NSPKU

A GUIDE TO DLA

CONTENTS

Section 1

Foreword

DLA (Disability Living Allowance) is awarded in circumstances where a person requires either substantially or significantly more care than that of a “normal” and “healthy” person. Someone who may have a disability. The important factor is the amount of CARE a person requires over and above someone without a disability.

In this booklet we will try to establish the important points in a DLA claim and an overview of the process involved.

Some people are uncomfortable claiming DLA for a person who has PKU, and deem them not to be disabled so therefore not eligible for the award. This is a personal issue for the individuals involved. The NSPKU has elected to take a neutral stance on the subject, whilst recognising the need for support required by the membership, should they decide to proceed with a claim.

DLA has three different rates. Higher, Middle and Lower rate. PKU more commonly attracts the middle rate (if awarded) but there are no hard and fast rules that can be applied in the way the award is granted. Some individuals attract Higher Rate, others Middle Rate and others, Lower rate. In a number of cases it is not awarded at all. It is purely down to the DLA assessor who deals with your particular case and their views on the validity of your claim given the evidence before them at that point in time.

Claiming DLA is not easy nor is it designed to be. The forms are detailed and lengthy and more often than not the initial claim will be rejected. This will require you to appeal against the assessors decision. Be prepared for this to happen. Be prepared to spend time and effort in pursuit of a claim. The Government will require detailed information before they agree to pay out the award. It can be frustrating, stressful and it can be off-putting. These are the emotions that you will feel if you decide to follow the process through.

Even after the appeal there is still the facility to take your case further if you do not agree with the Appeal Tribunals decision.

Not everybody, by definition, is entitled to DLA. Let us try and define WHO may be an individual who MAY be eligible for the award in section 2.

Section 2

• The Different Stages of a DLA Claim – Who is eligible?

There have been many successful claims for DLA by PKU sufferers so there is definitely a case for the award to be applied to the disorder. There is no age limit as to the application of the award but the criteria seems to be that PKU babies, until weaned are rarely awarded DLA and once the child is deemed to be able to administer his/her own diet, the award may cease to apply. This is not true for previously untreated PKU sufferers who have a different set of criteria. Again there are no hard and fast rules in the application of the award.

The award is not governed by the amount of "exchanges" in the diet. It is awarded according to the "Care Component" of the sufferer's particular circumstances. In the case of PKU it is the administering of the diet and supplements to control the Phenylalanine levels in the blood that is the "Care Component".

There are different stages in a DLA claim depending on whether or not the award is granted. If for instance, the award is granted at the first application then you will only have to go through one of the stages of the claim.

The Different Stages

The Initial Claim – You must firstly go to your local DSS and request a DLA Claim Pack. There are several forms enclosed, which are self-explanatory as to their pertinence to your particular claim.

In these forms you will find many different sections. Some will not be applicable to PKU, others will. These forms are changed in format on a regular basis so there are certain important points in certain sections of the form that you need to get across (See Chapter 3)

After completion of the form you will need to send it away by a certain date otherwise it will be invalid and you will have to fill in the forms again. This date will be stamped onto your claim pack at the time you pick it up at your DSS office.

The Reply – You will receive a decision regarding your claim within 6 weeks. If the claim is successful the reply will notify you of the rate, duration of award (anything from 1 – 17 years is possible) and other personal details about who the award is for.

If the decision is NOT to make the award, the reply will inform you of this fact. It will also inform you of the next stage and give you the reasons why the decision not to grant the award has been made. It will ask you if you require a review of the decision.

Review of the Decision – This is short and sweet and is unlikely to change from the original decision. It will inform you that the review has taken place and the decision of the review. It will inform you of the right to have your application reviewed further by an Appeals Tribunal and ask you whether you wish to pursue the claim through this channel.

