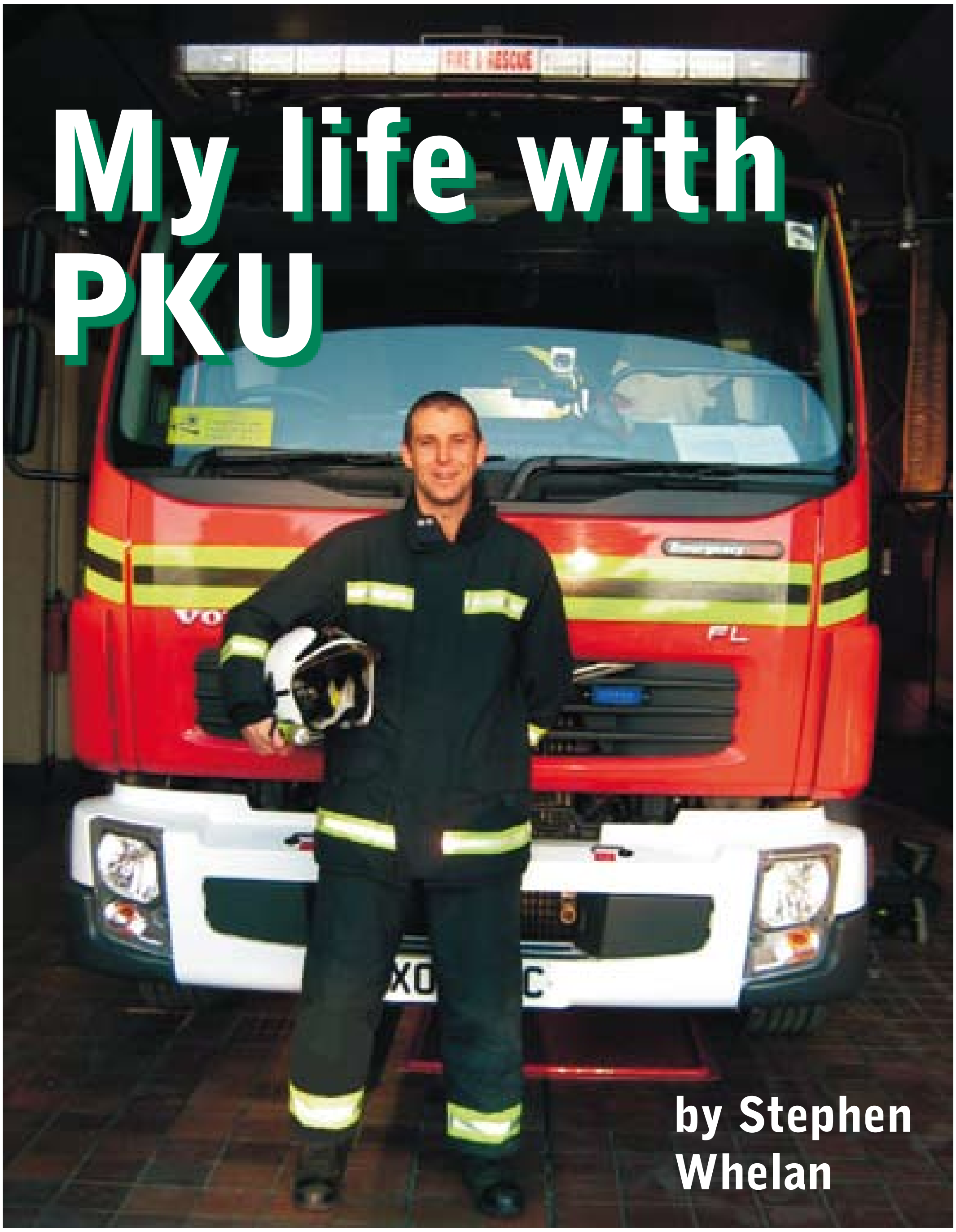
NSPKU
News&Views
The National Society for Phenylketonuria (UK) Ltd
Spring 2010
Issue 130

Inside this issue...

