NSPKU News&Views

Winter 2007

The National Society for Phenylketonuria (UK) Ltd

Issue 122

Inside this issue...

In Touch

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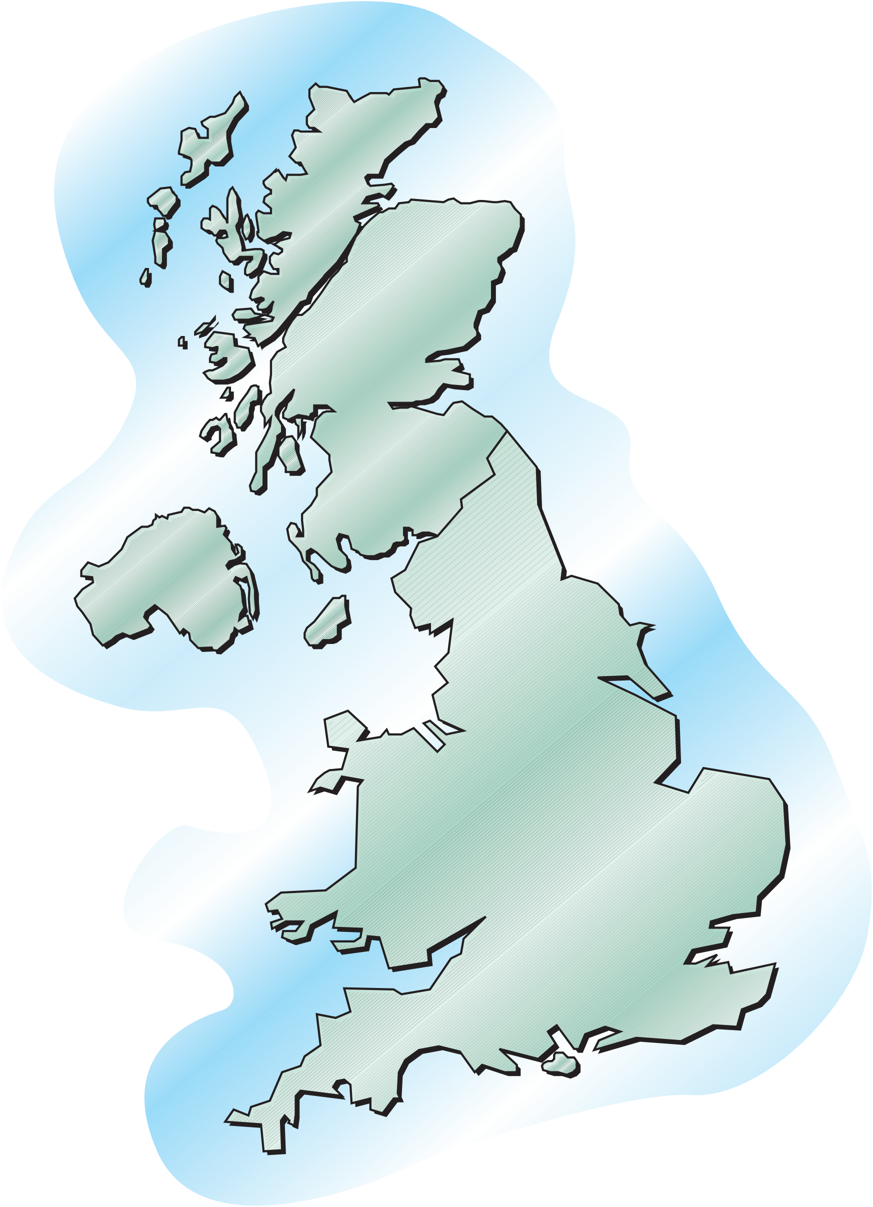


Contents

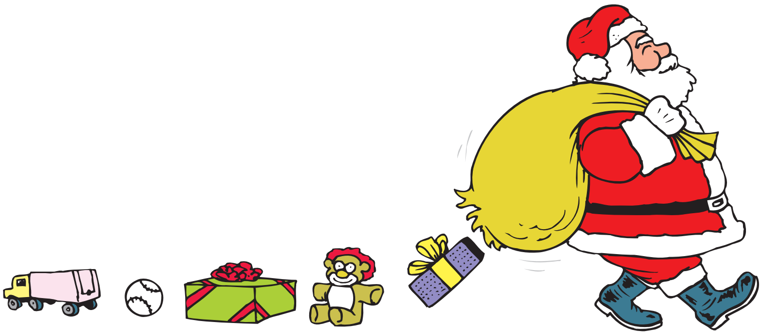
Stand-in Editor's Report...

I am pleased to report that Kiri and her family are all doing well. I am standing in as editor for this and the next News and Views and then all being well Kiri will take over again.

As I write this the shops are filling up with Christmas gifts and foods but I am looking beyond that to the next conference in Northampton at the end of February. I have included in my section a bit of detail about what we are doing this year and I hope that if you have never been to a conference you might be tempted to join us. I can guarantee you will learn a lot, have some fun and I hope will make some friends too.

I am always pleased to hear about anything useful you have found in the supermarket and love to receive the wrappers (and a bit of content) so that I can photograph the food and include it in the magazine. Please share your ideas with me and we can help one another…now that's not a bad resolution to make!

Eleanor Weetch



NSPKU
The National Society for Phenylketonuria (United Kingdom) Limited

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

Donations over £30 to present	£
Celine Morgan	500.00
The Mulberry Bush Day Care Nursery, Belfast	75.00
Tracey Readings - Grandmothers 90th Birthday	200.00
Georgia Willits (aged 8 years) - Garden Fete	600.00
Lesley Thomas	229.00
Carol McCloy	2,024.00
Rosebowl Golf Soc. (in memory of Angela Kerswill)	87.40
Elms Moar and Hazel Eunson - Joint Birthday Party	260.00
Andy & Sue Watson, Silver Wedding Celebrations	310.00
DWP Staff, Newcastle upon Tyne	620.02
Mr J Halstead	500.00
Mrs J Shave	45.54
Mrs J Cook	150.00
Weston Green Orthodontic Practice	200.00
Thanet First Principals Royal Arch Chapter - BBQ	436.00
Nadine Ornsby - London Marathon 2007	335.55
Paul and Tracey Murphy - London 10K run	700.00
Mr & Mrs Guest - Fundraising Day	1,915.00
Paul Henry - Great Manchester 10K Run	812.00

Treasurer's Report...

The end of year audit is now well underway (I hope!) and it promises to be another successful year financially. I have recently invested more of the Society's funds into a new high interest investment account thus spreading the Society's risk. The NSPKU is now also listed on a number of Charity donation websites including Ebay!

I have finally completed my Insurance Review and the Senior Officers have concluded that as the Society is currently financially sound we will bear the risk of contents and stock which actually have very little value and are spread throughout the country and invest more in Liability Insurance to include Trustees and Employees Fidelity insurance. I am currently contemplating what my next big project will be, ideas on a postcard to……

Julia Bailey
Treasurer

Competition for 8 to 18 years olds

We are rewriting our leaflet for teenagers and will be producing this in a FAQ (frequently asked questions) format. We need you to write the questions and we will write the answers. Simple one line questions such as 'Do I need to go to the PKU clinic even if my blood levels are good?' For each different question you ask, you will be entered into the competition to win Amazon.co.uk vouchers which you can spend on CDs, DVDs, books or almost anything.

The closing date for the competition is **14th February 2008** (easy date to remember) and the winners will be draw at the NSPKU conference.

The competition is open to anyone with PKU 8 to 18 year old (age as of the closing date) living in the UK. You may enter as many questions as you like by post to NSPKU Competition, PO Box 26642, London, N14 4ZF including your contact details, email to competition@nspku.org or text to 07983 688 664 (standard text rates apply, please ask the bill payers permission).

Letters

News & Views, 10 Silverdale Road, Chorlton M21 0SH
Email: editor@nspku.org

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

Dear News and Views,

I finally send you some cheques!!

I ran the London Marathon 2007 on behalf of my nephew Joshua Mancini (the biggest lad in the enclosed photo). I'm sorry its a long time coming, but collecting the money was far more a task than the marathon itself. I would have like to raise more for NSPKU, however my brother was born with Spina Bifida, so I ran for 2 charities (NSPKU and ASBAH).

Josh is brilliant, he is just starting grammar school. Last year I recommended him for a local papers children's award. He won one of the 8 prizes and we all got invited to a big presentation. This was to encourage him to keep sticking to his dietry restrictions.

