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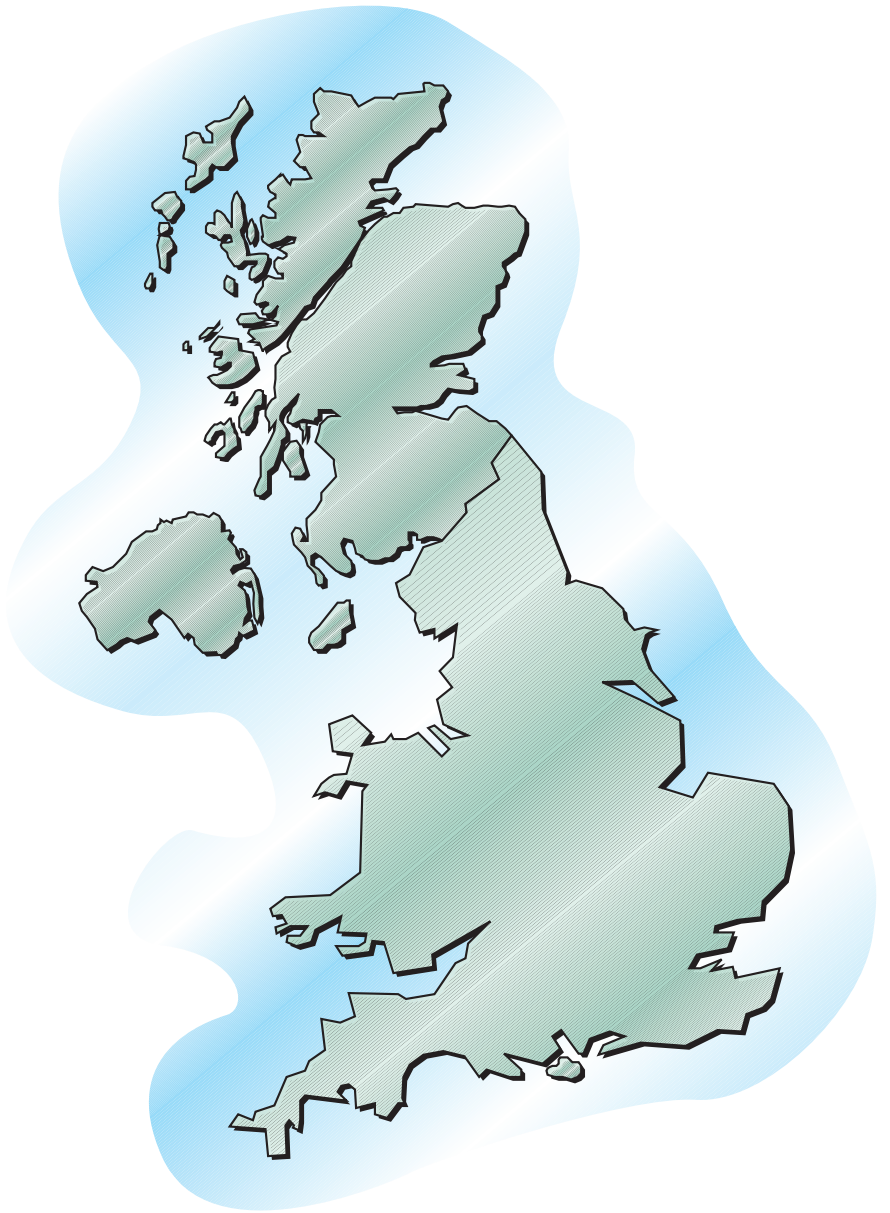
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Editor's Report...

We've had an interesting reaction to last issue's cover story. If you remember this was about the Kellies who wanted to share their frustrations at living with PKU. Some of you seemed relieved to see a feature that outlined the difficulties associated with the condition and to read an honest account of how hard it can be to manage. I think this is entirely reasonable and yet, I'd like to help! To this end, we have Danuta Orlowska's article this issue.

Danuta is a Clinical Psychologist with some experience helping people manage chronic conditions such as PKU. She has some invaluable advice on what to do when overcome with all the negative thoughts which occasionally but inevitably swamp all of us touched by PKU. Because we wanted to include her article in its entirety, I've kept the American item I promised you until next time.

As regards other PKU news, Eleanor Weetch has been travelling Europe for us, researching and networking. She has let us in on some of her very interesting thoughts and discoveries in her article. We have lots of fundraising stories and Eileen Green has included yet another fabulous recipe for us.

I hope you enjoyed your holiday time and we're very much looking forward to seeing as many of you as possible at the conference!

Happy New Year!
Kiri Thomas,
Editor.



The National Society for Phenylketonuria (United Kingdom) Limited

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Letters

News & Views, 10 Silverdale Road, Chorlton M21 0SH
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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,

Thank you for your article "The Kellies' Story -PKU is not always easy". PKU is *never easy*! Sometimes it is very hard" would be more to the point! I thank you for including this story on behalf of those of us who find ourselves isolated from your magazine for any number of reasons – all of which may be labelled "negative" but which are very real.

Our son, John, was born in 1965 and had a routine urine test (Guthrie tests were not used in England until later) which was as OK. However, we soon realised we had a very sick baby and spent 18 months trying to persuade our G.P. to let us take him to a specialist. The G.P. said we were worrying about nothing and kept fobbing us off until John was having up to 30 petit mal fits a day!

Eventually, he was diagnosed with PKU at 18 months by which time he was considerably brain damaged and suffering with all sorts of symptoms. He was put onto a PKU diet and his general health improved greatly, but not of course his irreversible brain damage!

To cut a long story short. John is now 43 years old with learning difficulties. We are in the fraught and difficult process of arranging for him to move into sheltered accommodation away from home. He is always going to need someone around 24/7.

The journey thus far has been a nightmare. Of course we love John dearly but we have had to battle all the way and have been constantly reminded of the raw deal we all received in the process. Not all of us can be "upbeat" as "News and Views would have us be!

Yours sincerely,
Mrs. E. Hellett.



Dear News and Views,

Please find enclosed a cheque for £310 for the NSPKU. This sum of money was raised at the gig outlined in the accompanying poster (see picture). An audience of around 75 people watched INDIESICE play a 2 hour set which is included songs from several popular bands, including Arctic Monkeys, Blur, Green Day, Proclaimers and Stereophonics.

I hope you can use this donation to continue your good work and support for people with PKU and having a grand-daughter with the condition I would like to think we are helping her along with others,

Yours sincerely,
Mr. D. Blackburn.



Dear News and Views,

Please find enclosed a cheque for £100 and a card donated by Bob Pinwill and Judith Blincow of the "Mermaid Inn" in Rye, Sussex. They own the pub where my husband Roger Kellie works. Roger and my family featured in last issue.

Many thanks,
Vicki Kellie.



Dear News and Views,

Our daughter Mae is 20 months old and has PKU. In March of this year, I decided that I would run a half marathon, taking place in October, to raise money for the NSPKU. In the beginning, I struggled to run half a mile so the thought of 13 was quite scary! I managed to rope in my sister Abi and a friend Lisa. Another friend Emma coached us. (See accompanying photo).



On the 12th October, we managed to complete the race and I have great pleasure in enclosing cheques totalling £604.50. We also managed to raise about £200.00 on the Just Giving site. All in all, a total of about £800.00.

I have found the NSPKU extremely helpful both in finding out about a condition about which I previously knew nothing and also in making me realise that we are not alone.