My life with PKU



by Stephen Whelan

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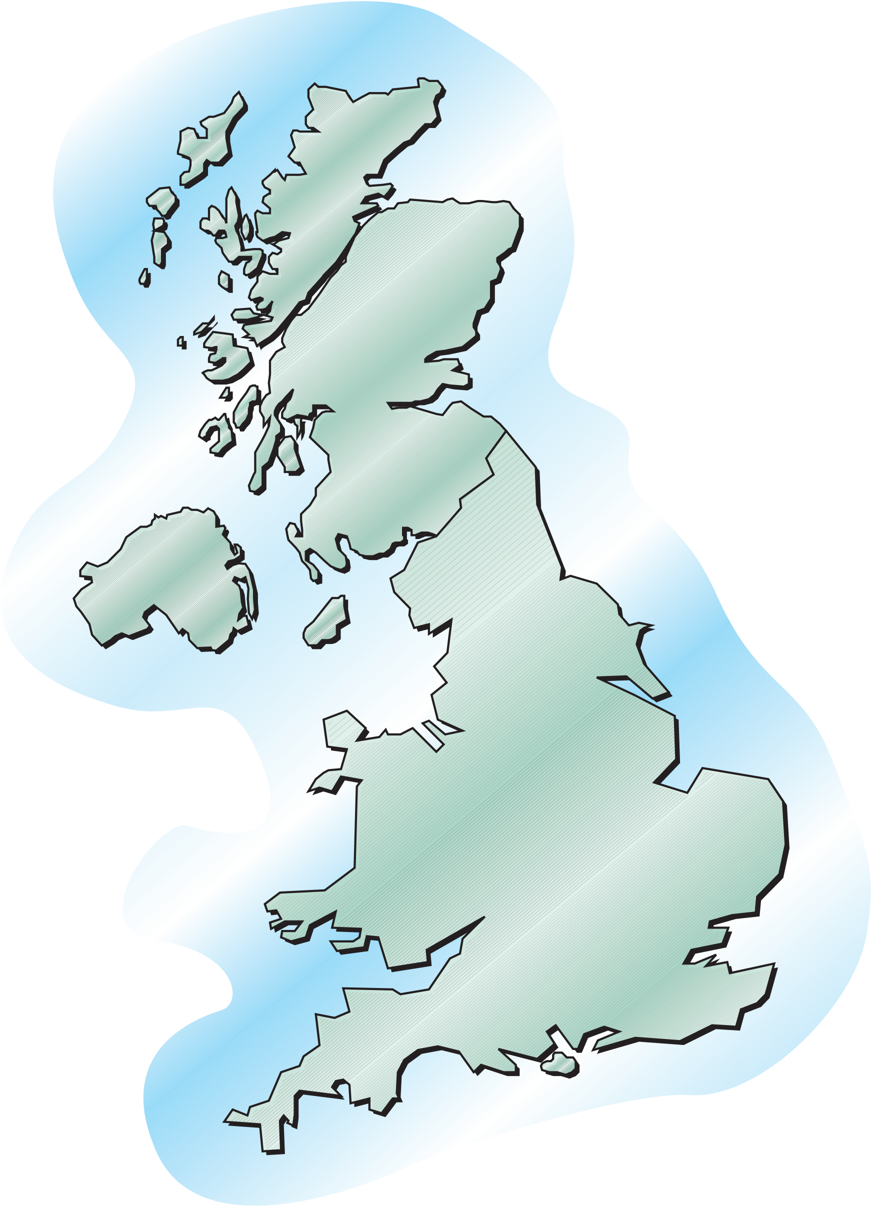

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Editor's Report...

Dear Readers

It is well into January as I write this and I cannot believe how quickly this month has flown by. It seems like only yesterday that we were over indulging in all things delicious!!

Many thanks to all those who have sent in bits and pieces for this issue. I was getting worried that it would be a "thin" one, but the members have once again risen to the challenge and filled the pages with interesting reading.

Hope to see many of you at the conference in March.

Anne Verster

Editor

Donations of over £30 for inclusion into News and Views Magazine

Name	Amount £
Chyna Appleton and Year 6 pupils @ Clifton Primary School	140.88
In memory of Mrs Barbara Woodall	980.00
Sam Leahy's Beaver Group	137.25

NSPKU
The National Society for Phenylketonuria (United Kingdom) Limited

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Letters

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

Dear News and Views,

I have just read through the Winter 2009 edition and the letters section with particular interest. The first letter, from Margaret Maksym, concerning her son who is interested in joining the RAF struck a chord with me as I have had a similar experience.

I am 38 years old, have PKU and have been on my diet since birth. In fact, I have been told that I was the first person detected as PKU using the newly introduced Guthrie test at Southampton General Hospital in March 1971. My father was in the Royal Navy and I always had an interest in joining. I joined the University Royal Naval Unit whilst at Bath University and pursued my application to join full time. Initially I was turned down due to PKU, however, after fighting the issue (at length) I was eventually accepted medically. I passed the Admiralty Interview Board in 1993, unfortunately there were very few spaces at this time and I was unsuccessful in gaining one of them.

Subsequently, after obtaining my Mechanical Engineering Degree my career path took me in to manufacturing engineering. After seven years in this profession I decided to follow my ambition for a more active career and joined the Fire Service. Ten years later I am still there enjoying myself as a Watch Manager and a member of the Urban Search and Rescue team in the brigade.

My advice to James and anyone else in this situation is to pursue their dream as the unexpected does happen!

I am more than willing to chat to anyone about my experiences with PKU and, if interested, write an article for the magazine.

Kind regards
Simon Whelan.

Dear News and Views,

We are pleased to enclose a cheque for £137.25 for NSPKU. This was raised by our son Sam's beaver group as part of a recent fund raising challenge. Sam is 6 years old and has PKU. The enclosed picture is of Sam in his Beaver's uniform. We would like to thank all his friends at Beavers for their efforts in raising these monies. If you could print his picture withy details of the monies raised, he would be so pleased.

Many Thanks
Sam's dad (Phil Leahy)

Dear News and Views,

Firstly, Happy New Year to you and your families.

This is the first time I have written to News and Views, my daughter Ruby is 3 and she has PKU. As I am so busy working full time and managing the diet, I don't often get time to send something in but wanted to let you know about a PKU story.

We own a house in France where we go every year for our holidays. Much more PKU friendly as I have everything I need over there!