I know my sister gets a lot out of your annual conferences and the whole family really enjoy going. I do try to go when possible and they are brilliant.

Thank you for all your support and hard work.
Kind regards

Nadine Omsby

Dear News and Views,

Please find enclosed a cheque for the NSPKU for £1915.

We have a son who is almost 3 years old and has PKU and 2 other boys who are non-PKU. We came to the Conference this year at Skipton and thought it was excellent and would like to thank everybody who made us feel welcome.

I recently organised more fund raising in August for the NSPKU which was a great success. On 18 August we held a summer carnival at our local caravan site which continued through to the evening with a disco and a vocalist. Unfortunately the weather was bad all day so we were unable to do the parade or have outside stalls but everything else continued indoors. We had a tombola, cake stall, nail art, toy and book stall etc and a raffle and auction in the evening.

Everybody enjoyed the day despite the weather and we raised lots of money. I will email you some photographs. There is a good one of our son Finn (PKU) with his dad who is dressed as Scooby Doo.

Yours faithfully
Lisa Guest

Dear News and Views,

Please find enclosed sponsorship money raised when Paul Henry, dad of Melissa, PKU, ran the Great Manchester 10K run.

We would like to thank family. Friends and work colleagues for their kind generosity and would especially like to thank First People Solutions who matched what was raised making the total collected £812.

Enclosed is a picture of Melissa which we would like, along with this letter to be included in the next News and Views.

Kind regards

Fiona and Paul Henry
Parents of Melissa, PKU

Letters

News & Views, 10 Silverdale Road, Chorlton M21 0SH
Email: editor@nspku.org

Dear News and Views,

Please find enclosed £700.00, raised by running the London 10k earlier this year.

Our daughter, Isabella, is 3y and has PKU. We found running the 10k a very rewarding way of raising funds for the NSPKU and hopefully this will be the first of many fund raisers.

Many thanks must go to all the generous people that sponsored us, to raise this amount was quite a challenge with so many charity events taking place.

Best wishes
Paul and Tracey Murphy

Dear News and Views,

Please find enclosed a cheque to the value of £240.00 being sponsor money collected for the Great Scottish Charity Walk held in June this year. I have enclosed a photograph of the 6 walkers who took part and of course No. 1 being my granddaughter Nicolle who is 13 years old and has PKU. Myself being No. 5, my youngest son No. 6 and 2, 4, and 5 being colleagues from the office. We had a great day and finished with a good time, although I must admit I found it quite hard at the end. Nicolle however was my inspiration and urged me on.

If our efforts are included in your next issue of News and Views I would appreciate if you could send me a copy to show Nicolle and the other walkers, I am quite willing to subscribe.

I have also enclosed a cheque for £45 being the donations from our collection tin in the office here at Abercorn Memorials.

Kind regards,
Grace Henderson

Dear News and Views,

Please accept the enclosed cheques for £700 and £25 as a donation.

Most of the £700 was raised by one of the parents Kenny Thomson and his brothers-in-law twins Craig and Guy who completed the Scottish Fresh'n'Lo 10K in September in a fantastic time of 56 minutes. Kenny had not run a 10K before and took up the challenge to raise funds for the Yorkhill Metabolic fund and for the NSPKU. In addition, I took up the challenge to run the Fresh'n'Lo half marathon on the same day and managed to get round in a fairly surprising 2 hours 4 mins without collapsing!

The Yorkhill fund is used for subsidising patient activity days, literature and the annual trip to the Outdoor Centre in Keswick for children with PKU.

Kenny has twin boys Bailey and Mason and Bailey has PKU. You can see them proudly wearing the medals after the race.

The £25 came from one of the other families as a donation to the NSPKU. Tammy and David have two daughters, the youngest Nicki has PKU.

I hope that next year we can inspire more of our families to take part in the major Scottish running event as it is great fun. The best part is running over the Kingston Bridge which links the North and South of Glasgow.

Yours sincerely
Barbara Cochrane
Metabolic Dietitian

Dear News and Views,

My youngest daughter Emily is 2 1/2 years old and has PKU My family and I attend St. Peters Catholic Church in Westgate on Sea.

Increasingly over the past few months a growing number of people have asked me what PKU is and how it affects Emily and the family. I decided to address the church and explain all about PKU, the diet and the NSPKU

The Union of Catholic Mothers were planning an Easter fayre, and decided to make it in aid of the NSPKU The fayre raised £115.00, in addition members of our congregation also donated money for the charity. There was also a subsequent collection that raised an additional £80.00.

During the service a visiting Police officer, Mr. Ken Pickett, a member of the Thanet Police Theatre Club pledged a further £200.00. The money had been raised earlier in the year through the Theatre Clubs annual pantomime, whose proceeds are split amongst various charities.

In all a total of £540.00 has been raised in aid of the NSPKU I would like to take this opportunity to thank everyone who helped to raise this money or gave a donation. It just goes to prove, there is always some-one out there who cares enough to help. You just have to ask…

Please find enclosed a cheque for £540.00

Kind regards,
Mrs. Jacqueline Burne

Dear News and Views,

We recently celebrated our silver wedding anniversary with a family meal in a local restaurant. We asked our family not to buy us any presents but instead for donations. As our children currently have ME we asked for donations to be split between the NSPKU and two ME charities (AYME and Tymes Trust) who have helped us in the last few years.

Dave & Lin Stening

Dear News and Views,

Please find enclosed a donation of £10.00 raised by my work colleague, Phil Taylor, by recycling aluminium.

Phil has raised thousands of pounds for charity over the years by collecting tin foil, bottle tops and aluminium drink cans, which are a valuable raw material. The aluminium industry pays collectors cash for empty drink cans making **'cash for cans recycling'** a great way to raise funds for good causes.

Phil has been recycling aluminium since his Grandfather, Norman Newton, sadly died in 2005. Norman walked miles every week around pubs, shops and market stalls to pick up empty cans. He became renown for his efforts in his home town of Hyde and people used to leave cans on his doorstep.

Other charities which have been helped by the cause include Help the Aged, Save the Children Fund the RNLI and animal welfare groups.

Phil has kindly donated the cash to the NSPKU in support of my daughter, Holly Chambers, who was diagnosed with Phenylketonuria in 1996 when she was just 15 days old.

On behalf of the NSPKU and all the other charities you have helped, I would like to say Thank-You Phil for all your hard work. People like you make a difference to the world and you should be very proud of yourself.

Yours sincerely
Mrs. L J Chambers, Stockport

Dear News and Views,

Please find enclosed cheques totalling £678.29 being donations made by family and friends of my father, Alan Swift, who sadly died on the 2 July 2007 after a three and a half year battle with lung cancer.

My father was a wonderful man who worked hard all his life and was a very proud family man. My father was married to my mother, Anne, and together they had three children and eight grandchildren who all loved him dearly.

We have chosen the NSPKU as this charity was particularly close to my father's heart since my eldest daughter Holly, now 11, was diagnosed with Phenylketonuia when she was just 15 days old.

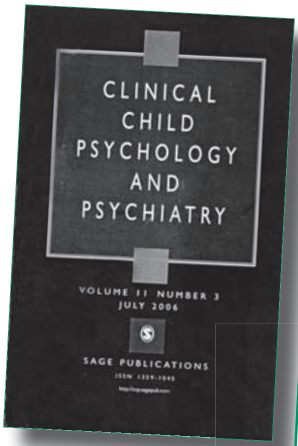
We hope this donation goes some way towards your research into this unfortunate condition.

Yours sincerely
Mrs. L J Chambers

Dear News and Views,

Please find enclosed a cheque for £527 and an additional cheque for £5. This is money raised for the NSPKU by Mrs Cathy Turner and me through our completion of a Hydro Active Woman's Challenge in September. As Cathy's granddaughter has the condition of PKU, we wanted to raise money for your charity specifically. We are acutely aware of the significance of donations your receive and how they go to help both people who have PKU and their families. I believe that should have already received the sum of £220 from **www.justliving.com**, which brings our total to £747.
I hope that this money will be of great use to you!

Best wishes!
Sam Nelson



CLINICAL CHILD PSYCHOLOGY AND PSYCHIATRY

VOLUME 11 NUMBER 3
JULY 2006

SAGE PUBLICATIONS

Many of you will remember the excellent presentation by Anna Brazier, clinical psychologist, and Claire Rowlands, mother of a child with PKU, at the NSPKU conference in Skipton in 2005. They talked about the escalating problems of getting a young child to take protein substitute and how they turned it around together.