Yours,
Lucy Burks.



Dear News and Views,

I am Lady Captain of Bramhall Park Golf Club this year. As such I have the privilege of having Lady Captain's Charity for this year. All our ladies subscribe to this.

My granddaughter, Georgia Willits, of Harpenden, Hertfordshire, has the PKU condition and is already a fund raiser for the charity. I too therefore decided I would make this my charity for the year.

I am delighted to say that £1,330 was raised, which incidentally is a record for our Ladies' Charity fund-raising, and I have much pleasure in enclosing a cheque for this amount.

Georgia, aged nine years, on a visit in the the summer, came to a Prize Presentation and thanked the Ladies for the monies raised at that stage.

Yours,
June Clark,
Lady Captain.



June Clark and her granddaughter Georgia Willits at Ladies Presentation 2008, Bramhall Golf Club



Dear News and Views,

Please find enclosed cheques (posted today) totalling £847.25 raised as a result of completing the three peaks challenge on the 11th and 12th of July this year. The challenge was actually organised by the Meningitis trust so the majority of the sponsorship rightly went to them, and it was only thanks to the kindness of friends, family and my colleagues and the students at the John Bentley School, Calne that the remaining sponsorship allocated to the NSPKU was so generous. I have attached two photos, one of me on top of Ben Nevis as evidence that the sponsorship money was genuinely earned and the second of my daughter Ella, 9, who has P.K.U and was the reason for my temporary loss of sanity as I dragged myself up three mountains without any sleep!

Yours,
A. Roberts



Why we Marched 100 Miles!



The Nijmegen Marchers with Micky Doyle 2nd on right

The Nijmegen International Four Days Marches are held annually during the third week in July in Nijmegen in the Netherlands with approximately 48,000 participants from all over the world taking part. Nijmegen is situated some 12 kms South of Arnhem close to the Dutch-German border. The Marches coincide with the annual Summer Festival in Nijmegen and take place over four consecutive days, commencing on Tuesday and finishing Friday. Each day's march covers a different route, however, they all start and finish at the same place; Nijmegen town centre for civilian entries and Heumensoord Camp (5kms south of Nijmegen) for military participants. Each day's march covers one of three distances (30, 40 or 50 kms) depending on the category of entry and the age of the marcher. All military participants have to complete the 40km route.

The Nijmegen Marches is a very prestigious international marching event and is not a race or formal military parade. Nevertheless, the British Military Contingent takes part in uniform and as such represents Her Majesty's Armed Forces in a foreign country with all the attendant requirements for maintaining the highest standards of conduct, dress, bearing and discipline at all times, both on and off the march.

Our chosen Work Charity for the year was the NSPKU and we have managed to raise £1,500 which is enclosed. So, thank you to all the people who took part in the march, to the sponsors and to the NSPKU for giving us help and advice in the past 7 years.

Micky and Karen Doyle.
(parents of Elisha Doyle aged 7, PKU)

ESPKU SPAIN 2007 and ICELAND 2008

– A report and reflection on two really different conferences.

Torremolinos, Spain 2007

The annual ESPKU conference was again held in Torremolinos. It is a popular venue, for good reason; easy to get to, sunny, has a hotel well acquainted with the PKU diet and the weekend falls over half-term with some good rates from the hotel.

There were some excellent presentations and as often is the case it was those living with the condition who made a great impression.

There were 2 presentations about untreated PKU; one by Dr Maria Gizewska from Poland and the other by Lesley Robertson who was supported by the carers of Janet, who was a participant in the research trial of treating previously untreated adults with PKU.

Dr Gizewska spoke about the situation for screening in Poland and their possible numbers of untreated patients. Screening began in 1964 but it took 20 years to cover all the country so she estimated they probably have more than 1500 who were not diagnosed at birth. She conducted a survey of some 1075 patients in institutions and found 17 with previously undiagnosed PKU. This is 1:60 of all those in institutions in Poland. This statistic she said would be helpful to give to homes in Poland.

She showed one of the worst cases I had seen of a young man so very badly affected by lack of treatment he was unable to walk, communicate and was clearly very limited in his life. He just rocked on his bed in a tight foetal position. The diet was started and progressive videos at varying time spans ended in this young man going to the park, playing with a ball and obviously so much happier in his life. The transformation was so remarkable that as I write this one year later the images are still fixed in my head.

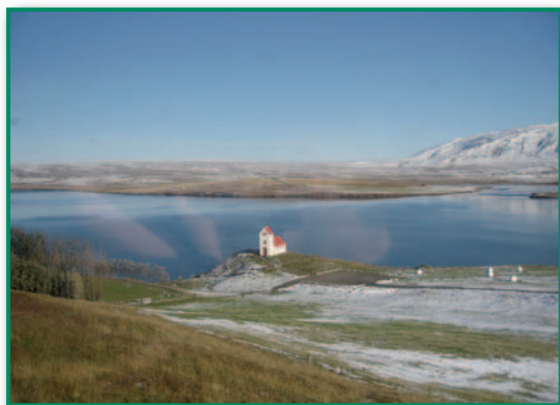
Many of you will have heard Lesley Robertson speak about the research trial of trying diet for previously untreated patients in the UK. This was a huge amount of work, lasting in total 4 years. So much was learnt through this work and what was so encouraging was the of 22 participants who were placed on the active (low phenylalanine diet) first (rather than the non-active diet) nearly 75% decided to keep to the diet because of improvement. For some, the move to the non-active diet caused so many problems they withdrew from the trial in order to keep to the low phenylalanine diet.

It was so nice to see Janet who had participated in the trial coming for a holiday to Torremolinos. Her carers were enthusiastic in their description of the change in Janet and it was clear to all that Janet was having a very good time at the conference. The diet takes a lot of effort as you know but with the kind of support Janet received it has the best chance of success. The diet does not help everyone missed at screening but when it does it is wonderful to see.

This was a conference for families and adults living life with PKU. Many of them spoke including a doctor from Germany who was there with her 3 children. Conferences are inspiring and encouraging and anyone with a new baby can gain much from attending. Many say it was a turning point for them to see teenagers and adults with PKU unidentifiable from those without the condition.



Lesley, Janet and her carer in Torremolinos



Beautiful Iceland

Reykjavik, Iceland. October 3-4th 2008

It was only on the plane coming back from the meeting that we realised this little country was going to make waves in ways non-medical.

This conference was superb and was the result of many people's hard work to make it happen. It was 6 years' ago that Iceland put themselves forward as hosts for the ESPKU meeting. The photograph is of Sibi and Jon both of whom have children with PKU and who played a role in getting the meeting off the ground. There are 9 families with PKU on the island.

This was truly an international meeting with delegates from most European countries as well as Canada and America. The Icelandic organizing committee together with the Scientific Advisory Committee put together an exciting programme with a focus on the latest news in treatment of PKU.

The following is a summary of 2 of the talks presented. The other talks will be covered in the next issue.

Gene Therapy

Cary Harding USA

In PKU there is a faulty gene for making the enzyme phenylalanine hydroxylase. Gene therapy is looking at correcting the faulty gene or adding a normal copy of the gene.

In 1994 Dr S. Woo in USA used a virus to correct the faulty gene but this only worked for 2 weeks because the immune system killed the virus as it recognises it as foreign. Great care has to be taken as an immune response can cause liver failure.

So what is the future of gene therapy?

Doctors and scientists are looking at an adapted product which lasts longer and is safe.