Last September we spent a couple of weeks there and unfortunately my little girl had a horrible accident when her finger was trapped in a door and she severed the tip of her finger. We were in hospital in the city of Limoges for three days. I do speak quite good French so this did help but it was very traumatic as she had to have a general anaesthetic and surgery and she was very distressed. I met the hospital dietician on our second day and somehow we managed to cover the food requirements (The bread rolls just survived as they were in the process of baking when the mad dash to the hospital happened!).

On the morning of the third day the dietician asked me if I would speak to a young lady whose baby was at the hospital – with a diagnosis of PKU within the last couple of days! I of course agreed and invited her to our room to meet Ruby (who was messily eating French chocolate cereal pops quite heartily by now!). I think it must have been a chance in a million, but is was very heartening to be able to tell this new mum about the condition and what was required. She was very upset when she found out but I was able to reassure her and she left much happier and very positive!

Something very good came out of something so bad after all. My Husband and I found it very isolating when we found out at 4 weeks, there was no-one who could explain it to us – like a PKU mum. The lady concerned lived in a French territories island somewhere very remote – so was going to move back to France to better manage the PKU.

Regards
Helen Davies.

Dear News and Views,

Please find enclosed cheques totalling £405 from donations made at the funeral of my mum, Joan Johnson.

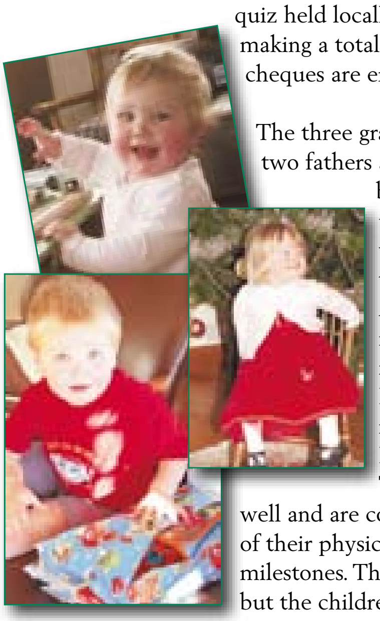
My granddaughter, Aimee Dickson, aged 4 has PKU. My mum was very proud of all her great grandchildren so my two brothers and I all agreed the money should go to the NSPKU as this is what she would have wanted.

Yours Sincerely
Hazel Buckworth

Dear News and Views,

In January, we celebrated our fortieth wedding anniversary and decided to have an in-house fund-raising dinner dance on new year's eve. We have three grandchildren with PKU and dedicated the funds raised to the NSPKU.

The event was extremely successful and not only did the eighty or so guests have a good time, we also managed to raise £3,000 for the charity. A pub quiz held locally also raised £200, making a total of £3,200. The cheques are enclosed.



The three grandchildren - the two fathers are our sons, but with two unconnected wives. Ifan, aged three years and Awen, aged fifteen months both live in Llandeilo, whilst Ffion, seventeen months, lives in Barnes, London. They are doing really well and are comfortably ahead of their physical and intellectual milestones. The diet is a discipline, but the children's' blood PKU levels remain within limits, except when they are ill. We enclose recent pictures of the children and hope that the money raised will contribute to promote the activities of NSPKU, from which we as a family have benefitted considerably.

With best wishes for a happy new year,
Yours sincerely
Terry and Pam Davies

Dear News and Views,

Please find enclosed donations to the total of £405.00 received in memory of the late **Mrs Joan Vienna Johnson** of 58 Leman Road, Gorleston, Norfolk who passed away on Thursday, 15 October, 2009

We respectfully ask you to acknowledge to the Daughter of the deceased: Mrs Hazel Buckworth, 80 Station Road South, Belton Norfolk NR3I 9AA

Yours Faithfully

June Pilgrim
Funeral Admin/Arranger
Anglia Co-Operative Funerals

Dear News and Views,

My name is Chyna Appleton and I am in year 6 at Clifton Primary School in Lytham St Annes. Every year at our school, Mr Culley (year 6 teacher), and his class organise a fundraising day for a charity chosen by the pupils. This year we chose the NSPKU because my big brother Sam aged 12 and my little sister Poppy aged 6, have PKU.

We had great fun raising money – we ran stalls like splat, hole in one, pick a prize and the infants and juniors thought it was really fun. Our head teacher, Mr Slater, thought our splat stall was the best as he got to splat my friend Megan with water over and over again!

In total, we raised £140.88 as well as raising awareness of PKU in my school.

Enclosed is a photo of my classmates.

Yours
sincerely
Chyna (and year 6 at Clifton)


Pasta
Burger Mix
Hot Breakfast
Pasta in Sauce
Spread
Dessert
Sausage Mix
Rice pudding

E.S.PKU CONFERENCE 2009 – *Belek, Antalya, Turkey*

Arriving in Turkey on 29th October was an auspicious day. It was the 80th Anniversary of the Turkish Republic. There were flags flying and pictures of Attaturk everywhere.

The Conference was held in a lovely Hotel on the southern Turkish coast just 30 minutes drive from Antalya airport. The Hotel has been purpose built with all the usual paraphernalia . The hotel layout was well thought out and I found the verdant surroundings very peaceful. The choice of normal food was excellent , although veal is not exactly PC. One salad bar had sculptured vegetables-see Eleanor's photos. The PKU food was not very well sign posted initially-but rectified later. I noticed that there were no scales.