Notification of Appeals Tribunal Hearing – You will be sent a Tribunal date and be requested to forward any information to the appropriate office that you think will be of relevance to the claim. (See Section 4 for the forwarding information)

The Tribunal – You will be required to attend the Tribunal in your selected Tribunal Office. This will normally be the nearest to your home if you so wish. You will face a panel of 3 assessors (see Section 5 – **Representation**). A Tribunal Judge (A selected member of the public who will have had previous judgemental experience) A Medical Professional and a Lay Member who normally has experience of appropriate and related matters will attend the hearing.
You will be quizzed as to the nature of your child's condition and it's complexities. It is normally not an intimidating affair and is normally relaxed, formal and in a smallish room. They will hear your appeal and send you out whilst they review your case and then call you back to hear their decision and invite your comments on that decision. If the decision is not to your liking they will offer you information on how to appeal against their decision.

Appeal to a Commissioner – You will be able to appeal against the Tribunal decision to a Commissioner. This must be in the context of a point of Law otherwise they will not consider your appeal. If this point of Law is regarded as non-applicable then legal re-dress must be sought through the courts.

The Court of Appeal – A higher Civil Court which will hear your case should the Commissioner rule against your claim.

Section 3

- ## The Initial Claim – Important Points

The Forms – Complicated and confusing at best. THERE ARE CERTAIN POINTS THAT NEED TO BE PRESENTED. The award of DLA is a fickle business and no two cases seem to be the same. On your form you need to drive certain points home to the assessor.

When there are questions relating to the point of people having to care for the claimant, you must emphasise the "Care factor" –

- **PKU is a genetically inherited disorder**

- **It is incurable**

- **The blood phenylalanine levels are controlled by diets and supplements through administration by the carer and not by the claimant**

- **Outline the supplements that are administered and the frequency and the difficulty of the administration**

- **Outline the blood sampling and its difficulties**

- **Outline the social difficulties (Parties – Dining Out – Support from friends and family and the education factor for them – School and peer pressure and taking of anti-social supplements)**

- **Outline the practical difficulties – shopping – special equipment (Bread makers, scales, blood taking devices and lancets – unpalability of the substitute breads and synthetic foods)**

- **Make them understand the result of a poorly managed diet and the fact that if the worst were to happen the burden on the State resources should the level of care be diminished**

- **There is normally a "summing up" on the final page of the form. Your final entry might be along these lines –**

• The Legal Argument – Its Importance

Time and time again, the appeals process, which is based upon legal criteria has to be used to endorse the DLA award for PKU. This is largely due to the lack of awareness that people have regarding the condition. This document is designed to make your application successful in the first instance. Of course there are no guarantees. Yet the legal establishment has consistently endorsed the MIDDLE rate award for PKU. This is because the legal case for the award is that:

- PKU is continuous
- PKU occurs in all places at all times
- PKU warrants more care than a "normal" child from someone other than the claimant

If you had to go to appeal or a commissioner's hearing these are the points in Law that would ensure a successful claim.

• How to get the Legal Argument into the Form

In the **Appendices** at the end of this booklet you will see lists of appeals and importantly a Commissioners report about the award for PKU. It is extremely important that you include these in your initial application. You will see on the following pages, the headings extracted from the DLA claimant form that you need to fill in. **Other areas of the form are not applicable to PKU and do not need to be filled in unless your child has other conditions. You will have to tick the box marked "NO".** The text under these headings are well tested responses and include references to these legal precedents which will aid your claim.

Genders and variables are highlighted in RED. You should adapt your answer accordingly in the context of *your* child. Any variance in dietary regime should also be taken into account. The headings are taken directly from the DLA application form "*How the child's* illness or disability affects them"

Because of the amount of text you may wish to attach an extra piece of paper with your form on which you can enter the information that the DSS require.

• About the Child

Tick the Boxes: "has physical disabilities"
And - "has a long term illness"