Sibi and Jon who organised the conference

Improving the diet with GMP (glycomacropeptide)

Prof. Denise Ney USA

GMP is a natural protein, produced during cheese making, which contains a minimal amount of phenylalanine (2.5 – 5 mg per gram of protein)

100lbs of milk produces 10lb of cheese curds and 90lbs of whey. GMP is one of 5 proteins in the whey and is the most abundant. It is an inexpensive food ingredient with an excellent safety record.

The GMP has been used to make low phenylalanine foods and drinks but containing all the other important protein for growth and repair, so it is a new form of protein substitute.

It has been used to make:

- Chocolate and Strawberry puddings
- Flavoured drinks
- Fruit Leather
- Crackers
- Crisp Cereal
- Salad Dressing

The GMP foods have been used to provide 15-20g protein servings and they have been rated as tasty!

A side effect of the GMP is that it also reduced the amount of the hormone ghelin. Ghelin is produced by the stomach and the level is reduced when we eat. It was reduced more after the GMP than for other protein substitutes so it could be used to satisfy hunger.

Being you with PKU:

How skills from cognitive behaviour therapy can help

Danuta Orlowska, Clinical Psychologist

Camden and Islington NHS Foundation Trust

In my role as a clinical psychologist, I work with some of the people who attend the Charles Dent Metabolic Unit at the National Hospital in London. I have met people with PKU as well as a range of other metabolic conditions. In another part of my job, I work with people with hearing loss, tinnitus or balance problems. Overall, my interest is in helping people to live as well as they can with, or despite, long-term health-related conditions. To do this, I often use aspects of cognitive therapy in my sessions.

You might have heard that there is a push for better access to cognitive therapy. But what is it? And can you benefit from the skills it teaches even if you are not severely distressed? How can you apply it to living with PKU? I will try to answer these questions in this article.

What is cognitive therapy?

The basic idea behind cognitive therapy is that what goes through our mind has an impact on how we feel and what we do. We all have things going through our minds – for example memories, things we were told by other people, things we tell ourselves to remember, maybe a little commentary on what we are doing. Some of these can be in the form of words, and some of them could be in the form of images.

Some of the things going through our minds could be neutral – *“remember to get a birthday card for Freddy”*. Some of them could be irritating, like the words of a song that keep going round and round our minds. Some of them can express pride in ourselves or admiration for others: *“I did a good job of organising the party for my friend”* or *“she did really well to achieve that, especially with everything that’s been troubling her recently”*.

However - and this is where cognitive therapy comes in - some of the things that go through our minds can be unhelpful. Some examples of unhelpful things could be: *“I’ll never be able to get this right”*, *“There’s no point in trying as things always go wrong”* and *“She didn’t say hello because she thinks I’m not good enough for her”*. What sort of impact do you think that these sorts of things will have on how someone might feel? And what impact will these different things have on what they might do?

In my talk at the NSPKU Conference in March 2008, I used an example of someone getting a promotion to help think about the impact of what goes through our minds and how we feel. I also collected possible reactions to this situation from participants at the London PKU Study day in October 2007.

So – imagine someone is offered a promotion. What might be going through their mind? How might they feel? (Note that feelings can usually be expressed in single words – you can have more than one feeling, but each can usually be described in one word.) here are some possible reactions.

What could be going through someone’s mind	How they might feel
I’ve been chosen	Pleased
I deserve this promotion as I’ve worked hard and my manager will support me	Proud, Confident
It’s a great opportunity to do something I value	Enthusiastic
This is a chance to get new experiences	Excited
It will mean longer hours, which will have a bad impact on the family	Concerned, Worried
I’ll become distant from colleagues I like	Sad
How on earth did I get this promotion?!	Surprised
It will help me pay of the mortgage and debts	Relieved
It’ll be easy	Confident (maybe over-confident)
I’m not sure I’m up to it	Anxious
My colleagues are just waiting for me to fail	More anxious



Danuta at the 2008 NSPKU conference

I'm no good and it's only a matter of time before they realise and fire me...
 And then I'll never get another job...
 And then I'll lose the house...
 And then I'll end up on the streets with no friends....

Even more anxious

What have we learned so far?

1. How we feel is not just linked to what is going on (the promotion), but also to what is going through our minds about it.
2. There are many things which can go through our minds about a situation – there isn't just one way of looking at it.
3. Different things going through our minds are linked with DIFFERENT feelings
4. Some of the things that go through our minds can be helpful; others can be unhelpful
5. Sometimes it's easy to spiral down through unhelpful thoughts to the worst case scenario.

So far in this example, we have only concentrated on what was going through someone's mind and how they might feel. But what about the impact of these different thoughts on what that person might do (or not do) when they start the new job?

If someone thought that they deserved the promotion and had support from their manager, what might they do (or not do)?

Maybe they would smile and behave in a friendly way, meet their new colleagues and ask about how things run, make notes on things and take part in some social activities at work. But what if they made a small mistake or didn't have some information (but still thought that they deserved the promotion and had support)? Maybe they would acknowledge the mistake and ask for help or training, but would take it all in their stride. They might say to themselves that they would not be expected to know everything about the new job straight away.

What about if they thought that their colleagues were just waiting for them to fail?

Maybe they would not act in such a friendly way, be easily distracted when they are being talked through new policies and make unclear notes. Then when they did make a small mistake, it might seem to prove that they were going to fail and they might see the mistake as bigger than it is. They might try to hide it, or work extra long hours (but maybe not very effectively) to try to deal with it alone. And they might think that it's all just a matter of time before they were found out, fired and ended up on the streets.

So what goes through someone's mind can have an impact on how they set about their new job. It can also have an impact on how they might deal with obstacles which they encounter.

What have we learned so far?

1. What goes through our minds affects how we feel and what we do (or don't do).
2. What goes through our minds might not be helpful or even true!

Cognitive therapy helps us to look at what is going through our minds and at what we do (or avoid doing). We can then learn to try to replace unhelpful responses with more helpful versions. That's not to say it's going to be easy or work overnight. As with learning anything new, it's going to take some time and effort and often a few mistakes along the way. However, the skills are useful and can apply across a range of situations.

Can you benefit from cognitive therapy skills even if you are not severely distressed?

Formal cognitive therapy is valuable and has been shown to have good results with a range of forms of distress, for example depression, anxiety and panic attacks. However, I would suggest that many of us can benefit from knowing about the skills and principles it involves even though we might not be severely distressed. For example, many of us can sometimes fall into unhelpful patterns of thinking. Being able to

spot and deal with unhelpful things going through our minds is an important part of looking after our well-being. It can help us to deal with some difficulties early on, rather than letting them become more significant parts of our lives.

Knowing about some of the skills used in cognitive therapy also allows people raising and teaching children to help them to become resilient and bounce back from set-backs. Imagine if a child did badly at learning something new and difficult. Then think about two of the possible reactions a child might have: "I must be really stupid so there's no point in trying this again" and "It was hard but I can ask someone for help and maybe do better next time". Which one of these is likely to be more helpful? There are some schools which now teach aspects of helpful thinking styles to their pupils. However, this may not in itself be enough as there are, sadly, children with very difficult backgrounds for whom more intensive professional help might be needed.

If you or your child feel very distressed, then it might be wise to talk to your GP. You can discuss whether cognitive therapy (or some other form of help) might be suitable and find out what local services there are for adults, children and families.