The Conference this year was split between Delegates (members of the ESPKU); Professionals and Patients & Families.

Delegates Program

The delegates met for two session . The first was on Thursday evening with an address by the new President David Albern highlighting what the coming year entails for the ESPKU-

- The EU Rare Disease Policy-each country must implement this.
- Defence of the food-labelling policy of the EU –the International Sweeteners Association want to remove the warning relating to Phe in chewing gum for example. (Note that the ESPKU has written to ALL MEP's to vote to reject the change.)
- further contact and exchange of information with Canada & the US
- emphasis on the exchange of information to facilitate a stronger voice in Europe.
- special guest was Dr Wachtel .

We then had a "speed dating" session so we could all get to know each other. It was good to put some names to faces.

The second session was the AGM on Friday morning at 8.30am where we voted to accept the membership for ARS VIVENDI of Poland and BOKS of Belgium.

Professionals

Eleanor – see Dietitian's report.

Patient & Families Program

This began on Friday with a series of workshops based on age-group. After lunch we were privileged to be given a talk by Manuela Stecher of Germany on untreated PKU. Manuella was born 1 week after testing for PKU began in Germany and was diagnosed as having PKU. Tragically, her sister who was born some years earlier was not. The sister has never been on diet.

We were shown a harrowing film of her sister's life in a home in the Black Forest. They are trying desperately to get her onto diet to see if it will improve her quality of life. Naturally the talk sparked a tidal wave of emotion in the audience-particularly amongst the Turkish families, as about 5% of the population are not tested at all. Even a German woman mentioned that a four year old had slipped through the net and wasn't picked up as PKU until 14 months old. Tragic times for some, and they need our support.

The next talk was from Yvonne Mille from Switzerland whose son is on BH4. She is very positive about the diet and told us about travelling with her son who had PKU.

I was intrigued to learn that her son enjoys playing Rugby .

Day Trip to Perge & Aspendos

We could see a storm brewing in the distance, but we were fortunate enough to make Perge and Aspendos before the heavens opened. And boy did they open!!!

Perge was originally inhabited by the Hellenics, then the Romans, then the Byzantines. The majority of the remains are unmistakingly Roman. We initially walked around a stadium which still showed its Hellenic architecture. Then, onto the town itself. The Romans had built an aqueduct -35 km long-to bring water to the town. An amazing feat.

The aqueduct brought water right to the centre, where it was then split into two channels

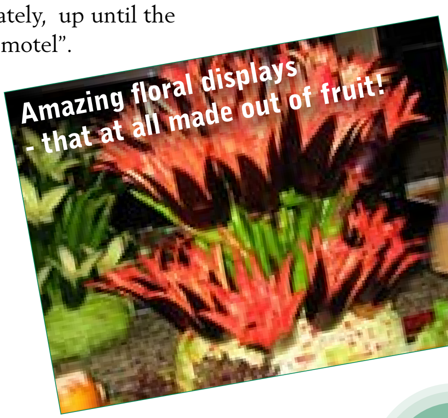
One channel for the hot baths, one channel for the cold .

After the Byzantines came the camel trains. Much of the entrance to the town was used as a "camel motel" .

After Perge we went to Aspendos –an amphitheatre. We were told it held 15,000 people.

Having resisted the urge to launch into a Shakespearean monologue on the stage, I climbed to the top and back before the heavens began to open. Unfortunately, up until the 1920's, this too was used as a "camel motel". We were told that it was Attaturk himself who told the local people to restore it to its former glory as best as possible.

On the coach journey back, we were able to see parts of the aqueduct that the Romans had built. An excellent lesson in history thoroughly enjoyed by all.


Amazing floral displays - that at all made out of fruit!

E.S.PKU goes fundraising

A review of the fund raising swim at our Annual E.S.PKU Conference in Turkey *by Dinah Lier (Vice-President of E.S.PKU)*

My personal conclusion: "We had a great and successful fund raising swim! The audience had its fun, the swimmers showed a great engagement and the sponsors enabled us to raise an excellent amount for the support of future PKU-research projects."

The begin of this project:

In 2008, after the new executive board of E.S.PKU has been elected, some new ideas on a possible future directions of the organisation were introduced and have been adopted and implemented until today. One of these projects was initialised by David Abeln, the President of E.S.PKU: the fund raising. The goal of this project is to raise money, together with our member associations, and like this we support the PKU-research with bundled forces.

As the executive board of E.S.PKU also wants to be active in the fund raising area – and not only asks its members to take action – I brought up the idea of organising a fund raising event at our annual conference in Turkey: the "fund raising swim".

Short information about the fund raising swim:

· Where and when did it take place? - The fund raising swim took place at our E.S.PKU Conference in Turkey, on Friday 30th October 2009. We were allowed to use the outdoor pool of the hotel to realise the fund raising swim.

· Who joined the swim? - 16 engaged simmers decided to jump into the pool to raise money to support the PKU-research. The swimmers were divided into the following categories: executive board of E.S.PKU, professionals, PKU adults and delegates.

· What were the conditions of the swim? - Each swimmer swum as far as possible within 15 minutes.

· How could the swimmers be supported by sponsors? - The sponsors could sign up to support one or more swimmers with an amount per 50m (of the swimmers swum distance) and/or a maximum amount. The registration for a sponsoring could be done via internet on the homepage (www.espku.jimdo.com), which has only been set up for this occasion, or on a registration form on location.