Following on from that they wrote a paper for Clinical Child Psychology and Psychiatry detailing their individual accounts of how it was for everyone involved and their experience of a conference.

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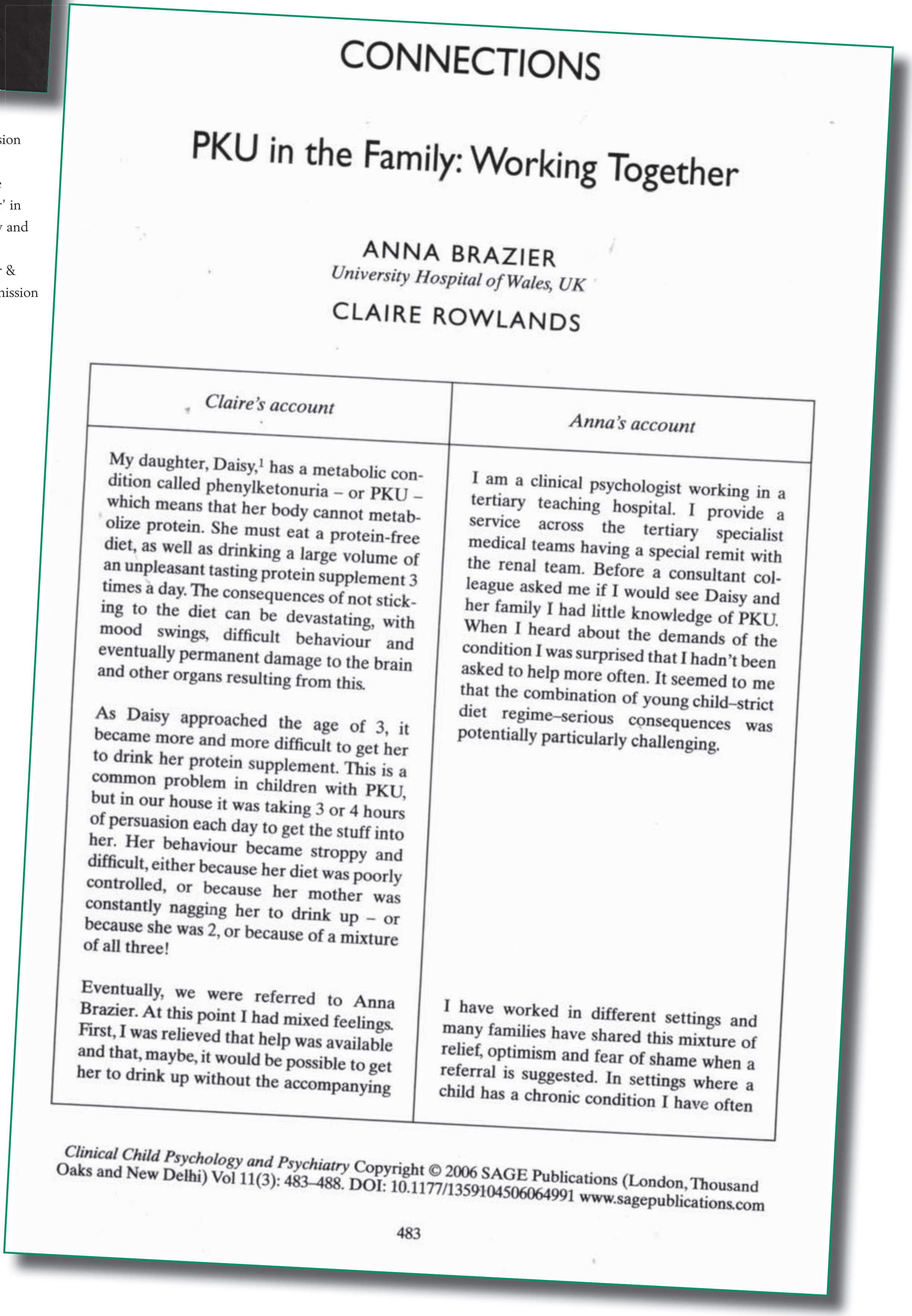

CONNECTIONS

PKU in the Family: Working Together

ANNA BRAZIER
University Hospital of Wales, UK

CLAIRE ROWLANDS

Claire's account	*Anna's account*
My daughter, Daisy,[1] has a metabolic condition called phenylketonuria – or PKU – which means that her body cannot metabolize protein. She must eat a protein-free diet, as well as drinking a large volume of an unpleasant tasting protein supplement 3 times a day. The consequences of not sticking to the diet can be devastating, with mood swings, difficult behaviour and eventually permanent damage to the brain and other organs resulting from this. As Daisy approached the age of 3, it became more and more difficult to get her to drink her protein supplement. This is a common problem in children with PKU, but in our house it was taking 3 or 4 hours of persuasion each day to get the stuff into her. Her behaviour became stroppy and difficult, either because her diet was poorly controlled, or because her mother was constantly nagging her to drink up – or because she was 2, or because of a mixture of all three! Eventually, we were referred to Anna Brazier. At this point I had mixed feelings. First, I was relieved that help was available and that, maybe, it would be possible to get her to drink up without the accompanying	I am a clinical psychologist working in a tertiary teaching hospital. I provide a service across the tertiary specialist medical teams having a special remit with the renal team. Before a consultant colleague asked me if I would see Daisy and her family I had little knowledge of PKU. When I heard about the demands of the condition I was surprised that I hadn't been asked to help more often. It seemed to me that the combination of young child–strict diet regime–serious consequences was potentially particularly challenging. I have worked in different settings and many families have shared this mixture of relief, optimism and fear of shame when a referral is suggested. In settings where a child has a chronic condition I have often

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drama and get back to a 'normal' family life. I was concerned, however, about sharing our family struggles with a stranger. In a way, I was embarrassed at my lack of 'control', and by my horribly behaved daughter. I didn't know what to expect. What are clinical psychologists? How do they work? I thought that maybe Anna would want to work with Daisy – and I knew she wouldn't get much sense there!

Of course, working with Anna proved to be completely painless and even enjoyable! She adopted a problem-solving approach and after just a couple of sessions of thinking about and around the problem, together we were able to formulate some strategies which began to turn Daisy's behaviour around.

After talking to Anna, I always felt as if I had been a bit thick! I began to see that *of course* positive consequences should follow good behaviour and that *of course* 'bad' behaviour should not be rewarded with lots of attention! It seemed so obvious with hindsight but had been anything but obvious to me when stuck in the middle of the problem.

