with good unsalted butter. My own soups seldom have stock in them. I rely on good technique to get the best flavour from the ingredient.

Home-made soups are worth the minimal effort they take for many reasons. For one, home-made soups can be awesomely nutritious. Secondly they can be stunningly delicious. Soup can be a satisfying and wholesome lunch, or it can be a delicate start to a meal.

Sweet carrot, smooth honey and spicy ginger have a natural affinity that makes this soup lip-smakingly tasty. However, the good, no, the great thing about soup is that you may have the makings of a terrific soup in the salad box of your fridge ready to knock together at a moments notice – all you need to do is follow the basic rules below.

#### Basic Soup Rules:

1. Use ratio of approximately 25% onion to the main vegetable ingredient.
2. Cut the vegetables into the smallest pieces possible i.e. 5mm dice. This reduces cooking time (an electric food slicer is handy for this)
3. Always add the boiling water to the vegetables as this reduced the time the soup is off the boil, during which it can stew and lose freshness.
4. Once cooked, liquidise the soup and cool it as quickly as possible, this keeps the quality and flavour.
5. It's much easier to make a big batch of soup. That way you can freeze it in handy-sized portions and then liquidise it once defrosted and re-heated.
6. The soup is cooked once the vegetables are soft and tender. Timing varies for different vegetables.

#### Approximate cooking time for vegetables:

Artichoke: 35 minutes  
Carrot: 45 minutes  
Cauliflower: 45 minutes  
Tomato: 20 minutes  
Parsnip: 50 minutes

## "Cheese" Substitutes & Flavours

### Cheese substitutes

*These are mostly made from soya or tofu and because these main ingredients are high in protein the cheese substitute tends to be high in protein too. Many of them contain as much protein as ordinary cheese. There are makes you will find in health food shops and the supermarkets such as Soya Kaas which provide 6g of protein in a 25gram serving. This would mean that you could only have 5g of the soya cheese for one exchange. It's not worth it and because the weight for one exchange is so small even a little over the required weight for one exchange can make a big difference. An extra 2.5g would give another half exchange!*

### So, what is suitable?

There is a vegan style of cheese made by American Natural Snacks which you might like to try. Vegans don't eat any animal products at all. (Many soya-based cheeses contain casein, which is a milk protein)

### American Natural Snacks

VeganRella Cheddar 1g protein per 25g serving.  
VeganRella Mozzarella 1g protein per 25 g serving.

### The Redwood Company

They produce a cheese substitute called **Cheezly**. Cheezly comes in various different flavours and is available from Tesco's, Sainsbury's and Holland and Barratt and other independent health food shops.

#### Protein contents:

Nacho Flavour 3.3g protein per 100g  
Bacon flavour 6.5g protein per 100g  
Grated Cheddar 3.1g per 100g  
Mature Cheddar Style Red and White 3.9g protein per 100g  
Garlic and Herb 3.6g protein per 100g  
Feta 1.42g protein per 100g

Cheezly can be melted, grated, and sliced. It can be added to low protein sauce and will melt in the sauce. As Cheezly does not contain any casein it will not stretch like ordinary cheese. If put on top of vegetables and heated it will melt and colour too.

### BISTO Cheese Granules

50mls made-up as directed gives half an exchange

### Home-Made Cheese Sauce

You can make your own cheese sauce by melting some Walker's Snaps Cheese Flavour into some low protein sauce. You get 65g of Snaps for one exchange. This is a lot of Snaps! In fact one 19g packet of Snaps contains only 0.3g of protein. To give a really good cheese flavour you could use 30g of Snaps or one and a half packets crushed and melted into the sauce and this would provide half an exchange. If you are unsure about how to count this product consult your dietitian who will advise you.

### General Dietary Ltd

This company also sells two cheese substitutes by mail order or through chemist.

Ener-G Cheddar 30g provides one exchange  
Ener-G Mozzarella 45g provides one exchange

### First Play Dietary Foods Ltd

This company used to sell a "cheese" powder but it has now been discontinued.

**ENER-G LOW PROTEIN IMITATION CHEESES, CHEDDAR and MOZZARELLA** can now be ordered from the pharmacist of any chemists and not just by mail order. The recommended price is £13.99 per 900g block. Members should check the price with their pharmacist when ordering. If assistance is required please telephone General Dietary Ltd on 020 8336 2323.

find  
us on  
the  
web  
@:  
**www.nspku.org**

**Can anyone translate into Greek?**

I was recently asked to provide some simple information for a family travelling to Greece and I do not have anything. Can anyone translate a piece of A4 for me? It wouldn't take too long and it would be very helpful for others travelling to this popular country for their holidays. Contact - nspku@ukonline.co.uk

**Discontinuation of products****Ultrapharm Ltd**

Ultrapharm regret that Aprotin Low Protein Bread Mix and Aprotin Low Protein Cake Mix has been discontinued by the Italian manufacturers.

**Difficulty in Obtaining Prescriptions**

Several of you have helped me with information about your difficulties in obtaining low protein items on prescription from your chemist. In most cases this has not been the problem with the chemist but with the wholesalers supplying the chemist. I am still anxious to hear from you if you haven't already contacted me.

A parent did contact me by email towards the end of February but unfortunately due to difficulties I was having with my email at that time I lost the

information. If you contacted me by email about your case and you haven't had a response from me would you be so kind as to send me another message?