On the homepage, there was also a flyer, which could be downloaded and used for publication of the fund raising swim.

The fund raising swim on Friday, 30th October 2009:

After spending a great and eventful day at the conference, a big group of people met at the outdoor pool of the hotel on Friday evening at 9pm. Usually the pool is closed by that time in the evening, but the hotel allowed us to use it for our event. Before the first group of swimmers started off, I announced the conditions of the fund raising swim to the swimmers and the audience. To ensure that the swimmers have got enough place to swim without being disturbed by each other, we arranged to start in two groups. Some of the swimmers counted their covered lengths by themselves and others preferred to ask a friend, who was in the audience, to count the amount of lengths, which he/she swum. While the swimmers proved their sportive efforts, the audience had additional entertainment by some nice music and a very helpful and amusing host of the hotel. And of course, everyone was able to get a drink at the pool bar.

The event was finished after approximately 45 minutes, which were quite exciting, sportive and amusing. As the water of the pool was quite cold, all the swimmers looked very much forward to getting a hot shower after their swim.

After our conference dinner, I was very proud to announce the result of our fund raising swim on Saturday night: The swimmers raised – thanks to their sponsors – approximately 4300,- Euro for future PKUresearch projects!

At this point, I would like to express my gratitude to my two helpers, who gave me great support in the organisation of this event – my sister Anja and my friend Déborah – and likewise to all the swimmers and sponsors! Thank you very much for your support!

The executive board of E.S.PKU would like to continue the project „E.S.PKU goes fund raising" and we will most likely organise similar fund raising events at our conferences in the future.

The feedback, which we got from some of the member associations, was very positive and I was very happy to hear that some of the delegates already announced that they will join the fund raising event, and help to raise money to support the PKU-research, next time.

Because they really do taste as good as they look...

All recipes developed, tried and tested by Eileen Green using:

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Fate Special Foods recipes

Hello

This cake has a really good flavour because of the lemon rind and the grated nutmeg. Try a piece with a cup of coffee. It is also perfect for pudding, and for a packed meal.

As nutmeg loses its flavour very quickly as soon as it is grated, try to buy whole nutmeg and grate it on a fine grater as and when you need it. If you can only buy ready grated or powdered nutmeg, you should use it up very quickly.

Try also to use strong flavoured apples in the cake, such as Cox's, or Braeburn or Granny Smiths and leave the peel on.

I use a cake tin about 22.5 cms square, and about 4 cms deep, but you can use a round tin, about 22cms diameter and 4cms deep

The cake freezes very well.

FATE GERMAN STYLE APPLE CAKE

Ingredients

250g Fate Low Protein Cake Mix

½ tsp grated nutmeg

Grated rind of half a lemon

65g soft margarine

125mls pure apple juice

3 large or 4 medium eating apples, preferably Cox's or Braeburns

Method

Pre~heat the oven Gas 6. 200°C 400°F

Grease the cake tin with butter or margarine. Core the apples and cut in half. Cut each piece into 5 or 6 wedges.

Place the Fate Low Protein Cake Mix into a mixing bowl and add the lemon rind and grated nutmeg.

Add the margarine and pour in the apple juice.

Mix quickly with a balloon whisk for about 1 min until blended well.

Pour into the greased tin.

Gently place the sliced apples in lines or an even pattern on the top. Do not press them down.

Place into a pre~heated oven for about 25 mins until risen and golden brown.

Leave in the tin to cool before turning out.

Serve warm or cold.

My life with PKU

As a 38 year old adult with PKU I felt my experiences maybe of interest to others with PKU and their families and as such have written the following article in the hope that it will reassure them that life can and will be normal, here's my story so far……

March 1971 – I arrived as a healthy 10 lb ½ oz baby in Southampton General Hospital. The Guthrie heel prick test had recently been introduced and when I was 8 days old my parents were called in to the doctor's office for the result. They were sat down and a dusty old medical dictionary from a nearby shelf was opened at 'P' in front of them. The doctor explained that the test gave a positive result and as such I was now officially a Phenylketonuria 'sufferer'. Whilst, pointing to a very short definition of PKU in the book, he added the confidence boosting statement 'read that and you're as wise as I am'.

It turned out that I was the first person in Hampshire to be detected with PKU and therefore my first two years were spent in and out of a unit near Southampton where my diet was formulated and I was assessed to determine its effect. There are stories about how I used to wander around the ward eating the other children's food, especially marrow which I seemed to love. Even the "nil by mouth" sign got nibbled! I apparently required a tarpaulin to be spread out around me whilst I was fed the protein supplement as it had a tendency to be projected some distance rather than be swallowed! I believe various types of supplement were tried but all seemed to resemble wallpaper paste and didn't taste much better. Thankfully the manufacturers have since improved the recipe which makes it infinitely more palatable.

