PKU - A Leaflet for Teenagers

The NSPKU produces various publications which provide information about Phenylketonuria for those with PKU and their carers.

Below is an extract of our leaflet for teenagers and young adults with PKU.

So you have PKU

As an infant you started a special diet and you have been seen regularly by doctors, dietitians, health visitors, psychologists and every other kind of -ist. Why has your health been so carefully monitored? It is due to the fact that PKU can be a serious condition unless it is properly treated. Good treatment allows normal health and development.

What now?

Most of you will want to know what to do now. From now on any decisions about your treatment will be your own so you need to be well informed about PKU. This leaflet is to help with some of the many questions you may have about the future.

Can you stop the diet?

This is a big one! You are still part of the first generation of well treated teenagers, so, really, you are still part of an experiment; but there is increasing evidence which suggests that phenylalanine levels should be kept under strict control. You should continue to follow what your doctor or dietitian has advised. Most people believe it is best to continue with the low phenylalanine diet, including adeqaute amounts of protein substitute, and to have regular blood tests. However, you are now taking control of your own life and the decision is yours about your treatment after being informed of the risks of high phenylalanine levels. Please discuss this with your hospital doctor.

Starting a family

Within the next few years you may want to have children of your own. If your partner is not a carrier then none of your children will have PKU. However, the chance of teaming up with a carrier within the population at large is approximately 1 in 60 and then each one of your children would have a 50-50 chance of having PKU. So normally there is a 1 in 120 chance of PKU for any child that you have. This chance becomes greater if marry a relative such as a cousin or if you marry someone who has a history of PKU in his/her family. This is something you would probably wish to discuss with your partner and possibly with a geneticist (a doctor who advises on possible inheritable defects). There are tests for carriers but these are not always very reliable. If you want advice about this you will need to see a geneticist.

Young women with PKU who want to have children should read the leaflet "Pregnancy in Women with Phenylketonuria". If you have any doubts about all this and have lost contact with your doctor, you can get information from the NSPKU.

A special note for girls

It is very important that you should be on a strict diet before you try to get pregnant.

Unplanned pregnancies are not ideal at the best of times but if you have PKU they are a much greater problem. The risk of damage to the baby is high if you were not on a strict diet before becoming pregnant. Diet in pregnancy has to be even more strict than in childhood. **If you think you might be pregnant you should contact your PKU clinic and your GP immediately.** Make sure that the GP understands the problem - they may not. You might know more. Explain about it.

REMEMBER

1. Keep your appointments with your hospital and dietitian even if you decide to discontinue dietary treatment.

2. Girls please read the leaflet on PKU and pregnancy.

3. Keep in contact with NSPKU.