Cognitive therapy is also available privately. If you choose to go down this route then look for someone who is a member of a professional body such as the British Psychological Society (www.bps.org.uk) and/or the British Association of Behavioural and Cognitive Psychotherapy (www.babcp.com).

So what are some basic cognitive therapy skills?

Some of the basic skills are

- i) spotting what is going through our minds
- ii) learning to change unhelpful aspects of what is going through our minds
- ii) learning to changing unhelpful aspects of what we do (or avoid doing).

When we notice a downturn in our mood, it can be useful to try to work out what things were going through our minds just before. These are often Automatic Negative Thoughts (I call these ANTs to make it easier to remember). They just come up in our minds as if from nowhere, are negative in tone and appear to be true. So in the example of the promotion, when we notice ourselves feeling anxious, we can try to work out what is going through our mind. It doesn't have to be a complete sentence or even make sense. Let's stick with the promotion example. Say someone had the following going through their mind: "I'm not sure I'm up to this promotion".

OK, now having found what it is that's going through our mind, one thing we can do is to remind ourselves is that just because something's gone through our mind, doesn't mean that it's true. I like to give a silly example to illustrate this point. I could think: "I am a green elephant..." At some level I have thought this, and written it down. But of course, we can spot that in this example, it isn't true.

However, when we are feeling low, thoughts like "nothing ever goes well for me" or "I'm stupid" might seem totally true and believable. If possible, we can try to remind ourselves that just because we've through something, doesn't mean it's true. One way we can do this is to remember: "a thought is not a fact".

So what do we do with any unhelpful thoughts we've spotted? Sometimes just telling ourselves that they are not true might be helpful. However, cognitive therapy also teaches us to learn to challenge them and come up with Balanced Alternative Thoughts (I call these BATs). We are not trying to ignore real difficulties. We are trying to be fair on ourselves and see both sides of the coin, not just one.

How do we change ANTs into BATs? It's not magic! When we notice a downturn in mood, first of all, try to spot what is going through our mind. To stay with the promotion example, say someone felt anxious and thought "I'm not sure I'm up to this promotion".

Here are some questions they could try to answer:

What's the evidence that it's true that 'I'm not up to this promotion'?

There might not be much actual evidence that this is the case.

What's the evidence that it's not true?

Well I have coped with learning new things in my job so far and so maybe I can learn new things to do with this promotion too.

Is it helpful or unhelpful to be thinking in this way?

It's probably pretty unhelpful.

Is there another way of looking at things?

Maybe it's normal to feel a bit anxious in this situation.

What would we say to a friend in such a situation?

I'd tell a friend it's probably normal to feel anxious but that it didn't mean that they weren't up to the new job.

Are there things that we are overlooking?

Well, I got the job against competition from others so others think that I can at least try. And anyway, there are training days for newly promoted staff as they can't be expected to know everything straight away.

When we look back on this situation in a year, what will that be like?

By next year I might be getting on so well that I might have forgotten that I ever felt anxious. Or I might even be looking for the next step!

I hope that this is clear so far. Can you see how 'I'm not sure I'm up to this promotion' is not very helpful, but that these other possible reactions (above) could be more helpful?

It is also helpful to know that there are some common types of unhelpful thinking. Here's a few examples.

1. 'All or nothing' thinking

This type of thinking sees things as totally wrong or totally right, black or white, either 0% or 100%. How realistic is this? Is it true that unless something's perfect it's totally useless? That if someone makes one mistake that they are a total failure?

0 -----100

I often draw this line between 0 and 100 and use this to help people think about the in-between areas. Things are rarely perfect. But even if they are not 100%, that doesn't mean that they are 0%. We might find that 80% or 50% is good. Even 20% could be OK (depending on what it is) and a whole lot better than nothing. For example, someone might think they can't guarantee that they will have a 100% good time at a party so they won't go. But it might be that a 50% good time at the party is better than sitting at home alone dwelling on unhappy things.

2. Over-generalising

In this type of thinking, we assume that after one thing has gone wrong, that it will always happen again. We don't necessarily know what's going to happen, but just because something difficult has happened once does not guarantee that it will happen again. It might, but it might not. So there might not be any point in someone telling themselves because they didn't get one job that they will never get another. In any case, the more they tell themselves they won't get the job, the worse they might feel when filling out their applications and the more mistakes they might make...

3. Mind reading

In this type of thinking we are sure that someone is reacting badly to us without knowing or checking what they are really thinking. Say someone we know didn't stop and say hello. We might think that this is because they don't like us. But what other reasons could there be? Could they have had some bad news? Maybe they didn't have their contact lenses in! If we have sometimes not stopped to talk to someone, what are possible reasons? They might not all be connected with not liking someone (though of course this is possible). We have complex minds, but not complex mind-reading skills!

4. Catastrophising

Catastrophising involves expecting that the worst case scenario will happen. To go back to the promotion example, it could be that if someone makes a small mistake, they might think that this means that they are incapable and about to be fired and will end up on the streets. How helpful is this? How do they know? What is it like to be going around thinking like this?

5. Using a mental filter

When we use a mental filter, even though there are things which have gone well, we look only at what has gone wrong. The good things are filtered out. Here's an example. What if we were giving a talk to our local community centre about a hobby or interest? Say we gave it and people asked questions, which we answered, but there was one question which was a bit tricky? Is it fair to say that the talk went wrong or was a disaster based on this one question? What could be the impact of thinking like that if we are asked to do a talk again?

Sometimes it can be helpful in itself to spot which of these unhelpful styles we are using...

Why not just tell someone to ‘think positive’?

The way that I try to explain this is that telling someone to ‘think positive’ misses the point. It means that their individual situation is not taken into account. What seems to be positive for one person may be unrealistic for another and set them up to fail. Saying “you can do it” or “I can do it” might not be easy and does not take real difficulties into account.

Here is an example I use to explain this. Say someone thinks: “I’ll swim the Channel”. OK – so this seems like a pretty positive thought. But not if it sets them up to fail or feel miserable. If they are training to do this, with the right support from swimming coaches and dieticians, then it might be a very helpful thing to think. But what if they are only an occasional weekend swimmer and can only manage half an hour in the pool? Then it might not be very realistic. What else could they think instead? Perhaps set a smaller goal to start with and see how they go?

Here’s another example of a thought which might seem negative. What if someone says “I can’t go out tonight”? Yes, but what about the context? If someone is coming down with a cold and has some holiday packing still to do before catching an early train the next day, it might be helpful not to go out. But if they have not had a social invitation for months and the alternative is sitting at home alone, then things are different. By not going out, someone might be missing an opportunity to get back into their social network and enjoy some time out of the house. The evening out might not be perfect, but it might not be as bad as they fear.

Another thing to consider is that if someone is distressed, what is it like to be told to ‘think positive’? They might not be able to do this. And then it might seem like there’s yet another thing that they can’t do and this might add to their distress. Telling someone to ‘think positive’ also doesn’t help people to start to solve their problems. So that’s why I don’t use the term ‘positive thinking’ in my work. I use the term ‘helpful thinking’ instead.

There is more to cognitive therapy than I have described so far. For example cognitive therapy can also look at why some of us have more of a tendency to react in unhelpful ways. Sometimes this is because of ways we learned to deal with situations we faced earlier in our lives. Sometimes we have learned a way of coping with difficult situations but try to use it in situations where it doesn’t work. Cognitive therapy can also help us change some of these patterns to more helpful ones. However, this article is just about the everyday level of unhelpful thinking styles.