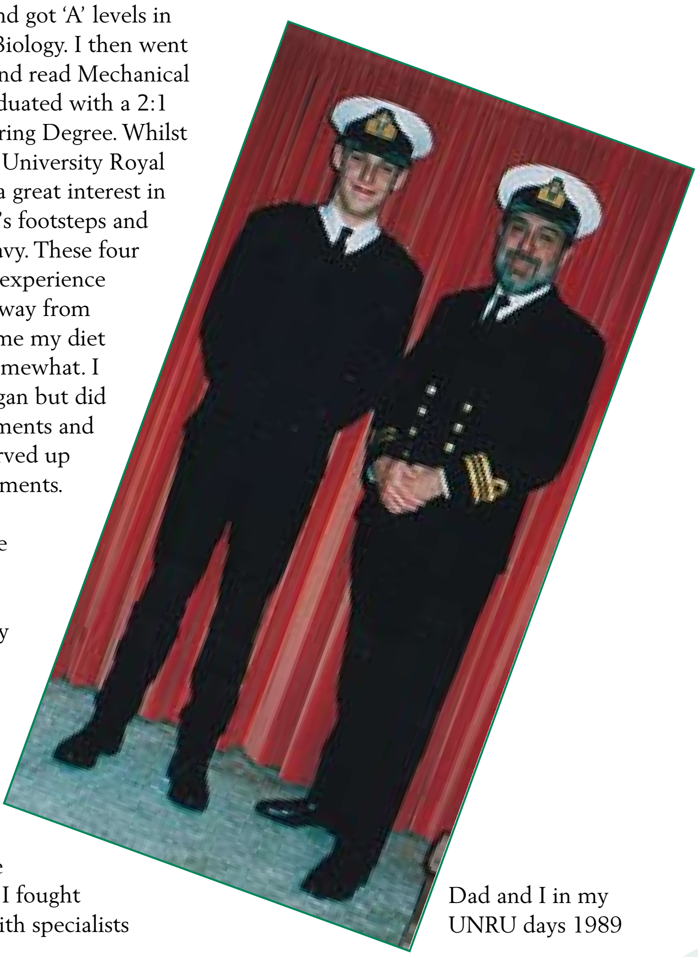
At this stage my parents were told that as soon as my brain was fully developed, at about 8 years old I would be able to come off of my diet and eat normally. As time went on, and as medical knowledge and understanding increased, the age at which I would be able to forget the diet slowly became greater and greater.


On a sailing trip in 1978

My younger years were spent in Devon and were fairly normal although school trips were very limited and holidays were non-existent. My diet consisted of half a weetabix and 4 tablespoons of milk for breakfast, lunch of cucumber sandwiches made with round tinned bread (which had a tendency to melt in the toaster and catch fire) and six chips and vegetables for dinner. I also had Aminogram and a couple of foul tasting vitamin / mineral supplements. My mum was absolutely fantastic - she made low protein biscuits and cakes for me and controlled my diet very strictly, including rushing me to the doctors after I had been given half a digestive biscuit by a neighbour who knew no better!

After gaining 7 'O' levels, I went on to sixth form college and got 'A' levels in Maths, Physics and Biology. I then went to Bath University and read Mechanical Engineering and graduated with a 2:1 Bachelor of Engineering Degree. Whilst at Bath, I joined the University Royal Naval Unit as I had a great interest in following in my dad's footsteps and joining the Royal Navy. These four years were fantastic experience and fun, but living away from home for the first time my diet inevitably slipped somewhat. I ate generally as a vegan but did not take any supplements and ate whatever was served up on the Naval deployments.

Following my degree I was employed as a Manufacturing Engineer at a factory in Paignton in Devon whilst I applied to join the Royal Navy. Understandably, they were not keen on the PKU and turned me down because of it. I fought this decision and, with specialists


Dad and I in my UNRU days 1989

At work 2010-01-20

backing, eventually got medically accepted. I attended the Admiralty Interview Board in 1993 and passed, unfortunately due to the small number of places available, I was not offered a post.

Whilst in Devon I met my future wife, Linda and continued to follow a very relaxed diet. I was made redundant and we moved to Hampshire continuing my career as an engineer for a further three years. My thoughts of the Royal Navy had diminished due to my new life with Linda, although I still wanted a more active career. In May 2000, after a lengthy application procedure, I finally joined the Fire Service and I'm pleased to say that my PKU did not worry them.

With my life a bit more settled, and after consulting with the paediatric dietitian in Portsmouth, I decided to go back on my diet and was amazed to discover all of the foods now available on prescription. I've since been referred and I'm now regularly seeing the adult PKU specialist in London.

Since then I have progressed to Watch Manager within the Fire Service and run my own watch. I am also now a member of the Fire Service Technical Rope Rescue Team and Urban Search and Rescue Team, which exists mainly as a response to the 9/11 and London bombings. This can result in national deployments in the event of particular major incidents. My PKU diet has not caused any problem at all as I am able to eat normally for short periods of time if absolutely necessary.

I consider my life now to be very good – I have a wife who I love, I am doing a job I love and I'm fit and healthy. Although PKU is a major consideration in life, with the support of my family and a bit of perseverance and motivation, it has not held me back or prevented me from achieving my goals.

Stephen Whelan

Rope rescue training 2006

PKU Christmas Parties

Bath

We had a Christmas PKU do at Pizza Hut in Bath at the beginning of December. Around 20 of us descended upon the restaurant including 7 children with PKU. Pizza Hut were brilliant and were more than happy to answer any questions we had. We took in low protein pizza bases and the children individually ordered the toppings they wanted. Pizza hut only charged us for the toppings and gave us take out boxes to take home any left over pizza. You can also view their menu online and look at the protein content of different foods. The children (and adults) all had a great time, some children who previously had not liked pizza even had a nibble. We held a secret Santa and each child had a present to take home. Many thanks to Pizza Hut who made our restaurant visit a thoroughly enjoyable and relaxed one and I am looking forward to doing the same next year. Maybe we could challenge a different restaurant to do the same.