• If the child needs someone with them when they are outdoors

Your Response: Tick the box – "Yes" - PKU is a dynamic condition. This means that the blood plasma levels of phenylalanine will respond immediately to whatever is eaten. This is the main factor that affects someone with PKU as high levels of phenylalanine "block" out the ability of other amino acids to feed brain growth. This may then result in retardation if sufficiently high levels are sustained. This can occur anywhere and at any time if the wrong foodstuff is consumed. The diet is extremely limited. No meat, fish, dairy products, pulses or nuts, meat substitutes, gelatine (chewable sweets), aspartame (diet and sweet drinks and chewing gum)
Children are notorious in the way that they "push" boundaries as part of their learning and life skills. They are often not great communicators and adults often "know better". Without correct supervision children with PKU are often offered "forbidden" foodstuffs without their parents knowledge, sometimes they are even encouraged to accept even if they refuse. Without immediate supervision it sometimes easier for the child to accept with resultant raised blood levels. This will often occur outdoors and in play situations where peer pressure is most intense. To quote a Social Security Commissioners decision in a successful appeal - **(R(A)1/73 – "the extra care that the condition requires, he would be in very realistic danger of being mentally retarded which in turn would require even more substantial levels of care"**

• Someone keeping an eye on the child

Your response: Tick the box – "Yes" – "During the Day" - This largely depends upon the supervision regarding the administering of the supplements and the foodstuff. – A meal takes up to 30 minutes maybe more to supervise and the supplements may last ALL DAY. The condition (PKU) of is not bound by constraint of time and occurs 24 hours per day. Food must be supervised whenever it is accessable. To quote a successful Appeal – ***(R9A)1/88 Appendix and R(A)5/90"He therefore would require continual supervision during the times that he consumes food, be it at any time"***

• Communicating with other people

Your response is dependent upon the condition of your child and the effects of PKU – This is entirely subjective and requires an answer from yourselves.

- ## Eating and Drinking

Your Response – "During the Day" – Strict dietary adherence. It may be of help to quote ***R(A)2/80 Social Security v Fairey*** **–** "-This is especially true of X. As the control of the blood plasma phenylalanine levels are dependent upon the administering of the diet (not just at mealtimes but throughout the day) Persuasion of a significant amount is required for X to consume the correct amount of food and therefore protein each day. No more, No less. His amino acid supplement*, which is extremely unpalatable, is a major bone of contention. As it is extremely unpleasant in both smell and taste, the process of administering it is arduous and time consuming. To administer this supplement to a child who has no disability (i.e. a "normal child") such as PKU, would be, if at all possible, a routine fraught with trauma. There is no difference with X. The only significant difference is that he ***<u>HAS</u>*** to have it".

***This is dependent upon the type of protein substitute your child takes. You may have to adapt your response accordingly.**

- ## Help with medication

***This is dependent upon the type of protein substitute your child takes. You may have to adapt your response accordingly.**

Your Response – "**During the day"** – X requires protein but is not allowed it as part of the dietary regime. He/She must therefore have her dietary needs heavily supplemented. He/She must take 50 aminogran tablets per day*, 2 vitamin tablet and one calcium tablet. This requires intense supervision. To quote a past Commissioners decision – ***R(A)1/87 – There can be little doubt that a PKU diagnosis involves parents in administering attention and supervision far in excess of that required of other children".***

*** This is dependent upon the type of protein substitute your child takes. You may have to adapt your response accordingly.**

- ## Help with therapy

Your response is dependent upon the condition of your child and the effects of PKU – This is entirely subjective and requires an answer from yourselves.

- ## Help with medical equipment

Your Response – **"During the day"** – X requires blood plasma phenylalanine level monitoring to ensure his/her levels are under control through the administration of the diet. This requires a blood test every 2 weeks which is arduous and cannot be carried out without supervision. To quote Lord Dening's Court of Appeal – ***R(A)2/80 – (regarding the blood levels) "There is also no compensatory mechanism relating to blood phenylalanine levels, required within their diet. This should be deemed "out of the ordinary"***

The child's mental health

Your response is dependent upon the condition of your child and the effects of PKU – This is entirely subjective and requires an answer from yourselves.

Help the child needs when they go out during the day or evening

Your response – "What they would do if they had the help they needed" – (When they go out during the day or evening) –

- School Mealtimes & Outside school mealtimes – playtimes
- School trips
- Visits to friends' houses & Parties/Eating out at any restaurant.

How many days a week?

- 7

How many times a day?

- Waking hours

How long do they usually need help for each time?

- Whenever he/she eats or when food is available/accessible

What help do they need from another person?

- Constant supervision during the time he/she is eating or when food is available/accessible.