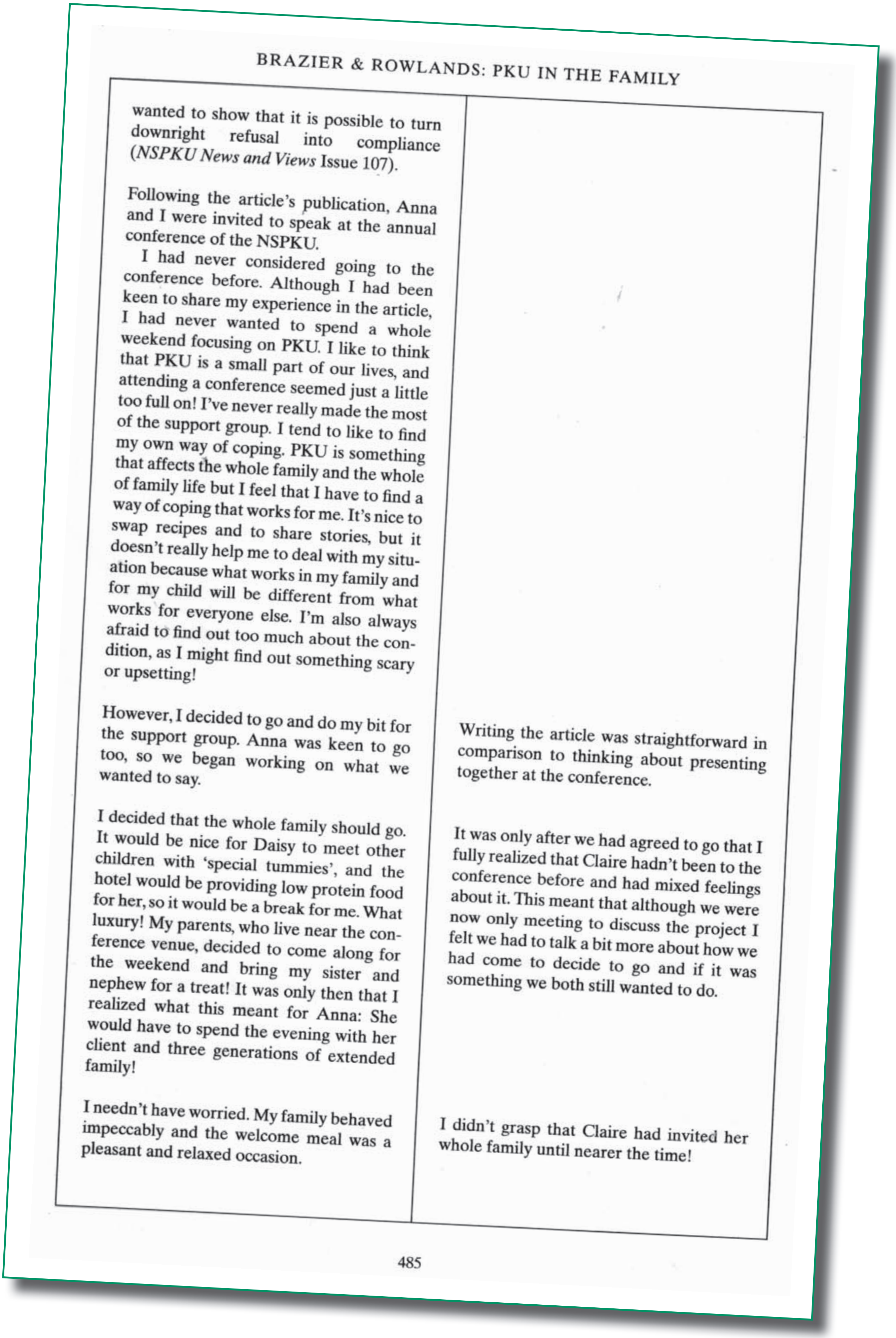
Neither of us can quite remember how it came about, but it was mooted that we should write an article about our experience for the newsletter of the support group, the NSPKU. I was keen to do this as I hoped that my experience would be of interest to other parents and that, if I could share some of the strategies and broad principles I had used, it might even be useful to other families in the same boat.

Anna and I decided that I would write my 'bit' first, and that she would add a commentary from her point of view. My first dilemma was how much personal matter to share with the wider PKU community. Eventually I decided on a no-holds-barred approach, as I was pretty sure that my experience was being repeated in PKU households up and down the country. I been told that a referral can feel like 'adding insult to injury'. I would like to hear more from Claire about what she thought I did or didn't do to help her feel, if you like, less embarrassed about the circle everyone had got into with Daisy's Maxamaid. How does she think services can best validate what are everyday experiences for families with a young child with PKU?

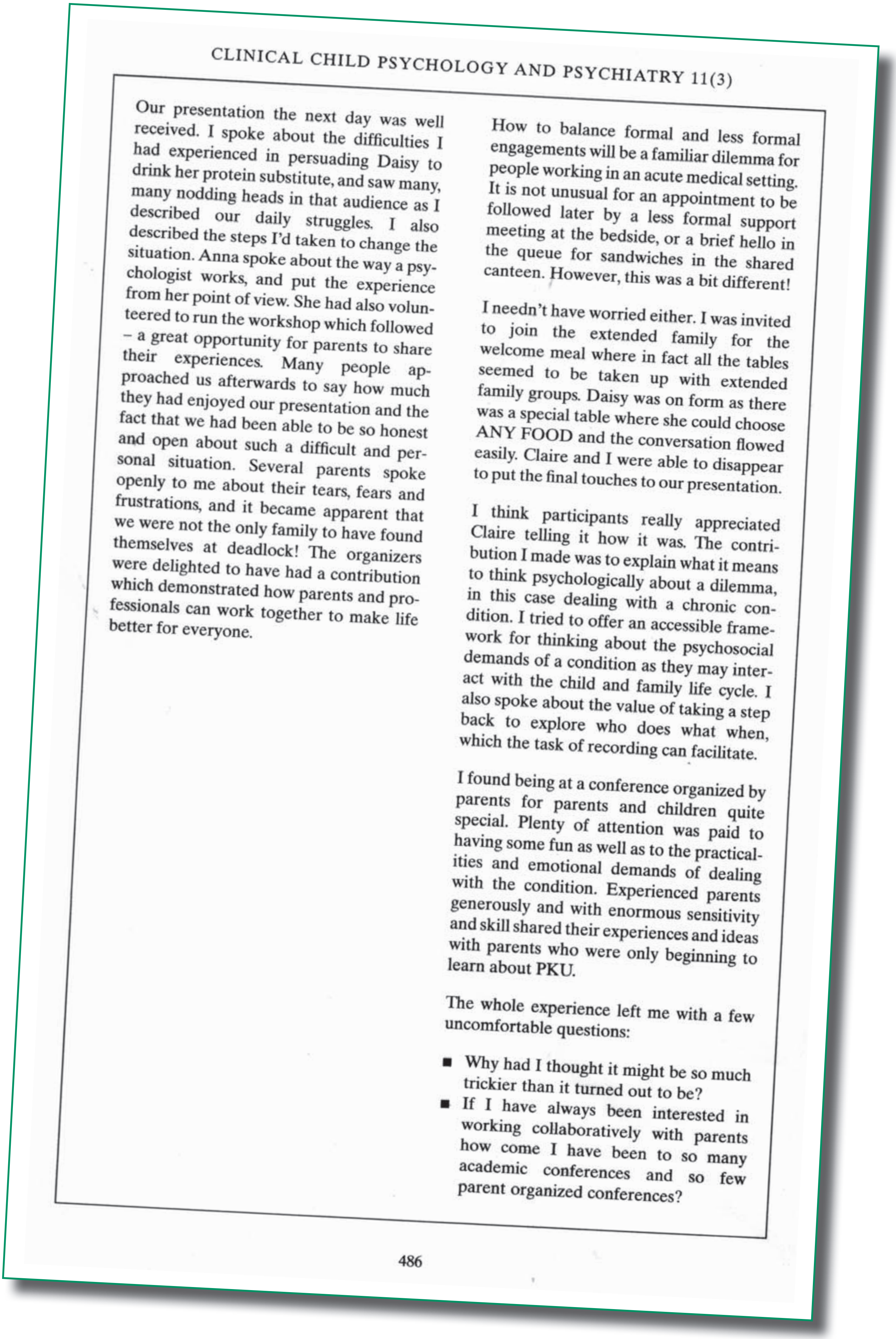
Again I think it would be helpful if Claire could identify some of the ingredients that made the experience OK for her. From my point of view I had met a family who were terrified that any changes to their regime would make matters worse, meaning Daisy could end up impaired. Their understandable terror had led to a bright 3-year-old calling all the shots.

Together we agreed that things couldn't get much worse as Daisy was getting hardly any of her drink despite everyone's best efforts. Suggesting no changes and some recording was sufficient to highlight the dance that everyone had got into. It became clear to Claire that Daisy was getting lots of attention for her delaying tactics with the drink. I think it was the recording which really highlighted how little of the Maxamaid Daisy was getting that allowed Claire to contemplate a change. Perhaps luckily, the first time Claire shrugged and said as soon as she had her drink they could go to the park, but in the meantime she would wash up and Daisy could play in the other room, Daisy shouted, 'I want my milk now!' After that she soon learned that the quicker she drank her milk the sooner she could have her cuddle, stripey tights or bedtime story.