Happy New Year
Kath Senior

Yorkshire

Around 60 children and their families had a fabulous time at this years' Christmas party in Leeds organised by the Yorkshire PKU support group. Everyone was in festive mood with games and fun being provided by a DJ / children's entertainer. Festive refreshments were provided by SHS, Vitaflo and the support group. Santa made time out from his busy schedule to pop in with festive surprises ably helped by bob the builder and a cute chick – the kids and adults were fascinated! There was also the opportunity to paint those nails and get your face painted.

The chance for parents, friends, adults and the kids to meet, chat and make some new friends in coming together was great to see. The Yorkshire support group are an enthusiastic bunch, well supported by dieticians, food manufacturers and others and the PKU family in Yorkshire continues to go from strength to strength. Please see the contact details on page 2 of this News and Views.

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Sponge Cake

Ingredients

50g (2oz) hard margarine or economy butter, at room temperature

50g (2oz) caster sugar

1x 5mlsp (1tsp) vanilla essence

115g (4$^{1}/_{2}$ oz) Loprofin Low Protein Mix

1x 5mlsp (1tsp) Loprofin Egg Replacer

1x 5mlsp (1tsp) baking powder

100ml (3$^{1}/_{2}$floz)Loproftn PKU Milk Drink

Oven temp: 190°C/375 °F/Gas Mark 5

Method

1. Lightly grease a 17.5cm (7”) round sandwich tin and line with non stick! silicone paper
2. Place margarine, sugar and vanilla essence in large bowl, beat for 1-2 mins until light in texture and creamy coloured.
3. Thoroughly mix together Loprofin Mix, Loprofin Egg Replacer and baking powder, stir into creamed mixture alternately with Loprofin PKU Milk Drink, until soft smooth batter is achieved. Do not overbeat.
4. Transfer mixture to prepared tin and level surface.
5. Bake cake in preheated oven for 15 mins, until well-risen and firm to touch. Cake will be very pale colour. Cool in tin for 5 mins before cooling on wire rack.
6. When cold cake may be split and sandwiched with jam or buttercream, top iced or dusted with icing sugar.

Makes 1 sandwich cake/4-6 portions

Additional Tips

Optional flavourings to be added at stage 3:

1. Grated rind 1 small orange
2. Grated rind 1 small lemon or lime
3. 1x 5mlsp (1tsp) coffee granules, dissolved in Loprofin PKU Milk Drink
4. 1x 2.5mlsp (1$^{1}/_{2}$ tsp) sweet spice (mixed spice, nutmeg or cinnamon)

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Dietitian's Report

On-line Guide to Free Fruit and Vegetables in the PKU diet

For some considerable time the Society has been working on a guide to all the fruits and vegetables which are free in the diet. This work was started by dietitians in Liverpool who felt we could use the information they had produced for a wider audience. At first we thought of producing an illustrated printed guide but as time went on and the problems of copywrite encountered (with using BBC pictures) we came to the conclusion it was easier and more useful to produce something on –line.

We wanted the guide to picture and explain a little about each fruit and vegetable, how they look and how to prepare them simply. Easy recipes and ideas and a guide to when they are in season have been included for each one. They are all beautifully illustrated. Of course you will recognise and know a lot of them but there are novel ways of using these foods and the more unusual are included to encourage experimenting.

We are calling this a 'draft first try' as we want to see what you think about it and very much want it to be interactive. I would be delighted to receive your comments and ideas so that your hints, tips and recipes can be shared with others and be included in the guide.

Edale Outdoor Activity Weekend July 16th to 18th 2010.

The popular activity weekend is running again and is open to any child with PKU aged 8 years to 11 years (junior school age). The idea is to make some steps towards independence as no parents are allowed! The children weigh out their own exchanges and organise their protein substitutes but with help on hand from experienced dietitians. We usually have 20 children and they sleep in single sex dormitories of 4 to 6 together. The weekend is filled with outdoor activities such as abseiling over a bridge, mountain climbing, canoeing and treasure trails.

The cost is around £80 for the weekend which includes everything. This is about half of the real cost so it is good value. The NSPKU can offer financial help to a child if needed.

To find out more or to put your child on the list of interested participants please ring me or email me using the details at the front of the magazine.

Amino Acid Analysis

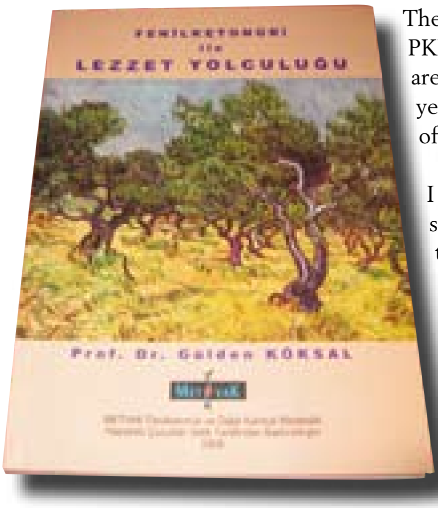
Every year to 18 months we organise an analysis of foods for phenylalanine content to further expand the choice and accuracy of the diet. This means that sometimes foods which were exchanges can be re-categorised and new foods can be introduced. Expanding the choice means the PKU diet can also be changing so less likelihood of boredom and frustration. Are there any foods you have wondered about using in the diet which we have not listed already? It would be really good to have your suggestions so please do contact me.