"What they do or would do if they had the help they need" (At home) –

- Eating food
- Administering of supplements
- Preparation and weighing of foodstuffs

How many days a week?

- 7

How many times a day?

- Waking hours

How long do they usually need help for each time?

- Whenever he/she eats or when food is available/accessible.

What help do they need from another person?

Constant supervision during the time he/she is eating and administration of supplements or when food is available/accessable.

- **Anything else about the way the child is affected by their illness or disabilities**

Your response – I feel it relevant to point out the legal determining regarding the awarding of DLA as this is a reasoned approach which will need to be arrived at in the event of the exhaustion of the application process.
CDLA/2188/2001 – Commissioner – J.P.Powell – "Appeal upon a question of Law" – "Section 8 quotes - it is said that even if the claimant does eat something which he should not, steps can be taken to avoid harm by adjusting his diet on the following days. However, it is necessary to supervise what the claimant eats in order to know whether he has eaten something he should not and how much and when he did so. Further, any adjustments made in the following days must be carefully monitored both during and between meals. I am, therefore, of the view that, despite the care with which its decision is constructed, the appeal tribunal erred in law in relation to the continual supervision test. I therefore allow the appeal"

Section 9 goes on to quote – "I consider that this is a case where it is expedient that I should exercise the powers conferred on me by section 14(8)(a)(ii) of the Social Security Act 1998, and make appropriate findings of fact and give the decision I consider appropriate in the light of them. That being so, I find as a fact that as the claimant suffers from phenylketonuria exceptional care needs to be taken with his diet. He must be supervised closely so that he eats exactly the right amount of the right things at the right times. Indeed, the amounts which he eats have to be carefully calculated. Further, great care must be taken to see that he does not eat even very small amounts of foods which he should not eat. If he does eat something which he should not, this must be noted and remedial action taken. Such action will often involve adjusting what he eats at the next meal or subsequent meals. I find as a fact that, because of those strict dietary requirements, the claimant requires continual supervision throughout the day in order to avoid substantial danger to himself.

I therefore apply for the middle rate award of Disability Living Allowance

Section 4

• What to do if Your Claim is Unsuccessful - The Appeal

Notification of an Unsuccessful Application – You will be informed of the decision regarding your application.

A successful application will be awarded at one of the aforementioned rates – Lower, Middle or Higher. If you are awarded at Lower or Middle you may wish to appeal against the decision and apply for the increased rate (Middle or Higher) In this case you also have re-course for Appeal.

You will be asked in the first instance if you wish to have your case reviewed. If you reply to the effect that you do, you must notify the Office dealing with your claim.

If the review is successful you will be awarded the appropriate rate.

If it is unsuccessful you will be given the right to appeal. Appeals must be sent to a central DSS Office, which you will be made aware of at the time. You will be given a geographical choice of which Office that you wish to attend.

You will be asked to forward any other relative documentation that relates to your appeal – ***<u>BE COMPREHENSIVE - FORWARD ALL EVIDENCE!</u>***

GET IN TOUCH WITH A WRO (WELFARE RIGHTS OFFICER) THROUGH YOUR LOCAL CAB (CITIZENS ADVICE BUREAU) – HE/SHE WILL BE INVALUABLE IN THE PROCESS OF YOUR APPEAL – HAVE HIM TALK YOU THROUGH THE EVIDENCE AND THE MANNER THAT IT SHOULD BE PRESENTED – HAVE HIM/HER ACCOMPANY YOU TO THE APPEAL – THESE PEOPLE KNOW THE SYSTEM AND WILL GUIDE YOU THROUGH THE APPEALS PROCESS – THEY WILL SIGNIFICANTLY INCREASE YOUR CHANCES OF A SUCCESSFUL APPEAL

EVIDENCE THAT YOU SHOULD BE SENT TO THE APPEALS SERVICE –

1. THE MANAGEMENT OF PKU – DOCUMENT – AVAILABLE FROM THE SOCIETY

2. LEGAL DECISIONS MADE AT PREVIOUS APPEALS (SEE OVER)

3. AN EXPLANATION TO THE APPEAL PANEL OF THE NATURE OF THE DISORDER AND ITS SOCIAL IMPLICATIONS (FOLLOWS “QUOTED CASES REGARDING PKU”)

SECTION 5

ATTENDING THE APPEAL TRIBUNAL

- Representation
- Preparation
- At the Tribunal – what to expect and what to do
- The Decision

Representation

If you have engaged the services of a WRO at this point, he will be able to nurture you through this process and offer sound and comforting advice on what the proceedings will entail.