How can we applying this to living with PKU?

The things I have written about so far can apply across our lives whether we have PKU or not. It’s about trying to get our mind to work for us not against us. Just as with other things, what goes through our minds can make a difference in PKU-related situations too.

Let’s think about setting goals. It’s often better to consider what we DO want to do rather than what we don’t. For example this might be going back to a PKU diet. Are there any ways of breaking down the goal into smaller steps along the way? How are you going to do this? By yourself? With help? Will you make things in advance and freeze them? When will you start? What about special occasions or meals out – how will you deal with these?

When we are setting goals, we can make a practical action plan and cover what we are going to do. However, is there something missing? What about setbacks? Things happen and sometimes it becomes impossible to stick to even the best plans. Quite often, our action plans don’t take setbacks into account and this might mean that we give up... especially if unhelpful things go through our minds.

At the London Study day in October 2007 I asked people to come up with helpful and unhelpful ways of looking at a lapse in PKU diet when someone has gone out. Here are some comments that were made by the participants. I have tried to link them up with possible feelings people might have as a result of these different things going through their minds. You might describe the feelings in other words – that’s fine! There doesn’t have to be a single way of labelling emotions.

What could be some unhelpful things going through someone’s mind after a lapse in diet?

How they might feel

Might as well give up – I won’t be able to cope with the diet

Frustrated
Annoyed with self

I failed – I can’t do it – might as well eat anything

Disappointed

What could be some helpful things going through someone's mind after a lapse in diet?**How they might feel**

You're only human	Calm
Tomorrow I can get back on diet	Hopeful
Might feel better tomorrow	Hopeful
You enjoyed it (the lapse of diet)!	Kind to self
My next meal can be a lower intake to adjust for the higher one	Calm
It was a bad day today but the rest of the week was OK	Kind to self, Calm
I can set a realistic target tomorrow for improvement not perfection	Calm
Can ask someone to help me tomorrow	Calm
I can review the reasons for the lapse and adjust/avoid things	Hopeful

Can you see how the second table contains statements and feelings which are so different to those in the first table?

One thing to understand is that setbacks are normal! Just because there has been a bit of a setback with the diet does not mean that it is a total failure or that there is no point in trying again. What would be more helpful than giving up on a valued goal? We can look at why there was a setback – was it a special occasion with no PKU food provided? Or were you feeling upset so you reached for your favourite food regardless? Or did you have to adjust to a sudden change of plan and didn't have time to take your PKU food? It won't be possible to avoid every difficult situation. However, it might be worth spending some time working out situations in which keeping to the PKU diet might be hard.

The next thing is to use your mind for you not against you! Just because it's happened once, does it mean that it will happen again? You can work on developing a coping plan for what you can do when faced with a difficult situation. You can also try to see what difference it makes to how you feel if you accept some setbacks as normal (and perhaps something to learn from). This is more likely to be helpful than blaming yourself and giving up.

Conclusion

Cognitive therapy can be seen as being about learning to use our minds for us and not against us and to do things which are helpful rather than unhelpful. We can benefit from the skills it teaches whether we are distressed or not as many of us fall into unhelpful patterns from time to time. For PKU-related and many other aspects of our lives, we can try to remember the following:

A thought is not a fact

The first thing that pops into our minds might not be helpful

Setbacks are normal and don't mean that we have to give up on our goals

If you would like to read more about this approach, you might like to look at this book:

Manage Your Mind: The Mental Fitness Guide (2007) Gillian Butler and Tony Hope.
Oxford University Press;
2nd Edition.
ISBN: 0 – 19 – 852772 - 1

All PKFoods are now available on prescription

The advertisement displays a variety of PKFoods products against an orange background. Products shown include: Chocolate Chip Cookies, Cinnamon Cookies, Orange Cookies, Pasta Specials, White Sliced Bread, Crispbread, Egg Replacer, Flour Mix, Cherry Jelly Mix, Orange Jelly Mix, aminex Cookies, aminex Biscuits, and aminex Rusks. At the bottom, the contact information for PKFoods is provided.

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

Fate Special Foods recipes



Hello,

This recipe is easy to do, freely allowed, and delicious. Also, its suitable for all the family to enjoy together, so what more do you need? Change the type of vegetables if you like, but the flavour of this combination is really good. Serve it hot with warm Fate bread, or Fate herb crackers.

The recipe makes about 2½ litres, and it freezes well.

FATE IRISH STEW

Ingredients

3 tbsp oil
300g onion
300g carrot
300g parsnip
300g swede
300g mushrooms
300g celery
1 x 400g tin tomatoes
400mls water
3 suitable vegetable stock cubes
few drops suitable gravy browning
pepper to season

Method

Chop the onion finely. Chop all the other vegetables into medium sized even pieces. Heat the oil in a large pan, and when it is hot, add the onion, carrot, parsnip, swede, mushrooms and celery. Cook on a high heat for about 10 mins until the vegetables are beginning to soften and turn lightly brown.

Add the tin of tomatoes, water, stock cubes, and a little gravy browning to give the stew a rich colour. Stir well and break the tomatoes up a little with the back of the spoon.

Season with pepper (you will probably not have to add any salt as the stock cubes can be salty enough)

Put a lid on the pan and bring it to the boil, then simmer gently for about 15-20 mins until the vegetables are cooked but not too soft. Take about 500mls of the stew, (vegetables and gravy) and liquidise until smooth, then put back into the pan with the rest of the stew. This will give the stew a richer texture. Bring back to the boil and serve with warm Fate bread or Fate Herb Crackers.



Perfect to serve with a low protein stew especially if you don't have many exchanges left for potatoes! Mint is our favourite herb for these crackers, as it really goes with the flavour of Fate Irish Stew, but you can use any other herb you fancy. This recipe makes about 30-35, so there's plenty for freezing. If you don't have a square biscuit cutter, cut into circles or long thin triangles.

FATE HERB CRACKERS

Ingredients

250g Fate Low Protein All-Purpose Mix
½ tsp salt and pepper to season
125g block margarine
4 tsp dried mint, or other dried herb
70mls water
Extra Fate All-Purpose Mix to roll out
Pre-heat the oven Gas 6. 200°C 400°F

Method

Place the Fate Low Protein All-Purpose Mix into a mixing bowl. Add the salt and season with pepper.

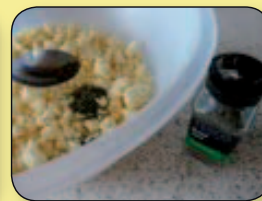
Add the margarine and rub in until the mixture resembles fine breadcrumbs, then continue to rub in until the mixture resembles coarse breadcrumbs. Stir in the dried mint.

Add the water all in one go and quickly mix with a metal spoon until the mixture is creamy. Do not worry if you think that the mixture is very soft, just leave it for a couple of minutes. Lightly dust the work surface with Fate All-Purpose Mix and knead the dough for about 30 seconds until smooth.

Roll out until quite thin, about 3-4mm. Cut into squares, circles or triangles and place on a baking tray.

Bake for 10-12 mins until lightly browned and crisp.

Place on a wire rack to cool. then simmer gently for about 15-20 mins until the vegetables are cooked but not too soft. Take about 500mls of the stew, (vegetables and gravy) and liquidise until smooth, then put back into the pan with the rest of the stew. This will give the stew a richer texture. Bring back to the boil and serve with warm Fate bread or Fate Herb Crackers.