Previous foods analysed for phenylalanine

ESPKU Belek, Turkey

The ESPKU meeting in Belek, Turkey at the end of October was the smaller meeting for the professionals but included many families from the host country as is usual. There is a good report on the meeting on the ESPKU web site (espku.org) but I thought you might be interested in what happens in Turkey.

Turkey has a population of 73 million with an incidence of PKU of 1:6000 (in 2008). That equates to 268 patients diagnosed in one year. All babies should be tested for PKU and they have a 95% uptake but there are babies born in more remote areas who are not screened. There are 25% consanguineous marriages when relations marry. The carrier rate is 1:25 (in the UK it is 1:50). In these families with a child with PKU 49% of the parents are related.



The medical teams work tirelessly to bring PKU to the attention of the public. Slogans are printed on Turkish lottery tickets and every year they have a PKU week in different parts of the Turkey.

I met Professor Gulden Koksal who proudly showed me a recipe book they have put together – the cover is of olive trees and is a painting by Vincent Van Gogh, Professor Koksal's favourite artist. There look to be some interesting recipes in the book but of course it is all in Turkish. However, we have a mother in the UK who can speak and translate Turkish so I have asked her to pick two recipes for us to try and we will print them in News and Views. (Turkey has few low protein foods but they are hoping to make some of their own eventually.)

There was a sponsored swim one evening when several brave souls swam many lengths at night. They raised over 4,700 euro for PKU research. You will see from the photos the next host countries – 2010 Denmark, 2011 Poland and 2012 UK.

Presentation of Honorary Membership of the NSPKU to Di Asplin

Dr Paul Griffiths, Consultant Biochemist and Head of Department and Director of Newborn Screening, told us about Di's career and her path to involvement in PKU. Di practised as a school nursing sister for 9 years (she was a famous footballer's nit nurse- sorry can't name him!) before doing health visitor training and then working as a health visitor for 2 years in Stafford. She joined the newborn screening/inherited metabolic disorders team on November 1st 1992 working with Beryl Holmes, Dr George Rylance, Dr Anne Green, Dr Anita MacDonald and later Dr Anupam Chakrapani. Beryl retired and Di took on the lead role of the nursing team and oversaw the management of a period of significant growth. The current nursing team is now 8 strong.

Di concentrated on newborn screening and had the difficult job of breaking the news to parents that their baby had an inherited metabolic condition. Di's professional but friendly and supportive approach has helped many parents through this difficult period. Di also taught midwives about newborn screening and how to collect blood spots, even going to Poland to teach their professionals. Di was the first nurse to sit on the NSPKU medical advisory panel, helping to produce leaflets and videos. She attended many conferences and some of you will remember her as Denise's Mum in the famous play The Royale Family acted in Margate in 2001. Denise's baby had PKU.

I was delighted to be at Di Asplin's retirement party on December 18th and to present her with honorary membership of the Society in recognition of all she has done for families with babies born with PKU and for her support of the NSPKU. I knew that I had known Di for a very long time but had not realised it was 17 years.

The retirement party was held in the conservatory of the Birmingham Children's Hospital and so many were there who had already retired as well as those still working but who found time out of their busy schedules to wish her well.

Di is one of those people who makes you smile, is an enthusiast, is someone who always supports and is very professional. I know she has been looking forward to spending more time with her husband Mick and her daughter and Grandson in Paris. She loves getting on a motor bike and I can just see her now heading off into the sunset to start another stage of life with typical enthusiasm. We shall miss her.

Ed's Recipe Page

Hairy Bikers Style Crumpets

I am a massive fan of the "hairy bikers" and was watching their show on telly a few weeks ago. They made crumpets and they looked so scrummy that I decided to try and make them for Kylie substituting low protein ingredients where necessary. They were a huge success, so I thought I would include the recipe for you to try. - ED

Method

Warm milk substitute/sno pro till tepid
Sift flour, yeast, salt, caster sugar till well mixed
Make a well in the middle and stir in the milk substitute/sno pro
Beat for 3-4minutes till thick
Cover with cling film and leave to stand in a warm place for 1 hour till doubled in size
Add bicarb mixed with warm water to the mix – beat in
Cover again and rest for 30 minutes in a warm place – should be well risen and bubbly
Heat a non-stick pan
Grease cooking rings (I used egg rings)
Put 3 dessert spoons of the mix into each ring – on a low heat.
Cook for a few minutes till the top is set
Flip for a minute or so
Remove and put on cooling rack

These can be eaten straight from the pan with butter and jam or toasted later to give a crispy outside with a soft inside. They can also be frozen.

Ingredients

350ml milk substitute/sno pro
450g all purpose mix
1 sachet yeast
½ teaspoon salt
1 tablespoon caster sugar
1 teaspoon bi-carbonate of soda
150ml warm water
Butter

PS: I used FATE flour.

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