Make sure that you are determined to establish your case. You have not come this far just to let the whole thing collapse. The panel will be aware of your conviction. If you do not possess this conviction there is little merit in proceeding the appeal to this stage. This will waste taxpayers‘ money and may result in a decision that will not be acceptable to you. This will make the ongoing procedure a near on impossible task. Have your WRO talk to you about this conviction and about it’s consequences.

The Appeal is or should not be an intimidating affair. There will be 1 Appeal Chairperson, 1 Medical Professional and 1 Lay Member. They will sit opposite to you across a Boardroom – like table.

They will ask you questions applicable to the evidence that you have offered and to your particular case.

Preparation

It may be of use to take substitute foodstuffs, supplements and examples of exchanges for the panel to try. More often than not, the supplement is unpalatable and so may sway the judgement. The substitute foodstuffs may also be offered for their palatability and so endorse the implications of the administering of the diet. Offer them the opportunity of a blood test with your Guthrie Pack!

At the Tribunal

Talk again about the social consequences mentioned earlier and the implications of non-compliance with the dietary regime.

Once you have stated your case, the Tribunal will ask you to leave the room whilst they consider you case. You will go the waiting room (rather like a Doctor’s Surgery)

After a short time they will call you back in for them to offer their decision.

- **The Decision**

After offering their decision, you will be given the opportunity to air your views on that decision.

If they give you a satisfactory decision you need take no further action and all the necessary arrangements for payment of the award will proceed.

If the decision is not to your liking (No award or a lower level of award than you were expecting) you **MUST MAKE SURE THAT THE NEXT RE-COURSE FOR YOUR CLAIM IS OUTLINED TO YOU – ask the Chairman for this next level of your claims Appeal after the decision.**

Section 6

• Appealing Further

If the Appeal tribunal's decision is not to your liking you are entitled to request a reason for the decision from the Chairman of your Appeal. You would be applying to The Commissioner for an appeal about the decision

Your request would be in writing and should read like this -:

The Appeals Service
Your Particular Office
Applicable to your Appeal

Your Name
Address
Post Code

National Insurance Number – **XX-XXXX-XX**
Reference Number – **Number of your Claim**
Date – **Today's Date**

Dear Sir

Re – Appeal against the tribunal decision for the award of DLA for X – Request for a full statement from the Chairman

I wish to appeal against the decision of the tribunal, in the case of an award at the **X** rate of DLA (**DATE OF DECISION**) because of a *point in law. Could you please forward a full statement of the Chairman's decision to myself at the above address. I will be seeking permission to appeal to a commissioner against the tribunal's decision on my **daughter's/son's** behalf.

Sincerely

X

Letter ends

*The point in law that you are referring to is the evidence provided by previous Tribunals and Commissioners.

You will then be invited to apply to the Commissioners for a similar hearing on an application basis. At this point you will need to consult a Solicitor who will best advise you on practise in law and how to proceed in the further advancement as regards your claim. **The following Commissioners Report should be forwarded with your appeal hearing date, it will help you with your claim. ALWAYS ATTEND THE APPEAL. A WRITTEN APPEAL WILL COMPROMISE YOUR CLAIM.**

Section 7

- ## Appendices -

Quoted Cases regarding PKU

R(A)2/80 Social Security v Fairey – help could include "persuading a person to do something like eating"

-This is especially true of X. As the control of the blood plasma phenylalanine levels are dependent upon the administering of the diet (not just at mealtimes but throughout the day) Persuasion of a significant amount is required for X to consume the correct amount of food and therefore protein each day. No more, No less. **His** amino acid supplement, which is extremely unpalatable, is a major bone of contention. As it is extremely unpleasant in both smell and taste, the process of administering it is arduous and time consuming. To administer this supplement to a child who has no disability (i.e. a "normal child") such as PKU, would be, if at all possible, a routine fraught with trauma. There is no difference with X. The only significant difference is that **he** **HAS** to have it.