AVAILABLE ON PRESCRIPTION:

Fate Low Protein All - Purpose Mix

Fate Low Protein Cake Mix

Fate Low Protein Chocolate Flavour Cake Mix



“As a mom with two daughters who both have PKU, I fully understand the low protein way of life. I have developed these mixes and many recipes to help everyone make great low protein food.”

Eileen Green



**Ask your Doctor to prescribe Fate mixes,
then ask your chemist to telephone our direct order line : 01215 22 44 33**

Helpline and General Enquiries Tel: 01215 22 44 34

Dietitian's Report

November 2008 Up-dated Pictorial Guide to the PKU Diet

This popular publication of pictures in a simple traffic light system has had 2 sections up-dated; ACBS items and crisps and snacks.

ACBS Items

There are now well over 120 food items on prescription for PKU. Many of these are allowed freely in the diet but an increasing number contain a significant amount of phenylalanine so they have to be counted as exchanges or half exchanges of protein. The picture guide makes it easy to see the full range on prescription and to identify whether the food is classed as 'free' or not. If it is an exchange food the value of the protein exchange is given.

Included in the guide:

SHS International Ltd- new pastas, desserts, cake mixes, cereals. All SHS items in new packaging

FirstPlay Dietary Foods Ltd- Hot Breakfast – all flavours, desserts, lemon cake, sweet spread, pasta in sauce, sausage mixes and burger mixes.

The picture guide is very helpful in identifying that the correct prescription has been given - gluten-free and not low protein can sometimes be given by mistake.

As the guide went to press new items were passed by ACBS so a STOP PRESS page is included so the guide is completely up to date.

Crisps and Snacks

This section has free and protein exchange items. There are now some snacks made from Cassava and tapioca which can be taken with out counting (provided all the other ingredients are 'free') and there are fruit crisps which are also 'free'. Vegetable crisps such as beetroot, parsnip and sweet potato are increasingly popular and these too

are included. How should they be counted? After a considerable amount of analysis a simple figure has been established.

By far the most featured are the potato and maize snacks which do have to be counted. Again, a simple and practical solution to the vast numbers has been given. All the packs (and over 30 are featured) have their protein exchange value given per packet.

The guide is in full colour.

How to obtain the guide:

Pictorial Guide with folder £15 (also includes a CD of the guide)

Pictorial Guide (pages only) with out folder £12.50 (also includes a CD of the guide)

Up-dated pages only £2.50

CD only £5

All prices include postage and packing within the UK)

Please make cheques/bank draft in pounds sterling made payable to NSPKU and send to:

NSPKU
PO Box 26642
London
N14 4ZF
Phone 020 8364 3010
Email info@nspku.org



Pages from the
Pictorial Guide



10 +1 Tips to Success with PKU

This is an A5 laminated card with top tips for success. The messages are simple and have come about through years of experience. No-one should be without a copy and I feel it is especially helpful to new families. Getting off to a good start is the key to success. The top tips card is 50p per copy and cheques should be made payable as above and sent to our charity address. You should receive your free copy in this issue.

Let's learn About PKU - age 3-6 years

This is the final section for the Let's Learn About PKU file which was published a couple of year's ago. The sooner children can be engaged in their diet the better and simple ideas of what to do are described. Building knowledge and confidence is the key to children taking over for themselves; we want to avoid the scenario of departure to university or leaving home being harder than it

needs to be....they will have other things to think about!

How to obtain the file or just the new section:

New section only for those who have the file – free

Whole Let's learn About PKU File – including all sections £30 (includes a CD)

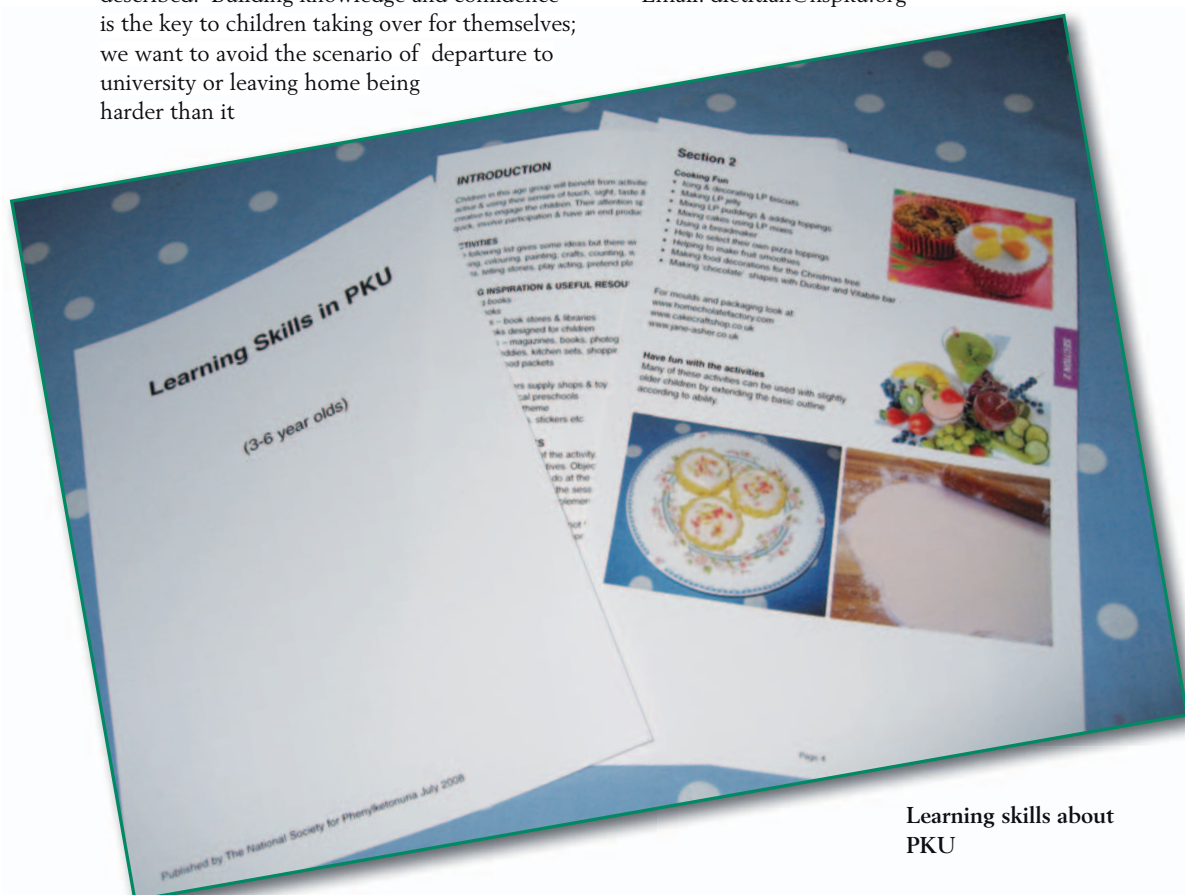
Cheques made payable to NSPKU.