Together Claire and I thought that writing the article in the way we did would help families in a similar situation take a step back and explore the changes they might be able to make with the support of friends and family. Claire said that she wanted to break the myth she felt was perpetuated in a busy outpatient clinic that everyone else was managing just fine.



wanted to show that it is possible to turn downright refusal into compliance (*NSPKU News and Views* Issue 107). Following the article's publication, Anna and I were invited to speak at the annual conference of the NSPKU. I had never considered going to the conference before. Although I had been keen to share my experience in the article, I had never wanted to spend a whole weekend focusing on PKU. I like to think that PKU is a small part of our lives, and attending a conference seemed just a little too full on! I've never really made the most of the support group. I tend to like to find my own way of coping. PKU is something that affects the whole family and the whole of family life but I feel that I have to find a way of coping that works for me. It's nice to swap recipes and to share stories, but it doesn't really help me to deal with my situation because what works in my family and for my child will be different from what works for everyone else. I'm also always afraid to find out too much about the condition, as I might find out something scary or upsetting!	
However, I decided to go and do my bit for the support group. Anna was keen to go too, so we began working on what we wanted to say.	Writing the article was straightforward in comparison to thinking about presenting together at the conference.
I decided that the whole family should go. It would be nice for Daisy to meet other children with 'special tummies', and the hotel would be providing low protein food for her, so it would be a break for me. What luxury! My parents, who live near the conference venue, decided to come along for the weekend and bring my sister and nephew for a treat! It was only then that I realized what this meant for Anna: She would have to spend the evening with her client and three generations of extended family!	It was only after we had agreed to go that I fully realized that Claire hadn't been to the conference before and had mixed feelings about it. This meant that although we were now only meeting to discuss the project I felt we had to talk a bit more about how we had come to decide to go and if it was something we both still wanted to do.
I needn't have worried. My family behaved impeccably and the welcome meal was a pleasant and relaxed occasion.	I didn't grasp that Claire had invited her whole family until nearer the time!



Our presentation the next day was well received. I spoke about the difficulties I had experienced in persuading Daisy to drink her protein substitute, and saw many, many nodding heads in that audience as I described our daily struggles. I also described the steps I'd taken to change the situation. Anna spoke about the way a psychologist works, and put the experience from her point of view. She had also volunteered to run the workshop which followed – a great opportunity for parents to share their experiences. Many people approached us afterwards to say how much they had enjoyed our presentation and the fact that we had been able to be so honest and open about such a difficult and personal situation. Several parents spoke openly to me about their tears, fears and frustrations, and it became apparent that we were not the only family to have found themselves at deadlock! The organizers were delighted to have had a contribution which demonstrated how parents and professionals can work together to make life better for everyone.

How to balance formal and less formal engagements will be a familiar dilemma for people working in an acute medical setting. It is not unusual for an appointment to be followed later by a less formal support meeting at the bedside, or a brief hello in the queue for sandwiches in the shared canteen. However, this was a bit different!

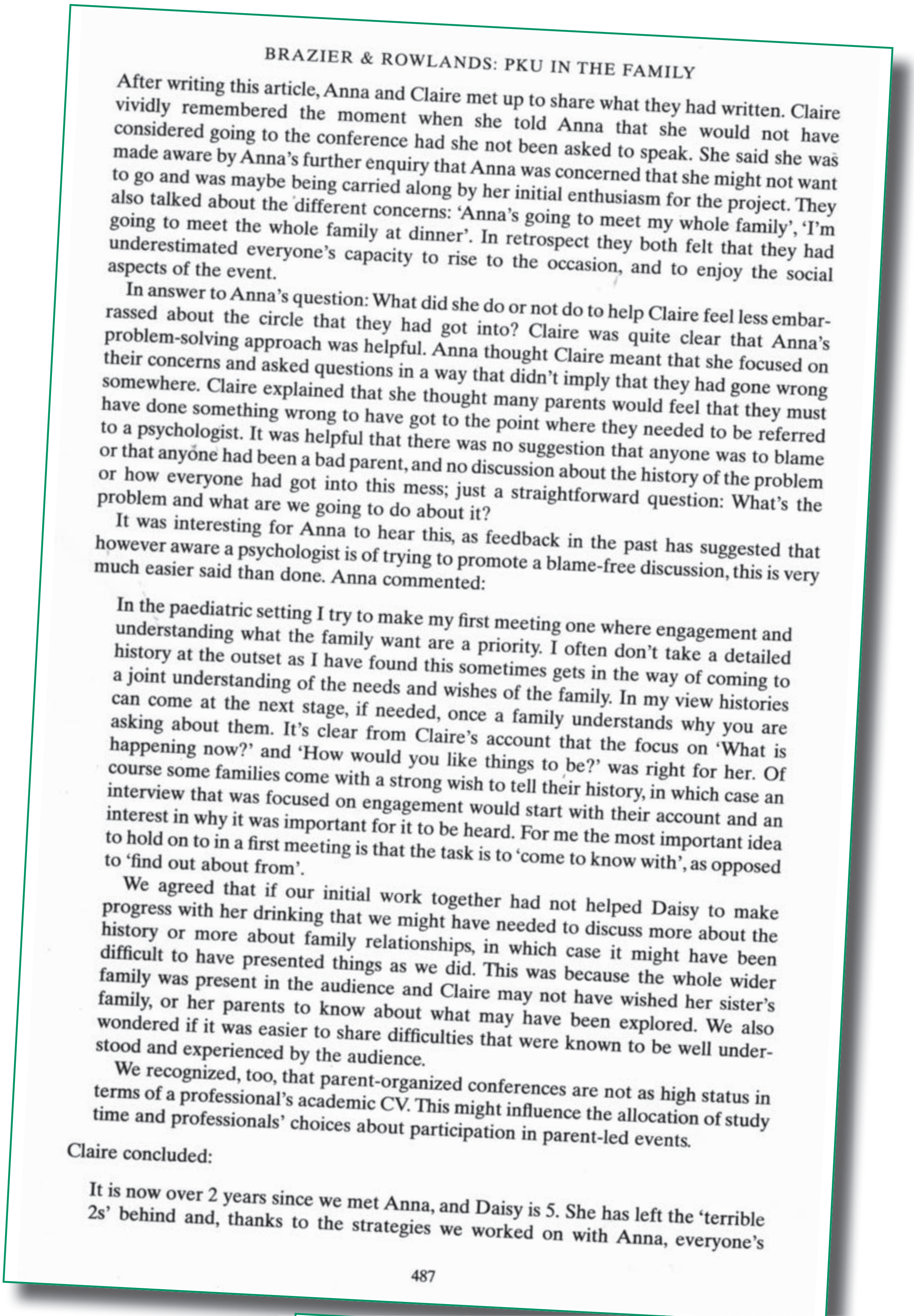
I needn't have worried either. I was invited to join the extended family for the welcome meal where in fact all the tables seemed to be taken up with extended family groups. Daisy was on form as there was a special table where she could choose ANY FOOD and the conversation flowed easily. Claire and I were able to disappear to put the final touches to our presentation.

I think participants really appreciated Claire telling it how it was. The contribution I made was to explain what it means to think psychologically about a dilemma, in this case dealing with a chronic condition. I tried to offer an accessible framework for thinking about the psychosocial demands of a condition as they may interact with the child and family life cycle. I also spoke about the value of taking a step back to explore who does what when, which the task of recording can facilitate.

I found being at a conference organized by parents for parents and children quite special. Plenty of attention was paid to having some fun as well as to the practicalities and emotional demands of dealing with the condition. Experienced parents generously and with enormous sensitivity and skill shared their experiences and ideas with parents who were only beginning to learn about PKU.

The whole experience left me with a few uncomfortable questions:

- Why had I thought it might be so much trickier than it turned out to be?
- If I have always been interested in working collaboratively with parents how come I have been to so many academic conferences and so few parent organized conferences?



After writing this article, Anna and Claire met up to share what they had written. Claire vividly remembered the moment when she told Anna that she would not have considered going to the conference had she not been asked to speak. She said she was made aware by Anna's further enquiry that Anna was concerned that she might not want to go and was maybe being carried along by her initial enthusiasm for the project. They also talked about the different concerns: 'Anna's going to meet my whole family', 'I'm going to meet the whole family at dinner'. In retrospect they both felt that they had underestimated everyone's capacity to rise to the occasion, and to enjoy the social aspects of the event.

In answer to Anna's question: What did she do or not do to help Claire feel less embarrassed about the circle that they had got into? Claire was quite clear that Anna's problem-solving approach was helpful. Anna thought Claire meant that she focused on their concerns and asked questions in a way that didn't imply that they had gone wrong somewhere. Claire explained that she thought many parents would feel that they must have done something wrong to have got to the point where they needed to be referred to a psychologist. It was helpful that there was no suggestion that anyone was to blame or that anyone had been a bad parent, and no discussion about the history of the problem or how everyone had got into this mess; just a straightforward question: What's the problem and what are we going to do about it?