R(A)2/80 Appendix

"Attention must be required throughout the day" or "occurring often"

The above brings us onto the frequency of the care component. X's diet is **his** treatment. **His** phenylalanine levels are to be desirably stable during the day using his intake of measured amounts of protein over the course of the day and the three times administration of the Maxamaid supplement at each mealtime. The actual term "occurring often" is largely relative to the amount of times that help is administered. In X's case the ingestion of protein is an ongoing process during the day and so the care that is required, because of **his** age, is a constant or continual process.

(R9A)1/88 Appendix and R(A)5/90 "continual means going on all the time".

X has the absence of an enzyme in **his** liver, which disables **his** body from converting phenylalanine into tyrosine. This will in turn, if left un-checked, lead to profound mental retardation. This is not isolated in its frequency. It is a permanent disablement, which is "continual" given the nature of the condition.
He therefore would require continual supervision during the times that **he** consumes food, be it at any time.

Social Security Commissoners decision R(A)1/73

"Substantial Danger"

Depending on the interpretation of "danger", it may be construed that if X were to be denied the extra care that the condition requires, he would be in very realistic danger of being mentally retarded which would in turn require even more substantial levels of care.

Social Security Contributions & Benefits Act 1992, section 72(6)

"Substantially in Excess" – "is outside the whole range of help that would be normally required by a child of the same age who is not disabled"

"Outside the whole range of help" This seems to be the mitigating factor. To establish the extra help. This can only be achieved through comparison with a "normal child".

- **Re-R (A) 2/80 – Lord Dening's Court of Appeal – "duties that are out of the ordinary"** A normal child does not attract the same level of care as a PKU child because a normal child does not have their foodstuffs weighed in exact amounts. There is also no compensatory mechanism relating to blood phenylalanine levels, required within their diet. This should be deemed "out of the ordinary".

R (A) 1/87 Paragraph 3

"The diet is extremely demanding and as all forms of protein are limited in its implementation, requires constant supervision. With poor control due to dietary indiscretion, the child is at risk of becoming mentally retarded"

The Commissioners went on to set out what was required in relation to diet with a child suffering from PKU.

"In the United Kingdom all babies have a blood test called the Guthrie Test a few days after birth (To detect the presence of PKU)

"Children suffering from PKU cannot cope with phenylalanine,…..found, in all protein foods"

"Unfortunately, that amino acid is ESSENTIAL for the children's growth and accordingly (although in general) , phenylalanine is to be avoided in the childrens' diet, a certain, carefully limited amount, is essential, and is imparted to them by means of what is known as a phenylalanine exchange list, which is a list of specific foods containing, in their prescribed weights, a set amount (50g) of phenylalanine. The number of such exchanges, which each child is to be allowed is individually assessed. It is then regularly re-assessed, and if necessary, varied following periodical blood tests"

A Past Commissioners Decision – R (A) 1/87

"To say that most children grow out of it (PKU) after the age of 10 is quite untrue and potentially dangerous"

"The Medical Research Council Working Group (1993) concluded that dietary control must continue into Adult life"

"There can be little doubt that a PKU diagnosis involves parents in administering attention and supervision far in excess of that required of other children"

R (A) 2/80 – Lord Dening’s Court of Appeal

This appeal refers to “duties that are out of the ordinary” in connection with ”bodily functions” –“ the extraordinary choosing, weighing and preparation of foods needed for a PKU child"

THE SOCIAL SECURITY COMMISSIONERS

Commissioner's Case No: CDLA/2188/2001

SOCIAL SECURITY CONTRIBUTIONS AND BENEFITS ACT 1992
SOCIAL SECURITY ADMINISTRATION ACT 1992
SOCIAL SECURITY ACT 1998

APPEAL FROM THE APPEAL TRIBUNAL
UPON A QUESTION OF LAW

COMMISSIONER: J.P. POWELL

Commissioner's File: CDLA/2188/2001

1. This is an appeal by the claimant, with my leave, against the decision of the Stockport appeal tribunal ("the appeal tribunal") given on 16th February 2001. For the reasons which I give, that decision is erroneous in point of law. I therefore allow the appeal and set it aside.