Available from:

Eleanor Weetch
Dietitian Advisor NSPKU
Skiers Spring Lodge,
Broad Carr Road,
Hoyland,
Barnsley
S74 9BU

Tel: 01226 742494

Email: dietitian@nspku.org



Learning skills about PKU

NEW
NOW AVAILABLE ON PRESCRIPTION



Family favourites for the Barbeque

Promin burgers are now available in two flavours, Original and Lamb & Mint and Promin sausages in three flavours, Original, Apple & Sage, and Tomato and Basil so all the family can enjoy the barbeque

Firstplay Dietary Foods was formed in 1993 to produce Promin Low Protein products from a small factory in Stockport, where we only produce low protein products which is great for people on a restricted diet as it minimises the risk of contamination. Our original low protein and gluten free pasta range, includes Promin Pasta and Promin Tri-Colour Pasta, now a well established brand and are available on prescription. The range also includes Imitation Rice, Pasta meal, Cous Cous and

Lasagna Sheets. By talking with PKU patients, parents and Dietitians a great range of tasty products have been developed.

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

For lunch or an evening meal: Pasta Shells in Tomato, Pepper and Herb sauce, or Pasta elbows in Cheese and Broccoli sauce and now Spirals in a spicy Moroccan sauce

A recent addition is our great tasting Burger Mix, you can easily shape it into burgers,

meatballs or even dinosaurs for the kids! - they taste great with chips or mixed with some of our pasta. Finish with Rice pudding - 3 flavours available or a Chocolate and banana dessert, there's a strawberry and vanilla one too. Please call us or visit the website for more information and keep sending your recipe and meal suggestions.

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



Always consult your dietitian before trying something new.

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

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

MINUTES OF THE 35th ANNUAL GENERAL MEETING OF THE NSPKU

Held at the Hilton Northampton, 100 Watering Lane, Collingtree, Northampton, NN4 0XW at 17.30 on 1st March 2008

PRESENT:

A list of those people present is attached, this being based on the attendance slips received.

MINUTE 1/01 - WELCOME BY CHAIR

The Society Chair, Dave Stening, welcomed everybody to the Annual General Meeting especially those attending for the first time.

MINUTE 2/01 – APOLOGIES FOR ABSENCE:

These have been received from Stewart and Ana Alexander, Lyn Stening, May & Jim Cairns.

MINUTE 3/01 – PROXY VOTING FORMS:

A total of 14 proxy voting forms have been received – Mr David Stening holds 4 votes and Mr Eric Lange holds 10 votes. 2 forms for Peter Bramley were invalid as he was not present.

MINUTE 4/01 - MINUTES OF THE 34th ANNUAL GENERAL MEETING:

Dave Stening reviewed the minutes of the 34th Annual General Meeting for accuracy.

Adoption of the minutes was proposed by Sarah Lawson and seconded by Duncan Noble-Nesbitt.

MINUTE 5/01 MATTERS ARISING:

There were no matters arising from the minutes of the 34th Annual General Meeting.

MINUTE 6/01 CHAIRMAN'S REPORT:

COM Meetings

The Council of Management has held 6 meetings since the last AGM – 3 here at The Hilton Hotel, Hinckley Northampton and 2 at The Rendezvous Hotel Skipton, Yorkshire and one at Hinckley Hotel, Leicestershire.

Study Days

During the year day conferences took place in Glasgow, jointly organised by the Newcastle and Glasgow teams, Bristol and the South West and the Adult PKU Day organised by SHS in London. Also there was a study day held in Newport South Wales and in Plymouth. All were well attended, very successful and supported by the Society.

Outward Bounds

The Society supported an outward bounds course at Edale Derbyshire for children aged 9 to 13. The next one is planned for 18th to 20th July.

Research

The Untreated PKU trial finished last year. There was a very successful and well attended study day on June 21st in London for all the carers where the details of the trial, and results were presented. We heard this morning about the details of the trial.

Amino Acid Analysis - 19 items analysed this year. This has enabled several new foods to be included in the latest Dietary Booklet.

Merchandise

Our merchandise sales have been quiet this year and we are continuing to review the affordability.

News and Views

Kiri Thomas continues to edit News and Views. However during her maternity leave Eleanor Weetch has stood in to continue the production.

Website

The Society's website continues to develop and is increasing in popularity as more of us gain access to the internet. We have had over 15,000 hits in the last 12 months. Not surprisingly we are seeing an increase in enquiries from non members and people with PKU around the world. Although this increases our workload it does show that the profile of the Society is being raised and we can only gain from this.

Helpline

The telephone helpline is manned by Lucy Welch and continues to provide an important first contact point for new parents and other organisations. Lucy continues to provide excellent support to members of COM and all of the membership and we are very grateful for her hard work.

Last year we changed our telephone helpline number to 0208 364 3010. This replaced the previous 0845 number which we have had for a number of years. We intend to keep the 0845 number available and it is redirected to the main helpline number. This change has reduced the cost to the Society of around £200 per year.

Last year we also introduced a text facility where we can provide help by SMS text messaging. The take-up has been slow to start with however a number of enquiries are beginning to come through this medium. The number is 07983 688 664.

We continue to maintain our telephone recorded information line. This does not replace the helpline but provides information about forthcoming events for those who cannot access the internet. The number is 0207 099 7431.

ESPKU

We continue to be an active member of the European Society for PKU. A number of the Council of Management attended the last annual meeting in Spain. We had some excellent reports on that meeting that will appear in News and Views very soon.

Newborn Screening Programme & PKU Register

The UK Newborn Screening Programme Centre has wound up its work on the old register and completed its exercise in obtaining consent from many of those on the register. There appears to be very little activity with the ongoing work of producing a new register due to lack of funding and so we will be actively seeking support from the Department of Health to restart this important work.

Child Protection

The Society clears the Council of Management members through the Criminal Records Bureau. Unfortunately the CRB have removed small organisations such as ourselves from their list of signatories. The effect of this is that we are having to pay an umbrella organisation to carry out our checks. Fortunately we have found Epilepsy Association who have offered to carry out our checks for a reasonable fee.

Conference

This year's conference has been organised by Sarah Lawson with the support of the whole of the Council of Management. It has been a major task particularly as the hotel staff changed a number of times during the last year.

Next year's conference is being planned and will be announced in the next month or so.

Last but not least, I would like to thank all the Council of Management, as well as Eleanor and Lucy, for working hard this last year to keep the Society running and in particular making this weekend happen. I would like to make a special thank you to Eleanor who continues to raise the profile of the Society in many ways.

MINUTE 7/01 MEDICAL ADVISORY PANEL REPORT**Purpose**

The Medical Advisory Panel of the NSPKU (MAP) provides a formal forum for members of the Council of Management to meet with medical professionals who are involved in the treatment of PKU patients. It comprises four representatives of the Council of Management, four clinicians, a clinical psychologist, a Consultant Chemical Pathologist, a Metabolic Nurse Specialist and six dietitians, including Eleanor

Meetings

The panel met twice in the last year, once in May at a meeting that included all members and once in November, a meeting for dietitians and COM members. Both meetings were held at the Birmingham Children's Hospital whom we thank for allowing us use of a meeting room free of charge.

Publications

MAP approves all new leaflets and documents prior to publication. In addition to this individual members have spent a considerable amount of time writing and assisting in the development of those we currently have in production. During the past year the Society published the following:

- Parents Leaflet
- Child with PKU
- Dietary Information Booklet (new format)
- FAQs for web site
- Fruit and Vegetable guide for web site

Membership

We would like to thank Clodagh Loughrey, Consultant Chemical Pathologist, Belfast who retired from MAP during the year.

We look forward to welcoming new members, Mark Sharrard, Consultant Paediatrician, Sheffield Children's Hospital

We would like to thank all the members of MAP who freely give of their time to progress the work of the Society. Their assistance, whether at meetings or times in between is invaluable to the work we do.