It was interesting for Anna to hear this, as feedback in the past has suggested that however aware a psychologist is of trying to promote a blame-free discussion, this is very much easier said than done. Anna commented:

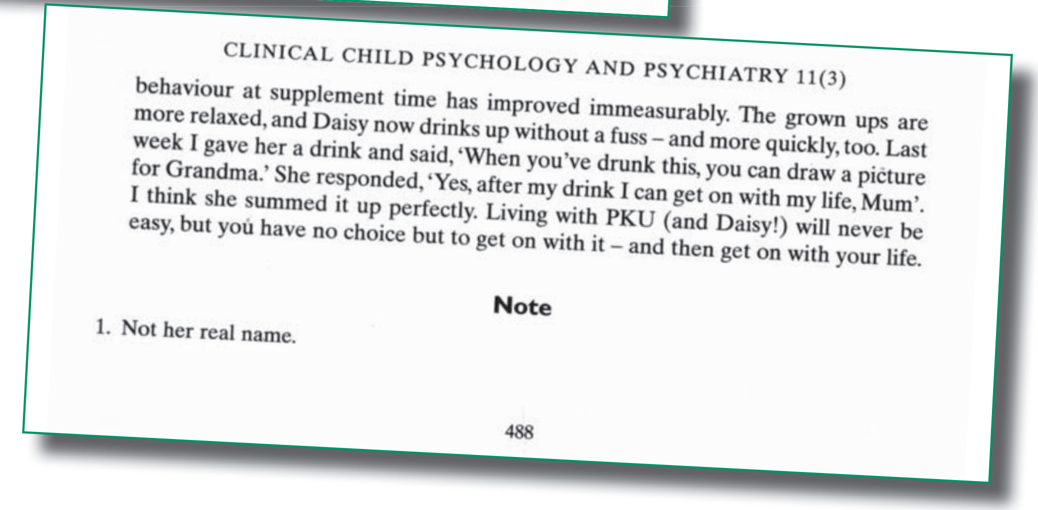
> In the paediatric setting I try to make my first meeting one where engagement and understanding what the family want are a priority. I often don't take a detailed history at the outset as I have found this sometimes gets in the way of coming to a joint understanding of the needs and wishes of the family. In my view histories can come at the next stage, if needed, once a family understands why you are asking about them. It's clear from Claire's account that the focus on 'What is happening now?' and 'How would you like things to be?' was right for her. Of course some families come with a strong wish to tell their history, in which case an interview that was focused on engagement would start with their account and an interest in why it was important for it to be heard. For me the most important idea to hold on to in a first meeting is that the task is to 'come to know with', as opposed to 'find out about from'.

We agreed that if our initial work together had not helped Daisy to make progress with her drinking that we might have needed to discuss more about the history or more about family relationships, in which case it might have been difficult to have presented things as we did. This was because the whole wider family was present in the audience and Claire may not have wished her sister's family, or her parents to know about what may have been explored. We also wondered if it was easier to share difficulties that were known to be well understood and experienced by the audience.

We recognized, too, that parent-organized conferences are not as high status in terms of a professional's academic CV. This might influence the allocation of study time and professionals' choices about participation in parent-led events.

Claire concluded:

> It is now over 2 years since we met Anna, and Daisy is 5. She has left the 'terrible 2s' behind and, thanks to the strategies we worked on with Anna, everyone's



> behaviour at supplement time has improved immeasurably. The grown ups are more relaxed, and Daisy now drinks up without a fuss – and more quickly, too. Last week I gave her a drink and said, 'When you've drunk this, you can draw a picture for Grandma.' She responded, 'Yes, after my drink I can get on with my life, Mum'. I think she summed it up perfectly. Living with PKU (and Daisy!) will never be easy, but you have no choice but to get on with it – and then get on with your life.

Note

1. Not her real name.

Lost in Translation? – not us!

Firstly to thank you for the 'very useful translations' on the NSPKU web site. Stephanie and myself recently visited Paris and took the translation document with us. It made such a difference when visiting restaurants. Admittedly we didn't try to pronounce the translation but asked that it was read. Everywhere we went people were so helpful and understood what we wanted. It was wonderful not to have the usual option of chips and salad! We were in the restaurant at the Eiffel Tower and the chef came and saw us. He prepared a wonderful meal for Stephanie and made it a very special occasion. More importantly everyone wanted to help and were intent on making every effort. In the past when we have requested a special meal it has been difficult to explain and I have sometimes thought that Stephanie was just thought of as a fussy eater. By using the explanation people were much more sympathetic and willing to help. A huge success and I am now much more confident travelling abroad. Ann thought you may be interested in the following things we have done but I am conscious that they are for very special occasions. However, she has asked that I let you know in case you want to pass this on.

We stayed at the Dream Castle hotel near Disneyland Paris. It was fantastic and the hotel were more than happy to prepare food for Stephanie at any time. I usually ask hotels to cook pasta for me and it is usually done well. However, this hotel not only prepared it but they presented it beautifully. Nothing was too much trouble and again with the help of my translation sheet they understood exactly what was required. The breakfast was buffet style but had absolutely everything you could want.

Again Stephanie's bread was toasted and presented in a small basket. I appreciate that this may not be important to many people but it is to us and it made it a special part of our holiday. Also the rooms have larger than average fridges which made it ideal for keeping food, protein substitute chilled.

And finally. We love Jamie Oliver and adapt many of his recipes so last year for Stephanie's 16th birthday we went to London and had lunch at Jamie Oliver's Fifteen restaurant. It was a wonderful experience because the staff knew exactly what was allowed. Even the waiter had a complete understanding of what would be suitable. They prepared a wonderful platter of different vegetable dishes. We took bread and they warmed this and served it with rosemary infused olive oil. Then they prepared a coffee dessert and presented this in an espresso cup. Everything was freshly prepared and even though nothing Stephanie had was on the menu they prepared a wonderful meal for her.

I suppose part of what made these events special was that Stephanie was not made to feel a nuisance or that she was being difficult and fussy. It also helps when people understand the diet and you don't have to keep saying 'sorry I can't have that'. Again thank you for the very useful travel information - we're planning our next trip already!

Sandra Bryan

Editor's note

Travel tips online

Travel tips in various languages are available to download from
http://www.nspku.org/travel.htm

How can I make sure my child isn't excluded from parties and play dates?

I think the most important thing is to have a positive attitude towards the diet and to be confident yourself about someone else dealing with your child's diet. If you are worried about it then your friends will worry too and will be less inclined to want to deal with it. The main message to get across is that if they accidentally eat the wrong thing it is not the end of the world – you just need to know so you can make adjustments later or be forewarned of a high blood result.

When my son was small his friends were used to him arriving with a lunch-box. This would contain either all or part of what he was going to eat. For a party it would contain a roll or sandwich, some “ nuggets” (PKU sausage mix rolled into nugget shapes), and a Rowntrees jelly pot. When I arrived at the party I would make up his own plate, add some exchanges from the food provided – some crisps, suitable sweet treats etc. I would then ask the parent to just empty the remnants into the lunch box and when I got home I could see what he had/hadn't eaten and sort out remaining exchanges accordingly. That way the parents didn't have to worry too much about the diet. His friends were pretty good at keeping an eye on what he ate and would make sure he didn't have anything he wasn't allowed! I would also have asked the parents in advance not to throw food wrappers away so I could check out what he could eat (however I did do a bit of bin rummaging in my time!!). Fortunately most parents these days buy the birthday cake so again I would ask them to keep the box so I could check the protein content. The cake usually ends up in the party bag, in fact I often used to ask the parents before hand if they would do this. I also used to have a list of sweets I could give to parents so they would know what to include in pass the parcel wrappers and in the party bag.

If the party was elsewhere e.g, a soft play area or bowling I would usually provide a Tupperware with salad in and provide a small set of scales for them to weigh an exchange of chips – I would write the amount of grams on a post it and stick it to the scales so they didn't have to worry. If I was doubtful about the drink that would be provided I would just put one in for him – a fruit shoot or something similar. It does depend on how confident the parent is as to how much you do for them or how much you allow them to do. Some would quite happily ring venue's, check out packaging etc and others just preferred to have everything provided.

With tea invites I would handover a lunchbox at school in the morning which may just contain a sausage, scales and supplement so they could add chips (or jacket potato) and salad or I would put in a portion of pasta sauce which could be heated up and some pasta to be cooked, also some biscuits for a snack and some fruit. Even if I had discussed it earlier I would always put instructions in making sure that I wrote that if a mistake was made it wasn't a huge problem and just reassurance to call if they were in doubt. I would also ask them to do the supplement but tell them that if it was a problem I would do it later at home. Again friends often liked getting involved and were very encouraging.