2. In exercise of the powers conferred on me by section 14(8)(a)(ii) of the Social Security Act 1998, I make the findings which I do below and give the decision which I consider appropriate in the light of them. My decision is that the claimant is entitled to the middle rate of the care component for the period from 24th November 2000 to 23rd November 2005, inclusive of both dates.

3. The issue in this appeal is whether or not the claimant satisfies the statutory conditions set out in section 72(1) of the Social Security Contributions and Benefits Act 1992, for an award of the middle rate of the care component of a disability living allowance. He is already in receipt of the lower rate of that component.

4. The claimant is a small boy. He was born on 24th November 1995. His father has been appointed to represent him in this matter. For simplicity, I shall simply refer to the "claimant" although, because of his age, all decisions and actions are taken or carried out by his appointee. The claimant has the misfortune to suffer from phenylketonuria – sometimes referred to as PKU. It may be helpful if I set out the relevant entry in the Oxford Concise Medical Dictionary.

> Phenylketonuria *n*, an inherited defect of protein metabolism causing an excess of the amino acid phenylalanine in the blood, which damages the nervous system and leads to severe mental retardation. Screening of newborn infants by testing a blood sample for phenylalanine (see Gurthrie test) enables the condition to be detected soon enough for dietary treatment to prevent any brain damage: the baby's diet contains proteins from which phenylalanine has been removed. The gene responsible for phenylketonuria is recessive so that a child is affected only if both parents are carriers of the defective gene.

Pages 52 and 53 of the papers are a copy of a letter dated 10th October 1996, written by the Chief Dietician of the Willink Biochemical Genetic Unit, which is part of the University of Manchester School of Medicine. That letter describes a very strict dietary regime which, at least when the letter was written, was backed up by “weekly blood tests, and regular hospital visits to review his blood levels, advise on dietary change and check on his growth and development”.

5. On 7th November 1997, a disability appeal tribunal sitting at Manchester awarded the claimant the middle rate of the care component for the period from 24th May 1997 to 23rd November 2000. The relevant decision notice will be found at page 65 of the papers. On 19th July 2000, the claimant applied to renew that award from and including 24th November 2000. On 26th July 2000, a decision maker decided that he was not entitled to either component of a disability living allowance from and including 24th November 2000. See pages 103 to 105 of the papers. A second decision maker reconsidered that decision but did not revise it.

6. The claimant appealed and his appeal came before the appeal tribunal on 16th February 2001. That was an oral hearing which the claimant’s father attended on his son’s behalf. He made it plain to the appeal tribunal that what the claimant as seeking was the middle rate of the care component and that the mobility component was not in issue. The evidence before the appeal tribunal did not refer to the mobility component. For that reason, and because there is no suggestion of any inability to walk, I shall confine myself to the care component. In the event, the claimant’s appeal succeeded in part. The appeal tribunal awarded the claimant the lowest rate of the care component for the period from 24th November 2000 to 23rd November 2005. This was on the grounds that the claimant required attention for a significant portion of a day and that his needs were in excess of those normally required by children of his age. That is, the appeal tribunal were of the view that section 72(6) of the Social Security Contributions and Benefits Act 1992 was satisfied.. The appeal tribunal declined to award the claimant the middle rate of the care component.

7. The appeal tribunal’s findings and reasons are set out in the statement of facts and reasons which appears at pages 116 to 120 of the papers. This is a long and careful decision and the chairman is to be commended for the amount of time and trouble which she spent writing it. The appeal tribunal accepted the evidence adduced on behalf of the claimant and made it plain that there was no evidential

conflict which it had to resolve. After recording that the tribunal was being asked to award the middle rate care of the care component, the statement goes on to say:

> … [The claimant's father] asked us to consider both the appellant's requirement for attention with his bodily functions during the day and his need for supervision during the day, to prevent him from eating anything which is outside the strict dietary programme imposed because of his PKU.
>
> We understood that eating prohibited foods, or eating foods which are allowed but either above of below the amount calculated in the exchanges has potentially serious consequences and that if this is not or cannot be rectified by adjusting subsequent exchanges the result is irreversible brain damage. There is no antidote, no emergency treatment equivalent to sugar for a hypoglycaemic attack or antihistamine for an allergy reaction.

