

# **Let's Learn About PKU**

A Resource for Health Professionals

For Children Age 7 – 11 Years

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## INTRODUCTION

### What is the purpose of this activities file?

It is to teach the child and their family about PKU and its treatment.

### Why a file of learning activities?

The treatment for PKU is complex and often hard to explain to children. They probably want to know about the following:

1. why they have PKU (when no one else in their family **may have** it).
2. how to be independent
3. how to manage away from home.
4. why they have to take protein substitute
5. why they need to avoid high protein foods.
6. how their body works.
7. how to take blood tests correctly.
8. how to deal with peer pressure.

All of these questions and skills need to be addressed if children are to be successful at managing PKU themselves. Learning starts from an early age. This file of games and activities has been produced to help young children to understand their PKU and start to manage it for themselves. Self-confidence and independence comes with knowledge, regular teaching and patience. Parents may find this helpful.

### Who designed these games and are they any good?

A team of dietitians, experienced in the treatment of PKU, teachers, clinical nurse specialists play therapists and people with PKU have been working on this project for over 2 years. The work has been sponsored by the National Society for Phenylketonuria. All the games and activities have been evaluated on children with PKU from all over the country to make sure they are age appropriate and work! Of course two children of the same age will have varying abilities, so start off with the simplest activities and work up.

### How do I use this file?

The file is divided into 5 sections:

- What is PKU and learning about the body
- Food and Diet
- Blood Monitoring
- Genetics
- Coping with PKU

Each section will stand on its own and is subdivided into different activities. Some of the activities require aids you will need to make for yourself but full instructions are given and they are not difficult to prepare. A resource list provided on page 5 is given and also information about where to obtain the things you need. You can adapt the games to suit your own needs and those of your children with PKU.

Children with PKU could do some of the games whilst waiting to see the doctor or when their parents are talking to a professional.

### **Where can I get further copies?**

Anything in the file can be copied using the disc provided. The sheets with a blue surround are also available from Birmingham Children's Hospital at a cost of 10p per sheet. Contact the hospital using the attached form. The form can be photocopied.

### **What did you think of the activities? Do you have ideas too?**

There are evaluation sheets at the front of the file and it would be very helpful to us to know what you and your patients with PKU think of the activities. Did you adapt them in any way? We would also be pleased to hear of any ideas you may have which we could include when the file is re-assessed. Please return this information to Eleanor Weetch, Society Dietitian, Skiers Spring Lodge, Broad Carr Road, Hoyland, Barnsley S74 9BU

### **Produced by:**

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### **Also with grateful thanks to the following who have made significant contributions to this file:**

Diane Asplin, Clinical Nurse Specialist in PKU, Birmingham Children's Hospital  
Anne Daly, Senior Dietitian, Birmingham Children's Hospital  
Elizabeth Parrott, Adult with PKU  
Play therapists  
Patients of all ages

# ORDER FORM

## Learning Skills Age 7-11 years

(All Activity sheets (AS) with blue border are available for 10p per sheet. Other items available as indicated.)

<b>What is PKU and Learning about the body</b>	<b>Number of copies</b>	<b>Total cost</b>
Identify the word (AS)		
How many words? (AS)		
Letter to letter (AS)		
PKU Facts (AS)		
PKU Word Search (AS)		
"Me and you have PKU" song sheet (AS)		
Card game "What Changes" £ 1.00 per set		
Growing and Changing (AS)		
All about Me Booklet 50p per booklet		
What's Inside? (AS)		
Your Diet (AS)		
The Best Diet (AS)		
"If you're special and you know it" song sheet (AS)		
"Oranges, Strawberries" song sheet (AS)		

<b>Genetics</b>	<b>Number of copies</b>	<b>Total cost</b>
How do I get PKU? (AS)		
Cut out PKU dolls (AS)		
Gene word search (AS)		

<b>Blood Monitoring</b>	<b>Number of copies</b>	<b>Total cost</b>
My Blood Test what things do I need? (AS)		
My Blood Equipment (AS)		
How to do my blood test (AS)		
How do they know what my blood phenylalanine is? (AS)		
Blood, blood, blood (AS)		
Blood test word search (AS)		

**Grand Total Cost: £**

**Please complete in capital letters**

**Name :**

**Address:**

All cheques made payable to: Dietetic Department Code 333050 PKU Fund

Send your completed order form, these details and your cheque to:

The Dietetic Department,  
Diana, Princess of Wales Children's Hospital,  
Steelhouse Lane, Birmingham, B4 6NH

## RESOURCE LIST

Large white board	Ikea, W H Smith, Office World
Small Magnets for pictures	Guide Shops, Hobbycraft, art and craft shops e.g. <a href="http://www.smitcraft.com">www.smitcraft.com</a> Tel.01252-342626 <a href="http://www.bakerross.co.uk">www.bakerross.co.uk</a> free catalogue tel: 0870-241-1867
Pictures of Foods	Supermarket magazines, labels from foods, photographs, manufacturers pictures, internet, try “Google”, ask families to collect Keep a ‘Pictures Box’
General Stationery	Ask hospital play specialists and try the hospital stationery catalogue
Magnetic Paint Available from B & Q.	Make a magnetic noticeboard by marking off an area of your wall and applying magnetic paint. Once dry you can paint over with ordinary paint.
Magnetic Sheets	A4 sheets that go into an ordinary printer. Avery J8867-3. PC World Pictures and words can be made up on the computer and used for the barometer game (Blood monitoring section) and the magnetic board in the Food and Diet section.
Useful catalogues:	School merit sticker book – Telephone 0900 068 1009 Ask Hospital school teacher to let you see their Resource Catalogues
2 printed booklets with PKU in mind	“My Diet Record Book” and “This is Me”, available from Vitaflo Ltd., 11-15 Century Buildings, Summers Road, Brunswick Business Park, Liverpool L3 4BL

Produced by Barbara Cochrane  
Metabolic Dietitian  
R.H.S.C Yorkhill, Glasgow L3 4BL.

**EVALUATION FORM****Name of Activity/(ies) used:****Objective****Did you find the instructions for the activity easy to follow?****Yes / No**

If no, what was confusing?

**Was anything missing in the information or materials required?****Yes / No**

If yes, what?

**How could the instructions be improved?****Did you have any problems carrying out the activities with the children?****Yes / No**

If yes, please describe.

**Has this activity prompted you to think of another activity that we might be able to include in this pack?**

If so, please give brief details and contact name / number.

Thank you for completing the Evaluation Form.

Please return it to Eleanor Weetch, NSPKU Dietitian, Skiers Spring Lodge, Broad Carr Road, Hoyland, Nr Barnsley, S74, 9BU.