To be honest I think in these situations food is the thing that is last on a child's mind – playing is much more important!

Julia Bailey

Low protein evening classes

It started as a chat about promoting cooking skills and ended up with a series of evening classes. That is what happens when you get 4 people around a table!

We have organised cookery days in the past in Glasgow and the uptake has been variable, hiring the university kitchen was expensive, so we were looking for something different to do. Mona Taylor, who is one of the best demonstrators I have yet to meet, so practical and has loads of brilliant ideas, along with Emma from SHS Nutricia, Debbie from Vitaflo and myself all organised, helped out and did the general running about during the evening.

We hit on the idea of a series of evening classes with a different theme each night, trying to develop a particular skill with the range of low protein foods.

Why is it when you are planning something it seems so far away! The next thing we knew we were taking boxes and bags into a man eating lift, up 4 floors to a home economics kitchen in a local high school.

We decided on one class per month with a different theme - Indian, Italian, USA and Chinese. This enabled us to focus on the many low protein foods and develop skills – such as cooking the pasta, rice or making bread along with many ways of using vegetables.

As we only had two hours for the class, most of the preparation was done in advance. I can still remember the many onions peeled and chopped. The smell in the car lasted for days afterwards. A file was prepared for each participant giving information on general store-cupboard ideas, shopping lists and the recipes for the evening.

We were thrilled with the response, with an average of around 24 people turning up each of the evenings. The participants ranged from parents of babies and toddlers with PKU, to young adults, parents, and carers of adults with late diagnosed PKU.

One of the many benefits from the evening apart from the fun we all had, was the information being passed from one person to the next. We felt that one of the aims was to try and get people together and help them feel they were not alone with dealing with such a rare condition, and from the chat and noise, it seemed that that objective was reached.

We are now preparing for the next series of evenings – cake making and decorating and pastry making. After Christmas we will be looking at healthy eating, (along with the general population of the UK!!)

The evening classes have certainly filled a need – whether it is bringing people together or developing skills, it seems to have worked. We just now have to work out how to get all the stuff up to the room without getting stuck in the lift!

Barbara Cochrane
Senior Dietitian
Glasgow

SUPPORT GROUPS AND CONTACTS...

Sussex

The **Sussex Support Group** are organizing a get together around Easter time. We are planning on going to CJ's Playland and Laserland in Burgess Hill and then food/drink at our house afterward.

Please contact me if you are interested in coming to this or future events.

Sue Greenhalgh
Telephone **01444 242788**
or email **sue.greenhalgh@airservicesuk.com**

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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

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Helpline and General Enquiries Tel: 01215 22 44 34

Fate Special Foods recipes

Hello,

My recipe this time is one that I get requests for all the time. They are easy to make and perfect for packed lunches and snacks at any time of day. They are also good served as a crisp accompaniment to low protein soups or stews. They keep well in the freezer, so it might be worth making double the recipe.

FATE SAVOURY BISCUITS

100g finely chopped onion
15 mls oil
200g Fate Low Protein All-Purpose Mix
Pinch of salt
100g block margarine
1 tsp oregano
1 tsp baking powder
60mls cold water
3 tsp tomato ketchup
Extra Fate All-Purpose Mix for rolling out
Pre-heat the oven, Gas Mark 6 (200°C or 400°F)

Heat a small pan and add the oil. Stir in the onions. Cook until soft and brown. Leave to cool.

In a bowl, stir together the Fate All-Purpose Mix, and salt. Rub in the margarine until the mixture resembles fine breadcrumbs. Stir in the oregano and baking powder.

Add the cooled, fried onions and mix well. Measure the tomato ketchup and water in a baby's bottle and pour it all in one go to the rubbed in mixture. Stir well to form a dough similar to pastry.

Lightly dust the work surface with extra Fate All-Purpose Mix and knead the dough for a few seconds until it is smooth. Then roll it out quite thinly. Cut into long thin strips about 5cms wide and cut through the strips at about every 10cms. Cut each piece into triangles.

Place onto a baking sheet (no need to grease) Bake in a preheated oven for 10-15 mins, until golden brown and crisp.

Cool on a wire rack.

ACBS foods for Pku

New foods to the list and including those with an exchange value

Recently there have been a number of foods passed by ACBS. Some of these do contain significant amounts of phenylalanine and need to be counted as exchanges or part exchanges.

At a recent meeting of the dietitians sitting on the Medical Advisory Panel of the NSPKU we looked at these foods, their ingredients, how they are made up and portion size.

The following recommendations have been made and will be included in future editions of the Dietary Information Booklet for the Treatment of PKU.

* Denotes new item

FirstPlay Dietary Foods Ltd	**Quantity**	**Exchange**
Promin Low Protein Pasta in Sauce		
*Moroccan Flavour	1 sachet	½ exchange
Cheese and Broccoli Flavour	1 sachet	1 exchange
Tomato,Pepper and Herb Flavour	1 sachet	1 exchange
Promin Low Protein Burger Mix	1 sachet	1 exchange
*Promin Low Protein Chocolate and Hazelnut Spread		Free
Promin Desserts		
*Strawberry and Vanilla	1 sachet	Free
*Chocolate and Banana	1 sachet	Free
SHS International Ltd		
Breakfast Cereal		
Loprofin Cereal Loops		Free
*Apple Cereal Flakes		Free
*Strawberry Cereal Flakes		Free
*Chocolate Cereal Flakes		Free
Snack Pots		
Curry Flavour	1 pot	½ exchange
Tomato and Basil Flavour	1 pot	½ exchange
Low Protein Milk		
Sno-Pro Drink	1 carton	½ exchange
Loprofin Drink	1 carton	½ exchange
Loprofin Dessert		
*Strawberry Flavour Made with Duocal or Calogen	1 serve	Free
*Strawberry Flavour Made with Sno-Pro or Loprofin milk	1 serve	Free
*Vanilla Flavour Made with Duocal or Calogen	1 serve	Free
*Vanilla Flavour Made with Sno-Pro or Loprofin Milk	1 serve	Free
*Chocolate Flavour Made with Duocal or Calogen	1 serve	Free
*Chocolate Flavour Made with Sno-Pro or Loprofin	1 serve	½ exchange

It is recommended that desserts should be limited to one serve per day.

NSPKU Annual Conference

February 29th to March 2nd 2008
The Hilton Hotel, Northamptonshire

The annual conference is nearly upon us again and this year we are considering the psychology of acceptance of the treatment. This includes professional help, a brother and sister's personal and moving experience of helping one another, the results of the 4 year trial of diet for previously untreated adults as well as hearing about research, practical information about useful foods newly on prescription and in the supermarket and a few competitions on exchanges and calculating them from food labels.

We are particularly fortunate this year to have two eminent psychologists speaking, one from the UK and one from Germany. Dr Peter Burgard from Heidelberg in Germany has been involved with PKU for a very long time and has a wealth of experience. I recently heard him speak in Spain at the ESPKU conference and his analogies are memorable, clear and practically helpful. It's interesting to hear about what happens in Germany too. Are they like us or not and what do they do? How does he explain about high levels to parents and children and what comparisons does he draw from the wider world to help us?

Dr Danuta Orlowska is a clinical psychologist working in London and is closely involved with the adult PKU centre at the Neurological Hospital. She will be talking about looking after our mental health. How can we do that? Are there some helpful tips? She will talk about how we can deal with unhelpful thoughts and then applying what we have learned to living with PKU.

It was last year that I attended an adult PKU study day in London and was inspired and impressed by Joe and Fiona O'Malley who are brother and sister. One has PKU the other does not and their story illustrates the importance of support and enthusiasm making a real difference to quality of life.

The trial of the diet for previously untreated adults with PKU has been a huge piece of work superbly managed and executed by research dietitian Lesley Robertson and psychologist Allayne Amos. Dr Philip Lee and Professor Glynis Murphy and the rest of the steering committee have all worked hard to undertake and complete the first double-blind cross-over trial in this group of people. We are also delighted that someone who took part in that trial along with her carer is also coming to the conference to talk about how it was from their point of view.

Dr Anita MacDonald is always busy doing research to help on a practical level and I know she will have something up her sleeve to tell us about.