As I understand its decision, the tribunal approached the appeal on the basis that that description of the claimant's dietary needs was correct.

8. In the part of its decision which appears at page 118 of the papers, the appeal tribunal decided that the claimant did not require continual supervision throughout the day in order to avoid the risk of danger to himself or others. It is a lengthy passage, and I mean no disrespect to the appeal tribunal by not quoting it. It is also a closely and carefully reasoned passage. Nevertheless, despite the care which has obviously gone into drafting them, the tribunal's reasons are, in my judgement, flawed. For example, it is said that even if the claimant does eat something which he should not, steps can be taken to avoid harm by adjusting his diet on the following days. However, it is necessary to supervise what the claimant eats in order to know whether he has eaten something he should not and how much and when he did so. Further, any adjustments made in the following days must be carefully monitored both during and between meals. I am, therefore, of the view that, despite the care with which its decision is constructed, the appeal tribunal erred in law in relation to the continual supervision test. I therefore allow the appeal.

9. I consider that this is a case where it is expedient that I should exercise the powers conferred on me by section 14(8)(a)(ii) of the Social Security Act 1998, and make appropriate findings of fact and give the decision I consider appropriate in the light of them. That being so, I find as a fact that as the claimant

suffers from phenylketonuria exceptional care needs to be taken with his diet. He must be supervised closely so that he eats exactly the right amount of the right things at the right times. Indeed, the amounts which he eats have to be carefully calculated. Further, great care must be taken to see that he does not eat even very small amounts of foods which he should not eat. If he does eat something which he should not, this must be noted and remedial action taken. Such action will often involve adjusting what he eats at the next meal or subsequent meals. I find as a fact that, because of those strict dietary requirements, the claimant requires continual supervision throughout the day in order to avoid substantial danger to himself. Of course, all children of the claimant's age require continual supervision. However, the claimant, because of his condition and the need to ensure that there is rigid adherence to his diet, requires a greater level of supervision than other children of his age. Section 72(6) is, therefore, satisfied. Putting it simply, it must be extremely difficult and involve a lot of supervision to ensure that the claimant does not eat a sweet or a biscuit or a packet of crisps when he should not.

10. It follows that the claimant is entitled to the middle rate of the care component. The appeal tribunal awarded the lower rate of that component for five years. I award the middle rate for the same period of five years. That is, from 24th November 2000 to 23rd November 2005 inclusive of both dates.

11. The claimant will be 10 on 24th November 2005. By then conditions will have changed. If he applies to renew the award, a fresh decision will have to be made. That decision will depend on the facts and evidence put before the decision maker in 2005. It may, for example, be harder or easier to satisfy section 72(6). The claimant's dietary needs may, but not necessarily will, have become easier. Much may happen. If a decision has to be made in 2005, it must be made on the facts prevailing at that time. I merely say this. It is in the interests of children who suffer from serious medical conditions that they learn how to manage their own care as early as possible so that they can lead independent lives. For example, the diabetic child who learns to give his or her own injections and carry out tests with a small blood monitor – something many children of eight or nine can do – can stay overnight with friends, go on school trips or holidays and do many other things that a diabetic child who is not able to inject himself or do a simple blood test cannot do. In saying this I express no views, one way or another, as to the future in relation to the claimant. The award which I have just made is no indication of the nature of any

future award or whether one should be made. Any future award will depend on the facts at the relevant time.

(Signed)	J.P. Powell Commissioner
Dated:	11th February 2002

Here are the contacts essential for the back-up for this information.

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E-mail – info@nspku.org

Web-site – http://www.nspku.org

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Acknowledgments –

Mike Duffy

Simon Kimpton

Julia Bailey

Pete Bramley