I also had an answerphone which wiped off all my messages if there was a power cut or the trip switch went in the house. As the system in my house is very sensitive this has happened a few times. If you do leave a message and I haven't returned your call within 2 days please try again. The old answerphone has now been replaced and all messages are saved with the new machine.

## Incorrect Labelling of Scotbloc Plain Chocolate Cake Covering

The chocolate cake covering was labelled as containing 0.3g or protein per 100g. This is wrong. The actual protein content is 3.6g protein per 100g. All future packaging is being changed but please be aware that this is not a free food.

Eleanor Weetch  
**Society Dietitian**

# Competition

*Do we have any*

*budding authors out there?*

Many of you will know of our publication called *Mummy, why can't I eat your food?* This has been a very much-used booklet and seems to fit all kinds of needs but it is now looking rather dated. Photographs seem to date more than text for example when did you last see a boy with his shoe laces tied and wearing a handknitted and fastened jacket?!

We would like to change the booklet into something which rather more tells a story about a little person with PKU. We think that the present booklet might be too difficult for a child of only 8 years and under to understand. Pictures of children, foods and outings might be nice which tell a simple story about PKU.

Can you take up the challenge? A father of a little girl with PKU (John Skidmore) has very kindly donated a prize of £50 in WH Smith's gift vouchers for the winner.

*The competition is open to all ages.*

*Please send your entries to me*

*The closing date is September 30th.*





# Fate Special Foods recipes



## FATE TOMATO AND ONION QUICHE

The idea for this recipe was given to me by my friend Anne, who has a daughter called Kylie who has PKU. Anne phoned one day and said she had made Quiches using Fate Savoury Pastry, a mixture of vegetables, and the Fate Omelette recipe. They were "devine" she said! So, of course, I had to have a go. This is the recipe I came up with.

You can vary the combination of lightly cooked vegetables and add any herbs or spices that you like (and are allowed).

Onions, peppers, mushrooms, tomatoes and courgettes, can all be used and combined with different herbs such as parsley, chives, oregano, or thyme makes a very tasty mixture. You can also make large quiches for cutting into portions, which I think look great, or you can make individual ones which are perfect for packed lunches.

It is such a great recipe to have for anytime, perfect eaten cold for lunch boxes or picnics, or served warm with salad for dinner! Also, a must for any buffet table!

First, prepare the filling (amounts do not have to be exact)

2 tbsp oil

20g butter

150g onion sliced

400g tin chopped tomatoes, drained, (or whole ones, drained and chopped)

1tbsp chopped fresh parsley, chives or other herbs.

salt and pepper to season

Heat a frying pan and add the oil and butter. Put in the sliced onions, and quickly fry over a high heat for about 3-5 mins until just softened and browned. Add the parsley or other herbs, and leave to cool. Pour the tin of tomatoes into a sieve, and leave for a while to drain the liquid away. (Discard the liquid or use it for something else.) Pre-heat the oven, Gas mark 6, 200°C 400°F.

Next, prepare the pastry (This is also included in the recipe sheet in the All-Purpose mix)

250g Fate All-Purpose Mix

\_ tsp salt

125g butter or block margarine

50mls water

little extra All-Purpose Mix to roll out

Place the All-Purpose Mix, into a mixing bowl, and stir in the salt. Rub in the butter until the mixture resembles fine breadcrumbs, then continue until it resembles coarse breadcrumbs. Add the water and mix quickly with a metal spoon until smooth. Do not worry if you think it is very soft, just leave to rest for a couple of minutes. Lightly dust the worksurface with a little extra All-Purpose Mix and knead the pastry a few times until smooth. Roll it out and line a 20cm (8.5inch) flan tin. Next, prepare the Fate Omelette mixture: (This is also included in the recipe sheet in the All-Purpose Mix

75g Fate All-Purpose Mix

1tsp baking powder

salt and pepper to season

30mls oil

100mls water

little yellow colouring (optional)

Place the All-Purpose Mix into a mixing bowl, add the baking powder and season with salt and pepper. Measure the oil and water into a separate jug, and add just a couple of drops of yellow colouring to make a light golden colour. Pour the water and oil mixture onto the dry ingredients and using an electric hand mixer, mix on high speed for about 1\_ mins. It will then be a smooth light mixture which looks like a light and creamy mayonnaise.

Then put the Quiche together: Add the cooled fried onion and herb mixture and the well drained tin of chopped tomatoes to the omelette mixture. Using a large metal spoon, very gently and lightly, stir everything together. Spoon it into the pastry case and spread it to the edges. Place into a preheated oven for about 30 mins until golden brown, firm and cooked through. The Quiche freezes well, just defrost and warm through.

## MUSHROOM QUICHE

Follow the recipe for Onion and Tomato Quiche, but just substitute the tomatoes for mushrooms. Still use onions and herbs to flavour. You will need about 150g mushrooms, sliced or cut into medium sized pieces. These need to be lightly cooked beforehand. You can cook them in the same pan with the sliced onions, and then leave them to cool before stirring into the omelette mixture.





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**Eileen Green**

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Children's Poloshirts (Red, White, Navy, Jade, Black, Dk Green) 3-4, 5-6, 7-8, 9-11 years		1ST CHOICE: 2ND CHOICE:	£6.00		
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