MINUTE 8/01 DIRECTORS REPORT:

The report, which had been prepared by the Society's Auditors, was presented to the meeting.

Adoption of the report was proposed by Kiri Thomas and seconded by Dr. John Noble-Nesbitt.

MINUTE 9/01 AUDITORS FINANCIAL REPORT:

The report, which had been prepared by the Society's Auditors, was presented to the meeting.

The Chair read out the conclusion from the Auditor's report: -

In our opinion:

- the financial statements give a true and fair view, in accordance with United Kingdom Generally Accepted Accounting Practice, of the state of the charity's affairs as at 31st October 2007 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended.
- the financial statements have been properly prepared in accordance with the Companies Act 1985 and
- the information given in the council of Managements' report is consistent with the financial statements.

Adoption of the report was proposed by Pat Kimpton and seconded by Kiri Thomas.

MINUTE 10/01 TREASURER'S REPORT:

This is a summary of accounts for the year ending 31st October 2007 which have been prepared by McDade Roberts Chartered Accountants.

A review of our activities for the past year can be found on page 3 of the financial statement and our objectives for the 2007/2008 financial year follow on page 3a. Our main aims for the coming year are;

- To further develop the pictorial guide to include simple meals
- To produce a guide to fruit and vegetables – preparation and cooking
- To review and update our current publications as appropriate
- To improve the way the Society is run by ensuring that our procedures are documented correctly and by ensuring that we comply with the current Health and Safety legislation.

We have again been fortunate enough to end the year in a profitable position. We have continued to reduce our costs, this year by 14% partly due to a decrease in the cost of producing News and Views and other publications. I would expect this cost to rise next year however because although we continue to assess the most cost effective format of our publications and the quantity we print we will be updating the Pictorial Guide during this year; a project which has been delayed while we wait for SHS to update their packaging. Our expenditure on last years conference was lower than expected; we continue to try to provide value for money at our conferences however as we are determined to find a venue in the south of the country there will inevitably be a greater burden on the Society.

Whilst our expenditure has fallen our income has remained largely the same this year. Our membership income is up 14%; Lucy has taken time this year to clean up our membership list and to remove members who are no longer responding to us. We now have more accurate information on our membership.

Our investments continue to perform well. This year our income from interest has increased by 44%. Just before the end of the financial year we opened a new investment account similar to the COIF fund to ensure that our financial risk is spread.

We have also re-assessed the Society's insurance needs this year. This has resulted in the cancellation of our contents policy as we believe the Society can bear the cost of any loss at present. We have however taken out policies for Trustees indemnity and employee fidelity. I would expect the overall cost of insurance to remain largely the same.

With the Untreated trial now over without the need of assistance from our research fund it remains at a healthy £23,000. We are continuing with the analysis of new foodstuffs and remain keen to provide funds for projects which would support the work of the Society.

We have once again been very fortunate with our sponsors and

I would like to take this opportunity to give our thanks to:

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

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

Our members have continued to be steady in their support this year and we would like to express our thanks to everyone who has supported the NSPKU throughout the year; especially to Mary Cullen & Mallachy who raised £5000 in the Dublin City marathon; Andover Golf Club, the Miskelly and Guest families for their considerable donations and of course our own Eric Lange who once again ran the marathon for us. And last but by no means least those who provide us with regular donations by direct debit or workplace schemes.

Finally I would like to personally thank Vicki King for her continuing hard work and support. Her role is gradually evolving and Vicki rises to each new challenge with efficiency and enthusiasm. She has proved to be a great asset to the Society.

MINUTE 11/01 APPOINTMENT OF AUDITORS FOR 2005/2006:

McDade Roberts have been appointed auditors for the period of 2007 to 2008.

Proposed by Kiri Thomas Seconded by Duncan Noble-Nesbitt

MINUTE 12/01 ELECTION OF COUNCIL OF MANAGEMENT:

The Chair expressed his thanks to the retiring members of the Council. The following members had reached the end of their term of office: -

Mr. Dave Stening and Julia Bailey

Nominations received for vacant positions:

Nominee	Proposed	Seconded
Mr Dave Stening	Mr Eric Lange	Lucy Welch
Julia Bailey	Mr Eric Lange	Lucy Welch

MINUTE 13/01 ANY OTHER BUSINESS:

None

The meeting was closed at 18.00.

NOTICE TO GUARANTOR MEMBERS OF THE SOCIETY

Notice is hereby given that the 36th Annual General Meeting of the **National Society for Phenylketonuria (United Kingdom) Limited** will be held on 21st March 2009 at the Rainbow International Hotel, Belgrave Road, Torquay, Devon, TQ2 5HJ 17.30 to consider the following business.

- 1 Welcome by the Chairman.
- 2 Apologies for Absence.
- 3 Notification of proxy voting slips received (by 18th March 2009).
- 4 Minutes of the 35th Annual General Meeting.
- 5 Matters arising from the 35th Minutes.
- 6 Chairman's report.
- 7 Medical Advisory Panel report.
- 8 Directors' report.
- 9 Auditors' report.
- 10 Honorary Treasurer's report and presentation of accounts.
- 11 Appointment of Honorary Auditors for the ensuing year.
- 12 Election to the Council of Management: - 5 people for 3 years - (Members retiring by rotation are John McKenzie, Peter Stockton, John Skidmore, Charlotte Tourgout, Mandy Macedo).
- 13 Any other business duly notified to the Secretary before 12.00 noon on 21st March 2009.
- 14 Closure of the meeting by the Chairman.

Eric Lange - Honorary Secretary

Enclosures:- Minutes of the 35th Annual General Meeting (In News and Views)
 Proxy voting form
 Nomination form

Proxy voting forms and Council of Management Nomination forms are available from the Administrator on info@nspku.org or by writing to NSPKU, PO Box 26642, London, N14 4ZF enclosing a self addressed envelope.



Apple Mincemeat Flan

Ingredients:

250g (9oz) Loprofin Low Protein Mix
 1.25mlsp (¼ tsp) ground cinnamon
 1.25mlsp (¼ tsp) ground mixed spice
 50g (2oz) caster sugar
 150g (6oz) economy butter
 300g (12oz) baking apple
 125g (5oz) Suitable sweet mincemeat
 1x15mlsp (1tbsp) demerara sugar

Oven temperature: 190°C/375°F/Gas Mark 5

20cm (8inch) loose bottomed flan tin

Method:

1. Combine the Loprofin Low Protein Mix, spices and caster sugar in a large bowl, thoroughly rub in the butter until the texture resembles fine crumbs.
2. Weigh off 150g (6oz) of crumbs and reserve.
3. Add sufficient water to the remaining crumbs to give a soft not sticky dough.
4. Lightly knead the dough until smooth on a surface dusted with Loprofin Low Protein Mix, roll out thickly and use to line the flan tin.
5. Peel core and chop the apple, mix with the mincemeat and spread evenly over the pastry base.
6. Pile the reserved crumbs on top of the apples and carefully spread to the edges, covering the fruit.
7. Level the crumbs before sprinkling with the demerara sugar. Bake in a pre-heated oven for 20-25 minutes, or until golden brown.
8. Serve hot or cold.

Serves 6-8 portions

NB: the flan will freeze successfully; cut into portions and freeze in strong polythene bags.

For more great tasting recipes, visit

www.lowproteinliving.co.uk



SHS Homeward
... delivered direct to your door

The one-stop-shop

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



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

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

For further information contact the Co-ordination Team on:

08457 623 605

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

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