We are running some practical sessions on working out exchanges as well as a competition or two to see how good you are at guessing exchanges!

All this is of great interest without doubt but the real benefit of being at the conference is the meeting of others in the same position (particularly important if you are at a smaller centre) and this is true for parents, children, teenagers and adults with PKU as well as the extended family. In this age of technology when we can all communicate so quickly and remotely I still think there is nothing more pleasurable than sharing a cup of tea or glass of something with a friend. All this and disco, parties, entertainment and outings are rolled into a weekend to remember. So why not give it a try?

SUPPORT GROUPS AND CONTACTS...

Bath and Bristol Area

I am a Mum with two girls with PKU, Effie who is 5 and Lola who is 2. I have been thinking for a while of starting a support group in the Bath and Bristol area and I wondered if there was anyone out there who might be interested. I thought perhaps we could start with coffee mornings to give the children a chance to meet other children with PKU, parents to share ideas and teenagers and adults to meet up. If you are interested you can contact me on **01225 469878** or **kathsenior@talktalk.net**

Dietitian's Report

I received the following letter from the mother of a young girl with PKU.

Hello Eleanor,
I found a dairy free cheese flavour sauce mix in Tesco yesterday, and my daughter really liked it! I don't recall you mentioning it in News and Views before? It's Free and Easy and has 0.5g of protein per 100g of reconstituted sauce. Does this count as free?

To echo what Janice Willis said, we also have had a good experience in Pizza Hut in Cardiff. We took our daughter's pizza in and they heated it up for her. She enjoyed lots of tasty bits from the salad bar too!

My reply: The Free and Easy Sauce is a good find. As the protein is over 0.3g per 100g then it does have to be counted but you get a generous 100g for ½ Exchange.

Another mother sent me 2 recipes which her two little girls love. It is using Marscapone cheese from Sainsbury's which contains 3.6g protein per 100g. This works out at 30g for 1 exchange

Tomato and Marscapone Pasta Sauce

Ingredients:
1 tbsp Olive Oil
1 red onion, peeled and chopped
1 garlic clove, peeled and crushed
400g Passata
Pinch of sugar
2 tablespoons torn basil leaves
30g Marscapone cheese = 1 exchange

Method:

1. Heat the olive oil in a saucepan and sauté the onion and garlic for 7-8 minutes. Stir in passata and sugar and simmer for 10 minutes with the lid on, stirring occasionally.

2. Remove from the heat, add the basil and blend in a food processor

3. Take out one portion of tomato sauce and add 1 exchange of Marscapone cheese. Stir until melted.

4. Serve with Low Protein pasta.

5. One exchange of Marscapone is more than enough. It also tastes good if you only use ½ exchange.

Low Protein Sausage Balls and Pepper Sauce

Ingredients:
Fate low protein sausages rolled into balls
1½ tbsp vegetable oil
2 shallots peeled and finely chopped
1½ red peppers
1 tsp tomato puree
3 tbsp chopped fresh basil
450ml vegetable stock – use Marigold Organic Swiss Vegetable Bouillon Cubes- they are Free

1. To make the red pepper sauce heat the oil in a frying pan, add the shallots and red peppers, sauté until softened. Stir in the remaining ingredients and season to taste. Bring to the boil and simmer for 15-20 minutes. Blend until smooth

2. Heat oil in a frying pan, add low protein sausage balls and sauté.

3. Transfer low protein sausage balls to a casserole and cover with pepper sauce and cook in a pre-heated oven 180C/350F/Gas4 for about 20 minutes

4. Serve with low protein rice/or exchange of ordinary rice or low protein spaghetti

The low protein sausage balls hold together well in the sauce and have a lovely fluffy texture.

If you have time you can roast and skin the peppers for the sauce.

New Products on Prescription

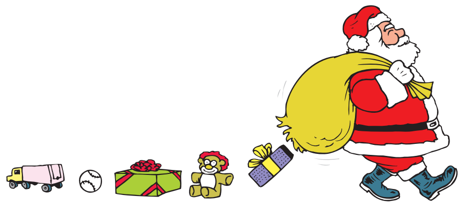
Following on from the explanation of how to count all the many exciting new foods on prescription I have taken a few pictures of ice cream puddings which are really quick and easy.

What's useful to go with the ice cream?

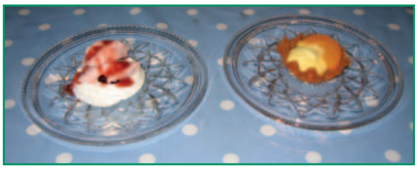
Wafer Cones:
Askey's waffle cones
1 cone = 1 exchange

Askey's party cornets
1 cone= ½ exchange

Brandy Snap Baskets
1 basket = ½ exchange



Meringue Nest 1 nest= ½ exchange



Fruit Sauces and Maple Syrup

Tinned and Fresh Fruit

Decorations eg Hundreds and Thousands, Jelly Tots

I have suggested only one serve of ice cream in a day as it does contain quite a lot of calories and as for everyone it's important to get the calories right!

Florida's Natural Sour String

These are made by the same company which makes the fruit nuggets. The string comes in individual little packets, 6 to a box, and would be nice in a packed lunch. Dr Anita MacDonald passed these to me at a meeting recently.

Aldi Olive Pesto Sauce

Julia, our treasurer, told me about this olive pesto. Pesto usually contains pine nuts which makes it high in protein but this one is made of all free ingredients so you don't have to count it. You could stir it through hot low protein pasta or even spread it on some low protein toast or dip some raw vegetables into it for a savoury dip.

Eleanor Weetch
Society Dietitian

Festive Muffins

Ingredients:

100g (4oz) soft margarine
100g (4oz) caster sugar
200g (8oz) Loprofin Low Protein Mix
2 x 5mlsp (2tsp) Loprofin Egg Replacer
2 x 5mlsp (2tsp) baking powder
1 x 5mlsp (1tsp) ground mixed spice
150ml (6floz) Loprofin PKU Milk Drink
2 x 5mlsp (2tsp) black treacle
175g (7oz) mincemeat *

Oven temperature:

190°C/375°F/Gas Mark 5

Method:

1. Place the margarine and sugar in a large bowl, beat well until light in texture and creamy coloured.
2. Combine the Loprofin Low Protein Mix, Loprofin Egg Replacer, baking powder and mixed spice.
3. Warm the treacle slightly and stir into the Loprofin PKU Milk Drink.
4. Beat the dry ingredients into the creamed mixture, alternately with the Loprofin PKU Milk Drink (one minute if using an electric hand mixer, 2-3 minutes with a wooden spoon), until a soft smooth batter is achieved.
5. Stir in the mincemeat.
6. Divide the mixture between 11-12 muffin cases in a large muffin tin.
7. Bake the muffins in a preheated oven for 20-25 minutes, until well risen and firm to touch. Cool on a wire rack.

Makes 11-12 large muffins

*Check with NSPKU Food List regarding a suitable brand.

Dietitian's note on mincemeat - use those with 1.5g protien per 100g or less and with no nuts.

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Specialist Dietary Foods

Freshly prepared PKU ready meals

Available near you*

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

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

Yes We Cook That!
To have a birthday cake and know that you can eat it all?

Yes We Cook That!
To have all this at Supermarket prices?

Yes... it is!
To know that we really understand PKU, really understand your diet and really know what exchanges are?

Yes... we do!

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

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

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*Available now in most of the UK and Ireland.

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Four tasty NEW products added

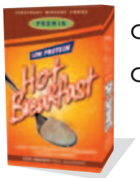
NEW

NOW AVAILABLE ON PRESCRIPTION

The Promin range just keeps growing which is good news when you are on a restricted diet, and because we are a family run company we can react to our customers needs thats why we keep adding new products to our range.

Two new desserts' chocolate and banana and strawberry and vanilla also a chocolate spread - the Kids will love this one and pasta spirals in a morroccan sauce.

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



Choose: 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 Brocolli sauce.

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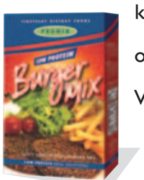

www.promin-pku.com

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

Promin Pasta and Promin Tri-Colour Pasta are now a well established brand and are available on prescription. The range also includes Imitation Rice, Pasta meal and Lasagna Sheets. By talking with PKU patients, parents and Dietitians new products have been developed to reflect your needs. Please call or visit the website for more information and keep sending your recipe suggestions.

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

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Always consult your dietitian before trying something new.

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